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Entwicklung, Pilotierung und Implementierung eines Verfahrens zur Darstellung der patientenzentrierten Ergebnisqualität in der spezialisierten ambulanten Palliativversorgung (SAPV)

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Zusammenfassung

Hintergrund: Die spezialisierte ambulante Palliativversorgung (SAPV) steht lebenslimitierend erkrankten Personen mit besonderem Versorgungsaufwand zur Verfügung. Sie verfolgt die Ziele Lebensqualität und Selbstbestimmung zu fördern, Leiden zu lindern und das Sterben in der häuslichen und familiären Umgebung zu ermöglichen. Die Darstellung der Versorgungsqualität ermöglicht es, Verbesserungspotentiale aufzuzeigen. Das subjektive Erleben der Betroffenen steht im Vordergrund, weshalb die Ergebnisqualität aus Perspektive von Patientinnen, Patienten und Angehörigen besonders relevant ist. Zusätzlich ermöglicht die Erhebung der patientenberichteten Ergebnisqualität mittels Patient-reported Outcome Measures (PROMs), die Versorgung unmittelbar an die Bedarfe von Patientinnen, Patienten und Angehörigen anzupassen. Die bisherige Dokumentation der SAPV in Hessen fokussierte die patientenberichtete Ergebnisqualität nur wenig. Diese Dissertation verfolgt das Ziel, die zentralen Themen einer gelungenen SAPV zu identifizieren sowie zu untersuchen, wie die regelhafte Anwendung von Instrumenten zur Erhebung der patientenzentrierten Ergebnisqualität inklusive PROMs in der täglichen SAPV in Hessen gelingen kann.

Methoden: Wir wählten ein Mixed Methods-Design. Zunächst wurden mit qualitativen Methoden die zentralen Themen identifiziert, die aus Perspektive von Patientinnen, Patienten, Angehörigen und medizinischem Fachpersonal zu einer gelungenen SAPV beitragen. Hierfür führten wir mittels eines Grounded Theory-Ansatzes teilnehmende Beobachtungen, Interviews und Fokusgruppen durch. Basierend auf diesen Erkenntnissen und einer Literaturübersicht wählten wir die folgenden Instrumente bzw. Fragebögen zur Erhebung der patientenberichteten Ergebnisqualität aus: Integrated Palliative Outcome Scale (IPOS), IPOS Views on Care (IPOS VoC) – Patientenversion, Phase of Illness in Palliative Care (PoI), 7-Item Kurzform des Zarit Caregiver Burden Interviews (ZBI-7).

Wir erprobten die Anwendung dieser Instrumente in fünf SAPV-Teams und evaluierten die Anwendung mittels Fokusgruppen und Feldnotizen zu Rückmeldungen der SAPV-Mitarbeitenden. In einem iterativen Prozess nahmen wir Anpassungen vor und evaluierten die Anpassungen. Anschließend implementierten wir die Instrumente in 19 SAPV Teams in Hessen und evaluierten die Anwendung mit einem Mixed Methods-Design bestehend aus Fokusgruppen und einer Online-Befragung. Wir triangulierten die Ergebnisse und leiteten Implikationen für eine dauerhafte Anwendung ab.

Ergebnisse: Zentrale Themen einer gelungenen SAPV sind aus Perspektive der Beteiligten die Kontrolle der komplexen Symptome, die Vermittlung eines Sicherheitsgefühls, die umfassende Fürsorge für Patientinnen, Patienten und

Angehörige, das Fördern der Beziehungsqualität, das Achten der Individualität und der Erhalt der Selbstbestimmung. Diese Themen sollten in der Arbeit der SAPV und bei der Darstellung der Versorgungsqualität berücksichtigt werden.

Die Pilotierung in fünf SAPV-Teams zeigte, dass die Integration von IPOS, IPOS Views on Care und PoI in die tägliche SAPV möglich ist. Der ZBI-7 wurde aus dem Instrumenten-Set entfernt, weil dieser sich in der praktischen Anwendung als nicht angemessen erwies. Für eine machbare, akzeptierte und von SAPV-Mitarbeitenden als angemessen empfundene Integration der Instrumente in die tägliche Versorgung muss die Belastung der Betroffenen geringgehalten werden und eine sensible Anwendung möglich sein. Des Weiteren muss die Administration handhabbar sein und die Nützlichkeit der Instrumenten-Anwendung vom medizinischen Fachpersonal verstanden werden.

Nach der Implementierung in 19 hessischen SAPV-Teams zeigte sich, dass die meisten SAPV-Mitarbeitenden die Anwendung der Instrumente in ihren Arbeitsalltag integrieren konnten. Teilweise fühlten sie sich unsicher in der Anwendung, hatten Bedenken Patientinnen, Patienten und Angehörige hierdurch zu belasten oder befürchteten, dass die Qualität ihrer Arbeit nicht richtig abgebildet wird. Für eine nachhaltige Anwendung müssen diese Bedenken adressiert und die Motivation gefördert werden. Hierfür muss das medizinische Fachpersonal verstehen, wie die Anwendung der Erhebungsinstrumente zur Verbesserung der SAPV beitragen sowie Patientinnen, Patienten und Angehörigen zugutekommen kann.

Diskussion/Schlussfolgerungen: Die implementierten Instrumente zur Darstellung der patientenzentrierten Ergebnisqualität stellen einen wesentlichen Baustein zur Evaluation der Versorgungsqualität in der SAPV dar, weil hiermit das subjektive Erleben der Patientinnen, Patienten und Angehörigen abgebildet werden kann. Die flächendeckende Anwendung schafft eine gute Datenbasis für weitere Forschung und kann Verbesserungspotential in der praktischen Arbeit aufzeigen. Die Integration in die tägliche Arbeit muss dauerhaft begleitet werden, was personelle, monetäre und zeitliche Ressourcen benötigt. Für die dauerhafte Anwendung sind die Nutzung der Instrumente in der Teamkommunikation, transparente und regelmäßige Auswertungen, fortlaufenden Schulungen, Peer-Support und die Vernetzung von SAPV-Teams notwendig, sodass Ängste verringert und die Motivation und das Wohlbefinden des medizinischen Fachpersonals hiermit gestärkt werden können. Zentral ist dabei, dass Professionelle den Nutzen für die Qualitätsdarstellung und insbesondere für die tägliche Arbeit erfahren.

Summary

Background: Specialized outpatient palliative care (SOPC) is available to persons with life-limiting diseases and complex care needs. It aims to improve quality of life and to relieve suffering. Measuring the quality of care enables health professionals to identify potential for improvement. As the subjective experience of the persons concerned has priority, the outcome from the perspective of patients and relatives is particularly relevant. In addition, the use of patient-reported outcomes measures (PROMs) enables care to be adapted to the needs of patients and their relatives. The documentation of SOPC in Hesse focused so far only little on patient-reported outcomes. This dissertation aims to identify the key issues of successful SOPC as well as to investigate how the regular use of patient-centred outcome measures including PROMs can succeed in daily SOPC in Hesse.

Methods: We chose to use a mixed methods design. First, we used qualitative methods to identify the key issues that contribute to successful SOPC from the perspective of patients, relatives, and professionals. For this purpose, we conducted participant observations, interviews, and focus groups using a grounded theory approach. Based on the findings and a literature overview, we chose to use the following patient-centred outcome measures: Integrated Palliative Outcome Scale (IPOS), IPOS Views on Care (IPOS VoC) - patient version, Phase of Illness in Palliative Care (PoI), 7-item short form of Zarit Caregiver Burden Interview (ZBI-7).

We tested the application of these measures in five SOPC-teams. We evaluated the application using focus groups and field notes on feedback from SOPC staff. In an iterative process, we refined use and evaluated the adjustments. Then, we implemented the use of the instruments in 19 SOPC teams in Hesse. We evaluated use using a mixed methods design including focus groups and an online survey. We triangulated the results and derived implications for a sustainable use.

Results: From the perspective of those involved, successful SOPC needs to treat complex symptoms, facilitate a sense of security, provide comprehensive care for patients and their relatives, promote the quality of relationships, respect individuality, and enable self-determination. These issues should be considered in daily SOPC and in the evaluation of the quality of care.

