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Implementation of Electronic Patient-Reported Outcome Measurement in Specialist Palliative Home Care

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List of Abbreviations

DGP	German Association for Palliative Medicine
EAPC	European Association of Palliative Care
eIPOS	electronic Integrated Palliative care Outcome Scale
eHealth	Electronic Health
ePROM	Electronic Patient-Reported Outcome Measurement
HCP	Health care professionals
ICT	Information and communication technologies
IPOS	Integrated Palliative care Outcome Scale
mHealth	Mobile health
PCOM	Patient-Centered Outcome Measurement
PROM	Patient-Reported Outcome Measurement
PC	Palliative Care
SPHC	Specialist Palliative Home Care
SPC	Specialist Palliative Care
REC	Research Ethics Committee

Publication list

Paper I

Burner-Fritsch I, Bolzani A, Hriskova K, Kolmhuber S, Bausewein C, Hodiamont F. **Challenges developing an electronic patient-reported outcome measurement for palliative home care: A qualitative interview and focus group study.** Palliative Medicine. 2023;37(2):265-274. doi:10.1177/02692163221141487

Paper II

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Appendix: Paper III

Burner-Fritsch I, Kolmhuber S, Hodiamont F, Bausewein C, Hriskova K**. Implementing ePROM in specialist palliative home care: the professionals' perspective – a mixed-methods study.** Palliative Care and Social Practice. 2023;17. doi:10.1177/26323524231186827

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Burner-Fritsch I & Hriskova K, Kolmhuber S, Hodiamont F, Schmaderer K, Bolzani A, Ramsenthaler C, Bausewein C: **Implementierung von elektronischem Patient-Reported Outcome Measurement in die SAPV – eine quasi-experimentelle mixed-**

methods Interventionsstudie. Presentation, *Wissenschaftliche Arbeitstage DGP, Göttingen, 2023.*

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Burner-Fritsch I, Kolmhuber S, Hodiamont F, Bausewein C & Hriskova K: **Digitale Erfassung von patient* innen-berichteten Outcomes in der SAPV: Die Perspektive der Professionellen. Ein Mixed-Methods-Sequential Explanatory Ansatz.** Presentation, *DGP Congress, Bremen, 2022*

Hriskova K & Burner-Fritsch I, Kolmhuber S, Hodiamont F, Ramsenthaler C, Wright S Bolzani A, Bausewein C: **Palli-MONITOR: a quasi-experimental mixed-methods interventional study of an electronic patient-reported outcome measurement system in German Specialist palliative home care.** Presentation, *DKVF, Berlin, 2022*

Bolzani A, Kupf S, Hodiamont F, Burner-Fritsch I, Bausewein C, Ramsenthaler C: **Measurement Equivalence of the Paper-based and Electronic Version of the Integrated Palliative Care Outcome Scale: A Randomised Crossover Trial.** Presentation, *EAPC World Congress, online, 2021.*

Burner-Fritsch I, Hriskova K, Kolmhuber S, Bolzani A, Hodiamont F, Bausewein C: **Implementing ePROM in Specialist Palliative Home Care: Professionals' Perspective.** Poster presentation, *EAPC World Congress, online, 2021.*

I. Burner-Fritsch, Hriskova K, Kolmhuber S, Bolzani A, Hodiamont F, Bausewein C: **Studienprotokoll: Evaluation der Implementierung von ePROM in der SAPV: die Perspektive der Mitarbeitenden.** Poster presentation, *Wissenschaftliche Arbeitstage DGP, online, 2021.*

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Burner-Fritsch I, Bolzani A, Hodiamont F, & Bausewein C (2020). **Implementierung von ePROM in die SAPV: Chancen und Hürden.** *DGP Congress, online, 2020.*

1. Contribution to the Publications

The information of the authors' contributions to the individual papers is structured after the Contributor Roles Taxonomy (CRediT).(1,2) Following the tables, there is a description about contributions of author of this thesis to the research project offering the framework to the scientific work presented here.

1.1 Contribution Paper I

Contribution	(Co-) Author
Conceptualisation	C. Bausewein, F. Hodiamont, I. Burner-Fritsch
Formal analysis	I. Burner-Fritsch
Funding acquisition	C. Bausewein, F. Hodiamont
Investigation	I. Burner-Fritsch
Methodology	C. Bausewein, F. Hodiamont, A. Bolzani, I. Burner-Fritsch
Project administration	C. Bausewein, A. Bolzani
Resources	C. Bausewein
Supervision	C. Bausewein, F. Hodiamont, A. Bolzani
Validation	K. Hriskova, S. Kolmhuber
Visualisation	I. Burner-Fritsch
Writing: original draft	I. Burner-Fritsch
Writing: review & editing	I. Burner-Fritsch

1.2 Contribution Paper II

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Investigation	S. Kupf, A. Bolzani, I. Burner-Fritsch
Methodology	C. Bausewein, C. Ramsenthaler, A. Bolzani,

Project administration	C. Bausewein, A. Bolzani
Resources	C. Bausewein
Supervision	C. Bausewein, C. Ramsenthaler
Validation	S. Kupf, A. Bolzani
Visualisation	C. Ramsenthaler
Writing: original draft	C. Ramsenthaler, A. Bolzani, I. Burner-Fritsch, S. Kupf
Writing: review & editing	C. Bausewein, F. Hodiamont, S. Kupf, I. Burner-Fritsch

1.3 Contribution Paper III (Anhang)

Contribution	(Co-) Author
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Formal analysis	I. Burner-Fritsch, S. Kolmhuber, K. Hriskova
Funding acquisition	C. Bausewein, F. Hodiamont
Investigation	I. Burner-Fritsch, S. Kolmhuber
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Writing: original draft	I. Burner-Fritsch, S. Kolmhuber, K. Hriskova
Writing: review & editing	I. Burner-Fritsch, K. Hriskova

The author of this thesis played a vital role in shaping the detailed configuration and was an important team member executing the Palli-MONITOR study. Her contribution comprised the planning and implementation of the recruitment procedures for each study phase of patients and professionals of the SPHC teams involved in the overall project. As a first step, she participated in the daily clinical care routine of the participating teams. In addition to the insights that were important for the implementation of the study, this

gave her the opportunity to get familiar with the staff members and to establish recruitment contacts. For the recruitment of patients in phase I, the author developed a concept that included close and regular communication with the staff of the study centres throughout the entire recruitment period. In phase II, patients were recruited for interviews in collaboration with the study nurses of the research team. Recruitment of professionals of the participating SPHC teams for focus groups discussions was planned and conducted by the author of this thesis.

Together with the support of other team members and the project lead, she designed the interview and focus group guides for qualitative data collection. Moreover, she jointly collected the qualitative data including patient interviews as well as focus groups with health care professionals. The author audio recorded interviews and focus groups and deeply reviewed the transcripts, prepared by an external office. Additionally, she captured impressions from the interviews and focus groups in postscripts which were not covered in the audio records.

The author planned and conducted the analytic process regarding all qualitative study parts supported by regular meetings in the research team. She deductively developed the initial coding framework based on the leading research questions and prior knowledge about the topic. After first analytic steps, the framework was refined with inductive subcategories drawn from the data material. After feedback from the research team, the author applied the final coding framework to the entire data corpus (trans- and postscripts and field notes). With the help of the team, she defined the specific research questions for the publications forming this thesis and meticulously prepared and analysed the qualitative data and wrote the analysis report. Integrated mixed-methods data analysis was conceptualized and jointly carried out together with the research team. Additionally, she formulated the publication's framework together with the support of other team members and the project lead, composing the original manuscripts (article I and III), while incorporating critical feedback from all authors. Moreover, she assumed responsibility as the corresponding author during the publication process (article I and III) and made significant contributions to editing and reviewing the manuscript in article II.

2. Introduction

Relevance of palliative care will extend due to current and future demographic development.(3) The challenge of the future will be to provide more care to people with existing structures and to maintain the quality of care.(4) Simultaneously, resources in health care staff are getting scarce and will need to be more specifically placed.(4) One answer to these challenges is to implement person-reported outcome measures - benefits in palliative care are proven on quality of care, outcomes on patient level, and resource use.(5) Moreover, experts are calling for the use of patient-reported data in order to foster person-centeredness and the possibility to customise care individually.(6) Quality of health care will no longer be measured only process and structure related, but related to individual outcome on patient level.(7) In German palliative care, implementation of PROM is lacking, even though its use is recommended.(8) Up to date digital realisation of PROMs could facilitate further development of PRO use in clinical care routine, especially in outpatient care settings.(9) The project Palli-MONITOR developed and implemented an electronic PROM in German specialist palliative home care.(10)

2.1 Digitalisation and health care

2.1.1 eHealth, mHealth, teleHealth: terms and definitions.

The term *digitalisation* is defined and used in various ways, but generally describing a digital translation of analogue activities and processes. A more specific definition for health care is offered by Iyamu et al (11): they are differing between digitisation, digitalisation and digital transformation. Digitisation is thereby described as a technical process in which existing analogue content is transformed into digital data. The process of transferring paper-based patient records into electronic versions is one such example. By extension, digitalisation also encompasses the cultural and organisational change necessary to incorporate technologies into the processes of service delivery and public health. Digital transformation, as an extension of this, is seen as a complex and multilayered process that is fundamentally changing culture, operating models and goals of health care systems. (11)

Within these definitions of digitalisation in the health sector, many other terms like eHealth, teleHealth or mHealth are used. To clarify the term eHealth, da Fonseca et al. (12) conducted a systematic review categorising 446 publications. As a result, they formed the four categories mobile health (mHealth), telemedicine/telehealth, technology and other. *mHealth* describes the use of mobile devices in the context of health care or

public health. This includes smartphone applications for diagnosis or treatment of diseases as for example already known for the oncological or psychiatric setting. Moreover, mHealth also describes wearable wireless sensors aiming to monitor patients' health status and transmitting this data between settings as already used in the treatment of diabetes. *Telemedicine* describes the interaction between providers and patients, usually via audio-visual information and communication technologies (ICT).(12) The interaction can be in-between health care professionals (doc2doc) or connecting health care professionals and patients (doc2patient).(13) Telemedicine might integrate medical data (e.g. an electronic patient journal) and other technology as for example using a digital connected stethoscope transmitting the data to support telemedical consultation.(14) In addition, *Telecare* describes care activities by means of virtual presence or virtual guidance, e,g, when caregivers on site are instructed by remote specialists.(15) The use of the term *telehealth* has a more inclusive character and emphasises the multidisciplinarity which is typical for some medical services. Besides this user-orientated categories of digitalisation in health care, *technology* entails systems of medical institutions, e.g. the development of encryptions to enable save processes for patients using their online medical record. In addition, this category also encompasses the development of mHealth devices as well as the use of Internet of Things (IoT), cloud storage or Big Data in the context of ehealth.(12) Da Fonseca et al define digital health processes and products, that cannot be captured by these three frameworks or a combination of them as "other".(12) Besides these definitions and shapes, the overarching goal of all digitisation in health care is to improve and secure quality of care.(16)

2.1.2 Progressing Digitalisation in Palliative Care: Potentials, Fears and Challenges

Due to demographic development, the global and local need for palliative care is rising.(17) The World Health Organisation defines Palliative Care as an approach to improve "*the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*".(18,19) As a figurehead of the palliative movement, Cicely Saunders developed the concept of total pain, embedding psychological, social and spiritual dimensions of pain equally next to its physical aspects.(20) Using the term palliative care instead of palliative medicine underlines this holistic character as well as its multi-professionality. Next to medical and care professionals, palliative care is also provided by social and spiritual workers, psychologists, physiotherapists, or respiratory

therapists.(4) The holistic and patient-centred approach of palliative care sometime seems to oppose ideas and expectations about the use of digital health technologies.

2.1.2.1 State of the art

The understanding of digitalisation is also reaching the field of palliative care. The European Association of Palliative Care (EAPC) lately revised their recommendations on standards and norms for palliative care in Europe and embedded the use of digital health technologies into their recommendations.(21) Meanwhile, the German Association of Palliative Medicine (DGP) published a working paper dealing with opportunities and challenges of digitalisation in palliative care, which states:

"*We see digital transformation with a focus on the needs of palliative care patients as a desirable goal to complement standard care and support person-centred, individualised and high-quality care."* (14)

However, overarching standards and routines in using digital technologies in German palliative care are lacking. The new federal framework contract for SAPV, for example, still does not include the requirement to use a digital documentation and billing system.(22) Nevertheless, various local initiatives towards digitalisation can be observed in recent years. mHealth application technologies offer the advantage of collecting data regardless of the location, and providing it to patients and providers to inform care planning. Referring back to Da Fonseca et al, *mHealth* development in palliative care means the use of digital ways of symptom monitoring, monitoring of vital parameters, or apps for self-tracking.(12,14) Even more vital are the developments regarding teleHealth to provide palliative care services over spatial distances or with a time lag to the patients. Several projects especially in community care settings pilot telemedicine or telecare interventions, as for example the project TANNE, aiming to improve palliative community and hospice care for neurological patients by providing specialist neurological expertise via telemedicine.(23) Progress in the category *technology* is less directly noticeable for patients or caregivers, but also has a significant impact on the way palliative care is implemented. In this context, the legal and statutory framework conditions also influence the development of digitalisation in palliative care. Regarding technology, the main challenge is interoperability, what is necessary to exchange digital information between different systems. In Germany, two laws (2015: "E-Health Gesetz" (24); 2019: "Digitale-Versorgung Gesetz"(25)) should provide the regulations for a digital infrastructure with high security standards as well as improve the basis for standardised and open interfaces. To enable all hospitals and practices to exchange information across sectors and

systems, implementation of a telematics infrastructure and a common standard for interfaces is fostered.(26)

2.1.2.2 Potentials, fears, and challenges

In principal, the use of eHealth technologies promises positive effects on patient-relevant outcomes such as overall mortality or quality of life (27) as well as patient empowerment (28) and a shift in power dynamics in the medical system (29). Caregivers are benefitting through simplified communication channels and new opportunities for (e.g. interdisciplinary) interaction.(30) Also, there is increasing evidence specifically in palliative care. Naoum et al. substantiate the cost-effectiveness of digital health interventions in palliative care(31). Significant benefits regarding education, information-sharing, decision-making, communication and costs are shown in Finucane et al.s' meta-review of digital health interventions in palliative care.(32)

Despite these benefits, progressing digitalisation also seems to cause discomfort in palliative care, maybe even more pronounced than in other medical fields. As this setting empathises the role of the relationship between patients and professionals as well as a holistic, patients-centred approach, fears of negative effects of the technologies on these dimensions can be observed.(21,33) Payne et al. underpin that the technological focus on quantifiable measures could lead to a loss of meaning of what cannot be so easily quantified and digitised such as existential and emotional concerns.(21) Moreover, dynamics like a resistance to change might play a role in palliative care professionals being sceptic regarding digital technological changing the way of delivering palliative care.(34) These explicit challenges of implementing digital technologies in palliative care might ground in the fact, that successful interventions always have to be developed according to setting specific conditions and needs. The Covid 19 pandemic also promoted the digitalisation of healthcare. One effect of the contact restrictions due to the Covid-19-pandemic was that medical services were ought to use digital supported care and partly overcame their prejudices.(35–40)

The argument that older or less technically trained people may have disadvantages with the ongoing digitalisation in palliative care is losing its power.(21) Stepping forward in time, eHealth will mean benefit for more and more patients in vulnerable situations as digital divide narrows over time.(41) Hancock et al. demonstrated in their systematic review that telehealth use in palliative care in the UK is increasing, but future research for evaluation needed (42). This should explicitly include professionals' experience with use of digital technologies.(41)

2.2 Patient-reported Outcome Measurement (PROM) in Palliative Care

In palliative care, the gold standard of assessing symptom burden and needs is by the patients themselves through Patient-Reported Outcome Measurement.(43)

2.2.1 Development and state of the art

Outcome measures play a pivotal role in detecting patients' needs, with the goal of improving their quality of life, alleviating suffering, and facilitating the assessment of the quality of care received.(44,45) In the realm of palliative care, outcome measures in both patient and staff-completed versions exist to enable outcome assessment at the end of life. Nevertheless, the gold standard is to capture the patients' own perspective as far as this is possible.(46,47) This can be facilitated with Patient-Reported Outcome Measures (PROMs), validated questionnaires asking for patients' perception of their health status and wellbeing.(48) Primarily used for measurement of outcomes in clinical trials, positive effects of PROM implementation in clinical care routine are by now widely proven.(49,50) In palliative care, there is evidence that using PROMs supports identification of unknown palliative needs, improves emotional and psychological patient outcomes as well as patient-professional communication, increases patient empowerment and quality and effectiveness of care.(45,46,51,52) Moreover, including PROMs in care routines is fostering the patients' role into one of a central stakeholder in decision making, what can be understood as empowerment.(53)

In view of these advantages, guidelines are recommending PROM use.(43,54) However, the routine use of PROMs in palliative care is still deficient.(54,55) Barriers for successful implementation of PROMs were identified in recent research: health care professionals are questioning the impact of PROMs, fear additional timely burden through their use or are concerned of being assessed by PROM implementation.(56–61) Following the increasing digitalisation in health care, digital implementation of PROMs is progressively being explored and implemented in areas of clinical care. Specific concerns about digital PROMs (ePROM) in palliative care are the doubt that patients can use ePROMs independently or the fear that this technical approach will reduce the individuality of care and personal contact.(60) However, digital implementation of PROM could overcome barriers in analogue paper-based PROM usage, particularly in home care settings.(21,54,55) One requirement for the fruitful realisation of digital PROMs is to design the tool meeting the particular demands and prerequisites of the settings.(57) Presently, there are several initiatives dedicated to electronic Patient-Reported Outcome Measures (ePROM) in the

field of palliative care. The European MyPal project evolves a electronic PROM system to encourage palliative care for paediatric and adult patients with blood cancers.(62,63) In Germany, the MySUPPORT project focussed on PROM implementation in different areas of palliative care.(60) Karamanidou et al. identified in their systematic review 24 studies about current ePROM-based health interventions for palliative cancer care, of which nine were study protocols.(9)

2.2.2 The Integrated Palliative Care Outcome Scale and its digital version eIPOS

The Palliative care Outcome Scale (POS) was designed as a questionnaire for patients with advanced oncological disease that encompasses more than topics of physical symptoms or questions around quality of life.(64) The POS Group now comprehends of a large pool of instruments in many languages, that can be used in a variety of ways to assess outcomes in various palliative care environments.(65) A further derivative of the POS is the Integrated Palliative care Outcome Scale (IPOS), an internationally recommended instrument to measure palliative symptom burden and problems, used in various settings and populations. The questionnaire measures in 17 items patients' affection regarding physical symptoms, emotional and spiritual concerns as well as communicational and practical issues and has undergone testing in numerous palliative care settings, both inpatient and home care.(8,47,66–68) IPOS is available as proxy-measure used by carers or as PROM-tool with use through the patient. (43,54) Next to classic outcome measurement, the questionnaire is lately utilised to screen patients’ palliative care needs.(69) In the course of progressive digitalisation in the healthcare sector as well as daily life, the patient reported outcome measurement is also becoming increasingly electronic (ePROM).(9) The utilisation of ePROM presents numerous benefits for palliative care, particularly within the framework of specialist palliative home care: these advantages encompass cost-effective administration, scalability, device adaptability to sensory limitations, instant automated analysis, and the potential for seamless integration into an electronic patient record system.(70) However, the comparability or measurement equivalence of paper-based questionnaire and their digital realisations cannot be presumed - it is advisable to empirically assess the equivalence of scores and the alignment between administration modes.(71) The digital version of IPOS, eIPOS, was developed in an iterative-participative process of stakeholder involvement and its measurement equivalence was proofed following the ISPOR ePRO Good Research Practices Task Force Report recommendations.(72,73)