Piloting in five SOPC teams showed that integrating IPOS, IPOS Views on Care and PoI into daily SOPC is feasible. We removed ZBI-7 from the set of measures, because it was not found to be appropriate in practical use. For a feasible, acceptable and appropriate integration of the measures into daily care, the burden on patients and relatives must be kept to a minimum and sensitive use must be enabled. Furthermore, the administration must be manageable and the usefulness of the measures must be understood.

After implementation in 19 Hessian SOPC teams, it became apparent that the majority of professionals were able to integrate the application into their daily work. Some professionals felt unconfident in the application, had concerns to burden patients and relatives, or feared that the quality of their work would not be properly reflected. For sustainable use, these concerns must be addressed and motivation must be encouraged. To do this, professionals need to understand how use of the measures can help to improve SOPC and how it can benefit those affected.

Discussion and conclusion: The implemented patient-centred outcome measures represent an essential component for the evaluation of the quality of care in SOPC, because the subjective experience of patients and relatives can be shown. The state-wide application creates a good data basis for further research and can show potential for improvement in practical work. The sustainable integration into the daily work needs permanent support, which requires monetary and time resources. For sustainable application, the use of the instruments in the teams' communication, transparent and regular analyses, ongoing training, peer support and networking of SOPC teams is necessary, so that fears can be reduced and the motivation and comfort of the professionals can be strengthened. It is key, that professionals experience the benefits for quality evaluation and especially for their daily work.

Abkürzungsverzeichnis

- Az. = Aktenzeichen
- COREQ = Consolidated criteria for reporting qualitative research
- C-POS = Children's Palliative Care Outcome Scale
- EAPC = European Association for Palliative Care
- ELSAH = Evaluation der Spezialisierten Ambulanten Palliativversorgung (SAPV) am Beispiel von Hessen
- G-BA = Gemeinsamer Bundesausschuss
- IPOS = Integrated Palliative Outcome Scale
- IPOS VoC = IPOS Views on Care
- MMARS = Mixed Methods Article Reporting Standards
- NHPR = Nationales Hospiz und Palliativregister
- NoMAD-Instrument = Normalization MeAsure Development-Instrument
- NPT = Normalization Process Theory
- OACC = Outcome Assessment and Complexity Collaborative Initiative
- PCOC = Palliative Care Outcomes Collaboration
- PCOM = Patient-centered Outcome Measure
- PoI = Phase of Illness in Palliative Care
- PRISMA = Reflecting the Positive DiveRsities of European PrIorities for ReSearch and Measurement in End-of-Life Care
- PROM = Patient-reported Outcome Measure
- SAPV = Spezialisierte ambulante Palliativversorgung
- SAPV-KJ = SAPV für Kinder und Jugendliche
- WHO = Weltgesundheitsorganisation
- ZBI-7 = 7-Item Kurzform des Zarit Caregiver Burden Interviews

Abbildungsverzeichnis

Abbildung 1: Verortung der Publikationen in der ELSAH-Studie 5

1 Einleitung

1.1 Relevanz

Die Palliativversorgung dient der Verbesserung der Lebensqualität von Personen mit lebenslimitierenden Erkrankungen und deren Angehörigen [91]. Sie kann im stationären Setting zum Beispiel auf Palliativstationen erbracht werden, in Hospizen oder im häuslichen Umfeld der Betroffenen. Im ambulanten Setting wird die allgemeine ambulante Palliativversorgung unter anderem von Hausärztinnen und Hausärzten, Pflegediensten und Pflegeheimen erbracht [76]. Für Personen mit einer komplexen Versorgungssituation bietet die spezialisierte ambulante Palliativversorgung (SAPV) zusätzlich spezialisierte Unterstützung inklusive einer Rufbereitschaft rund um die Uhr an [67]. Sie verfolgt die Ziele, die Lebensqualität und Selbstbestimmung zu fördern, sowie Leiden zu lindern [35]. In den interdisziplinären SAPV-Teams arbeiten vor allem Ärztinnen und Ärzte sowie Pflegefachkräfte mit einer Palliative Care Weiterbildung. Diese Professionen werden ergänzt um Mitarbeitende der Administration, sowie in seltenen Fällen um Fachkräfte der Psychologie und der Sozialarbeit [67].

In Deutschland nahmen 13,1 % aller Verstorbenen im Jahr 2016 SAPV in Anspruch, wobei die regionale Verteilung heterogen war [21]. Dies entspricht deutschlandweit Ausgaben der gesetzlichen Krankenversicherung von insgesamt 400,6 Millionen Euro für Leistungen der SAPV [36]. In Hessen betrug die Inanspruchnahme 16,4 % [21]. Die meisten in Hessen in den Jahren 2014-2018 von SAPV versorgten Erwachsenen (70,7 %) litten dabei an einer onkologischen Grunderkrankung [41]. Häufige nicht-onkologische Erkrankungen waren die des Nervensystems und des Kreislaufsystems [44]. Eine Versorgung dauerte durchschnittlich 23 Tage mit einem Median von 13 Tagen, wobei Versorgungen auch kürzer als einen Tag andauern können [41]. Im Jahr 2014 gab es in Deutschland bereits mehr als 270 SAPV-Teams, mit steigender Tendenz in Deutschland und ganz Europa [5, 79].

Leistungserbringer der Palliativversorgung sind angehalten, freiwillig anonymisierte Versorgungsdaten in das Nationale Hospiz- und Palliativregister (NHPR) einzutragen. Der Schwerpunkt des Kerndatensatzes liegt allerdings auf Struktur- und Prozessqualität [19]. Die einheitliche Dokumentation der hessischen SAPV-Teams beruhte vor unserem Forschungsprojekt ELSAH („Evaluation der Spezialisierten Ambulanten Palliativversorgung (SAPV) am Beispiel von Hessen“) ebenfalls auf dem Kerndatensatz des NHPR [30]. Bisher gab es in Deutschland aber kein Verfahren, welches die Versorgungsqualität der SAPV umfassend darstellen kann und dabei auf die Ergebnisqualität und insbesondere patientenrelevante Outcomes fokussiert. Die patientenrelevanten Outcomes sind im Kontext der SAPV aber besonders relevant, da der Fokus nicht auf klassischen Merkmalen der Ergebnisbeurteilung wie Morbidität und Mortalität liegt, sondern das subjektive Erleben der Betroffenen im Vordergrund steht. Die Erhebung der Patientenperspektive während der Versorgung ermöglicht unerkannte Bedarfe offenzulegen und die Versorgung individuell anzupassen [9]. Die Darstellung der Versorgungsqualität ermöglicht zudem Verbesserungspotenzial aufzuzeigen und bei der Verwendung von standardisierten Instrumenten sogar einen Vergleich über einzelne SAPV-Teams oder Regionen hinaus.

1.2 Stand der Forschung

Die Messung von patientenberichteter Ergebnisqualität in der Palliativversorgung nimmt international an Bedeutung zu [22]. Die Europäische Gesellschaft für Palliative Care (EAPC) empfiehlt die Verwendung von validierten Instrumenten zur patientenberichteten Ergebnisqualität, sogenannten „patient-reported outcome measures“ (PROMs) [9]. PROMs werden von Patientinnen und Patienten selbst bewertet (Selbsteinschätzung). Einige Instrumente erlauben ebenfalls die Bewertung der Ergebnisqualität durch Angehörige und medizinisches Fachpersonal (Fremdeinschätzung), wenn die Patientinnen und Patienten selbst nicht in der Lage hierzu sind. Diese werden in der Literatur auch als „patient-centered outcome measures“ (PCOMs) bezeichnet [29]. Das PRISMA-Projekt (Reflecting the Positive DiveRsities of European PrIorities for ReSearch and Measurement in End-of-Life Care) zielte darauf ab, Empfehlungen zur Auswahl und Implementierung von Instrumenten zur patientenberichteten Ergebnisqualität in der Palliativversorgung zu geben. Das Projektteam empfiehlt in der täglichen Routineversorgung Instrumente zu verwenden, deren Umfang und Komplexität für lebenslimitierend erkrankte Personen geeignet ist, die Pflegende und Familien einbeziehen und die alle relevanten Themenfelder abdecken [8].