2.3 German Specialist Palliative Home Care: An extraordinary setting testing digital tools?

Palliative care is integral component of the German healthcare system with specific legislation regulating its provision. It is also included in medical and nursing education as a compulsory subject.(74–76) General and specialist palliative care are distinguished.(77,78) Apart from palliative care units, inpatient hospices, or palliative outpatient clinics, specialist palliative care can also be provided in the patients' living environment. This Specialist Palliative Home Care (SPHC) is available in Germany since 2007 for patients suffering from advanced disease and complex symptom burden.(79) Nationwide, over 360 SPHC teams are currently providing care for an annually increasing number of patients - in 2020 nearly 145,000 prescriptions were counted.(80) Prescribed by general practitioner or hospital physicians, SPHC aims to sustain and improve patients' quality of life and self-determination and enables them to maintain dignity until the end of life in their familiar environment.(22) In many cases, it becomes feasible to fulfil the patient's desire to pass away at home.(81) Therefore, this professional care not only focusses on the control of physical symptoms control: emotional and spiritual support are vital elements of care as well as coordination of involved (professional) carers, as general practitioners.(82,83) This holistic and patient-centred care lasts from few days over several weeks to months and is provided by multi-professional teams.(80) SPHC is offered by medical and care professionals, additionally and outside the regular financing, teams can include professionals for e.g., physiotherapy, respiratory therapy, or psychologists. Specialist palliative home care is provided in different intensity levels, the higher ones include a telephonic 24-hours emergency system.(22) The characteristics of the patient groups cared for vary from team to team, maybe due to complementary services provided in the region. This is another reason why the SPHC organisational structures differ between teams in terms of nature of care, composition of SPHC teams, or cooperation with other health care services.(84) The teams have an individually regulated duration and intensity of care (e.g., frequency of home visits or telephone contacts), which is also due to different types of financial contracts with the health insurance companies.(85) Most SPHC teams use electronic record systems. However, standardised assessments are not widely used, especially palliative care symptoms and concerns of patients and/or their informal caregivers are not measured in a standardised way.(81) Until now, comprehensive coverage of SPHC teams in Germany can be assumed.(86)

2.4 ePROM in SPHC: Development and Feasibility testing - Project “Palli-MONITOR”

After providing insights in the framing topics of palliative care, outcome measurement and digitalisation in health care, the following chapter introduces the research project that provides the framework for the publications of the dissertation. The study “Palli-MONITOR – Monitoring of Palliative Care Symptoms and Concerns in Specialist Palliative Home Care Using an Electronic Version of the Integrated Palliative Care Outcome Scale" was conducted between 2018 and 2022 and funded by the Federal Joint Committee German Innovation Fund (Innovationsausschuss des Gemeinsamen Bundesausschuss, grant number 01VSF17014), aiming to design and test an digital system enabling patient-reported outcome measurement for palliative home care.(10) The research ethics committee at the Medical Faculty of the Ludwig-Maximilians-University Munich, Germany, approved all study parts (18-815; 18-871; 19-512; 19-586; 19-585) and the project is registered at clinicaltrials.gov (NCT03879668).

2.4.1 Aims and objectives

The overarching goal of the project Palli-MONITOR was to deliver basic findings to design a following phase III study, assessing the impacts on care of the intervention *eIPOS* (see Figure 2: Intervention - eIPOS for SPHC). The main aim of phase I (development) was the development validated electronic version of eIPOS, acceptable for patients and professionals. Therefore, objectives were to investigate barriers and facilitators of an electronic PROM instrument used in SPHC (I) as wells as to proof the measurement equivalence of the paper IPOS and its digital realisation eIPOS (II). Overall goal of the study phase II (feasibility/piloting) was to explore the use of ePROM in SPHC. The corresponding objectives were therefore to pilot if the use of eIPOS is feasible, focussing on the user recruitment, completion of the digital questionnaires, user rates and technical viability of the eIPOS system (I); to explore perceived impacts on care and effects on processes (II); to investigate the appropriateness of ePROM use for patients and HCPs in the setting of SPHC. (10)

2.4.2 Study design and methodological approaches

The design was based on the MRC research framework for complex interventions and covered its first two phases "Development of the intervention (I)" and "Feasibility/piloting (II)".(87) Phase I started with a qualitative interview and focus group pre-study with patients and HCPs from the participating SPHC teams, informing the development of

eIPOS.(72) Additionally, it included a randomized-controlled trial, demonstrating the measurement equivalence from IPOS paper version versus its digitalised version eIPOS.(73) The study phase II encompassed a quantitative quasi-experimental intervention study with a retrospective and a prospective control group, focus groups with SPHC professionals, and interviews with patients using eIPOS.(10) Due to pandemic challenges in HCP recruitment, we extended phase II with an online survey with HCPs using eIPOS, to ensure valid results regarding our objectives.(88)

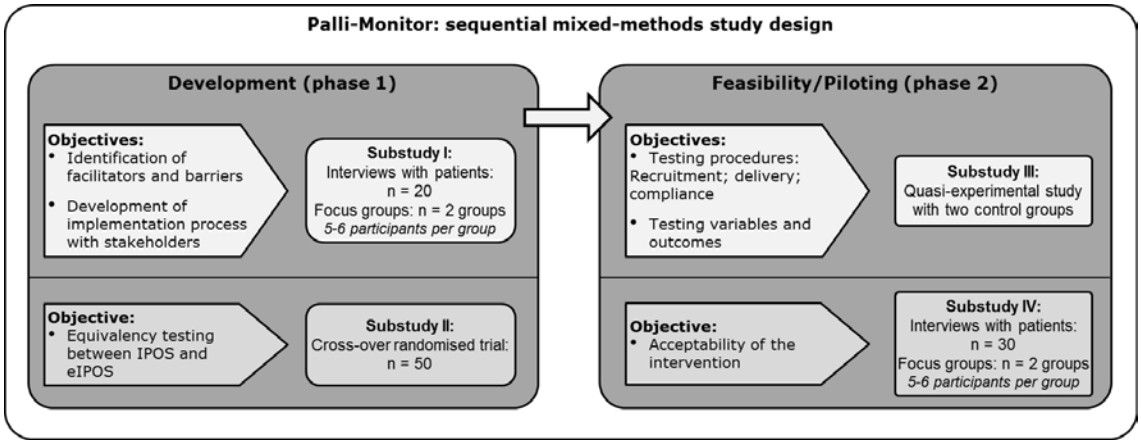

Figure 1: Study design of the project Palli-MONITOR (52)

The setting refers to the context in which the research project is conducted and involves five SPHC teams in Bavaria, Germany (see 2.3). The developed and tested intervention in the Palli-MONITOR study encompasses the use of the eIPOS for patients cared for by a SPHC team, the transmission of the information into the software system of the caretaking team as well as the integration of this patient reported outcomes to inform care (see Figure 2: Intervention - eIPOS for SPHC). (10,72)

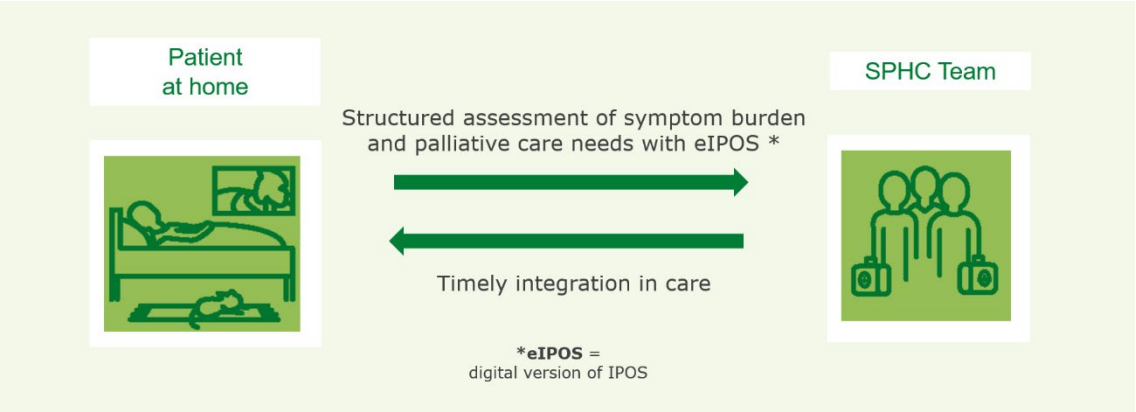

Figure 2: Intervention - eIPOS for SPHC

2.4.3 Results and significance: Developing and piloting a digital intervention focussing stakeholder participation

The results and significance of the Palli-MONITOR study are pioneering in advancing the field of digitalisation in homebased palliative care. Even though the intervention and the setting are quite focussed, the results are suitable to inform a much wider range of ideas regarding the development of digital technologies in health care (and especially in fields with vulnerable users) as well as the implementation of interventions in clinical care routine. Next to the direct goal of informing the further development and implementation of the intervention – the eIPOS use in SPHC setting –, the results offer deep insights into relevant processes around patients using (digital) questionnaires and integrating new (patient-reported outcome measurement) systems into clinical practice. The significance of the results lies in the focus of stakeholder involvement throughout the several phases and sub-studies. Therefore, the findings offer relevances set by the experts of the specific settings – hereby SPHC patients and professionals. Next to the direct participation of stakeholders in the concrete research, a patient and public involvement group, consisting from palliative care patients and relatives as well as volunteers in palliative care, accompanied the whole study, critically reflecting the approaches and procedures and offering valuable inputs to the research team.

Moreover, the Palli-MONITOR study is significant in its development and testing of a digital version of a widely used PROM tool in palliative care. By supporting the efficiency and accuracy of patient-centred care in the SPHC setting, the implementation of eIPOS can contribute to the evolving landscape of outcome measurements in palliative care. The results of the Palli-MONITOR study offer valuable insights that can inform future research and implementation of ePROM (electronic Patient-Reported Outcome Measures) in palliative care settings. With the increasing emphasis on measuring patient outcomes in palliative care as seen in several PCOC implementation as Australia or Ireland, the implementation of ePROMs can enhance the quality of life for patients and their families by enabling healthcare professionals to provide better care.(5,6)

2.5 Objectives and contents of this thesis

The overarching topic of this thesis is the implementation of digital patient reported outcome measurement in German specialist palliative home care. While the first publication presents a qualitative study about involving patients and professionals in the development of the digital PRO tool, the second paper describes the process of proving the measurement equivalence between the digital eIPOS and the original paper version. The

third paper, included as supplementary material, focusses on the use of eIPOS in SPHC care routine and offers insights to the health care professionals' perception of the tool. The results offer insights about the first successful implementation of ePROM in German SPHC. In the following paragraph, the chapters of the main publications of this thesis are briefly introduced:

Chapter 5 refers to a qualitative interview and focus group study with SPHC patients and professionals identifying challenges in the development of eIPOS.

Chapter 6 refers to a randomised-controlled trial proofing the measurement equivalence between the paper-based IPOS and its electronic adaptation eIPOS. Following the ISPOR recommendations, the results show a nearly perfect concordance for most of the items.

Chapter 7 refers to the article in the appendix which offers insights in the health care professionals' perspective on the use of eIPOS in SPHC clinical care routine. This sequential mixed-methods study contributes findings regarding the feasibility of ePROM in palliative home care from a stakeholder perception.

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3. Zusammenfassung

Aufgrund der zahlreichen Potenziale für gesteigerte Qualität, Effizienz, Sichtbarkeit und Patient:innenzentierung der Versorgung werden patient:innenberichtete Outcomes zunehmend strukturiert erfasst und zur Gestaltung der Versorgung verwendet. Im Zuge der fortschreitenden Digitalisierung des Gesundheitswesens wird auch patient:innenberichtete Outcome Messung (PROM) immer öfter digital umgesetzt. In der Spezialisierten Ambulanten Palliativversorgung (SAPV) wurde patient:innenberichtete Outcome Messung bisher weder papierbasiert noch digital standardmäßig angewendet. Ein international renommiertes und für zahlreiche Settings und Patient:innengruppen der Palliativversorgung validiertes Instrument zur strukturierten Erfassung von Symptombelastungen und Problemen ist die Integrierte Palliative Care Outcome Skala (IPOS). Diese Arbeit hat zum Ziel, die Entwicklung und Implementierung eines digitalen PROM (ePROM) unter Verwendung des IPOS für die SAPV zu untersuchen.

Dafür wurde zunächst in fünf am Projekt „Palli-MONITOR“ beteiligten SAPV-Teams eine explorative qualitative Studie durchgeführt, die umfassende Erkenntnisse zu Herausforderungen bei der Entwicklung der elektronischen Adaption des IPOS (eIPOS) und deren Implementierung in die Versorgungsroutine aufgezeigt (Artikel I): SAPV-Patient:innen testeten die Betaversion des eIPOS und berichteten in leitfadengestützten Interviews über ihre Erfahrungen mit dem Instrument. Mitarbeitende der SAPV diskutierten in Fokusgruppen die Grundidee des eIPOS und seine mögliche Implementierung in ihrer klinischen Praxis. Die Ergebnisse bilden Herausforderungen der Implementierung des eIPOS auf individueller (Patient:innen, Professionelle) sowie struktureller und organisatorischer Ebene ab. Auf individuellem Level wurde hinsichtlich der Verwendung des eIPOS der Allgemeinzustand der Patient:innen, ihre divergierende Digitalkompetenz und -ausstattung sowie Aspekte des technischen Designs des digitalen Fragebogen als herausfordernd identifiziert. Die Nutzung des eIPOS förderte die Reflexion der aktuellen palliativen Situation, was teils als empowernd, teils als belastend empfunden wurde. Die Ergebnisse auf Ebene der Professionellen betrafen den Prozess des Empfangens und der Nutzung von eIPOS-Informationen in die klinischen Versorgungsroutine. Auf organisatorischer und struktureller Ebene wurden herausfordernde Faktoren wie die potenzielle Untergrabung des etablierten 24-Stunden-Notrufs durch eIPOS identifiziert. Darüber hinaus betonen die Studienergebnisse das Potenzial von ePROM für Patient:innen in früheren Stadien oder weniger intensiven Stufen der ambulanten Palliativversorgung. Die Studie unterstreicht die Relevanz der Einbeziehung zentraler Stakeholder in Entwicklungsprozesse digitaler Gesundheitsinnovationen und betont die Notwendigkeit, dabei auch

die kulturspezifischen Rahmenbedingungen unterschiedlicher Versorgungssettings zu berücksichtigen.

Bei der digitalen Umsetzung eines Instruments zur strukturierten Erfassung patient:innenberichteter Outcomes wie des IPOS kann nicht automatisch davon ausgegangen werden, dass die psychometrischen Eigenschaften über die verschiedenen Anwendungsformen des Fragebogens gleichbleibend sind. Deshalb beschäftigt sich der zweite Artikel mit dem Nachweis der Messäquivalenz zwischen der validierten Papierversion der IPOS und ihrer digitalen Adaption eIPOS. Dazu wurde eine multizentrische randomisiert kontrollierte Studie durchgeführt, bei der fünfzig Palliativpatient:innen den IPOS in beiden Anwendungsmodalitäten mit einer 30-minütigen washout-Periode ausfüllten. Die Kohorte hatte ein medianes Alter von 69 Jahren (Spanne 24 – 95), die Teilnehmenden waren zu 56% männlich und hatten in 16% der Fälle keine onkologische Grunderkrankung. Die Anwendungsreihenfolge wurde randomisiert (elektronisch-paper n=26; papier-elektronisch n=24). Die Intraklassen-Korrelationskoeffizienten (ICCs) zeigten außergewöhnlich starke Übereinstimmung für den Gesamtscore (ICC 0,99, 95%-KI 0,98–1,00). Die am wenigsten robusten ICC-Werte wurden für die Symptome "Appetitlosigkeit" und "Schläfrigkeit" ermittelt (ICC 0,95, 95% CI 0,92-0,97). Von den siebzehn IPOS-Items erreichten neun ICCs über 0,98. Darüber hinaus zeigten alle Subskalen ebenfalls ICC-Werte über 0,98. Abgesehen von dem Subscore 'Kommunikation' (F_{mode} = 5,9, p = 0,019) wurden keine statistisch signifikanten Effekte für Ausfüllmodus, Ausfüllreihenfolge, Alter oder deren Interaktionen für die Gesamtpunktzahl von IPOS und seine Subskalen festgestellt. Die Mehrheit der Teilnehmenden (58%) bevorzugte den eIPOS. In der Teilnehmendengruppe der über 75-Jährigen bevorzugten 53% die Papierversion. Bei den Freitextantworten in den beiden Versionen wiesen lediglich drei Einträge bei der Frage nach Hauptproblemen und Sorgen Unterschiede auf. Die Ergebnisse liefern bei einer nahezu perfekten Übereinstimmung bei 17 von 21 Items den Nachweis der Messäquivalenz zwischen IPOS und eIPOS.

Auf Basis der bisher gewonnenen Erkenntnisse wurde der eIPOS in den Versorgungsalltag von vier SAPV-Teams implementiert. Der dritte Artikel im Anhang beschäftigt sich mit der Perspektive der SAPV-Mitarbeitenden auf die Implementierung und Nutzung des eIPOS im Versorgungsalltag, bei der Patient:innen ihre Symptombelastungen und Probleme regelmäßig durch den eIPOS erfassten, die Ergebnisse zeitnah digital in die elektronische Fallakte übermittelt wurden und so für die Versorgungsplanung zur Verfügung standen. Die Erkenntnisse wurden durch die Durchführung einer Studie im Mixed-Methods Sequential Explanatory Design gewonnen. Initial wurden alle Pflegekräfte & Ärzt*innen der vier SAPV-Teams, die den eIPOS nutzen eingeladen, ihre Erfahrungen

mit dem eIPOS in einem Online-Survey anzugeben. Divergierende oder unklare Ergebnisse der Umfrage wurden anschließend in zwei Online-Fokusgruppen diskutiert. Die Rücklaufquote des Online-Survey betrug n=32 (von n=52 eingeladenen Fachkräften); es wurden zwei Fokusgruppen (n=3; n=4) durchgeführt. Der eIPOS wurde von allen Teilnehmenden genutzt, wenn auch nicht von allen regelmäßig. Es wurden Verbesserungen der Versorgung wahrgenommen. Die teilnehmenden Teams unterscheiden sich stark hinsichtlich Organisationsstruktur und Versorgungsprozessen. Ein großer Einflussfaktor für die Haltung der Fachkräfte zum eIPOS war der individuell wahrgenommene Nutzungsaufwand. Hindernisse und Verbesserungsvorschläge wurden hinsichtlich technischer Aspekte, Setting, Implementierung in den Versorgungsalltag und Studienbedingungen identifiziert. SAPV-Fachkräfte sahen Potenziale des eIPOS wie Unterstützung des Symptomassessments, insbesondere im psychosozialen Bereich, und der Förderung einer patient:innenzentrierten Versorgung besonders bei Nutzung des eIPOS in frühen Stadien der ambulanten Palliativversorgung. Voraussetzung zur Entfaltung der Potenziale ist, dass der eIPOS in Arbeitsroutinen implementierbar ist und technisch eine bessere Wahrnehmbarkeit der Informationen unterstützt wird.

Die Anwendung des eIPOS in anderen Settings wie beispielsweise der allgemeinen ambulanten Palliativversorgung sowie die Einbeziehung versorgender Angehöriger in die Nutzung des eIPOS wird empfohlen.

Zusammenfassend bieten die Ergebnisse, die im Rahmen der Dissertation gewonnen wurden, ein umfassenden Erkenntnisgewinn zu unterschiedlichen Aspekten der Implementierung digitaler patient:innenberichteter Outcome Messung in der ambulanten Palliativversorgung. Auch bei Erfüllung formaler Kriterien wie dem Nachweis der Messäquivalenz der digitalen Adaption eines validierten papierbasierten Instruments existieren umrahmend zahlreiche weniger greifbare Herausforderungen, denen mit dem Ziel eine erfolgreiche Implementierung zu erreichen, begegnet werden muss. Diese für den Bereich der SAPV exemplarisch aufgezeigten Detailergebnisse unterstreichen übergeordnet die Bedeutung der Beteiligung relevanter Stakeholder in Entwicklungs- und Implementierungsprozesse digitaler Gesundheitsinnovationen sowie die Notwendigkeit, spezifische Versorgungskulturen zu verstehen und zu berücksichtigen. Digitalisierung im Gesundheitswesen ist ein unaufhaltsam fortschreitender Prozess, zentral ist nunmehr die partizipative Gestaltung dieses Prozesses, um Entwicklungen zum Wohle aller davon Betroffener zu gestalten.

4. Abstract

As the use of patient-reported outcome measures is proven to advance outcomes, quality, and effectiveness of care, its implementation in clinical care routine is fostered. The focus on patient-centred care of palliative care means that PROMs are also becoming particularly relevant in this setting. The integration of electronic patient-reported outcome measures (ePROMs) offers promising advantages over traditional paper-based methods, including improved efficiency, reduced patient burden, and enhanced data analysis capabilities. Moreover, the digital implementation of PROMs might be an option to meet organisational and structural barriers preventing successful application, especially in palliative home care. The Integrated Palliative Outcome Scale (IPOS) measures palliative care patients` symptom burden and problems in 17 items, using a holistic understanding of burden of physical symptoms as well as psychological, social and spiritual issues and practical problems. The project “Palli-MONITOR” was developing and piloting a system for ePROM in German Specialist Palliative Home Care (SHPC), using the electronic version of the Integrated Palliative Outcome Scale (eIPOS) as PROM-tool.

The aim of this thesis, therefore, is to investigate the implementation of ePROM is SPHC. Following the Medical Research Council (MCR) Framework for Complex Interventions, the first step in implementing an ePROM is to gain an understanding of barriers and facilitators in the implementation process (article I). Digital implementation of PROM questionnaires as eIPOS also require evidence about measurement equivalence between the paper version and its electronic adaption, as it cannot be assumed that the psychometric properties of PROM questionnaires are stable across the different modes of administration (article II). Implementing an ePRO system in clinical care routine demands a process of change wherefor involvement and attitude of stakeholders is crucial for its success. Feasibility and acceptance of the intervention therefore need to be explored through understanding the health care professionals (HCP) perspective regarding the implementation of the ePROM system in SPHC (article II, appendix).

In the first article, SHPC patients tested a beta version of eIPOS and shared their experiences and wishes about the development of the instrument in semi-structured interviews. SPHC professionals discussed challenges in developing and implementing the ePROM system for routine care in focus groups. Interview and focus group transcripts as well as field notes and postscripts were analysed using the framework approach. A multi-site randomised crossover trial with a within-subject comparison of the two modes using a washout period of 30 min was adapted in the second article, to test the measurement equivalence between the IPOS paper and digital version. The research design

of the third article employed a sequential explanatory mixed-methods approach (quantitative before qualitative study), containing an anonymous online questionnaire study before qualitative focus group discussions. Equivocal findings from the survey were deliberated upon in two focus group sessions. Descriptive and univariable statistics were used to analyse quantitative survey data, the framework approach was utilized for the qualitative analysis. Additionally, we used joint displays performing the integrated analysis of our quantitative and qualitative finding.

The findings presented in the first paper provide a comprehensive portrait of the challenges designing a digital PROM system for palliative home care at both the individual and organisational levels, reflecting both patients' and health care professionals' viewpoint. Patients outlined potential challenges associated with using electronic questionnaires due to their declining health as well as their internet familiarity and the technical design of eIPOS. Use of eIPOS prompted patients to contemplate their circumstances, some of them experienced this as burdensome. Results on the HCP level related to processes of receiving and using eIPOS information in clinical care procedures. On an organisational and structural level, challenging factors such as the possible subversion of the established 24/7 emergency call system through eIPOS were identified. Additionally, HCPs emphasised the capability of ePROM use for patients in less intensive levels of palliative home care. Our results published in the second paper confirm the measurement equivalence of IPOS and eIPOS: Fifty participants were assigned randomly to complete IPOS in two different modalities: electronic-paper (n=26); paper-electronic (n=24). The median age of the cohort was 69 years (range 24 – 95). Among the participants, 56% were male, and 16% presented with non-oncological diseases. The Intraclass Correlation Coefficients (ICCs) demonstrated exceptionally strong agreement for the overall score (ICC 0.99, 95% CI 0.98–1.00). The least robust ICC values were noted for the items 'Appetite loss' and 'Drowsiness' (ICC 0.95, 95% CI 0.92–0.97). Out of the seventeen items, nine exhibited Intraclass Correlation Coefficients (ICCs) exceeding 0.98. Additionally, all subscales also displayed ICC values surpassing 0.98. There were no statistically significant effects observed for mode, order, age, or their interactions on both the total score of IPOS and its sub scores, except for 'Communication' (F_{mode} = 5.9, p = 0.019). The electronic version was favoured by 58% of the participants. Within the subgroup aged 75 years and above, 53% expressed a preference for the paper-based IPOS. Notably, only three free-text responses regarding main problems exhibited discrepancies between the two versions. Results of the third article present the HCPs' perspective of the active use of an ePROM system in clinical practice. Invitations were extended to all HCP belonging to the four SPHC teams, totalling 52 potential participants. Of these,

n=32 HCP engaged in the survey, n=7 took participated the focus groups. HCP acknowledged the potential of incorporating ePROM within the realm of palliative home care. However, they emphasized that the feasibility of such implementation depends on its user-friendly nature and seamless integration into clinical care routine.

In summary, the findings presented in this thesis provide substantial understanding and evidence about different aspects of implementing an ePROM system in palliative home care. The thesis highlights the benefit of stakeholder involvement in the development and implementation process of digital health innovations and accentuates that the specific culture must be taken into account. In conclusion, the integration of ePROMs in (specialist) palliative home care has the potential to transform the way patient outcomes are measured and monitored. By utilising technology, HCP can gain valuable insights into patient experiences, symptom burden, and concerns, ultimately leading to more patient-centred and effective care, which might be anyway inevitable in times to come.

5. Paper I

“Challenges developing an electronic patient-reported outcome measurement for palliative home care: A qualitative interview and focus group study”

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Challenges developing an electronic patient-reported outcome measurement for palliative home care: A qualitative interview and focus group study

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Abstract

Background: Patient-reported outcome measures have the potential to improve outcomes, quality, and effectiveness of care. Digital use of patient-reported outcome measures could be an option to foster implementation in palliative care. The *Palli-MONITOR* study focused on developing and testing an electronic patient-reported outcome measure in specialised palliative home care. As part of this study, we examined setting-specific challenges for the development of the measure.

Aim: We aimed to identify and explore challenges for the development of electronic patient-reported outcome measures as standardised assessment in specialised palliative home care.

Design: Qualitative approach with semi-structured interviews and focus groups. Data were thematically analysed using the framework method.

Setting/Participants: Patients and professionals from five German palliative home care teams.

Results: Patients described potential problems in using electronic questionnaires due to their deteriorating health. Answering the electronic questionnaire encouraged patients to reflect on their current palliative situation, which was partly perceived as burdensome. Identified concerns and questions regarding the future roll-out of electronic patient-reported outcome measurement addressed the process of receiving and using the provided information in clinical care routine. Challenging factors on organisational and structural level were the potential undermining of the established 24-h emergency call system and the potential use for patients.

Conclusions: Our results provide a multifaceted picture of challenges developing electronic systems for patient-reported outcome measurement in palliative home care on the individual and organisational level. The study underpins the benefit of stakeholder involvement creating digital health innovations and emphasises the importance to therefore mind setting specific culture.

Keywords

Palliative care, patient-reported outcome measures, telemedicine, stakeholder participation

What is already known about this topic?

- Use of patient-reported outcome measurement in routine care has potential to enhance patients` outcomes, as well as quality and effectiveness of care
- Implementation of electronic patient-reported outcome measurement in palliative care is challenging and development requires integration of field specific aspects
- German specialised palliative home care varies broadly regarding clinical care routines and organisational structures

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What this paper adds?

- At the patient level, challenges for the use of electronic patient-reported outcome measurement were identified in terms of patients' current health status, their familiarity in using internet-enabled devices and the design of the electronic patient-reported outcome measurement instrument.
- To implement the use of electronic patient-reported outcome measurement in palliative home care, it is necessary to understand in which way health care professionals are able to receive and react to the information received via electronic patient-reported outcome measurements.
- Developing an electronic patient-reported outcome measurement tool for palliative home care requires a concept that supports existing organisational structures.

Implications for practice, theory or policy

- The development of digital health interventions such as electronic patient-reported outcome measurement must take the specific cultures of each setting into account.
- This study underpins the importance of including stakeholders as experts of their life-worlds in the development of new health technologies.

Background

The use of patient-reported outcome measures (PROMs) may have the potential to enhance effectiveness and quality of care by improving communication between patient and health care professionals, symptom monitoring, identification of unknown palliative needs and patient empowerment.[1–5] Despite official recommendations, the routine use of PROMs in palliative care is still insufficient.[4,6] A challenge for successful implementation of PROMs is to develop the tool according to setting specific requirements and conditions.[7] Additional barriers are health care professionals' concerns of being assessed by using the measures or their resistance against change.[7] It is known from previous studies in German specialised palliative home care and from other clinical disciplines that a digital realisation of PROMs (ePROMs) is an option to overcome health care professionals' fear of additional workload due to PROM implementation.[8,9] However, health care professionals suspect digital and standardised PROMs to cause a loss of personal contact as well as an inadequate/insufficient and one-dimensional symptom assessment.[10] Nevertheless, digital PROMs are increasingly researched and integrated in the development of care models. The European *MyPal project* is currently developing a digital patient-reported outcome system to support palliative care for paediatric and adult patients with blood cancer.[11] In Germany, the project *MySUPPORT* aims to implement PROMs in different palliative care settings via a web-based application.[10] However, little is known about the use of ePROMs in the community setting and in patients with complex symptom burden in home care. The project *Palli-MONITOR* focuses on the development and feasibility of an ePROM/electronic version of the Integrated Palliative Care Outcome Scale (eIPOS) in German specialised palliative home care.[12] For the suitability of ePROMs in this setting, user friendliness on the patient-level is paramount as they have to deal with illness-related limitations.[5] The decentral structures and high heterogeneity of German specialised palliative home care may include even more unrecognised challenges regarding the development of an ePROM for this setting.[13] In addition to the challenges on the structural and organisational level, the perspectives of stakeholders must also be considered for a sustainable implementation of ePROMs.[14] Therefore, the aim of this study was to identify and explore challenges in developing a feasible ePROM in the particular setting of specialised palliative home care prior to the roll-out.

Methods

Study design

We conducted a multi-centre qualitative interview and focus group study. According to social constructivist theory, we understand the world to be dynamic and socially constructed. As individuals` perspective of reality is shaped by their experiences and views, we consider the interpretative paradigm as an appropriate philosophical base exploring challenges developing health care interventions.[14,15] Reporting of this study is based on the COREQ Checklist.[16]

Intervention

The study is part of the project *Palli-MONITOR*, a multicentre, sequential mixed-methods, two-phase development and feasibility study (following the MRC framework: MRC-phase I), aiming to pilot the implementation of an ePROM system in five participating palliative home care teams (trial registration: ClinicalTrials.gov NCT03879668).[12]

IPOS is an internationally tested and widely used patient and proxy questionnaire for measuring palliative symptom burden and concerns of patients with advanced disease, asking in 17 items about the impact of physical, emotional, spiritual and practical issues on patients and their families.[17] The electronic version used in this study (eIPOS) was provided via an existing app/web-app for ePROM. During an introductory visit, the patients learned how to use eIPOS on their own web-enabled device, supported by the researcher (IBF), if necessary. Patients received patient-individual codes, and instructed to visit a website for the eIPOS, completing it 1–2 times a week for at least 2 weeks. They could choose between an overview version of the whole questionnaire or presentation of single questions (one question displayed per slide). As the objective of this sub-study was to understand stakeholder perspectives on the planned ePROM procedure, the electronic system was not set up to forward data in patient records and entered values were not forwarded to the clinical team at that time. Patients were repeatedly and at the end of each completed eIPOS made aware that the specialist palliative home care team will not receive the entered information.

Setting

The study was conducted in five specialised palliative home care teams in Bavaria, Germany. Two of the teams were located in an urban and two in rural regions, one team was located in a mixed urban-rural region. None of the teams used PROMs as standardised assessment at the time of data collection.

Population

Patient interviews: Inclusion criteria were (i) currently receiving palliative home care by one of the participating teams, (ii) not too distressed or ill to participate in the study (assessed by the clinical team), (iii) sufficiently fluent in German, and (iv) the use of an own web-enabled device.

Focus Groups with health care professionals: Participation was possible for (i) physicians and nurses working in the participating teams and (ii) being sufficiently fluent in German.

Recruitment and sampling

Patient interviews: Patients were recruited from the participating teams and purposively sampled according to the following criteria: age (−60/ 60–75/ 75+), sex (f/m/d), region (urban/urban-rural/rural), technical experience (beginner/advanced; assessed by the recruiting health care professionals).

Focus Groups with health care professionals: Participants were recruited in the participating teams, purposively sampled with the following criteria: profession (nurse/physician), sex, and region of their home care team.

All participants provided written informed consent.

Data collection

Patient Interviews: Impressions from the introductory visit regarding participants' use of internet-based devices or first reactions on the eIPOS were captured in field notes. Participants completed eIPOS repeatedly in a 1–2 weeks test phase and afterwards reported their experiences in a semi-structured interview. Interviews were conducted face-to-face (by IBF) in the participants' home. To avoid response bias, the patient and the interviewer were preferably alone. However, considering the potential vulnerability of the interviewee, the participant could also choose a family carer to be present during the interview.

The interview guide covered questions on patients' experiences testing the eIPOS regarding preferred frequency of eIPOS-use, technical challenges, handling of the device in relation to the patient's condition; impact of completing eIPOS on patients' emotional state, and opinion about the current design of eIPOS. Discussions with health care professionals from the participating teams and researchers' impressions (IBF, AB) from field observations during their site visits supported the development of the interview guide. Additional methodological experts/ researchers and a patient and public involvement (PPI) group supported its further development. We assumed to reach data saturation with 20 interviews, as this number would allow covering the scope of our purposeful sampling, considering criteria of age and sex of the participants, as well as the region (urban/rural) of the responsible SHPC-team.

Focus Groups with health care professionals: Due to geographical distances between some of the teams, we planned to conduct two focus groups in two different regions. One site was chosen to ensure short travel for health care professionals of the urban teams, the other focus group was located to be reached easily for health care professionals of the rural teams.

As the participants did not have any own experience with eIPOS at the time of the focus groups, a short input illustrated the basic idea of eIPOS and its conceivable implementation in clinical practice. The focus group guide covered questions on possible challenges, potentials, and acceptance of electronic monitoring of patient reported palliative care needs in specialised palliative home care.

Interviews and focus groups were audio-recorded and transcribed verbatim using anonymisation by a professional transcription office. Additionally, the researcher (IBF) noted for each interview and focus group impressions of the recorded situation and relevant information expressed outside the audio recording in postscripts.

Data analysis

The data corpus included the transcripts of interviews and focus groups, postscripts, and field notes covering the introductory patient's visit. We conducted thematic analysis using the framework approach.[18] Our framework was developed following a deductive-inductive approach. Initial categories based on former knowledge and the research question were deductively applied to the data corpus, followed by an inductive identification of additional categories and subthemes.[19] Two researchers (IBF, AB) tested the primary matrix considering inter-coder-reliability and subsequently adapted the structure of the framework. Each step of the analysis process was accompanied by regular multidisciplinary team meetings. MAXQDA® v.2018.2 was used for data management.

Ethics

Ethical approval was obtained from the Research Ethics Committee of the Ludwig-Maximilians-University Munich (Ref: 18-815). With respect to the partly very vulnerable sample (interviews with patients), we considered ethical aspects regularly, also jointly with the participating teams. To avoid unreasonable burden, voluntary nature of participation was repeatedly emphasised throughout the research process and participants were encouraged to leave the study if they showed signs of distress.[20]

Results

Patient interviews

From March to October 2019, we recruited 21 patients for the study. Seven patients declined the introductory visit due to deterioration. The introductory visit was conducted with 14 patients. Afterwards, two patients decided not to participate in the interview and testing phase because their health deteriorated, and one patient declined to participate after reading the eIPOS questions. Eleven patients completed the testing phase of eIPOS and were interviewed subsequently. Additionally, two patients refused to participate in the testing phase and interview but allowed the researcher (IBF) to use the field notes from their introductory visit. For participants' details see Table 1.

Table 1. Interviews with patients – details and participants.

Number of participates: introductory visit; *n*	13
Number of participates: testing phase & interview; *n*	11
Duration interviews; media (range)	
min	23(15–50)
Main diagnosis; *n(%)*	
oncological	7(64)
Nnon-oncological	4(36)
Gender, *n(%)*	
Female	5(45)
Male	6(55)
Age (Years), *n%*	
−60	6(55)
60–75	2(18)
75+	3(27)
Techinical support by family care giver, *n(%)*	1(19)
Internet-enabled device used in testing phase, *n(%)*	
Smartphone	4
Tablet	1
Laptop	3
PC	3
Region; *n(%)*	
Urban	3(27)
urban-rural	3(27)
rural	5(45)

Table 2. Focus groups with professionals – details and participants.

Focus group	1	2
Number of participates; *n*	5	7
Duration, *min*	61	80
Gender, *n(%)*		
Female	3 (60)	7 (100)
Male	2 (40)	0 (0)
Profession, *n* (%)		
Nurse	4 (80)	5 (71)
Physician	1 (20)	2 (29)
Region; *n* (%)		
Urban	5 (100)	0 (0)
urban-rural	0 (0)	1 (14)
rural	0 (0)	6 (86)

Focus groups with health care professionals

In summer 2019, we conducted two focus groups. Twelve health care professionals from the five participating teams involved in the overall project participated (see Table 2). Details of health care professionals are not further specified due to risk of identification.

Our framework organised the inherent information from the data corpus in seven deductively developed categories (see Figure 1).

In a further step we systematised our findings and present them as challenges in developing an ePROM from the perspectives of patients or health care professionals. These are complemented by challenges related to basic organisation and structure of the home care teams (see Figure 1).

Challenges at patient level

Identified challenges at patient level in all categories are reported below.