1.2.1 Zentrale Themen der SAPV

Die Palliativversorgung ist aufgrund von dynamischen Krankheitsverläufen, sich verändernden Bedarfen und bestehenden Versorgungs- und Familienstrukturen komplex. Die Interaktion der beteiligten Patientinnen und Patienten, Angehörigen und dem medizinischen Fachpersonal spielt dabei eine zentrale Rolle [69]. Zu einer erfolgreichen Versorgung tragen daher Antizipation, eine gewisse Hingabe, Flexibilität und eine gute Teamarbeit bei [16]. Eine Studie in der bayerischen SAPV beschrieb Qualität als Zusammenspiel von Normalisierung der palliativen Ausnahmesituation, körperlicher Symptomkontrolle und Vermittlung eines umfassendes Sicherheitsgefühls [82]. Eine schwedische Studie schlussfolgerte ebenfalls, dass für

Patientinnen, Patienten und deren Angehörige in der SAPV vor allem Sicherheit und Kontinuität wichtig sind [53]. Betroffene befürworteten außerdem eine adäquate, verlässliche und partnerschaftliche Versorgung der SAPV-Mitarbeitenden unter Einbezug der Betroffenen. Die Missachtung der Bedarfe führte zu einer als schlecht empfundenen Versorgungsqualität [54]. Für Hinterbliebene war die Vorbereitung auf und der Umgang mit dem Versterben unter anderem ein wichtiger Aspekt für eine gelungene Versorgung [4]. Der Stand der Wissenschaft gibt damit Anhaltspunkte, welche Themen aus bestimmten Perspektiven relevant sind, allerdings fehlt eine umfassende Untersuchung aller relevanten Themen und Perspektiven, die eine gelungene Versorgung im komplexen Setting der SAPV beeinflussen.

1.2.2 Machbarkeit, Akzeptanz und Angemessenheit

Neben der Empfehlung, dass die Instrumente alle relevanten Themen abdecken sollen, definiert das PRISMA-Projekt „gute“ Instrumente als valide, reliabel und veränderungssensitiv, sowie für die Anwendung in der Palliativversorgung geeignet und akzeptabel für die anwendenden Personen [8]. Darauf aufbauend stellte die Outcome Assessment and Complexity Collaborative Initiative (OACC) ein Set von Instrumenten vor, welche den genannten Kriterien entsprechen. Dies beinhaltet unter anderem:

- Integrated Palliative Outcome Scale (IPOS) [43]
- IPOS Views on Care (IPOS VoC) – Patientenversion [1, 49]
- Phase of Illness in Palliative Care (PoI) [23]
- 7-Item Kurzform des Zarit Caregiver Burden Interviews (ZBI-7) [38, 45]

Die Studienlage zur routinemäßigen Anwendung dieser Instrumente in der spezialisierten, ambulanten Palliativversorgung ist rar, einige Studien beschrieben aber die Anwendung im stationären Palliativsetting [7, 10, 51]. Das medizinische Fachpersonal befürwortete hierbei die Erhebung und das Monitoring der Patientensituation sowie die Evaluation von Leistungserbringern, während Zeitmangel, die Belastung von Patientinnen, Patienten und Angehörigen, fehlende Anleitung und fehlendes Training zum Verzicht der Anwendung führten [7]. Eine Studie in verschiedenen deutschen Palliativsettings zeigte, dass das medizinische Fachpersonal eine Standardisierung und Technisierung der Versorgung befürchtete [77]. Ergebnisse aus anderen Settings sind allerdings nicht direkt übertragbar, da sich die SAPV von anderen Formen der Palliativversorgung zum Beispiel in Hinblick auf die Population, Versorgungsprozesse und den Einbezug der Familie unterscheidet [13, 46, 76]. Es wird stattdessen empfohlen, bei der Implementierung von PROMs in der Palliativversorgung spezifische Hindernisse in dem Setting zu identifizieren und zu beseitigten, sowie die Anwendungsprozesse in der jeweiligen Organisation anzupassen [3, 34].

1.2.3 Implementierung und dauerhafte Anwendung

Die flächendeckende, routinemäßige Anwendung eines einheitlichen Verfahrens zur Darstellung der Versorgungsqualität fördert eine gute Datenbasis und ermöglicht den Vergleich verschiedener Teams. Die Implementierung in mehreren Teams schafft zusätzliche Herausforderungen, weil im Sinne einer guten Reliabilität die Prozesse in jedem Team möglichst ähnlich sein sollten, aber gleichzeitig die verschiedenen Kontexte wie Arbeitsabläufe, Erfahrungen und Teamstrukturen berücksichtigt werden müssen.

Die australische Palliative Care Outcomes Collaboration (PCOC) hat ein Programm zur routinemäßigen Anwendung von PROMs in der Palliativversorgung etabliert, welches den teilnehmenden Leistungsanbietern u.a. halbjährliche Berichte über ihre Versorgung zur Verfügung stellt und damit ein Benchmarking ermöglicht. Es wird in verschiedenen Settings, unter anderem in der spezialisierten häuslichen Palliativversorgung angewandt [24, 88]. Bei einer teamübergreifenden Implementierung von Qualitätsindikatoren in der belgischen SAPV zeigte sich, dass die Einstellung des Teams, eine gute Teamleitung und eine finanzielle Aufwandsentschädigung vom medizinischen Fachpersonal als förderlich eingeschätzt wurden [61]. Für eine bessere Akzeptanz und weniger Ängste wurden ein fortlaufendes Training zur Anwendung und Ergebnisinterpretation sowie eine unterstützende Teamleitung benannt [48]. Nach der Implementierung der OACC Instrumente in der Routineversorgung mehrerer spezialisierter Palliativsettings empfahlen Pinto et al. die Personen im Team und Teamstrukturen bei der Implementierung von PROMs zu berücksichtigten, genauso wie die Vor- und Nachteile der Innovation, nationale und politische Einflussfaktoren. Außerdem empfahlen die Autorinnen und Autoren eine schrittweise Einführung und regelmäßige Rückmeldung von erfahrenen Anwendern und Befürwortern der PROMs [72].