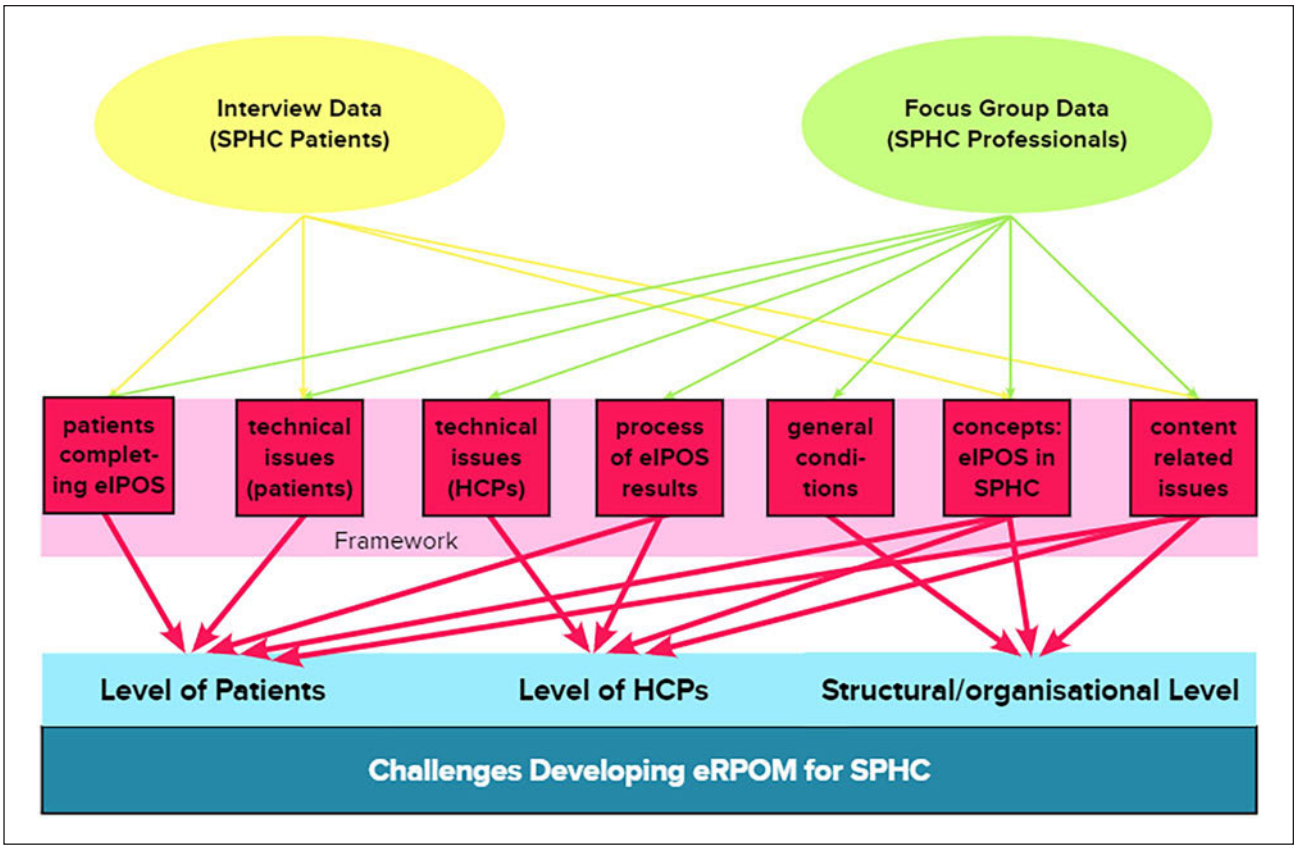

Figure 1. Data base, framework and structured reporting of challenges developing ePROM for SPHC.

ePROM-use depending on current condition: health care professionals expressed concerns that many of their patients might not be able to use eIPOS on their own, due to high symptom burden very poor general condition or other illness-related limitations.

> *Now when I take a closer look, I find it difficult to find patients who are able [to use eIPOS]. There are many who are no longer able to do this.*
>
> (Health care professional 1)

Health care professionals' concerns that patients' condition might not allow independent ePROM use were mirrored in the difficult recruitment process for the patient-interviews. In the focus groups, a repeatedly proposed solution to this challenge was to involve relatives in the use of eIPOS. Patients indicated that the actual act of completing eIPOS depends on their current health state. One patient described that he completed eIPOS especially when he felt unwell to document or communicate this. Other patients tended only to use eIPOS on 'good days', everything else would mean too much burden in situations where they are confronted with, for example, intense pain, severe vomiting, or psychological problems. Patients in a more stable condition and/or with non-oncological diseases preferred a lower frequency of eIPOS use, because they felt that noteworthy changes were not as frequent.

Patients' challenges in eIPOS-use connected with internet familiarity and technical design: Patients also reported challenges using eIPOS on their own web-based device. Although the inclusion criteria stipulated the patients' use of an internet-enabled device, participants reported problems with opening eIPOS, ticking the answers or electronically submitting the questionnaire. Some patients forgot how to open the internet browser on their device or did not find the field where to add the personal code for opening eIPOS. For submitting the completed questionnaire, patients had to use a specific button at the end of eIPOS. Participants often oversaw this button and consequently did not send the completed questionnaire. Another challenge using eIPOS on smartphones was that due to the small display size, some patients had difficulties in ticking the correct answer boxes on the touch screen.

Patients also commented on the design of the eIPOS and preferred an overview of the whole questionnaire rather than presentation of single questions (one question displayed per page). One reason for this was that using the single question version, some patients felt

burdened by the length of the questionnaire. Furthermore, participants tended to be confused when seeing eIPOS for the first time during the introductory visit and/or had problems to understand the questions.

> *Personally, I find this overall version more useful because I can read through it straight away and then I have an overview. Then I know, aha, I can write that [symptom] in there, write that in here, write that in there.*
>
> *(Patient 10, 55 years)*

Another reason for preferring the overview-version was the desire to re-check the previous questions and answers or the following items to decide whether to quote a specific symptom burden or palliative need with this question or whether it might fit better in another place. Furthermore, some patients felt burdened by the list of potential symptoms, even not experiencing them.

Effects on patients: Already completing the eIPOS had an impact on patients - even without forwarding the results to the teams. Some patients perceived the regular use of the electronic questionnaire as a task they had to fulfil and as an additional activity they had to integrate into their daily routine characterised by the terminal situation. A patient described that she was annoyed by the regular task of completing the eIPOS. Further challenges for patients were the necessity of getting out of bed to sit in front of the computer for completing eIPOS if they did not use a smartphone or tablet. Also, participants felt it required a quiet and unescorted moment confronting themselves with the questions of eIPOS.

Completion of eIPOS focussing on physical, psychological, social, and spiritual dimensions requires patients to engage in a holistic process of reflection of their current situation. Some participants appreciated this effect, reporting that this reflection helped them to cope with the current symptom burden by focussing and noting it on eIPOS or by applying appropriate self-help measures afterwards:

> *'Because then I also thought, man, how were the last three days, that I reflect a bit. I thought that was good. And somehow, I am a bit more precise with, uh, that I think about what was a main problem or a concern and what was a symptom. [. . .] I think this is good, because only through this can I somehow, yes, deal with it or, yes, heal, (laughs) no, not heal, but go into acceptance or see that I really do something. Heat pads or whatever'*.
>
> (Patient 4, 58 years)

Other participants described how they tried to supress their current situation as much as possible in everyday life and that using eIPOS undermined this coping strategy. One potential participant refused the use after reading the questions of eIPOS in the introductory visit, pointing out that he was not willing to be '*rudely*' directed regularly to his situation by the questionnaire.

Challenges of ePROM use in specialist palliative home care: health care professional level

In the focus groups, health care professionals discussed various challenges connected to the uncertainties regarding the actual implementation concept of eIPOS in concrete clinical practice. General concerns were that eIPOS might not bring any new information because of the close and intensive care relation between patients and health care professionals and that an electronic assessment system could not be used by many of their patients. Further challenges were linked thematically to the process of receiving the information electronically transmitted via eIPOS as well as to health care professionals' potential use of eIPOS information.

Concerns and requirements of health care professionals receiving eIPOS: Focus group participants raised the questions which health care professionals from the multidisciplinary team is responsible to assess the eIPOS-reported symptom burden and concerns and when this should happen. Most of them would prefer to receive new eIPOS information in the morning when daily planning is organised. Nevertheless, health care professionals emphasised that time resources are scarce then and reading out a comprehensive list of patient-reported symptom burden and problems in eIPOS might be challenging. They suggested a distinction between relevant symptoms and others that do not require immediate reaction from the team. Symptoms and problems reported via eIPOS like 'loss of appetite', 'feeling depressed' or 'practical problems' were assessed as non-urgent for current daily planning. Furthermore, health care professionals generally mentioned the fear to miss out patients' current need for support, if for some reason they do not check the documentation software for, for example, half a day:

> *But then the question is, do I notice it at all, am I on the computer or am I on a home visit?*
>
> (Health care professional 3)

To support reception process of eIPOS in the software itself, health care professionals expressed the need of a pop-up message indicating a new eIPOS. Moreover, most of the focus group participants asked for a warning signal in the software, highlighting patients with high values or deteriorating symptoms reported via eIPOS.

Another aspect is the interpretation of eIPOS information provided by the patients. Health care professionals

mentioned a process of assessing the reported values in context of their knowledge about the patients:

> *Mr. [name patient], if he has a two [*in the eIPOS-scale for self-assessing symptom burden; editors' note*], then I know, okay, that's a four. So, yes, you just know that, when you have visited him [. . .] several times and when you know him*.
>
> (Health care professional 2)

Furthermore, health care professionals emphasised that the eIPOS values are only able to give a hint and mentioned the need of further assessment to valid reported values and understand underlying needs.

Challenges – use of eIPOS information: Participating health care professionals discussed challenges how to react on eIPOS-reported values. One crucial aspect was how to deal with the potential expectation of patients to receive a prompt reaction:

> *The question is: [. . .] Is it really meant in such a way that we have to react directly on a reporting in the system? That is quite relevant. And what if it occurs at 2 o'clock in the morning? And what if at the weekend? How is it communicated to the patient?*
>
> (Health care professional 9)
>
> *The question is, when do you have to react and how?*
>
> (Health care professional 7)

Some focus group participants were unsure whether the team would be able to respond appropriately to all aspects returned in the eIPOS because of limited team resources, for example, psychological or spiritual support.

> Health care professional *3: And that means, I think, that we can't or won't take action about every single issue [*eIPOS-reported symptom burden or problem; editors` note*], I don't know, maybe it's sometimes better to let sleeping dogs lie*.
>
> Health care professional *2: That it is made clear that things are, um, inevitably, um, going down.*

These results also highlight that it might be challenging if patients notice that there is no response from the health care professionals regarding the reported symptom burden or problems.

Developing ePROM for specialised palliative home care: Challenges on the organisational and structural level

Organisational challenges: In the focus groups and some interviews, specific procedures of using ePROM in the daily care routine of palliative home care were reflected. Uncertainties related to the actual implementation concept of eIPOS in concrete clinical practice and that the ePROM-tool might reduce personal contact to the patients and undermine the existing 24 h-emergency call system. Another aspect pointed to the 3-day period used in eIPOS whereas some participating teams had daily contact with their patients.

> *The questionnaire asks for the last three days. Which symptoms in the last three days. If he has severe pain on day one, how can I tell if day one with severe pain has already been treated? [. . .] There was already medication on demand. There was already a visit, etc. How can I differentiate that, so that I don't have even more work to do?*
>
> (Health care professional 5)

Challenges related to structural preconditions: health care professionals emphasised that specialised palliative home care can only be provided for patients with complex symptom burden. Due to scarce resources teams give priority to patients in acute crisis and pause care for patients where the situations stabilise again:

> *But because we have become more of a crisis team, we are back to the point where we all say: Which patients are suitable for this [*eIPOS, editors` note*]? Because if they are so stable that they can or want to deal with something like that, they are actually so stable that we pause with the care*.
>
> (Health care professional 8)

Health care professionals suggested using ePROM in less intensive levels of care, which usually also mean less contact between the team and the patient: In this situation, eIPOS could serve as an indicator for increasing the intensity of care due to increasing symptom burden. Health care professionals recommended the shared use of ePROM across the different intensity level of palliative home care to support patients' changes between the services.

Discussion

Main findings

We aimed to identify and explore challenges for developing an ePROM for standardised assessment in specialised palliative home care. Our results draw a comprehensive picture of these challenges on patients' and health care professionals' level as well as on the organisational and structural level. Main findings regarding the patients' level are that the general use of ePROM in a status of deteriorating health is challenging, which was reflected in (i) the short time period patients are cared for by specialised

palliative home care, (ii) insufficient equipment with own web-enabled devices, and (iii) challenging recruitment of interview partners due to poor general condition. The health status of only a very small proportion of patients from the participating teams allowed participation in the testing phase of the eIPOS with an own web-enabled device. This correlates with previous studies in palliative care indicating that some patients' general condition might be too poor to use PROMs.[21–23] Our results suggest that this could be overcome for the setting of palliative home care by family caregivers using ePROMs as proxies, as it is already recommended for the implementation of paper-based PROM use.[9]

The poor health condition also hampered patients' participation in the qualitative interviews. As no new aspect emerged in the last two interviews, we concluded that data saturation was reached after the 11th interview to avoid burdening further interview partners.

Furthermore, our findings recommend ePROM use already in earlier stages of palliative home care and its use across the different services. This idea goes in line with identified need of electronic patient record supporting the share and exchange of information across different palliative care settings.[24] Corresponding to other studies our results demonstrate that using eIPOS enables reflective processes on patients' level.[1,25] However, this could also be a barrier to ePROM use in case of evoking negative emotions when faced with current or potential symptom burden. A study of the feasibility of paper-based PROMs in German specialised palliative home care identified health care professionals' concerns about burdening patients in this way.[9] In contrast, our results suggest that the use of ePROMs could also serve as a facilitator as it allows patients to better understand and express the perception of their illness.

Moreover, our findings illustrate how health care professionals in palliative home care imagine the process of receiving ePROM information and reacting to them. Corresponding to previous studies in specialised palliative care in the UK and various palliative care settings in Germany, we noticed a fear that ePROM-use could reduce personal interaction between patients and health care professionals.[10,21] Our findings about the low acceptance of ePROM by health care professionals doubting the potential benefits provide another challenge in implementing ePROM in palliative home care.[7,9,10]

Furthermore, the technical implementation regarding, for example, the design of the patients' questionnaire or the display of the ePROMs in the teams' documentation system, plays a crucial role for acceptance.[21] As the participating teams did not use standardised PROM assessment in daily care routine before, it might be possible that identified challenges relate generally to the routine use of standardised measurement of patient reported outcomes and not explicitly to its electronic realisation.

Beyond the individual or team level, our results confirm that digital innovations need to support, rather than undermine the existing organisation of clinical care and fit into structural preconditions, as shown in previous research.[26] In this regard, we consider the very divergent organisational structures in German specialised palliative home care as particularly challenging to develop a generally suitable ePROM system.

Strengths and weaknesses

Our qualitative approach supported explorative investigation of challenges for the development of a setting specific ePROM system. We managed to included later user groups in a participatory idea, as requested for studies focussing on digital health approaches.[27] As participants were recruited from five palliative home care teams, differing considerably regarding clinical care organisation, regional setting, and their collaboration with a network of complementary care structures, our results represent a broad spectrum of backgrounds and views.

Because the overall project followed the MRC framework[28] that recommends an exploratory study prior to implementing the intervention into clinical practice, only the patients had personal experience with eIPOS which could be seen as a weakness. Medical professionals had no experience with eIPOS at the time the focus groups were conducted. However, we attempted to mitigate this weakness by introducing the concept of eIPOS in the focus groups to bring all participants on the same level of knowledge. Furthermore, due to inclusion criteria the patient-related results represent only a (small) part of patients in the home care setting as only comparatively stable patients were included.

What this paper adds

This study provides stakeholder generated insights about challenges that should be faced when developing a field-specific electronic assessment system. This created the base for the following parts of the Palli-MONITOR-study following MRC phase 2 (feasibility/piloting) where the eIPOS-intervention was modelled based on the stakeholders' insights. Using the example of specialised palliative home care, our results demonstrate the need of an adaption of ePROM-tools to the setting – not only to the obvious structural conditions, but to something, what could be captured with the term of setting specific culture.[29]

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Author contributions

IBF: data collection, analysis, interpretation of data, led the writing process and drafted original article and reviewing for critically important content interpretation of data and reviewing for critically important content. AB: reviewing data for critically important content. KH: conceptualisation, supported the writing process. SK: conceptualisation, supported the writing process. FH: obtained funding, conceptualisation and design, supported the writing process, critical review of the final manuscript. CB: obtained funding, conceptualisation and design, supported the writing process, critical review of the final manuscript.

All authors take responsibility for appropriate portions of the content of this article.

Data sharing and management

Due to the high sensitivity of qualitative interview and focus group data, data is only available on reasonable request in German language.

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Supplemental material

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6. Paper II

“Measurement equivalence of the paper-based and electronic version of the Integrated Palliative care Outcome Scale (IPOS): A randomised crossover trial.”

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Measurement equivalence of the paper-based and electronic version of the Integrated Palliative care Outcome Scale (IPOS): A randomised crossover trial

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Abstract

Background: The Integrated Palliative Care Outcome Scale (IPOS) validly and reliably measures symptoms and concerns of those receiving palliative care.

Aim: To determine the equivalence of the paper version with an electronic version of the IPOS (eIPOS).

Design: Multicentre randomised crossover trial (NCT03879668) with a within-subject comparison of the two modes (washout period 30 min).

Setting/Participants: Convenience sample of specialist inpatient and palliative home care patients aged over 18 years with cancer and non-cancer conditions was recruited. Scores were compared using intraclass correlation coefficients (ICC), Bland-Altman plots and via a mixed-effects analysis of variance.

Results: Fifty patients were randomised to complete paper-electronic ($n = 24$) and electronic-paper ($n = 26$) IPOS with median age 69 years (range 24–95), 56% male, 16% non-cancer. The ICCs showed very high concordance for the total score (ICC 0.99, 95% CI 0.98–1.00), lowest ICCs being observed for symptoms 'Appetite loss' and 'Drowsiness' (ICC 0.95, 95% CI 0.92–0.97). Nine of seventeen items had ICCs above 0.98, as did all subscales. No statistically significant mode, order, age, and interaction effects were observed for IPOS total score and subscales, except for 'Communication' ($F_{mode} = 5.9$, $p = 0.019$). Fifty-eight percent preferred the electronic version. In the group 75+ years, 53% preferred the paper version. Only three entries in the free-text main problems differed between the versions.

Conclusion: The very high equivalence in scores and free text between the IPOS and the eIPOS demonstrates that eIPOS is feasible and reliable in an older palliative population.

Keywords

Palliative care, integrated palliative care outcome scale, mode of administration, agreement, crossover trial, patient-reported outcome measure

What is already known about the topic?

- The implementation of electronic self-reported versions may offer several advantages to palliative and hospice care, especially when fully integrated within an electronic patient health record or to help patients with sensory impairment.
- The typically older palliative population might pose a barrier to the electronic implementation of patient-centred outcome measures.
- Psychometric properties cannot be assumed stable across administration modes, necessitating a careful electronic adaptation of paper versions.

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What this paper adds?

- This randomised crossover trial in palliative patients showed the equivalence of scores between the self-completed paper and electronic version of the Integrated Palliative care Outcome Scale with near perfect agreement reached for 17 out of 21 items.
- No version took longer to complete. Overall, 58% preferred the electronic version. Only in the group of 75 years or older, slightly more than half preferred the paper version for self-completion.

Implications for practice, theory or policy

- The high agreement and good acceptability of the electronic version of the Integrated Palliative care Outcome Scale was achieved via careful early involvement of patients and staff within a co-design framework.
- Implementation of electronic assessment of patient-centred outcomes in palliative care is feasible once setting-specific barriers and facilitators are acknowledged and addressed in close collaboration with all stakeholders.

Introduction

Outcome measures are instruments that allow the assessment of change in a patient's health status over time. Due to their patient-centredness, they play an increasingly important role in palliative care. Outcome measures are central for identifying patients' needs, aiming at enhancing quality of life and the relief of suffering, and support evaluating the standard of care received.[1–3] In palliative care, both patient and staff-completed versions of outcome measures exist to enable outcome measurement at the end of life.[4–6]

One such outcome measure for palliative care is the Integrated Palliative care Outcome Scale (IPOS) that has been studied extensively over the past years and has seen many developments and adaptations to different settings, conditions and populations.[6,7] Next to the Edmonton Symptom Assessment Scale,[8,9] it is one of the most widely used measures in the field.[4,5,10,11] The IPOS assesses how much a patient is affected by symptoms, emotional concerns as well as communication and practical issues. The validity of the measure (in terms of structural validity, content, construct and criterion validity), its reliability and sensitivity to change have been demonstrated in several international studies for the inpatient, hospice, and specialist home care setting.[6,7,12,13]

The implementation of electronic self-reported outcomes may offer several advantages to the palliative care and the specialist home care setting in particular, such as low administration cost, scalability, adaptability on devices for those with sensory impairments, immediate automated analysis, and the possibility for full integration into an electronic patient record system.[14] The implementation in routine care could lead to shorter reaction times of staff to emerging symptoms/problems or crises, and ultimately to improved patient outcomes.[3] A few such systems for electronic capture with full integration of automated symptom monitoring have been established in oncology in recent years.[15] Only a handful of systems have been implemented in palliative care.[3,16–20]

Despite these advantages and their usefulness, electronic outcome measures are not commonly implemented in the palliative care setting, with only 25% of studies in palliative care and advanced oncology reporting using electronic versions.[5] Fearing the loss of personal contact while judging face-to-face interactions as more suitable in routine palliative care are named as the most important barriers.[21] A further barrier to electronic assessment in the home care setting may be that patients are typically older, and thus belong to a population with associated lower levels of computer and internet usage.[22–24] Moreover, psychometric properties of questionnaires cannot be assumed stable across administration modes,[25] and it is thus recommended to empirically evaluate score equivalence and accordance of modes.

We therefore conducted a randomised crossover trial to test the score equivalence of paper and electronic versions of the IPOS for individual items, subscale scores and the total score. We hypothesised equivalence between the two administration modes.

Methods

Study design

This study was a multicentre, randomised, single-blinded, two-arm crossover trial of 5 months' duration and is part of the project Palli-MONITOR, a multicentre, sequential mixed-methods, two-phase development and feasibility study (NCT03879668; https://clinicaltrials.gov/show/NCT03879668).[26] The study is reported in accordance with the CONSORT crossover guideline.[27] No changes to the original study protocol were made.[26]

The crossover design is the preferred design for establishing measurement equivalence between different modes of administration as per guidelines.[25,28,29] Patients were randomly assigned to two groups defined by the order of mode of administration (paper version of the IPOS first, group 'P-E' vs. electronic completion of the eIPOS first, group 'E-P').

Trial participants and settings

Participants either received specialised (five services) or general palliative home care (two services) or specialist palliative inpatient care at the university hospital's inpatient unit. Eight study sites in Bavaria, Germany, participated from May to September 2019 representing both an urban and rural palliative population. Eligibility criteria were aged 18 years with advanced and incurable malignant or non-malignant disease, the capacity to give written informed consent and being sufficiently fluent in German to complete both questionnaire versions. Exclusion criteria were cognitive impairment or being in a poor general condition or actively dying, as judged by the patient's clinical team. All patients who agreed to participate gave written informed consent. The study was approved by the Medical Institutional Ethics Committee of the University Hospital Munich (REC ref no: 18-871). No further ethical issues emerged during the study.

Interventions and procedures

Patients were screened consecutively for inclusion in the study. Eligible patients, who agreed to share contact details, were contacted by the study team, and informed about the study. If they were interested to participate, a member of the study team contacted them in person to give more information and take written informed consent. Patients were assigned a seven-digit identification number. Allocation to administration order was done by the principal investigator, based on a computer-generated 1:1 schedule (enuvo).[30] The patient then completed both paper IPOS and eIPOS in randomised order, with a 30-min washout period between administrations. The washout period was optimised to the palliative care setting, striking a balance between fluctuating symptom burden, and mitigating recall bias and carry-over effects. Both modes were completed in one visit lasting 45–60 min.

Neither the clinical staff nor the participants were blinded to the result of the randomisation. The statistician conducting the analysis was blinded to group allocation. Assignment to trial arm was concealed on a paper until written informed consent was obtained from participants.

The IPOS is a short 17-item outcome instrument to assess palliative-care related symptoms and concerns in generalist and specialist PC settings.[6,7] The items cover physical symptoms (e.g. pain, shortness of breath, fatigue etc.), emotional concerns (patient and family anxiety, depression, feeling at peace), and communication & practical problems (sharing feelings, information needs, practical problems). Patients can designate their three main symptoms and problems as well as name and rate additional symptoms not included in the symptom list. All closed items are scored on a 5-point Likert scale ranging from 0 'not at all' to 5 'overwhelmingly'. A sum score of all items and three subscale scores can be calculated.[6,12] The paper IPOS can be obtained from www.pos-pal.org.

We used the paper-based, setting-specific 3-day or 7-day recall version of IPOS validated for the German context.[6] Its electronic adaptation was developed to resemble the paper version as closely as possible based on results from an interview study with patients testing a pilot version.[26] For free-text items, patients could enter symptoms and problems in short-answer boxes. Rated items on the IPOS could be answered by selecting the appropriate box on the five-point Likert scale. The eIPOS was provided on all operating systems (Apple, Windows, Android) and devices (e.g. laptop, computer, tablet, smartphone). Navigation buttons at the end of each screen allowed navigation through the questionnaire. Participants could progress to the next item without answers being mandated in eIPOS.

Data collection

For concordance, all answers to open-text and closed items on the IPOS were recorded for both the paper and eIPOS version. The time to complete was taken after each administration. Preference was asked using a closed question. Socio-demographic data included age, gender, nationality, main diagnosis, main care provider, device and operating system used and general use of electronic devices (daily, several times per week, once per week, less than once a week).

Statistical analysis

Sample size. With a power of 80%, a target intraclass correlation coefficient (ICC) of 0.9 and a significance level of $\alpha = 0.05$, the calculated sample size is 47. Considering possible dropouts, it was planned to include 50 participants.

Data analysis. Data management and analyses were conducted with SPSS 27[31] and R 4.0.[32] Data are described via means and standard deviations (SD) for continuous and absolute frequencies and percentages for categorical variables. All data is presented for the whole sample and separately per trial arm. The distribution of scores for quantitative items is compared graphically and via the percentage of floor or ceiling effects (>15% of participants scoring the lowest or highest response option)[33] between the modes. A mixed-effects 2×2 analysis of variance model was used to assess mode effect (within-subject factor), order effect (between-subject factor) and the mode $\times$ order interaction effect. A significant order and interaction would indicate carry-over effects. Additionally, age was fitted as a covariate to evaluate any statistically significant mode $\times$ age effect. Four univariate

mixed-effects models were run with IPOS Total Sum score, IPOS subscale scores and time to complete as dependent variables.

Following guidelines and other research,[25,34–36] the concordance of the IPOS and eIPOS was evaluated using intraclass correlation coefficients (two-way mixed effects model for absolute agreement) with 95% confidence intervals, ranging from 0 to 1, for all individual IPOS items and the subscales and total score. An ICC of >0.90 was considered indicating excellent agreement.[37,38] Prevalence- and bias-adjusted kappa coefficients were additionally used to take possible bias between modes and distributional floor and ceiling effects into account.[39] To assess the magnitude of possible systematic error, we also present the mean difference of scale scores between modes. Data were evaluated graphically by Bland-Altman plots.[40] The score difference (paper minus electronic) was plotted against the average paper and electronic score for each individual, including 95% limits of agreement calculated by $1.96 \times SD_{difference}$. Any systematic bias is thus separated from random measurement error.

A statistical significance level of 5% was used for all analyses. Missing items were imputed with the scale's median. A sensitivity analysis with the imputed data did not produce different results due to the very low rate of missing data.

Results

Participants

A total of 66 eligible patients were invited to participate. Of these, 50 accepted the invitation and were randomised to either 'paper-electronic (P-E)' or 'electronic-paper (E-P)' order. Of those participating in the trial, almost all patients completed all items in both versions. Only one score on the item *Poor mobility* was missing for the paper version, and one score for the item *Sharing feelings* was missing for eIPOS. The trial flow is shown in Figure 1.

There were no significant differences between those allocated to the two orders. The mean age of participants was 67.9 years (SD: 13.6), 56% were male. Demographic details are given in Table 1. Participants accessed the eIPOS most commonly on a tablet (68%), followed by laptop (16%) and PC or mobile phone (8%, respectively). Slightly over half of the sample used their device daily, 6% only used it less than once per week.

Descriptive statistics

Descriptive statistics for the distribution of scores on the IPOS and the eIPOS are provided in Table 2. The mean and median scores between the two modes only differed in the first decimal. Small consistent differences existed for the proportion of floor and ceiling effects with the eIPOS showing a slightly smaller proportion of floor effects in four symptom items, two of the four emotional subscale items, and all Communication & practical problems subscale items. The score distribution is presented graphically in Supplemental Figures 1 and 2 for the IPOS and the eIPOS. Fifty-eight percent of patients preferred the electronic version, 40% the paper version.

Mode equivalence

The mixed-effects analysis of variance with mode and order as the two main effects showed mean differences of −0.1 for the IPOS subscale scores and −0.3 for the IPOS total score when comparing the IPOS to the eIPOS. Table 3 shows that all mode and order effects as well as interaction effects were statistically non-significant, except for a statistically significant mode effect for the IPOS Communication & Practical problems subscale (F ($2,48$) = 5.9, $p < 0.019$). None of the mode $\times$ age interaction effects were statistically significant. Table 4 presents results for the outcome mean time to complete for both modes. There was no statistically significant order, mode, or interaction effect for time to complete. However, the paper and electronic versions differed significantly between age groups with patients aged 60 years or younger requiring the shortest time to complete both modes.

All ICCs for the comparison of IPOS and eIPOS were $\geqslant 0.95$ (see Table 5). *Appetite loss* and *Drowsiness* presented the lowest ICCs with 0.95 (95% CI: 0.92; 0.97). *Constipation* and *Feeling not at peace* (spiritual concerns) had ICCs of 0.96 (95% CI: 0.94; 0.98). Four items (*Family anxiety*, *Feeling depressed*, *Fatigue*, *Nausea*) had ICCs of 0.97 (95% CI: 0.95; 0.98). All other items showed ICCs of 0.98 or above. The lowest kappa score was found for *Drowsiness* ($\kappa = 0.78$), followed by *Appetite loss* and the IPOS Emotional concerns subscale with $\kappa = 0.82$, respectively. Nine items, two subscales and the IPOS total score showed κ above 0.92.

Bland-Altman plots for the three subscales and the IPOS total scores for the comparison of paper version and eIPOS are presented in Supplemental Appendix 2. The systematic bias was largest for the IPOS total score with mean difference −0.13 (limits of agreement: −3.14; 2.89), followed by the IPOS Communication & Practical problems subscale ($M_{diff} = -0.10$, limits of agreement: −0.69; 0.49). The IPOS Emotional concerns subscale showed a systematic bias of −0.08 (limits of agreement: −1.61; 1.45). The IPOS Physical symptoms subscale was measured without a systematic bias between the modes ($M_{diff} = 0.00$, limits of agreement: −1.94; 1.94).

Concordance of free-text answers

Thirteen participants overall did not volunteer any free-text main problems. Of those indicating main problems, 81% showed exact concordance of answers. Volunteered

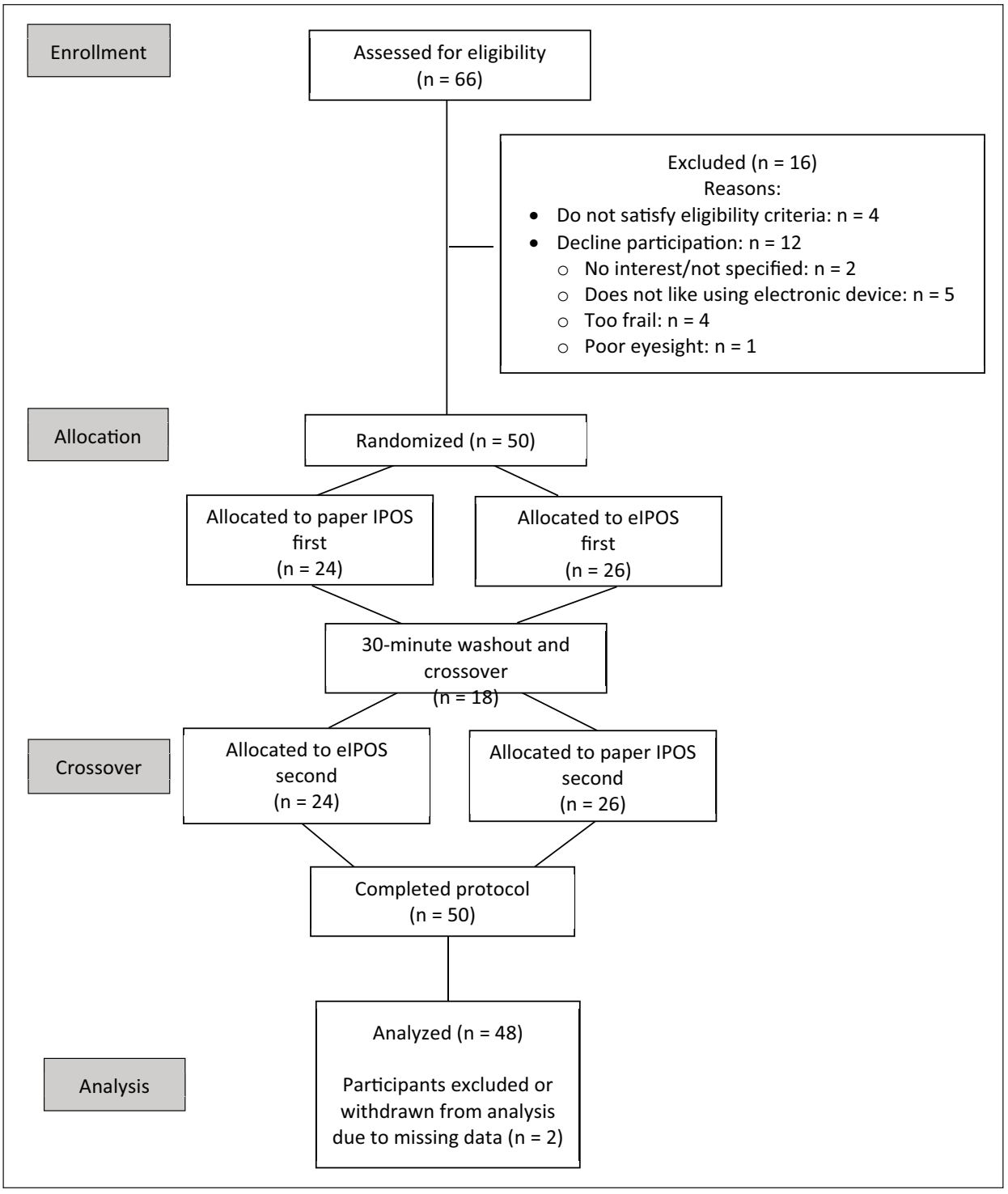

Figure 1. Flow diagram for crossover trial of paper versus electronic version of IPOS in palliative care.

problems were mainly physical symptoms. Four persons volunteered different problems in the electronic version and three changed the order of main problems.

Twelve patients volunteered additional symptoms at the end of the IPOS symptom list. The concordance was nearly perfect, with one person scoring one symptom differently.

Discussion

Main findings/results of the study

The results of this randomised crossover trial indicate highly comparable and concordant responses between the paper version of IPOS and the eIPOS, at the total

Table 1. Demographic and clinical characteristics of study participants (*n* = 50).

	All (*n* = 50)	Paper IPOS first (*n* = 24)	eIPOS first (*n* = 26)
Age, years			
Mean ± SD	67.9 (13.6)	68.4 (13.3)	67.4 (14.2)
Median (IQR)	69 (60–77)	67 (60.25–78.5)	71 (56.5–76.25)
⩽ 60 years	13 (26)	6 (25.0)	7 (26.9)
61–74 years	20 (40)	11 (45.8)	9 (34.6)
75 + years	17 (34)	7 (29.2)	10 (38.5)
Sex			
Male	28 (56.0)	14 (58.3)	14 (53.8)
Female	22 (44.0)	10 (41.7)	12 (46.2)
Nationality			
German	44 (88.0)	21 (87.5)	23 (88.5)
Other	6 (12.0)	3 (12.5)	3 (11.5)
Diagnosis			
Cancer	42 (84.0)	20 (83.3)	22 (84.6)
Non-cancer	8 (16.0)	4 (16.7)	4 (15.4)
Cancer: Digestive organs	10 (20.0)	6 (25.0)	4 (15.4)
Respiratory tract	5 (10.0)	3 (12.5)	2 (7.7)
Genitourinary tract	9 (18.0)	5 (20.8)	4 (15.4)
Breast	8 (16.0)	4 (16.7)	4 (15.4)
Lymph/Haematopoietic	1 (2.0)	0 (0)	1 (3.8)
Brain	4 (8.0)	1 (4.2)	3 (11.5)
Other cancer[a]	5 (10.0)	1 (4.2)	4 (15.4)
Non-cancer: COPD or ILD	3 (6.0)	1 (4.2)	2 (7.7)
Renal failure	2 (4.0)	1 (4.2)	1 (3.8)
Heart failure	2 (4.0)	2 (8.3)	0 (0)
Other non-cancer[b]	1 (2.0)	0 (0)	1 (3.8)
Setting			
Inpatient palliative care	22 (44.0)	11 (45.8)	11 (42.3)
Specialist palliative home care	22 (44.0)	10 (41.7)	12 (46.2)
General home care service	6 (12.0)	3 (12.5)	3 (11.5)
Device			
PC	4 (8.0)	1 (4.2)	3 (11.5)
Laptop	8 (16.0)	2 (8.3)	6 (23.1)
Tablet	34 (68.0)	18 (75.0)	16 (61.5)
Mobile phone	4 (8.0)	3 (12.5)	1 (3.8)
Operating system			
Apple	34 (68.0)	19 (79.2)	15 (57.7)
Windows	11 (22.0)	3 (12.5)	8 (30.8)
Android	5 (10.0)	2 (8.3)	3 (11.5)
Use of electronic or mobile devices			
Daily	26 (52.0)	13 (54.2)	13 (50.0)
Several times per week	9 (18.0)	4 (16.7)	5 (19.2)
Once per week	2 (4.0)	0 (0)	2 (7.7)
Less than once per week	3 (6.0)	1 (4.2)	2 (7.7)
Never	10 (20.0)	6 (25.0)	4 (15.4)

[a]Other cancers: Thyroid cancer, Ewing sarcoma, Pharynx cancer, Melanoma, [b]Other non-cancer: Unspecified non-cancer condition.
COPD: chronic obstructive pulmonary disease; eIPOS: electronic version of IPOS; ILD: interstitial lung disease; IQR: interquartile range; IPOS: Integrated Palliative care Outcome Scale; PC: personal computer; SD: standard deviation.

score, the subscale scores, and the individual item level. Mean summary and subscale score differences were very small (<1% of score ranges) and non-significant throughout all analyses. ICCs between paper and electronic scores were very high, significant and all exceeded the cut-off of >0.90.[24,25,28,29] *Appetite loss*, *Constipation*, *Drowsiness* and *Feeling not at peace* showed the lowest ICCs in comparison to other items, the subscales, and the total score.

Table 2. Sample statistics for the paper and electronic IPOS versions (n = 50).