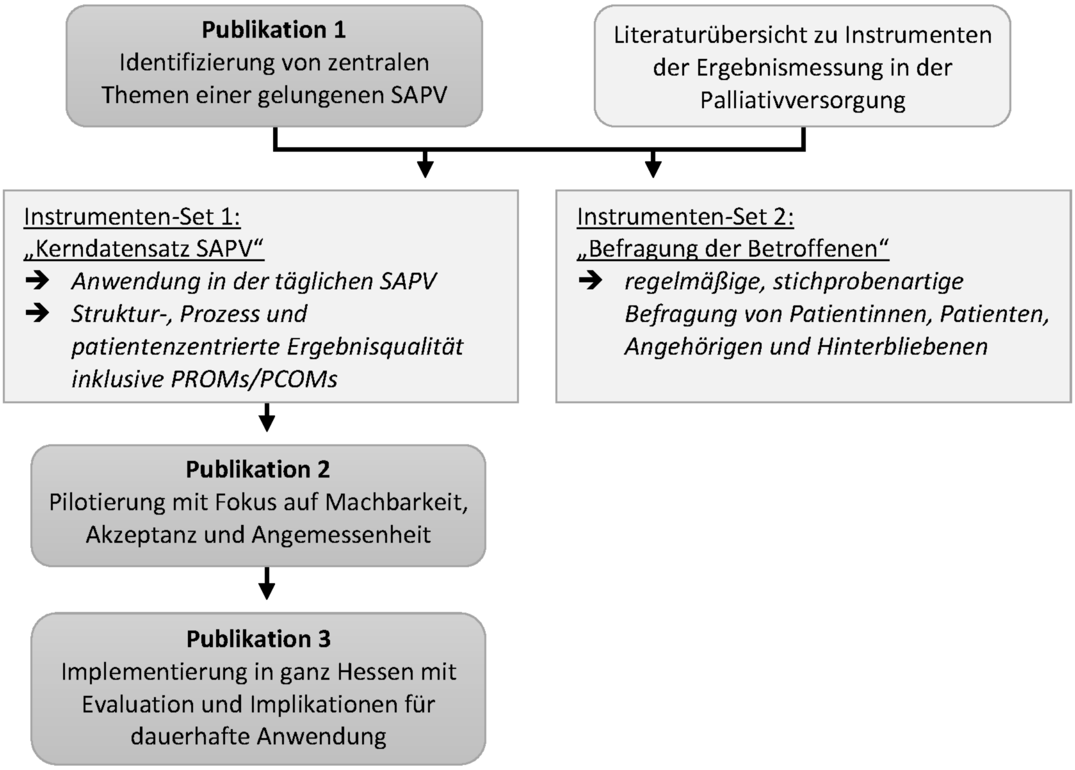
1.3 Ziel der Forschungsarbeit

1.3.1 Einordnung ins Forschungsprojekt ELSAH

Das übergeordnete Ziel des Forschungsprojektes ELSAH (Evaluation der Spezialisierten Ambulanten Palliativversorgung (SAPV) am Beispiel von Hessen) war es ein Verfahren zu entwickeln, zu pilotieren und zu implementieren, welches die Qualität der SAPV darstellen kann. Diese Dissertation ist aus dem Forschungsprojekt ELSAH hervorgegangen.

Im Verlauf des Forschungsprojektes ELSAH zeigte sich, dass das finale Verfahren zur Darstellung der Versorgungsqualität aus zwei Instrumenten-Sets bestehen wird. Diese Dissertation fokussiert Instrumenten-Set 1, welches PROMs und PCOMs in den Arbeitsalltag der SAPV integriert (Abbildung 1, linke Hälfte). Diese Instrumente zur Messung der patientenzentrierten Ergebnisqualität werden neu implementiert und ersetzen teilweise die bestehende Symptomdokumentation. Das zweite Instrumenten-Set, welches als eine regelmäßige, stichprobenartige Befragung von Patientinnen, Patienten, Angehörigen und Hinterbliebenen gestaltet wird, sowie die Literaturübersicht werden in dieser Dissertation nicht behandelt (Abbildung 1, rechte Hälfte).

Abbildung 1: Verortung der Publikationen in der ELSAH-Studie



1.3.2 Ziel der Dissertation

Diese Dissertation verfolgt das Ziel die zentralen Themen einer gelungenen SAPV zu identifizieren sowie zu untersuchen, wie die regelhafte Anwendung von Instrumenten zur Erhebung der patientenzentrierten Ergebnisqualität inklusive PROMs in der täglichen SAPV in Hessen gelingen kann.

Zu Identifizierung der zentralen Themen wurde in Publikation 1 zunächst folgende Fragestellung untersucht:

- Was trägt aus Sicht von Patientinnen und Patienten, deren Angehörigen und an der Versorgung beteiligtem medizinischen Fachpersonal zu einer gelungenen Versorgung bei?

Aufbauend auf diesen Ergebnissen und einer Literaturübersicht über Instrumente zur Messung der Ergebnisqualität wurde das Verfahren zur Darstellung der Versorgungsqualität entwickelt [41]. Basierend auf der Annahme, dass die Kontextfaktoren die Machbarkeit, Akzeptanz und empfundene Angemessenheit der Anwendung beeinflussen, lautete die Fragestellung von Publikation 2 [86]:

- Wie kann die Anwendung von IPOS, IPOS Views on Care und ZBI-7 machbar, akzeptabel und angemessen in die tägliche SAPV integriert werden?

Um zu untersuchen, wie die Anwendung der Instrumente in ganz Hessen funktioniert, lautete die Fragestellung von Publikation 3:

- Wie beurteilt das medizinische Fachpersonal die Anwendung von Phase of Illness in Palliative Care, IPOS, IPOS Views on Care – Patientenversion und „Blick auf die Versorgung“ – Angehörigenversion in der täglichen Versorgung und welche Erkenntnisse lassen sich für eine landesweite Implementierung und nachhaltige Anwendung ableiten?

2 Zusammenfassung der publizierten Ergebnisse

Diese kumulative Dissertation umfasst zwei qualitative Publikationen sowie eine Mixed Methods-Publikation, die entsprechend eines sequentiellen Designs aufeinander aufbauen. Das Forschungsprojekt wurde von der Ethikkommission des Fachbereichs Medizin der Philipps-Universität Marburg geprüft und für alle Schritte ein positives Ethikvotum erteilt (Az. 34/17 am 27.4.2017 und Az. 47/18 am 05.04.2018). Die Studie wurde gefördert vom Innovationsfonds des Gemeinsamen Bundesausschusses (Förderkennzeichen: 01VSF16006). Das Studienprotokoll wurde veröffentlicht [60].

2.1 Publikation 1: Zentrale Themen einer gelungenen SAPV

Seipp H, Haasenritter J, Hach M, Becker D, Ulrich L-R, Schütze D, Engler J, Michel C, Bösner S, Kuss K (2021) How can we ensure the success of specialised palliative home-care? A qualitative study (ELSAH) identifying key issues from the perspective of patients, relatives and health professionals. Palliat Med 35(10):1844-–1855. doi:10.1177/02692163211026516 (Impact-Factor: 5.713)

Hintergrund: Für die Entwicklung eines Verfahrens zur Darstellung der Versorgungsqualität war es zunächst notwendig die zentralen Themen zu identifizieren, welche die Versorgungsqualität in der SAPV beeinflussen.

Fragestellung: In dieser Arbeit verfolgten wir das Ziel die Themen zu identifizieren, die aus Sicht des beteiligten medizinischen Fachpersonals sowie Patientinnen, Patienten und Angehörigen zum Gelingen einer spezialisierten, ambulanten Palliativversorgung beitragen [83].

Methoden: Wir wählten ein qualitatives Design basierend auf den Prinzipien der Grounded Theory, um die Sichtweise der Beteiligten zu verstehen [18, 87]. Wir führten fünf teilnehmende Beobachtungen durch, in welchen wir Mitarbeitende der SAPV-Teams an einem typischen Arbeitstag begleiteten. Hierdurch konnten wir die Arbeit der SAPV in der praktischen Umsetzung beobachten und die Teilnahme von kommunikativ oder kognitiv eingeschränkten Patientinnen und Patienten ermöglichen [26].

Weiterhin interviewten wir Mitarbeitende der SAPV-Teams (n=21) und Kooperationspartner der SAPV-Teams (n=9) anhand eines teilstrukturierten Leitfadens [33]. Dies schloss SAPV-Pflegekräfte, SAPV-Ärztinnen und -Ärzte, eine Sozialarbeiterin, Hausärzte, Mitarbeiterinnen ambulanter Hospizdienste sowie Seelsorger und eine Seelsorgerin ein. Wir interviewten außerdem Patientinnen und Patienten (n=14) sowie Angehörige (n=14) mit einem teilstrukturierten Interviewleitfaden. Zusätzlich führten wir zwei Fokusgruppen mit SAPV-Mitarbeitenden durch, um durch die Diskussion weitere Ideen, Schwerpunkte und Differenzen identifizieren zu können [74].

Entsprechend des iterativen Ansatzes der Grounded Theory erfolgten Datenerhebung und Analyse parallel. Wir verschriftlichten und pseudonymisierten alle Primärdaten und analysierten sie mit Hilfe der Software MAXQDA [89]. Wir triangulierten die Ergebnisse der verschiedenen Datenerhebungsmethoden. In einer dritten Fokusgruppe erfolgte die kommunikative Validierung der vorläufigen Ergebnisse als sogenannter Member Check [55]. Hier präsentierten und diskutierten wir die vorläufigen Ergebnisse mit Mitarbeitenden der SAPV-Teams und finalisierten die Ergebnisse im Anschluss.