	Paper IPOS				eIPOS			
	Mean (SD)	Median	% floor	% ceiling	Mean (SD)	Median	% floor	% ceiling
Pain	1.9 (1.1)	2	12	8	1.9 (1.2)	2	14	8
Shortness of breath	1.2 (1.3)	1	44	2	1.3 (1.3)	1	42	4
Fatigue	2.6 (1.1)	3	8	22	2.6 (1.1)	3	6	24
Nausea	1.3 (1.2)	1	36	6	1.2 (1.2)	1	36	6
Vomiting	0.7 (1.1)	0	64	4	0.7 (1.1)	0	64	4
Appetite loss	1.6 (1.3)	2	30	8	1.6 (1.3)	2	26	8
Constipation	1.2 (1.4)	0	52	8	1.3 (1.4)	1	46	8
Dry mouth	1.4 (1.3)	1	34	6	1.4 (1.3)	1	34	6
Drowsiness	2.2 (1.1)	2	8	8	2.2 (1.1)	2	10	10
Poor mobility	2.9 (1.1)	3	4	34	2.8 (1.1)	3	4	30
Patient anxiety	2.4 (1.3)	2	12	22	2.4 (1.2)	2,5	6	20
Family anxiety	2.9 (1.0)	3	2	32	2.9 (1.0)	3	2	34
Depressed	2.2 (1.3)	2	12	18	2.2 (1.2)	2	12	14
Not at peace	1.2 (1.0)	1	18	4	1.3 (0.9)	1	12	2
Sharing feelings	0.8 (0.9)	1	42	2	0.9 (0.9)	1	40	2
Information needs	0.9 (0.9)	1	34	4	0.9 (0.9)	1	32	4
Practical problems	1.1 (1.2)	1	40	6	1.1 (1.2)	1	38	6
IPOS total score	28.4 (9.0)	28	4	0	28.7 (8.8)	29	4	0
IPOS Physical symptoms	17.0 (6.9)	16	8	2	17.1 (6.9)	17	8	2
IPOS Emotional concerns	8.7 (3.8)	8,5	10	18	8.8 (3.6)	9	10	14
IPOS Communication & Practical problems	2.8 (2.3)	3	44	2	2.9 (2.3)	3	40	2

eIPOS: electronic version of IPOS; IPOS: Integrated Palliative care Outcome Scale; SD: standard deviation.

Table 3. Results of mixed-effects 2 × 2 analysis of variance (Mode: Paper or electronic, Order: P-E vs. E-P, Interaction, Covariate: age) in n = 50 palliative patients.

	Paper IPOS	eIPOS	Mean of paired differences	F^a, p			
	Mean (SD)	Mean (SD)	P–E (SD_{diff})	Mode effect	Order effect	Mode × order	Mode × age
IPOS total score	28.4 (9.0)	28.7 (8.8)	−0.3 (1.9)	F = 1.3 p = 0.258	F = 0.8 p = 0.381	F = 0.3 p = 0.572	F = 0.8 p = 0.373
IPOS Physical symptoms	17.0 (6.9)	17.1 (6.9)	−0.1 (1.3)	F = 0.4 p = 0.511	F = 1.4 p = 0.244	F = 0.1 p = 0.808	F = 0.8 p = 0.377
IPOS Emotional concerns	8.7 (3.8)	8.8 (3.6)	−0.1 (0.7)	F = 0.5 p = 0.466	F = 0.1 p = 0.984	F = 0.2 p = 0.699	F = 0.0 p = 0.984
IPOS Communication and Practical problems	2.8 (2.3)	2.9 (2.3)	−0.1 (0.3)	F = 5.9 p = 0.019	F = 0.1 p = 0.957	F = 2.3 p = 0.137	F = 3.6 p = 0.062

[a]All degrees of freedom for the F ratio: 2, 48 (except for Mode × age interaction).
F ratios and p-values in bold are statistically significant on the 5% level.
eIPOS: electronic version of IPOS; F: F ratio; IPOS: Integrated Palliative care Outcome Scale; p: p-value; P-E: Mean difference between paper and electronic version of the IPOS; SD: standard deviation; SD_{diff}: Standard deviation of the difference.

The concordance extends to volunteered main problems and concerns as well as volunteered symptoms. The preference for the eIPOS was higher than for the paper version. A mode × age interaction effect was shown for the IPOS Communications & Practical problems subscale, and a significant age effect was shown for completion time.

What this study adds

Compared to studies assessing the concordance of paper and electronic versions of outcome measures in populations of patients with advanced diseases (mostly cancer),[36,41–44] our sample comprised older patients, an equal gender distribution with a more heterogenous disease variety due to its palliative sampling frame. Contrary to the age and gender bias in equivalence studies reported in general clinical populations,[24,45] a significant mode × age interaction effect was only observed for items *Sharing feelings with family/friends*, *Information needs* and *Practical problems*. Symptoms and emotional concerns were reported in equal manner between the modes. This shows that electronic adaptations of

Table 4. Results of mixed-effects 2 × 2 analysis of variance for outcome mean time to complete in *n* = 50 palliative patients.

		Paper IPOS		eIPOS			
	No. of patients	Mean Time	95% CI	Mean Time	95%	M_{diff}	95% CI
All patients	50	5.82	5.28, 6.36	5.81	5.19, 6.42	0.01	−0.22, 0.24
Patients by order of administration							
Order P-E	24	6.35	5.46, 7.24	6.21	5.19, 7.22	0.15	−0.26, 0.55
Order E-P	26	5.33	4.68, 5.97	5.44	4.68, 6.20	−0.12	−0.37, 0.14
Patients by age, in years*							
⩽60	13	4.35	3.39, 5.31	3.81	2.80, 4.81		
61–74	20	6.15	5.38, 6.92	6.13	5.32, 6.93		
75+	17	6.56	5.72, 7.40	6.97	6.09, 7.85		

CI: confidence interval; E-P: eIPOS first, then paper version; eIPOS: electronic version of IPOS; IPOS: Integrated Palliative care Outcome Scale; M_{diff}: Mean of the difference; P-E: paper version of IPOS first, then eIPOS.
*Paper version: Differences for time to complete among age groups: *F(2, 47)* = 6.7, *p* = 0.003; Electronic version: *F(2, 47)* = 11.9, $p < 0.001$.

Table 5. Spearman correlations, prevalence and bias adjusted kappa coefficients (PABAK), mean differences (with 95% confidence interval), intraclass correlation coefficients for the agreement between paper IPOS and eIPOS (*n* = 50).

	r_s	PABAK	M_{diff} (95% CI)	ICC (95% CI)
Pain	0.97	0.92	0.00 (−0.08; 0.08)	0.98 (0.98; 0.99)
Shortness of breath	0.99	0.96	−0.04 (−0.09; 0.02)	0.99 (0.99; 1.00)
Fatigue	0.95	0.88	0.00 (−0.10; 0.10)	0.97 (0.96; 0.98)
Nausea	0.98	0.92	0.04 (−0.04; 0.12)	0.97 (0.96; 0.98)
Vomiting	0.99	0.96	0.00 (−0.06; 0.06)	0.98 (0.97; 0.99)
Appetite loss	0.94	0.82	−0.06 (−0.18; 0.06)	0.95 (0.92; 0.97)
Constipation	0.96	0.86	−0.06 (−0.17; 0.05)	0.96 (0.94; 0.98)
Dry mouth	0.99	0.94	–0.02 (−0.09; 0.05)	0.98 (0.97; 0.99)
Drowsiness	0.89	0.78	–0.02 (–0.15; 0.11)	0.95 (0.92; 0.97)
Poor mobility	0.95	0.92	0.04 (−0.04; 0.12)	0.98 (0.97; 0.99)
Patient anxiety	0.97	0.88	−0.04 (−0.14; 0.06)	0.98 (0.97; 0.99)
Family anxiety	0.92	0.86	−0.02 (−0.13; 0.09)	0.97 (0.95; 0.98)
Depressed	0.93	0.88	0.02 (−0.10; 0.14)	0.97 (0.95; 0.98)
Not at peace	0.94	0.88	−0.04 (−0.14; 0.06)	0.96 (0.94; 0.98)
Sharing feelings	0.96	0.94	−0.06 (−0.13; 0.01)	0.98 (0.97; 0.99)
Information needs	0.97	0.98	−0.02 (−0.06; 0.02)	0.99 (0.98; 1.00)
Practical problems	0.98	0.98	−0.02 (−0.06; 0.02)	0.99 (0.99; 1.00)
IPOS total score	0.98	0.99	−0.13 (−0.57; 0.32)	0.99 (0.99; 1.00)
IPOS Physical symptoms	0.99	0.94	0.00 (−0.29; 0.29)	0.99 (0.98; 1.00)
IPOS Emotional concerns	0.98	0.82	−0.08 (–0.30; 0.14)	0.99 (0.98; 0.99)
IPOS Communication & Practical problems	0.99	0.94	−0.10 (−0.19; −0.01)	0.99 (0.99; 1.00)

CI: confidence interval; ICC: intraclass correlation coefficient; IPOS: Integrated Palliative care Outcome Scale; M_{diff}: Mean difference; PABAK: prevalence and bias-adjusted Kappa; r_s: Spearman's rho.

measures are possible despite the challenging palliative setting.

With the exception of one study in cancer patients,[44] equivalence studies report a higher preference for electronic versions of PROs for 52%–67% of the sample.[36,41–43] Since qualitative data is missing, this preference is not explained. Equivalence studies in general populations with non-advanced disease indicate that the preference of electronic outcome measures is strongly a function of age.[24,45] In palliative care, however, advanced illness and a traditional focus on delivering interventions via expert face-to-face communication coupled with a generally older population may hinder the successful implementation of electronic versions. A successful inclusion of self and proxy-reported electronic measures within an outpatient hospice population has been shown in the past.[17,46] It is also worth pointing out that electronic completion of outcome measures does not preclude face-to-face interaction and follow-up communication.

The level of concordance of the paper and electronic versions of a self-reported outcomes found in the present study was excellent. The agreement found was higher

than in similar studies testing the equivalence for quality of life and/or morbidity measures and showing acceptable to good ICCs of ⩾0.7,[41,43] or moderate to good agreement based on weighted kappa coefficients.[36,42,44] None of these cited studies, however, reached consistently high ICCs across both the total score and almost all subscale scores as we did in our study. Systematically reviewed features leading to high agreement have been coupled to randomised designs of shorter duration,[22,24,47] features clearly met in our study. High agreement may also be attributable to the deliberate early involvement of patients in the development of the electronic version via co-design. Additional research is needed to understand how visual factors contribute to high agreement between paper and electronic versions. To help older adults and/or those with peripheral neuropathy, qualitative evidence has also supported stylus or pen entry of data into electronic devices instead of the more common swipe-and-touch techniques.[48]

With the demonstration of high reproducibility and concordance between the two versions, the regular use of electronic IPOS in palliative home care may help harness the power of rapid, real-time assessment and feedback to patients and clinicians. This might also enhance interdisciplinary communication and care.[49,50] The setting itself need not be a barrier for the successful adoption of electronic versions.[51–53] However, implementation strategies need to recognise barriers and facilitators specific to the setting and a close collaboration with care teams is paramount.[49,54,55]

Limitations of the study

First, including only cognitively able patients might have resulted in a sampling bias, as up to 90% of palliative patients demonstrate some form of cognitive impairment before death.[56] Proxy-rated staff versions are available, but no proxy version for informal caregivers exists yet. Both should be tested for measurement equivalence when migrating to an electronic version. Second, the timing of assessments and selecting the appropriate washout period is a challenge in PC due to the fast-changing symptom burden specifically in inpatient populations as evidenced by often low to moderate test-retest reliability of measures.[6] Albeit we could not detect a significant order effect, these carryover effects cannot be excluded. The lower kappa values for the emotional subscale may point towards differences in interpretation of the underlying constructs being measured by the items and should be addressed in future studies on content and cross-cultural validity.[57]

Conclusion

Following the recommendations of the ISPOR guidelines, the results show that eIPOS is a valid and reliable measure in the palliative setting. Paper and electronic versions of the IPOS can be considered equivalent and interchangeable. This means a fundamental step towards a more widespread routine implementation of measures and their positive effects for the palliative home care setting. The challenge of using data from electronically implemented outcome measures effectively in routine clinical care remains, so that these measures can foster the patient-professional dialogue and help professionals deliver high-quality care.

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Author contribution

CB is the chief investigator and responsible for the design of this study. AB is the principle investigator and responsible for the conduct of this study. CB, FH, CR and AB conceptualised the study. SK, IBF and AB collected the data. SK and CR analysed the data. CR drafted the manuscript, with the support of AB, IBF, and SK. All authors provided critical feedback to the manuscript, read and approved the final draft.

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Ethics and consent

This crossover trial received research ethics approval from the local research ethics committee of the LMU University Hospital Munich (REC ref no: 18-871). All participants provided informed written consent. All study procedures adhere to the World Medical Association Declaration of Helsinki.

Data management and sharing

Due to data sharing restrictions set out by the ethics committee and the local data governance department, the full datasets used and analysed are only available from the corresponding author on reasonable request. R code for analyses can be obtained via contacting the corresponding author.

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Supplemental material

Supplemental material for this article is available online.

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7. Appendix: Paper III

“Implementing ePROM in specialized palliative home care:

the professionals‘ perspective – a mixed methods study”

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Implementing ePROM in specialist palliative home care: the professionals' perspective – a mixed-methods study

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Abstract

Background: Over the last decades, patient-reported outcome measures (PROM) have been developed for a better understanding of patient needs. The Integrated Palliative Care Outcome Scale (IPOS) is an internationally recommended PROM in palliative care. The validated electronic version of IPOS (eIPOS) was implemented in four German specialist palliative home care (SPHC) teams for use in everyday clinical practice. Patients reported symptoms and concerns via eIPOS, which were transmitted directly to the electronic patient record of the respective SPHC team.

Objectives: The aim of the study was to describe and explore the health care professionals' (HCPs') experiences regarding acceptance and use of eIPOS in clinical practice in SPHC.

Design: The mixed-methods sequential explanatory design comprised an anonymized quantitative online survey followed by qualitative focus groups.

Methods: The online survey asked in both closed and open questions for HCP's experience with eIPOS. Ambiguous results from the survey were discussed in two focus groups. Survey data were analysed with descriptive and univariable statistics, and the framework approach was used for qualitative data. In a further step, we conducted integrated analysis of quantitative and qualitative results using joint displays.

Results: All HCPs of the four SPHC teams ($n = 52$) were invited to participate. HCPs participating in the survey ($n = 32$) and the focus groups ($n = 7$) saw potentials for implementing ePROM in palliative home care – as far as it is technically easy to handle and can be easily integrated into clinical practice.

Conclusion: Successful use of ePROMs is affected by the possibility of easy integration into the teams' different structures and processes and the HCPs' perceptions of potentials regarding ePROM use in SPHC.

Registration. The study is registered on clinicaltrials.org (NCT03879668).

Plain Language Summary

The use of electronic patient-reported outcome measures in specialist palliative home care: what do professionals think about it? A mixed-methods study

Patient-reported outcome measures (PROMs) are short questionnaires developed to assess a patient's health status at a particular point in time. The Integrated Palliative Care Outcome Scale (IPOS) is such a questionnaire, and eIPOS is an electronic version of IPOS. IPOS asks about patients' symptoms and problems when they suffer from advanced diseases. We conducted this study to understand what health care professionals (HCPs) think about electronic PROMs (ePROMs) in palliative home care. We first asked the HCPs to answer questions in an online survey. Then, HCPs discussed the use of eIPOS in small discussion groups. This study design is called 'Mixed-Methods sequential design'. We found that all

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HCPs used the information they received through eIPOS – some frequently and some less often. Many HCPs see potential in using ePROMs to support care. For example, because ePROMs help them to understand patients' symptoms and problems better. However, they also pointed out that eIPOS needs technical improvement. Also, the procedures of eIPOS need to fit into the work routine of the palliative care team. The findings demonstrate the perspectives of HCPs on ePROM. These are valuable to understand how ePROM can be implemented in palliative home care. We can also learn about how to implement other digital tools in other settings of palliative care.

Keywords: electronic patient-reported outcome measures, palliative care, palliative home care, patient-reported outcome measurement, professionals' perspective

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Introduction

Health systems around the world are facing major challenges as the number of older people with multi-morbid conditions increases and the need for palliative care will rise.[1] To address the current challenges, variations in the quality of health care need to be approached by improving outcomes.[2] The best way to achieve this is to measure individual patient-centred outcomes.[3] Patient-reported outcome measures (PROMs) are validated questionnaires completed by patients to measure their perceptions of their own health status/well-being.[4] With the increasing adaptation of internet-enabled devices in our everyday life, electronic PROMs (ePROMs) appear as a feasible option to improve the quality of assessment and could play an important role in the development of new digital health interventions.[5] Electronic as well as classic PROMs can be used at a single point of time to support multiperspective assessment or regularly, to measure the effectiveness of care interventions or monitor health status. Use in palliative care settings shows that (e)PROMs can potentially foster person-centredness, patient empowerment, better communication and support identification of not recognized symptoms.[6–9] Exemplary instruments developed especially for palliative care include the Edmonton Symptom Assessment Scale,[10] the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative[11] or the Palliative Care Outcome Scale (POS).[12] The Integrated POS (IPOS), as a further development of the POS, is a widely recommended PROM in palliative care and validated in many languages as well as diverse palliative care setting.[13–16] When palliative care patients are no longer able to provide information about their palliative care needs, IPOS can be also used as proxy tool by professionals. It covers patients' main concerns, common symptom burden, patient/family distress, existential well-being, sharing feelings with family or friends, information received and practical concerns, in 17 items within a timeframe of 3 or 7 days.[14]

Given the afore-mentioned benefits of (e)PROM use, we conducted the project Palli-MONTOR ('Monitoring of palliative care needs in specialist home-based palliative care using an electronic version of the Integrated Palliative Care Outcome Scale', clinical trials NCT03879668), which aims to test the electronic version of the previously validated paper-based IPOS (eIPOS) in a German specialist palliative home care (SPHC) setting.[17,18] Multi-professional teams are typical for SPHC which provide end-of-life care for patients with complex symptom burden using a holistic and patient-centred approach.[19] Implementation means the systematic introduction of an innovation, using a planned process with the goal of integration into in daily care routine.[20]

Despite potential benefits, implementing innovations such as ePROMs holds various challenges. Dealing with stakeholders' resistance is one great potential barrier for the success of implementing change.[21] Thus, health care professionals (HCPs) and patients are important factors for the success of the implementation process in health care. Therefore, our study aimed to describe and explore the HCPs' experiences of using the eIPOS in everyday clinical practice in SPHC. The objectives of the study were: (i) the effort of eIPOS use, (ii) its implications on care as well as (iii) developed routines in clinical practice.

Materials and methods

Study design

Based on the taxonomy of Creswell and Plano Clark, a mixed-methods sequential explanatory design was chosen to gain deeper understanding of HCPs' perspective.[22] This mixed-methods study followed the guidelines for the design, implementation and reporting of findings of the good reporting of a mixed-methods study (GRAMMS).[23] First, a specially developed and anonymized online survey was addressed to all HCPs of the four SPHC teams participating in the overall project ($n=52$). To help interpret ambiguous results of the online survey, they were discussed with HCPs from the four participating SPHC teams in two online focus groups via zoom (see Figure 1). The details about the overall project 'Palli-MONITOR' are described elsewhere.[18] The overall project consists of phase I (development) and II (feasibility) following the Medical Research Council framework for complex interventions,[24] and the reported study was part of the feasibility phase. Briefly, the eIPOS was implemented in four SPHC teams without experience in PROM for use in clinical routine. Patients cared for by the teams reported their symptom burden and concerns via eIPOS. Values completed online were transmitted directly into the electronic patient record of the responsible SPHC team, and professionals were required to view the transmitted values before the next planed patient contact.