Ergebnisse: Wir identifizierten sechs zentrale Themen, deren Berücksichtigung aus Perspektive der Beteiligten zu einer gelungenen spezialisierten, ambulanten Palliativversorgung (SAPV) beitragen: Das erste zentrale Thema ist die „Kontrolle der komplexen Symptome“. Dies umfasst das bestmögliche Verringern von Leiden sowohl durch körperliche Beschwerden als auch durch psychische und emotionale Belastungen. Die Symptomkontrolle stellt häufig zu Beginn einer Versorgung eine zentrale Aufgabe dar, während nach erfolgter medikamentöser Einstellung häufig psychische, soziale und spirituelle Themen in den Vordergrund rücken. Gelungene Symptomkontrolle schafft Vertrauen zwischen Betroffenen und dem medizinischen Fachpersonal und gibt Freiraum, sich anderen relevanten Themen zu widmen.

Die „umfassende Fürsorge“ des SAPV-Teams stellt das zweite relevante Thema dar. Es beinhaltet die Organisation und Koordination der Versorgung unter Einbindung bestehender Versorgungsstrukturen. Ebenso beschreiben die Teilnehmenden die Berücksichtigung der spirituellen und sozialen Bedarfe der Patientinnen und Patienten als relevanten Bestandteil. Das Einbinden der Angehörigen und Berücksichtigung auch deren Bedürfnisse ist ein weiteres Merkmal der umfassenden Fürsorge.

Das dritte zentrale Thema gelungener SAPV ist ein „Sicherheitsgefühl“, was den Betroffenen durch das SAPV-Team vermittelt wird. Es wird gefördert durch dessen Erreichbarkeit rund um die Uhr, der Antizipation von Bedarfen und Vorbereitung möglicher Krisen, sowie dem Empowerment von Patientinnen, Patienten und deren Angehörigen. Das gegenseitige Kennen der Beteiligten und die Kompetenz, welche das SAPV-Team sowohl auf die medizinische Versorgung bezogen als auch im Umgang mit dem Sterben vermittelt, stärkt ebenfalls das Sicherheitsgefühl.

Das „Fördern der Beziehungsqualität“ zwischen Betroffenen und Mitarbeitenden des SAPV-Teams trägt ebenfalls zu einer gelungenen Versorgung bei. Dies beinhaltet einen respektvollen und würdevollen, empathischen und zugleich professionellen Umgang mit

Betroffenen. Eine gute Beziehungsqualität fördert eine vertrauensvolle Zusammenarbeit und ermöglicht auch sensible Themen der Betroffenen anzugehen.

Als fünftes zentrales Thema identifizierten wir das „Achten der Individualität“. Hierzu gehören das konstante Erfragen und Berücksichtigen der individuellen Wünsche und Bedürfnisse.

Das sechste zentrale Thema ist das „Erhalten der Selbstbestimmung“. Hierzu zählt das objektive, neutrale Aufklären über die vorhandenen Möglichkeiten, auf Wunsch auch das Geben professioneller Empfehlungen. Zur Selbstbestimmung gehört es, die Entscheidung der Patientinnen, Patienten und Angehörigen auch dann zu akzeptieren, wenn sie der Meinung des medizinischen Fachpersonals widersprechen.

<u>Diskussion/Schlussfolgerungen:</u> Mit Blick auf die Individualität der Patientinnen, Patienten und Angehörigen kann die Relevanz der einzelnen Themen in der Versorgung unterschiedlich stark ausgeprägt sein. Hier ist es die professionelle Aufgabe der SAPV-Teams herauszufinden, welche Themen in der jeweiligen Versorgung und zum jeweiligen Zeitpunkt relevant sind und wie sie adressiert werden können. Es ist anzunehmen, dass die systematische Dokumentation dieser Themen dazu beitragen kann, dass Patientenbedarfe besser berücksichtigen werden können. Diese zentralen Themen sollten daher in einem Verfahren zur Darstellung der Versorgungsqualität beinhaltet sein. Die folgende Auswahl der Erhebungsinstrumente in unserem Forschungsprojekt erfolgte anhand dieser Erkenntnisse.

Darstellung des eigenen Anteils an der Publikation

<u>Autorinnen und Autoren:</u> Hannah Seipp (HS), Jörg Haasenritter (JH), Michaela Hach (MH), Dorothée Becker (DB), Lisa-Rebecca Ulrich (LRU), Dania Schütze (DS), Jennifer Engler (JE), Cathrin Michel (CM), Stefan Bösner (SB) und Katrin Kuss (KK)

JH, MH, LRU und SB planten und entwickelten das Forschungsprojekt. HS, JH, SB und KK planten die Datenerhebung und führten sie durch. HS koordinierte die Studiendurchführung federführend. MH und DB bereiteten das Studienteam auf die Zusammenarbeit mit Palliativpatientinnen, -patienten und Angehörigen vor und unterstützen die Rekrutierung der Studienteilnehmenden. HS, JH, SB und KK codierten, analysierten und interpretierten die Forschungsdaten. HS entwarf das Konzept und das Modell der „Zentralen Themen“ zum Gelingen der SAPV. CM, LRU, JE, DS, MH und DB unterstützten die Analyse und Interpretation der Daten. HS schrieb federführend das Manuskript und übernahm die Einreichung und Überarbeitung.

2.2 Publikation 2: Machbarkeit, Akzeptanz, Angemessenheit in der täglichen SAPV

Seipp H, Haasenritter J, Hach M, Becker D, Schütze D, Engler J, Ploeger C, Bösner S, Kuss K (2022) Integrating patient- and caregiver-reported outcome measures into the daily care routines of specialised outpatient palliative care: a qualitative study (ELSAH) on feasibility, acceptability and appropriateness. BMC Palliat Care 21(1):60. doi:10.1186/s12904-022-00944-1 (Impact-Factor: 3.113)

Hintergrund: Basierend auf den identifizierten zentralen Themen und einer Literaturübersicht über Instrumente zur Messung der Ergebnisqualität entwickelten wir ein Instrumenten-Set. Es besteht aus validierten Instrumenten inklusive PROMs, die bereits in anderen Settings der Palliativversorgung angewandt wurden.

Fragestellung: In dieser Pilotierung wurde untersucht, wie die Anwendung der Instrumente „Integrated Palliative Outcome Scale" (IPOS) [43], „IPOS Views on Care" (IPOS VoC) [1, 49] und die 7-Item Kurzform das „Zarit Burden Interview" (ZBI-7) [38, 45] durchführbar, akzeptabel und angemessen in die tägliche Arbeit der SAPV integriert werden kann [84].

Methoden: Wir schulten fünf hessische SAPV-Teams in der Anwendung der Instrumente. Die Anwendung erfolgte zunächst papierbasiert, im Verlauf wurden die Instrumente in die elektronischen Dokumentationssysteme der Teams integriert. Die Mitarbeitenden der SAPV-Teams wendeten die Instrumente in der täglichen Versorgung an. Wir wählten ein qualitatives Design, um die Rückmeldungen der SAPV-Mitarbeitenden erfassen und verstehen zu können. Zum einen fertigten wir Feldnotizen von allen Treffen und Kontakten (persönlich, telefonisch, per Mail) an [71]. Zum anderen führten wir zwei Fokusgruppen mit Mitarbeitenden (n=14) von zwei der anwendenden SAPV-Teams durch [74]. Wir triangulierten verschiedene Methoden der Datenerhebung. Die qualitative Inhaltsanalyse erfolgte mithilfe der Software MAXQDA in einem iterativen Prozess parallel zur Anwendung der Instrumente [57, 89]. Die Anwendung wurde entsprechend der Ergebnisse fortlaufend angepasst, die Anpassungen im weiteren Verlauf erprobt und Rückmeldungen hierzu eingeholt.

Ergebnisse: Die Akzeptanz sowie die von den SAPV-Mitarbeitenden empfundene Angemessenheit der Instrumenten-Anwendung wurde durch die Befürchtung eingeschränkt, dass Patientinnen, Patienten und Angehörigen hierdurch belastet werden könnten. Gefördert wurden die Akzeptanz und empfundene Angemessenheit durch ein gutes Verständnis der Nützlichkeit für die praktische Arbeit und damit verbunden auch die empfundene Nützlichkeit für die Patientinnen, Patienten und Angehörigen. Dies wurde eingeschränkt durch grundsätzliche Zweifel an der Nützlichkeit von PROMs zur Darstellung der Versorgungsqualität. Die Validität wurde aufgrund der Abhängigkeit der Betroffenen vom SAPV-Team und der subjektiven Beantwortung der Items durch Betroffene oder SAPV-Mitarbeitende angezweifelt. Generell zeigte sich eine Furcht vor Falschinterpretation der Daten verbunden mit der Sorge, dass sich eine gute Qualität der praktischen Arbeit nicht durch die Instrumente abbilden lässt, insbesondere, weil sich die Gesundheit der Betroffenen naturgemäß bis zum Versterben verschlechtert. Die Schulung der SAPV-Mitarbeitenden wurde als Konsequenz um die Aspekte Nutzen für die praktische Arbeit, Nutzen für die Betroffenen und Nutzen zur Qualitätsdarstellung erweitert.

Die Möglichkeit einer sensiblen Anwendung förderte die Machbarkeit und Akzeptanz der SAPV-Mitarbeitenden: Da Zeitvorgaben und die exakten Formulierungen der Instrumenten-Items in der praktischen Anwendung Schwierigkeiten bereiteten, ermöglichten wir die Fragen ins Gespräch einzubinden („Interviewverfahren“) und überließen den SAPV-Mitarbeitenden die Entscheidung, wann ein Thema mit Patientinnen und Patienten besprochen werden kann und wann ihrer professionellen Einschätzung nach auf eine Selbsteinschätzung verzichtet werden sollte. Für diese Fälle ermöglichten wir die Fremdeinschätzung durch Angehörige oder SAPV-Mitarbeitende.

Fördernd für die Machbarkeit und Akzeptanz der Instrumenten-Anwendung war eine praktikable Verwaltung. Die Einbindung in die elektronische Dokumentation war unabdingbar, um eine Doppeldokumentation und administrativen Mehraufwand zu vermindern. Die Einbindung der Angehörigen in die Erhebung wurde von den SAPV-Mitarbeitenden begrüßt. Die SAPV-Mitarbeitenden machten aber auch deutlich, dass manchmal einzelne Items wie z.B. Lebensqualität weder durch die Patientinnen und Patienten selbst noch durch die Fremdeinschätzung von Angehörigen oder das medizinische Fachpersonal bewertet werden können. Für diese Fälle wurde die Option hinzugefügt, dass ein Item zu diesem Zeitpunkt als „nicht beantwortbar“ dokumentiert werden kann.

Spezielle Rückmeldungen zu den einzelnen Instrumenten wurden ebenfalls erhoben, analysiert und in der Publikation dargestellt. Die SAPV-Mitarbeitenden kritisierten u.a., dass der ZBI-7 Fragebogen die Beziehung zwischen Patientinnen, Patienten und Angehörigen verschlechtern kann und zu undifferenzierte Aussagen liefert. Weil es sich aufgrund dessen für die Anwendung in der täglichen SAPV als unangemessen und nicht akzeptabel herausstellte, entfernten wir den ZBI-7 aus dem Instrumenten-Set und entwickelten stattdessen „Blick auf die Versorgung“ – Angehörigenversion; basierend auf IPOS VoC – Patientenversion).

Diskussion/Schlussfolgerungen: Es zeigte sich, dass eine machbare, akzeptable und angemessene Anwendung der genannten Instrumente in der täglichen SAPV möglich ist. Hierfür sollte die Belastung von Patientinnen, Patienten und Angehörigen durch die Anwendung geringgehalten werden. Des Weiteren sollte der Nutzen für die praktische Arbeit und zur Darstellung der Versorgungsqualität verstehbar sein, eine sensible Anwendung ermöglicht werden und die Verwaltung handhabbar sein.

Darstellung des eigenen Anteils an der Publikation

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JH, MH und SB konzipierten das Forschungsprojekt. HS, JH, SB und KK planten und führten die Datenerhebung durch. MH und DB unterstützen die Rekrutierung und Zusammenarbeit mit den SAPV-Teams. HS schulte die SAPV-Teams in der Anwendung, war Hauptansprechpartnerin für Feedback und Probleme der Teams während der gesamten Pilotierungsphase und entwickelte Verbesserungsprozesse für die Anwendung des Verfahrens. HS, JH, SB und KK codierten und analysierten die Forschungsdaten und konzeptualisierten die Ergebnisse. DS, JE, CP, MH und DB unterstützten die Analyse und Interpretation der Daten. HS schrieb federführend das Manuskript und übernahm die Einreichung und Überarbeitung.

2.3 Publikation 3: Hessenweite Implementierung, Evaluation und Implikationen für eine dauerhafte Anwendung

Seipp H, Haasenritter J, Hach M, Becker D, Schütze D, Engler J, Bösner S, Kuss K (2022) State-wide implementation of patient-reported outcome measures (PROMs) in specialized outpatient palliative care teams (ELSAH): A mixed-methods evaluation and implications for their sustainable use. BMC Palliat Care 21(1):216. doi:10.1186/s12904-022-01109-w (Impact-Factor: 3.113)

Hintergrund: Das Verfahren zur Darstellung der Versorgungsqualität der SAPV soll bei allen hessischen SAPV-Teams implementiert werden und eine gemeinsame Datenbasis schaffen. Die Implementierung und Anwendung der Instrumente in vielen SAPV-Teams mit unterschiedlichen Arbeitsweisen, Historien und Strukturen sowie vielen beteiligten Professionellen stellt eine Herausforderung für eine nachhaltige Anwendung dar.

Fragestellung: In dieser Publikation untersuchten wir, wie die Mitarbeitenden der SAPV-Teams in Hessen die Anwendung der Instrumente „Integrated Palliative Outcome Scale“ (IPOS) [16], „IPOS Views on Care“ (IPOS VoC) – Patientenversion [17, 18], Views On

Care - Angehörigenversion und die „Phase of Illness“ [23] in der täglichen Versorgung bewerten und welche Aspekte für eine dauerhafte Nutzung besonderer Aufmerksamkeit bedürfen [85].

Methoden: Wir implementierten das Instrumenten-Set in der täglichen Versorgung in 19 SAPV-Teams in Hessen. Zur Evaluation wählten wir ein Mixed Methods-Design bestehend aus einer quantitativen Online-Befragung, um niedrigschwellig die Perspektive von möglichst vielen Beteiligten zu erheben, sowie drei Fokusgruppen mit Mitarbeitenden (n=14) der SAPV-Teams, um die Sichtweisen in die Tiefe verstehen zu können. Hierbei orientierten wir uns an der Normalization Process Theory (NPT). Die NPT fokussiert die Arbeit, die geleistet werden muss, um Praktiken zu implementieren, in bestehende Handlungen einzubetten und aufrechtzuerhalten. Die Theorie berücksichtigt dabei die vier Kernkonzepte Kohärenz, kognitive Partizipation, gemeinsames Handeln und reflexives Monitoring [63].

Für die Online-Befragung verwendeten wird das NoMAD-Instrument (Normalization MeAsure Development). Dieses generische Instrument erfragt auf einer fünfstufigen Likert-Skala (starke Zustimmung bis starke Ablehnung) die Bewertung von Aussagen, die sich auf die Kernkonzepte der NPT beziehen [32, 78] . Wir analysierten die Häufigkeiten deskriptiv. Der Fokusgruppen-Leitfaden orientierte sich ebenfalls an der NPT. Die qualitative Inhaltsanalyse erfolgte gemischt deduktiv-induktiv [58].

Für die Mixed Methods-Integration triangulierten wir die Ergebnisse der beiden Erhebungsformen auf der Interpretationsebene, indem wir eine „convergence coding matrix“ erstellten [68]. Hierbei untersuchten wir die quantitativen und qualitativen Kernergebnisse auf Konvergenzen, Dissonanzen, ergänzende und fehlende Informationen und erarbeiteten für jede Komponente eine Methoden-übergreifende Zusammenfassung. Anschließend untersuchten wir wiederkehrende Themen unter der Annahme, dass sie Einfluss auf die nachhaltige Anwendung haben.