Setting and participants

Participating teams were recruited in scope of the overall study Palli-MONITOR. As SPHC provides holistic end-of-life care with symptom control and support regarding psychological, social or spiritual issues, multi-professional teams consist of nurses and doctors and partly additional professions like social workers, psychologists or physiotherapists. All provide care for adult patients with complex symptom burden, suffering from life limiting oncological or non-oncological disease. Apart from this, structure and organization of the participating teams differ widely. Two teams are located in rural and two in urban regions of Bavaria, Germany. The participating teams are working with two different software (SW) systems for documentation and administration, which offer the same functions but differ in design and workflows. For example, the button indicating that a patient usually uses eIPOS is only visible after opening the patient's individual case report in SW1, while SW2 makes this button visible in the overview of all patients. Access to the eIPOS report sent by the patients is similar: In both software programmes, the individual case report must be opened to see the values from eIPOS. The urban teams participating in the study are using SW1, whereas the rural teams use SW2.

In both online-survey and focus groups, participants were informed about the respective parts of the study and the option to drop out at any time. Informed consent was provided via a dialog box at the beginning of the survey and with signed consent declaration of focus groups' participants, respectively. The study population included all 52 HPCs (physicians and nurses) of the SPHC teams, being actively involved in the use of eIPOS. All were invited to participate in the online survey. As the objective of the study was understanding professionals' experience using eIPOS in SPHC as part of the overall study Palli-MONITOR, the basic sample was determined by the number of professionals working in the respective teams. Due to the small sample, we did not collect any information about gender, age, profession and experience to ensure anonymity in the small and highly connected German SPHC setting. Purposeful sampling for the focus groups was informed by the results of the online survey. To foster multi-perspectives in the discussion, we aimed for a diverse group composition considering the following criteria: region (urban/rural), used IT-system (SW1/SW2) and profession (nurse/physician). It was possible for HCPs to participate in both the survey and the focus groups.

Data collection

Data collection took place in April and May 2021.

Online Survey. All physicians and nurses of the four SPHC teams were invited via email to participate. The questionnaire was based on a survey used in a similar project in Freiburg, Germany.[26] Our questions focussed on the following topics, as their importance is highlighted by relevant literature: the effort of use, the ability to integrate the system and its role in daily care routine.[20,27–29] The survey contained closed questions asking for the HCPs' experiences with eIPOS in routine care and open questions to report barriers and suggestions for improvement. The survey questions are

Table 1: Study Design
Visual Model for Mixed-Methods Sequential Explanatory Approach
(Based on Ivankova, Creswell & Stick 2006)

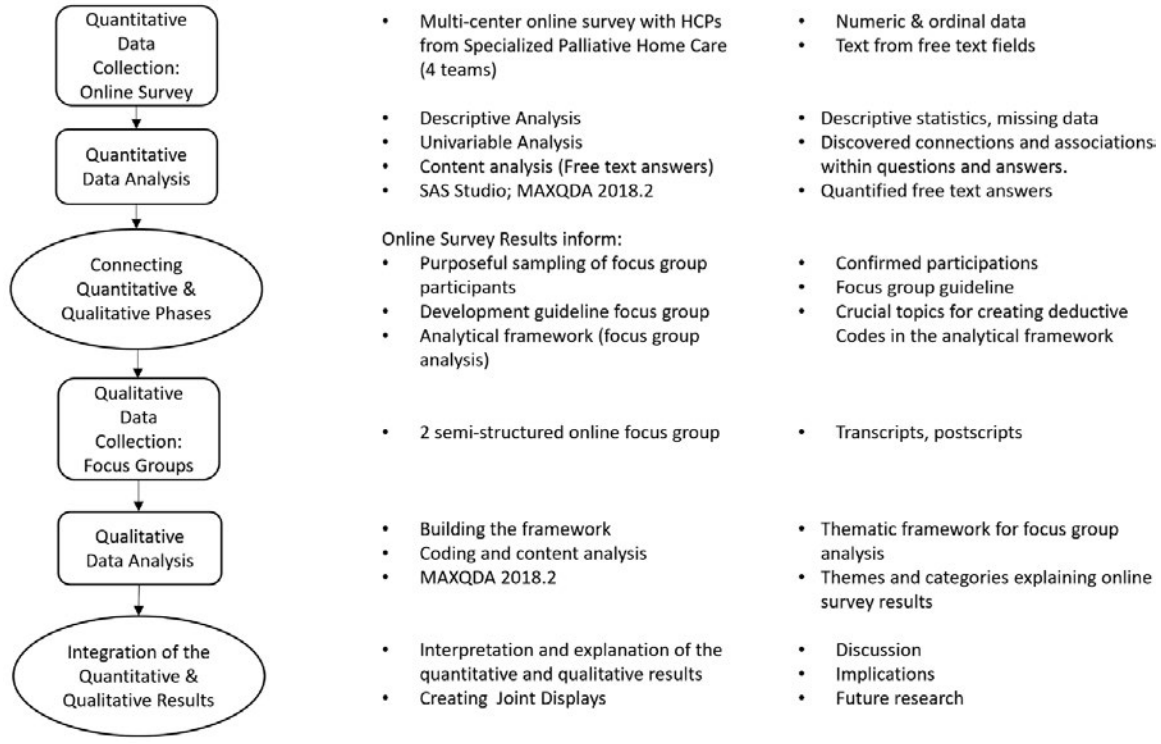


Figure 1. Study design: visual model for mixed-methods sequential explanatory approach (based on Ivankova, et al. 2006).[25]

summarized in Table 1. The completion time was estimated to be about 7 min. Participants were able to skip questions and complete the survey in one or more sessions. After cognitive testing, small adjustments were made before the start of the survey. The survey was open for 4 weeks. After 2 weeks, the HCPs received an email as reminder.

Focus groups. Subsequently, we conducted semi-structured online focus groups to explore contrasting experiences of the participants. To counter recruitment problems, we offered two focus groups at different times of the day. The interview guide was informed by results of the online survey and covered the following topics: attitude towards eIPOS (personal and in the team), use of the eIPOS in daily care in the SPHC setting technical implementation. Two researchers moderated the groups (IBF and KH), and one researcher (SK) provided technical support during the discussion. The conversations were audio recorded and transcribed verbatim; postscripts saved information that were not captured in the audios. To ensure confidentiality, all data were anonymized.

Analysis

Data were analysed in three phases: descriptive analysis of the online survey, qualitative analysis of transcripts and postscripts of the focus groups and an integrated analysis of both quantitative and qualitative data.

Online Survey. The closed survey questions were analysed descriptively, and the absolute and relative frequencies were reported. The Chi-square test and the Fischer exact test were used to test for statistically significant differences between categorical variables. Due to the small sample size, only the Fischer exact test was reported. The objective of the univariable tests was to examine the dependence of the effort of use, frequency of use, perceived changes and software type on other factors identified in the survey. Univariable analysis was conducted with SAS Studio (SAS

Table 1. Descriptive statistics.

Questions	Answers	*n* = 32	%
To what extent do you agree with the following statements regarding the patients' recording of symptoms and palliative care needs using eIPOS?			
Looked at the patients' statements	*Never*	0	0
	Seldom	7	21.9
	Sometimes	8	25.0
	Often	13	40.6
	Always	4	12.5
Discussed the patients' statements in the team	*Never*	0	0
	Seldom	6	18.8
	Sometimes	16	50.0
	Often	7	21.9
	Always	3	9.4
Better identification of patients' symptoms and palliative needs by using eIPOS	*Never*	1	3.1
	Seldom	13	40.6
	Sometimes	11	34.4
	Often	7	21.9
	Always	0	0
Better identification of patients' burden by using eIPOS	*Never*	1	3.1
	Seldom	8	25.0
	Sometimes	15	46.9
	Often	8	25.0
	Always	0	0
Adaption of care based on patients' responses	*Never*	9	28.1
	Seldom	8	25.0
	Sometimes	9	28.1
	Often	6	18.8
	Always	0	0
Information provided by the patients was useful for HCPs' work	*Never*	4	12.5
	Seldom	7	21.9
	Sometimes	10	31.3
	Often	8	25.0
	Always	3	9.4

(Continued)

Table 1. (Continued)

Questions	Answers	*n* = 32	%
Information provided by the patients as an opportunity to address certain topics with patients	*Never*	6	18.8
	Seldom	9	28.1
	Sometimes	11	34.4
	Often	6	18.8
	Always	0	0
Patients' statements as an opportunity to discuss the patients' stresses with colleagues	*Never*	5	15.6
	Seldom	11	34.4
	Sometimes	8	25.0
	Often	7	21.9
	Always	1	3.1
Have you noticed any changes as a result of using eIPOS (in clinical practice)?			
Changes in treatment of physical stress/ symptoms	*Worsening*	1	3.1
	No change	17	53.1
	Improvement	13	40.6
	I don't know	1	3.1
Changes in counselling for social problems	*Worsening*	0	0
	No change	16	50.0
	Improvement	10	31.3
	I don't know	6	18.8
Changes in patients' quality of life	*Worsening*	0	0
	No change	14	43.8
	Improvement	14	43.8
	I don't know	4	12.5
Changes in doctor–patient communication	*Worsening*	0	0
	No change	13	40.6
	Improvement	16	50.0
	I don't know	3	9.4
Changes in communication about patients' burdens in the team	*Worsening*	0	0
	No change	14	43.8
	Improvement	14	43.8
	I don`t know	4	12.5

(Continued)

Table 1. (Continued)

Questions	Answers	*n* = 32	%
To what extent do you agree with the following statements regarding the integration of *electronic* recording of patients' symptoms and palliative care needs into clinical practice?			
Successfully developed routines for the use of the patients' data	*Agree*	7	21.9
	Neutral	10	31.3
	Disagree	15	46.9
Effort of using the patients' data is appropriate with the benefit	*Agree*	6	18.8
	Neutral	11	34.4
	Disagree	15	46.9
Display of the eIPOS in the documentation system allows easy inclusion of patients' information	*Agree*	14	43.8
	Neutral	5	15.6
	Disagree	13	40.6
How do you estimate the effort of using eIPOS for . . .			
HCPs	*Particularly low*	3	9.4
	Low	22	68.8
	High	5	15.6
	Particularly high	0	0
	I don't know	2	6.3
Would you support further use of eIPOS after the project period?			
	No	13	40.6
	Yes, without changes	7	21.9
	Yes, with changes (free-text):	10	31.3
	Implementation	2	
	Technology	5	
	Setting	3	
	Missing	2	6.3
What suggestions do you have for improving the electronic recording of patients' symptoms and palliative care needs? (multiple answers are possible)			
	Implementation	3	9.4
	Technology	7	21.9
	Setting	3	9.4
	None	3	9.4
	PROM	3	9.4
	Others	1	3.1
	Not reported	16	50.0

(Continued)

Table 1. (Continued)

Questions	Answers	*n* = 32	%
What barriers did you perceive during the project? (multiple answers are possible)			
	Implementation and study conditions	11	34.4
	Technology	6	18.8
	Setting	14	43.8
	None	2	6.3
	COVID-19	1	3.1
	Others	1	3.1
	Not reported	7	21.9
Which documentation system do you use?			
	Software 1	12	37.5
	Software 2	19	59.4
	Missing	1	3.1

9.04.01M6P110718). Qualitative content analysis was performed to examine the free-text answers, using MAXQDAv.2018.2.[30] Analytic consensus was reached through coding review by the research team (IBF, SK and KH).

Focus Groups. To analyse transcripts and postscripts, we followed the framework approach using MAXQDAv.2018.2. The framework approach developed by Ritchie and Lewis allows transparent and structured management and analysis of qualitative data.[31] After getting familiar with the data material and identifying important topics, the content is displayed in thematic charts that allow further analysis and interpretation.[32] Our thematic framework was built with both deductive codes derived from the results of the online survey and inductive codes to cover all aspects of the data. Coding reviews and discussion of disagreements in the team (IBF, SK and KH) supported consistent analysis.

Integration. For the integrated analysis of both data sets, we developed joint displays.[22] These combine the quantitative detailed results with thematically matching qualitative data. The goal of the triangulation was to elucidate the survey outcomes with our qualitative findings.

Results

The overall response rate in the online survey was 62% (32/52). Nineteen out of 32 participants (59%) used software SW2, and 12/32 (38%) participants used software SW1. One participant did not answer this question. One of the nine questions, which asked whether the IPOS could be considered a suitable basis for an ePROM, was misinterpreted by most participants. The answers referred to the implemented electronic IPOS instead of the IPOS as a suitable digital PROM instrument. Therefore, it was not included in the analysis. For an overview of descriptive survey results, see Table 1. Table 2 shows the results of the univariable analysis. In the two focus groups (FG1 $n = 3$ and FG2 $n = 4$), four participants used SW2 and three participants used SW1.

eIPOS as support tool in everyday care

All participants had opened eIPOS and looked at the patients' statements during the project at least once ($n = 32$), more than 50% even often or always ($n = 17$). Furthermore, all HCPs had discussed patients' statements submitted via eIPOS in the team, about one-third even often or always ($n = 10$). Participants who opened eIPOS regularly (always/often) had a 43 times higher chance to discuss patients' statements in the team

Table 2. Univariable analysis.

	Effort of use for HCPs		**OR [95% CI]**	***p* Value**
	Low, *n* (%)	**High, *n* (%)**		
Information provided by eIPOS perceived as useful:			16 [1.09; 234.25]	0.06
Seldom, sometimes, often, always	24 (80.0%)	3 (10.0%)		
Never (ref.)	1 (3.3%)	2 (6.7%)		
	Software type		**OR [95%-CI]**	***p* Value**
	SW1, *n* (%)	**SW2, *n* (%)**		
Effort of using the patients' data perceived as commensurate with the benefit			12.86 [1.27; 130.54]	0.02
Agree	5 (16.1%)	1 (3.2%)		
Neutral/disagree (ref.)	7 (22.6%)	18 (58.1%)		
Wish for further use of eIPOS			1.78 [0.38; 8.23]	0.70
Yes	8 (27.6%)	9 (31.0%)		
No (ref.)	4 (13.8%)	8 (27.6%)		
Effort of use for HCPs			0.84 [0.12; 6.03]	1.00
Low	9 (30.0%)	16 (53.3%)		
High (ref.)	2 (6.7%)	3 (10.0%)		
Display of eIPOS in software allows easy integration of patients' information			0.24 [0.05; 1.19]	0.14
Agree	3 (9.7%)	11 (35.5%)		
Neutral/disagree (ref.)	9 (29.03%)	8 (25.8%)		
	Opened eIPOS		**OR [95%-CI]**	***p* Value**
	always/often, *n* (%)	**sometimes/ seldom, *n* (%)**		
Successfully developed routines for the use of the patients' data			4.80 [1.07; 21.45]	0.07
Agree/neutral	12 (37.5%)	5 (15.6%)		
Disagree (ref.)	5 (15.6%)	10 (31.3%)		

CI, confidence interval; OR, odds ratio.
ref. indicates the reference categories.

($p = 0.0003$). In the focus group, it was mentioned that differences between patients' statements and HCPs' assessment were a good starting point for discussion in the team. Nearly all HCPs ($n = 31$, 97%) experienced a better identification of patients' burden or symptoms and palliative care needs in the study period at least once. However, 23/32 (72%) stated that this happened only *seldom* or *sometimes* regarding the patients' burden, and 24/32 (75%) saw only *seldom* or *sometimes* better identification of symptoms and care needs.

In the discussion, professionals claimed that the free-text questions of eIPOS are of special interest for identification of unrecognized aspects. Benefits using eIPOS were mainly perceived in the identification of psychosocial issues. A total of 28 participants (88%) stated that the information

sent via eIPOS was useful for their work and 23 (72%) adapted care. One HCP explained in which way he used the provided information: *"Is it at the computer in the morning for team coordination. And seeing [. . .] that someone has clicked a three or a four, simply gave me a hint that we have to be active today"* (HCP, SW2 user). The large majority of the HCPs ($n = 26$, 81%) perceived no effect of eIPOS on their relationship with the patients. Nevertheless, a focus group participant voiced concerns that the relationship with patients could be negatively affected in case eIPOS-reported symptom burden might not be followed by reaction from the team because the patients' statements are not noted timely. For most participants in the survey, the information provided by the patients can be seen as an opportunity to address certain topics with the patients ($n = 26$, 81%) or to discuss with colleagues ($n = 27$, 84%), even though many stated that this was only *seldom* the case (address topics with patients: $n = 9$, 28%; discuss with colleagues: $n = 11$, 34%). One HCP described that eIPOS revealed differences between patients' views on symptom burden and the HCPs' assessment, what was a particular impetus for in-team discussions.

eIPOS use: implications on care

Leaving *I don't know*-answers aside, 13 participants perceived an improvement in the treatment of physical symptoms, while 17 HCPs did not notice any change. Regarding psychosocial aspects of care, no change was perceived by 13 participants in the treatment of mental distress, whereas slightly more HCPs noticed an improvement ($n = 15$). Half of the HCPs noted an improvement in the patients' quality of life ($n = 14$). Mostly no change was perceived in counselling for social problems ($n = 16$), accompanying during existential crises ($n = 18$) or in spiritual concerns ($n = 29$). Regarding communication, 16 HCPs perceived improvement in the exchange with patients and 14 participants noticed positive effects on the intra-team communication. In the focus group, one HCP explained that psychological issues often suffer in case of hectic workflow. Focusing on communication about crucial aspects, speaking about spiritual issues might be neglected: *"So for me, it would be, if then, these free fields and these psycho-social and emotional issues. Were you at peace with yourself? After all that's a nice question, [usually] I don't ask it like that"* (HCP, SW2 user). Professionals assumed that for some patients it might be easier to mention psychological issues, typing them in eIPOS.

Implementing eIPOS in daily care routine

Nearly half of the survey participants ($n = 15$, 47%) expressed that they had not developed routines for using patients' information from eIPOS in clinical practice. Focus group results revealed that the digital information display did not meet the needs, especially regarding SW1. Because an active 'search' for newly transmitted values was required, eIPOS was often not opened until the documentation was entered after a patient contact. However, seven professionals (22%) reported successful integration into the individual clinical practice. In one of the focus groups, an SW2 user discussed with an SW1 user how their teams are dealing with the newly arriving eIPOS. The SW2 user described the clinical care routine in her team with a person who coordinates patients to the staff in the morning: *"If I as a staff member get five patients, then I have to check the documentation of each patient in our documentation system in the morning. And … then I also open eIPOS. Just like I read my colleagues' documentation from before to get an overview again. Because you're not at work every day … because maybe yesterday a colleague was taking care of this patient"*.

This seems to be different in SW1 users' team, where HCPs do not share patients among each other and are very involved in their current situation. Therefore, in this team, HCPs do not check the documentation every day. Another focus group participant from the second team using SW1 confirms this practice for his own team. The conclusion from this dialogue between focus group participants about the different routines with eIPOS in SPHC is reflected by SW2 user: *"Ah, ok! That's the reason, it just depends on the way the work is done!"*. Interestingly, the second team using SW2 was unable to develop routines for using eIPOS information in daily practice but did not indicate workflow as the reason. Rather, it was due to the patient population with a high complex symptom burden and very short treatment duration, as reported by one focus group participant. Only a few patients in this team were able to use eIPOS. However, univariable analysis showed that HCPs who opened eIPOS regularly (always/often) had a 12 times higher chance to report successfully developed routines for the use of eIPOS ($p = 0.06$).

Effort of using eIPOS

The majority ($n = 25$, 78%) assessed the effort of using eIPOS as low. However, in the focus groups, at least one HCP using SW1 perceived the efforts of integrating eIPOS as too high. Furthermore, the effort of using the patients' data was perceived for nearly half of the professionals as not appropriate with the benefit ($n = 15$, 47%), though for six participants (19%), the effort–benefit relation was good. Univariable analysis showed statistical significance with the used software: HCPs who used SW1 had a nearly 13 times higher chance of perceiving the effort–benefit ratio as appropriate ($p = 0.02$). The assessment regarding the display of eIPOS was divided: 14 participants (44%) agreed that the readout in the documentation system allows easy inclusion of patients' information; however, 13 HCPs (41%) stated the opposite. This difference was not statistically significant ($p = 0.14$). The discussion in the focus groups unveiled relevant differences between the two software systems. In SW2, all patients using eIPOS were labelled by a button in the patient overview. Clicking on it, the HCP could easily see transmitted values: *"When I open it, I see the button: that's a patient who is taking part in the study. And I can click on it and see it [values transmitted via eIPOS] right away"* (HCP, SW2 user). In contrast, in SW1, the team needed to select the particular patient, before a button indicating eIPOS use appeared. A discussion between two HCPs indicated that differences in software design were not the main reason for the varied perception of effort. They made clear that divergent organizational structure of clinical practice is of great impact as well.

Suggestions for improvement

More than half of the survey participants ($n = 17$, 53%) wished to use eIPOS after the project period. However, more than half of them ($n = 10$) linked this wish to necessary changes. Most of their comments addressed a change regarding technical issues ($n = 5$), three referred to the setting of SPHC and two related it to the implementation process. A detailed overview of the suggestions for improvement as well as of perceived barriers is provided in the joint display of the results from the focus groups and survey (see Figure 2).

Focus groups provided further results about eIPOS use. HCPs revealed the advantages using eIPOS in additional settings and populations of palliative home care (see Table 3). Support from relatives was mentioned as one possibility to enable eIPOS use for patients with high symptom burden or little technical practice.

Discussion

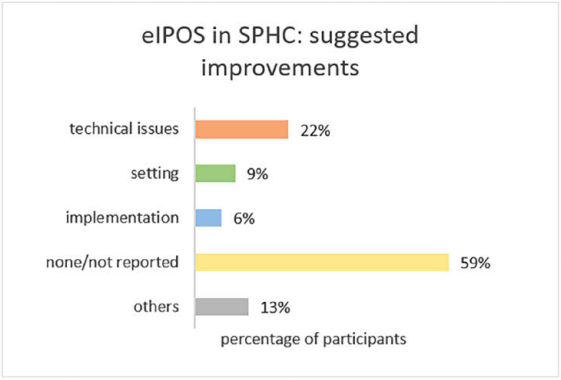
To our knowledge, this is one of the first studies to describe and explore the perspective of HCPs on the use of electronic PROMs in the clinical practice of SPHC. An important finding was that all HCPs had accessed the information provided via eIPOS and had discussed the patient statements submitted via eIPOS in their teams. Many HCPs felt that patients' distress or symptoms and palliative care needs were sometimes better recognized thanks to eIPOS. The focus groups revealed differences between the two software programmes used in the four teams. However, the software itself was not the reason for whether the introduction of eIPOS was successful in everyday care. Rather, it was due to the specific organizational structure of the clinical practice and the patients cared for in the teams.

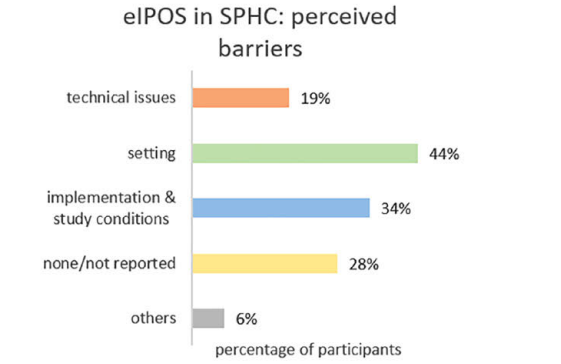
HCPs' perception on ePROM in (specialist) palliative home care

The results of the online survey highlighted that all HCPs reviewed the information provided through eIPOS. However, the online survey and focus groups showed that not all managed to check eIPOS regularly. Nevertheless, compared with other results, our findings show a relatively good compliance of HCPs using ePROM. Taarnhøj *et al.*[33] found low compliance of physicians, but here ePROM software was not integrated into regular documentation software and the physicians had to log into a different software system. We found no difference between HCPs using the two different software systems. Compared with those who did not check eIPOS regularly, HCPs opening eIPOS often or always endorse future use of eIPOS in SPHC. Focus group results explain that those HCPs having more concrete experience with eIPOS use were more likely to report benefits or potentials. This is corroborated by previous findings that prove the motivation of HCPs as a main factor for PROM use.[27,34] Furthermore, we identified perceived improvement in team communication as another factor influencing HCPs' wish for further use of eIPOS.

eIPOS in SPHC: Suggested Improvements & Percieved Barriers

Quantitative Results





Qualitative Results

Technical issues:

- *"So, as I mentioned at the beginning, we have many patients, especially older ones, who can hardly or not at all deal with such technology, and that makes it difficult. Yes."* [2]
- *„It would be very important that when a patient has filled in a new eIPOS, that there simply has to be some signal in the software,. […] that it pops up somewhere, that we then actively look in [*the eIPOS*]."* [1]
- *"If the patient ticks 3 or 4 [*in eIPOS*] that a warning signal appears somewhere, that one might at least get an exclamation mark in [*the software*]."*[2]

Setting:

- *„The seriously ill and dying [*patients*], for them eIPOS is not helpful."*[1]
- *„It is difficult for patients to establish themselves* [with eIPOS] *because of the short periods they spend in SPHC. They are often able to use it only for a short time, then they are simply in too bad general condition."*[2]

Implementation & study sonditions:

- *"We didn't rely on* [eIPOS] *to pop up for us in time. Because of that, we're in the old system ... we haven't actually changed anything."* [1]
- *"We have the big meeting* [once a week]. *And then it was already an issue, who is eligible? So* [eIPOS*] has always been well promoted by* [study nurse]. […] *But so often nothing came of it because the patients were simply not suitable."* [2]

[1] (HCP, SW1 user) [2](HCP, SW2 user)

Integrated Results

Technical issues:

The majority of suggested improvements addressed technical issues, as well as a relevant part of perceived barriers. Qualitative findings further explain these issues. One focus is on the used software: the professionals wish for a pop-up signal indicating new eIPOS results as well as for a red flag system warning in case of high symptom burden or deteriorating values. Another aspect seems to be SPHC-patients` low technical experience, some do not have access to internet.

Setting:

Characteristics of the SPHC setting were the major barrier perceived during the project. In HCPs` perspective there was room for improvement regarding this aspect. Qualitative results underlines these findings as SPHC is often characterized by crisis-ridden and short duration of care. SPHC-patients` poor general condition mostly does not allow personal use of eIPOS. Therefore, HCPs recommend use of eIPOS for other settings than SPHC, e. g. for earlier stages of palliative home care.

Implementation & study conditions:

Study conditions frequently were perceived as barriers, as another challenge HCPs mentioned implementation aspects. Qualitative findings illustrate these factors: HCPs reported how inclusion criteria excluded patients who they considered as potential eIPOS users. For example, patients fulfilling the inclusion criteria TV often could not participate, due to poor general condition. Realization of eIPOS under study conditions didn't match the normal care routines of all participating teams.

Figure 2. Joint display of the integrated data: eIPOS in SPHC - suggested improvements and perceived barriers.

Table 3. Additional qualitative results.

Topic 1: Potentials regarding detecting and monitoring symptom burden
With those patients who were able to use eIPOS, HCPs identified the potential for clinical care routine. Symptoms and problems reported via eIPOS offer additional information compared with what has been documented by HCPs or what topics patients bring up in phone calls or face-to-face conversations, for example, about psychosocial issues. In addition, eIPOS results support organization and priority setting in clinical care routines.

- *"We didn't have many patients that could [use eIPOS]. But for those, who did, I found it great as a supplement. I sit at the computer in the morning for team coordination. And seeing . . . that someone clicked a 3 or a 4, simply gave me a hint that we have to be active today"*. (HCP, SW2 user)
- *"I always found it exciting to see what . . . the doctor writes down and what the patient directly submits [via eIPOS]. It is not always so completely identical. Or there is simply another aspect that has become visible"*. (HCP, SW2 user)
- *"I believe that patients don't usually say they are worried or that their family is worried in face-to-face conversations or on the telephone. . . . This often became more clear looking the eIPOS"*. (HCP, SW1 user)
- *"It's also good that you can enter free text. . . . Things are brought to the point there that . . . often cannot be addressed in conversation . . . But you can then go into it in the conversation, if it has already been mentioned"*. (HCP, SW1 user)

Topic 2: Advantages of eIPOS in different settings and populations
HCPs emphasized the advantages of eIPOS use as a monitoring system for palliative care patients who are in intermitted or less close contact with their care team. As concrete settings, participants suggest eIPOS implementation in lower intensity levels of SPHC or for early integration palliative care patients in general palliative care and mention the possibility to include the general practitioner into eIPOS usage.

- *"Well, that would be very interesting, especially for those patients who are not currently being cared for [but have been cared for]. These are patients who ... are more stable [so called 'stillgelegte' patients]. Especially for those patients, it would be very, very helpful to have a monitoring system, which actually gives signals: Now you have to contact them."*. (HCP, SW1 user)
- *It is sometimes a bit difficult to communicate when you say: "We will have to reduce the intensity of care". Of course, you don't say it like that. But if you then say: . . . "but we still have here, in any case, a tool [eIPOS] with which we can stay in close contact". And so you would have the opportunity to offer them [the patients] something that also gives security"*. (HCP, SW1 user)
- *"I have often thought to myself that it is a pity, that the patients we have in the so-called coordination [SPHC, less intensive level of care] would be more suitable for eIPOS. And of course it would be ideal if eIPOS results could be passed on directly to the GP"*. (HCP, SW2 user)
- *"[eIPOS] for . . . early integration [of palliative care patients], that would be good. We often don't really cover it with SPHC. We don't have the capacity to take people so early. And I think it would be good if they were fitter"*. (HCP, SW1 user)

Effort of using eIPOS and integration of eIPOS into the daily care routine

While former studies described PROM use as time-consuming,[35,36] our results regarding cost–benefit assessment were more divers. Most HCPs estimated the effort for the use of eIPOS as low. However, almost half of them stated that the benefit–effort ratio was not appropriate. As eIPOS realization differed between the two software systems, we tested association between perceived effort and documentation system. While we found no statistical significance here, documentation system proved to have a statistically significant influence on benefit-effort relation (in favour of SW1). In addition, the focus groups revealed that display of the submitted eIPOS in the patient record was an important aspect in the perception of HCPs. Nevertheless, our findings conformed the perceived effort of use to be an important factor that should be considered in the implementation of ePROM. For example, HCPs perceiving effort as low had a 16 times higher chance to interpret eIPOS values as helpful. This is consistent with former studies, showing that natural integration of PROMs' feedback might reduce perceived effort.[27] Furthermore, the results of the focus groups showed that the respective organizational structure and workflows in the teams are very important aspects for the successful integration of eIPOS. While the two teams using SW1 reported that they do not check documentation records on a daily basis, one team using SW2

stated the opposite, due to the completely different workflows. Therefore, there was the opportunity for them to check the transmitted eIPOS values regularly. The other team using SW2 worked with a closely integrated home care team. As a result, this team mainly supported patients in crisis situations who were not able to use eIPOS. Therefore, the team rarely had the opportunity to become proficient in its use. Grol and Wensing explained that implemented changes must also fit into the existing workflow.[20] These results confirm previous studies that found the key factor for successful implementation of (e)PROM to be the smooth integration into organizational structures[34] as well as the perceived effort.[27,29,33,35]

Implications of eIPOS on care

Focusing on the setting of SPHC, our study underpins results of previous studies describing more benefits of PROM use, for example, regarding support of recognition of patients' symptom burden and needs as well as improvement of communication with the patients and care.[6,9,13,37,38] In our study, some respondents indicated that they noticed an improvement in the communication in the team. This result is also consistent with former findings.[39] In the focus groups, HCPs identified a main benefit of eIPOS as tool to address and integrate psychosocial issues even more. This seems to be especially relevant, as participants stated that this aspect of holistic care tends to be neglected for the benefit of physical symptom burden in a crisis-ridden care situation. In a previous study, HCPs without experience with the ePROM stated in an interview that they doubted the suitability of this standardized assessment for psychosocial issues.[40] These concerns have been eliminated by our findings. HCPs who noticed improvement in patients' quality of life using eIPOS were more likely to see better identification in both patients' burden and symptoms and palliative needs.

Suggestions for improvement and perceived barriers

HCPs saw a need for improvement, especially in the technical implementation of eIPOS information in the patient record. In line with other studies, our data primarily support that the electronic implementation of PROM promotes effectiveness – assuming that the technical design meets the individual needs of the setting.[26,41–43] However, adjusting technical issues does not help to overcome all setting specific barriers: our results confirm that many patients in SPHC might be too ill for (e)PROM use, as seen already in former research.[13,38] Summarizing our results, most participants saw the potential of ePROM use in home-based palliative care – as far as it is technically easy to handle and can be easily integrated into daily work. An impressive and novel result is the connection between the different structures and processes of clinical practice in the participating teams and the HCPs' perceptions of potentials regarding ePROM use in SPHC. HCPs suggested using eIPOS in home-based palliative care with less ill patients, involving general practitioners and family caregivers.

Strengths and weaknesses

Due to the small sample of professionals and the close contact between the research team and the participating teams, age and gender were not indicated in the online survey to ensure anonymity. As a result, however, important confounding factors are missing from our analysis. This must be taken into account in the interpretation. Due to the COVID-19 pandemic and prolonged high workload in the SPHC teams, recruitment for the focus group discussion was challenging – the number of participants was low. However, the mixed-methods design compensated for this weakness. Mostly, integrating the data, qualitative findings provided explanation and deeper understanding of the quantitative results. Nevertheless, some contradictory results of the survey and focus groups could not be clarified with the available data. One reason could be that the survey was open to all HCPs who have experience with eIPOS, while participation in the focus groups was only possible for a few. As our results about professionals' perspectives on ePROM use in palliative home care are based on a feasibility study of eIPOS in SPHC, some detailed findings are context and setting specific, for example, when addressing explicit organizational structures of SPHC or eIPOS-specific content. However, our general results about ePROM use in palliative home care can be also partly transferred to provide starting points for further research using alternative tools in different settings or populations of palliative care.

Conclusion

Successful use of ePROM is crucially affected by the possibility of naturally integrating the system

into the existing workflow. As the structure of SPHC in Germany is extremely diverse, we found varying HCPs' perspectives on eIPOS. In some teams, structural and organizational issues mean that patients can only be cared for in SPHC in acute crisis and only shortly before they die. Introducing ePROM in this condition is disadvantageous; therefore, HCPs participating in our study recommend the use of ePROM in earlier stages of palliative home care or supported by relatives. On a policy level, equalization of SPHC framework conditions would be desirable.

Declarations

Ethics approval and consent to participate

The study was approved by the local research ethics committee at the Medical Faculty of Ludwig-Maximilians-University Munich (19-585). Written informed consent to participate was obtained from all participants.

Consent for publication

Informed consent for publication was provided by all participants.

Author contributions

Isabel Burner-Fritsch: Data curation; Formal analysis; Investigation; Methodology; Writing – original draft.

Stefanie Kolmhuber: Data curation; Formal analysis; Investigation; Methodology; Writing – original draft.

Farina Hodiamont: Conceptualization; Funding acquisition; Methodology; Resources; Writing – review & editing.

Claudia Bausewein: Conceptualization; Funding acquisition; Methodology; Project administration; Resources; Supervision; Validation; Writing – review & editing.

Katerina Hriskova: Conceptualization; Data curation; Formal analysis; Methodology; Project administration; Supervision; Writing – review & editing.

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Competing interests

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Availability of data and materials

All data are available in German from the corresponding author on reasonable request.

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Supplemental material

Supplemental material for this article is available online.

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8. Danksagung

Die vorliegende Dissertation entstand in der Zeit von August 2020 bis Dezember 2023 an der Klinik und Poliklinik für Palliativmedizin, Klinikum der Universität München, geleitet von Prof. Dr. med. Claudia Bausewein. Ich möchte mich an dieser Stelle bei all jenen bedanken, die mich in dieser Zeit am Klinikum und außerhalb persönlich und beruflich begleitet und unterstützt haben.

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9. Curriculum Vitae

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AKADEMISCHER WERDEGANG / AUS- UND WEITERBILDUNGEN

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Katholische Stiftungshochschule München, Campus Benediktbeuern	Benediktbeuern
Dozententätigkeit | ***im Rahmen der BSc und MSc/MBA Fernstudiengänge***	seit 2021
Middlesex University in Kooperation mit KMU Akademie Management AG	Linz
Promotionsprojekt | ***elektronische Patient-Reported Outcome Measures in der SAPV***	seit 2020
Ludwig-Maximilians-Universität	München
Wiss. Mitarbeiterin | ***Projekt Palli-MONITOR***	seit 2018
Lehrstuhl für Palliativmedizin, LMU Klinikum	München
Weiterbildung zur Ethikberaterin im Gesundheitswesen	2020 – 2021
Diakonie Bayern	Nürnberg
Research Assistant | ***Forschungsgruppe „Gender and Diversity in Science and Engineering“***	2016 – 2017
Munich Center for Technology in Society (MCTS), Technische Universität	München
Master of Arts | ***Hauptfach: Soziologie, Nebenfach: Gender Studies***	2015 – 2018
Ludwig-Maximilians-Universität	München
Bachelor of Arts | ***Hauptfach: Soziologie, Nebenfach: Politikwissenschaften***	2011 – 2015
Ludwig-Maximilians-Universität	München
Staatlich geprüfte Kinderpflegerin	2008
Bildungszentrum für Hauswirtschaft und Sozialwesen Miesbach	Miesbach

INTERESSENSCHWERPUNKTE

Lebensende & Palliative Care. Digitalisierung, Ambulante Versorgung, Patient:innenzentrierung in der Versorgung
Ethik. Forschungsethik, Ethik im Gesundheitswesen, Ethik am Lebensende
Sozialforschung. Methoden und Methodologie Qualitativer Forschung, Mixed-Methods-Designs, Partizipative Forschung, Grounded Theory, teilnehmende Beobachtung, Interviewführung

MITGLIEDSCHAFTEN UND AUSZEICHNUNGEN

Deutsche Gesellschaft für Palliativmedizin (DGP):
Sprecherin der AG Digitalisierung; Mitarbeit im Redaktionsteam der Kampagne #dasistpalliativ
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Externe Reviewerin:
International Journal of Qualitative Methods (IJQM), Forum Qualitative Sozialforschung (FQS), Zeitschrift für Palliativmedizin
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PUBLIKATIONEN

Dialekt in der qualitativen Sozialforschung in print
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Positionspapier Deutsche Gesellschaft für Palliativmedizin, AG Digitalisierung

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Geflüchtete, Arbeit und Traditionsbetriebe im bayerischen Dorf. Eine Ethnographie. 2018
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Palli-MONITOR: a quasi-experimental mixed-methods interventional study of an 2022
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Burner-Fritsch & Hriskova et al. Bei: Deutscher Kongress für Versorgungsforschung, Vortrag
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Burner-Fritsch & Kolmhuber et al. Bei: Kongress der Deutschen Gesellschaft für Palliativmedizin, Vortrag
Bremen, September 2022.

Ethical considerations practicing qualitative health research with terminally ill research partners. 2022
Burner-Fritsch Bei: Research Ethics in Qualitative Health Research – International Spring School, Vortrag
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Implementing ePROM in Specialised Palliative Home Care: Professionals' Perspective. 2021
Burner-Fritsch et al. Bei: 17. EAPC World Congress, Posterpräsentation
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Understanding Facilitators and Barriers for the Implementation of ePROM 2021
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Fachakademie für Sozialpädagogik München 2006 – 2008
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