Ergebnisse: Die Mitarbeitenden der SAPV-Teams gaben mehrheitlich an, dass die Anwendung der Instrumente ein normaler Bestandteil ihrer Arbeit geworden ist. Es zeigte sich, dass einige Mitarbeitende die Integration in die tägliche Arbeit als noch nicht gelungen empfanden. Auch wussten nicht alle Mitarbeitenden, wie sie die Instrumente anwenden können, um Nutzen für die tägliche Arbeit zu haben. Ebenso wurde die Nützlichkeit für die Darstellung der Versorgungsqualität teilweise angezweifelt.

Neben dem Verständnis für den Nutzen der Anwendung beeinflusste die Motivation das Engagement zur Anwendung der Instrumente. Die Motivation der SAPV-Mitarbeitenden wurde beeinflusst von dem erwarteten Nutzen und Unsicherheiten in der Anwendung.

Förderlich waren der Austausch der Teams untereinander sowie teambezogene Auswertungen. Wir fanden Ängste der SAPV-Mitarbeitenden vor negativen Konsequenzen durch Fehlinterpretation der Daten. Außerdem fürchteten sie, dass die Anwendung die Beziehungsqualität zu den Patientinnen, Patienten und Angehörigen verschlechtern könnte, was zu einer verringerten Anwendungsmotivation und erschwerten Einbettung in die tägliche Arbeit führte.

Spezifische Rückmeldungen zu den einzelnen Instrumenten zeigten, dass IPOS und IPOS Phase of Illness als hilfreich für die tägliche Arbeit erachtet werden. Einzelne psychosoziale IPOS-Items wie z.B. „Ängste“, „Gefühle teilen“ und „in Frieden sein“ bereiteten Probleme in der Anwendung. Auch IPOS Views on Care bereitete Probleme in der praktischen Umsetzung.

Diskussion/Schlussfolgerungen: Obwohl die meisten Mitarbeitenden die Anwendung der Instrumente als einen normalen Bestandteil ihrer täglichen Arbeit empfanden, zeigten sich Unsicherheiten zum Nutzen in der praktischen Arbeit und zur Qualitätsdarstellung. Die Faktoren, welche die Motivation beeinflussen, sowie die Ängste der SAPV-Mitarbeitenden bedürfen für die weitere Anwendung besondere Aufmerksamkeit.

Die Anwendung schien bei den Mitarbeitenden verschiedener hessischer SAPV-Teams unterschiedlich gut zu funktionieren. Die breite Implementierung in vielen Teams bietet hierbei die Möglichkeit Schulungen zum Thema ressourcensparend durchzuführen und durch teamübergreifenden Austausch Probleme gemeinsam zu lösen. Sinnvoll erscheint hierbei die Etablierung einer koordinierenden Institution, wie sie vom Fachverband SAPV in Hessen repräsentiert wird, welche die dauerhafte Anwendung begleitet und fördert.

Darstellung des eigenen Anteils an der Publikation

Autorinnen und Autoren: Hannah Seipp (HS), Jörg Haasenritter (JH), Michaela Hach (MH), Dorothée Becker (DB), Dania Schütze (DS), Jennifer Engler (JE), Stefan Bösner (SB) und Katrin Kuss (KK)

JH, MH und SB konzipierten das Forschungsprojekt. HS, KK und JH planten und führten die Datenerhebung durch. MH und DB unterstützen die Rekrutierung und Zusammenarbeit mit den SAPV-Teams. HS, JH und KK codierten und analysierten die qualitativen und quantitativen Forschungsdaten. HS führte die Mixed Methods-Integration durch und konzeptualisierte federführend die Ergebnisse mit der Unterstützung von KK und JH. SB, DS, JE, MH und DB unterstützten die Analyse und Interpretation der Daten. HS schrieb federführend das Manuskript und übernahm die Einreichung und Überarbeitung.

3 Diskussion

3.1 Zusammenfassung und übergeordnete Diskussion der Artikel

Im Rahmen dieser Arbeit entwickelten und implementierten wir ein Verfahren zur Darstellung der Ergebnisqualität in der täglichen SAPV, welches die relevanten Themen aus Sicht der Beteiligten abbildet und für SAPV-Mitarbeitende machbar, akzeptabel und angemessen in die tägliche Arbeit integriert werden kann. Die Evaluation zeigte, dass die Anwendung in der täglichen Arbeit möglich ist, allerdings auch Barrieren auftreten. Für die nachhaltige Anwendung in ganz Hessen sind dauerhaft begleitende Schulungen, Peer-Support und die Vernetzung von SAPV-Teams notwendig.

Als Themen, die zu einer gelungenen SAPV beitragen, identifizierten auch andere Studien die Kontrolle komplexer Symptome und das Vermitteln eines Sicherheitsgefühls [53, 64, 80, 81]. Die Kooperation mit Versorgungspartnern wird ebenfalls in anderen Studien als relevant benannt, allerdings zeigt sich, dass sie in der Praxis z.B. mit Hausärztinnen und Hausärzten unterschiedlich stark gelebt wird [21, 80]. Ergänzend zu unseren Ergebnissen identifizierten Klarare et al., dass die SAPV-Teamleitung und die Teamressourcen Einfluss auf das Gelingen einer Versorgung haben [52]. Genauso wie Aparicio et al. fanden wir heraus, dass die Förderung der Beziehungsqualität und der Einbindung und Fürsorge für die Angehörigen im Setting der SAPV besonders relevant ist [4]. Es zeigte sich, dass insbesondere die über medizinische Versorgung hinausgehenden Aspekte wie Beziehungsqualität, Achtung der Individualität und Selbstbestimmung einen großen Anteil am Gelingen der SAPV haben. Dennoch zeigte eine andere Studie, dass es für Pflegekräfte in der SAPV aufgrund der medizinischen Orientierung der Versorgung manchmal nicht möglich ist, den psychosozialen Themen von Patientinnen, Patienten und Angehörigen ausreichend Raum zu geben [37]. Das bestätigt, dass diese Aspekte bei der Darstellung der Versorgungsqualität berücksichtigt und die Nutzung der patientenberichteten Ergebnisqualität in der praktischen Arbeit gefördert werden sollte.

Bei der Anwendung der Instrumente im Arbeitsalltag der SAPV bereiteten insbesondere die Integration der psychosozialen Themen wie Lebensqualität, „in Frieden-sein“, Patienten-Ängste oder die Ängste der Angehörigen Probleme. Sowohl bei der Erprobung in wenigen Teams, als auch bei der Implementierung in ganz Hessen zeigte sich, dass sich die SAPV-Mitarbeitenden bei der Anwendung einzelner Items unwohl fühlten. Das medizinische Fachpersonal beschrieb, dass sie die Themen an sich als wichtig erachten, die Erhebung mit den genannten Instrumenten ihnen aber nicht angemessen erschien. Hier zeigten auch andere Studien, dass es wichtig ist die Erhebung der Items zu trainieren, da Umformulierungen den Sinn verfälschen und die psychometrischen Eigenschaften ändern können [39, 72]. Im deutschsprachigen Raum gibt es Erfahrungen mit den deutschsprachigen, validierten Versionen, aber auch hier zeigte sich, dass die Anwendung von Phase of Illness und IPOS nicht selbsterklärend war, sondern fortlaufenden Schulungsaufwand benötigte [62, 65]. Zu VoC gibt es keine Erfahrungen im deutschsprachigen Raum, es liegen nur wenige internationale Anwendungsstudien vor [73]. Während sich ZBI-7 in unserer Studie als nicht akzeptabel und nicht angemessen erwies, kamen Kühnel et al. zu dem Ergebnis, dass ihre nach der ELSAH-Studie publizierte deutschsprachige, validierte ZBI-7-Version in vielen Palliativsettings angewandt werden kann. Sie schränken aber selbst ein, dass nur wenige zuhause pflegende Angehörige an ihrer Studie teilnahmen [59]. Auch die ELSAH-Übersetzung von VoC-Patientenversion und „Blick auf die Versorgung“ Angehörigenversion ist nicht validiert. Die OACC hat in Version 2 der Instrumenten-Empfehlung zwei zusätzliche Fragen für pflegende Angehörige herausgegeben, die unserer „Blick auf die Versorgung – Angehörigenversion“ stark ähneln [90]. Folglich herrscht Einigkeit, dass das subjektive Erleben der Angehörigen ebenfalls in einem Verfahren zur Darstellung der Versorgungsqualität berücksichtigt werden sollte. Es ist allerdings weiter unklar, welches Instrument sich für die Anwendung in der SAPV eignet und international vergleichbar ist.

In einer schwedischen Studie bewerteten die Patientinnen und Patienten die Anwendung von IPOS in der SAPV als gute Gesprächsgrundlage, die ihnen vermittelte, dass die Versorgung individuell an sie angepasst war [47]. SAPV-Mitarbeitende in unserer Studie fürchteten aber Betroffene durch die Forschung und Anwendung der PROMs zu belasten. Dies kann dazu führen, dass SAPV-Mitarbeitende die Beteiligung von Patientinnen, Patienten und Angehörigen verhindern (Gatekeeping), obwohl die Belastung durch angepasste Strategien geringgehalten werden kann. Eine generelle Forschungskultur in Palliativteams ist dabei förderlich um das Verständnis für Forschung zu verbessern und Ängste zu verringern [40].

SAPV-Mitarbeitende befürchteten bei uns wie in der Studie von Jansky et al. eine zunehmende Technisierung und dadurch Schwächung der Beziehungsqualität zwischen SAPV-Mitarbeitenden und Patientinnen, Patienten und Angehörigen [50]. Benze et al. erprobten die PROM Selbsteinschätzung in der SAPV via Smartphone App [12]. Andere Autoren vermuten, dass die Digitalisierung von PROMs eine zeitnahe und zielgerichtete Versorgung fördert, sowie mehr Freiraum für den persönlichen Kontakt schaffen kann, bisher fehlen allerdings Best Practice-Beispiele hierfür [15, 70].

Es zeigte sich, dass medizinisches Fachpersonal für die Akzeptanz, die empfundene Angemessenheit und die nachhaltige Anwendung von PROMs sowohl deren Nutzen für die tägliche Arbeit als auch für die Darstellung der Versorgungsqualität verstehen muss. Hierdurch können die Motivation gesteigert und Ängste reduziert, sowie die Anwendung verbessert werden. Erfahrungen der Anwendung im stationären Setting zeigten, dass nicht alle Professionellen einen Sinn in der Anwendung von PROMs sehen. Die Autoren erläutern, dass die Priorität der Anwendung von PROMs innerhalb der Arbeit verortet wird und je nach Druck der Leitung, der Institution oder des Gesundheitssystems dies als mehr oder weniger relevant bewertet wird [56]. Bradshaw et al. zeigten, dass, wenn medizinisches Fachpersonal keinen Mehrwert für ihren Arbeitsalltag sahen, die Erhebungen als sinnlos abgetan wurden [14]. Dadurch wird aber das kollektive Handeln geschwächt und die Normalisierung im Arbeitsalltag behindert [63]. Die Autoren zeigten außerdem, dass die Nutzung der Ergebnisse in der Teamkommunikation die Motivation zur Anwendung steigerte, weil hierdurch deutlich wurde, wie die Instrumente die tägliche Arbeit fördern können [14]. Das Team einer Palliativstation setzte dies so um, dass die IPOS- und Phase of Illness-Werte der jeweiligen Patientinnen und Patienten bei der Teambesprechung farblich codiert für alle sichtbar angezeigt wurden [10]. Generell kann die Darstellung von PROs durch grafische Darstellungen unterstützt werden [6]. Transparenz und das Kennen von Berichten für externe Stellen wie beispielsweisen den G-BA können gleichzeitig Ängste vor Fehlinterpretationen reduzieren. Es ist anzunehmen, dass mit steigendem Verständnis und Motivation der Anwendenden auch die Genauigkeit der Erhebungen („Fidelity“) gestärkt werden kann, wodurch eine bessere Datenbasis zur Verfügung steht [75].

3.2 Stärken und Limitationen

Patientinnen, Patienten und Angehörige sind während der Versorgung vom SAPV-Team abhängig. Da die Instrumente (PROMs) nicht anonym angewandt werden können, stellt sich die Frage, ob sie ehrlich sind oder vermeintlich erwünschte Antworten (Soziale Erwünschtheit) provoziert werden. Hier kommt es ebenfalls auf das Fingerspitzengefühl der SAPV-Mitarbeitenden an, zu kommunizieren, dass eine ehrliche Beantwortung für die eigene Versorgung und zur Verbesserung des Teams wichtig ist und kritische Rückmeldungen keine Nachteile hervorrufen. Zur umfassenden Darstellung der Versorgungsqualität sollten dennoch die PROMs mit anderen Erhebungen wie regelmäßigen pseudonymisierten Befragung von Patientinnen und Patienten und der retrospektiven Bewertung von Hinterbliebenen kombiniert werden.

Da die Rekrutierung von Patientinnen, Patienten und Angehörigen über die SAPV-Teams erfolgte, kann ein Selektionsbias nicht ausgeschlossen werden. Während die Patientenbeteiligung bei der Identifizierung der zentralen Themen durch die Partizipation in Interviews und teilnehmenden Beobachtungen gewährleistet war, fokussierte das weitere Vorgehen die Perspektive der SAPV-Mitarbeitenden. Da die SAPV bereits stark patientenzentriert arbeitet, wurden die Bedürfnisse von Betroffenen von den SAPV-Mitarbeitenden so gut wie möglich mitgedacht. Das purposive Sampling bei der Rekrutierung von Teilnehmenden für Interviews, Fokusgruppen, Teilnehmende Beobachtungen und die Pilotierung in wenigen Teams ermöglichte eine Bandbreite an Versorgungssituationen und Disziplinen einzubeziehen. Gestärkt wurde das Modell der zentralen Themen durch die Diskussion und kommunikative Validierung mit teilnehmenden SAPV-Mitarbeitenden.

Auch bei der Teilnahme des medizinischen Fachpersonals in den Fokusgruppen ist ein Selektionsbias zugunsten der an Qualitätsverbesserung interessierten Mitarbeitenden anzunehmen. Allerdings wurden insbesondere in den Fokusgruppen auch kritische Aspekte offen geäußert und diskutiert. Durch die Kombination mit dem anonymen Online-Survey hatten kritische Stimmen außerdem die niedrigschwellige Möglichkeit zur Partizipation. Das Mixed Methods-Design unserer Studie mit Triangulation verschiedener qualitativer und quantitativer Methoden und die Beteiligung vieler Perspektiven ermöglichte ein umfassendes Bild zu erhalten [31]. Die Interdisziplinarität unseres Forschungsteams stärkte die Analysen.

Eine weitere Stärke der Studie ist die Implementierung in der realen Versorgung (routine care), was studienbedingte Verzerrungen reduziert und die Übertragbarkeit stärkt [2]. Publikation 1 wurde vom Fachjournal SAGE Palliative Medicine honoriert als „Editors Choice“ des Monats Dezember 2021, da es „die Leser besonders interessant oder nützlich finden könnten“ [25]. Die Auszeichnung dieses Journals, welches sich an Palliativforscher, aber vor allem auch Praktiker der Versorgung richtet, drückt die Relevanz für die praktische Arbeit der Palliativversorgung aus.

3.3 Implikationen für Forschung und Praxis

In unserer Studie zeigte sich, dass die „Dokumentation“ oft losgelöst von der praktischen Versorgung betrachtet wird und dadurch als belastend empfunden wird, obwohl diese auch zu den pflegefachlichen Kernaufgaben zählt [11]. Diehl et al. zeigten, dass sich Palliativpflegekräfte in Deutschland unter anderem durch organisatorische Belange wie häufige patientenferne Aufgaben und Zeitdruck belastet fühlen, aber auch der Informationsaustausch mit anderen Fachkräften eine Belastung darstellt. Die 160-stündige Palliativ Care Weiterbildung, die in der SAPV für alle Pflegekräfte vorgeschrieben ist, stellte dabei einen Entlastungsfaktor dar. Fortbildungen wurden von den Pflegekräften als Ressource erlebt [20]. Es kann daher angenommen werden, dass

Fortbildungen zur Anwendung von PROMs ebenfalls die Belastung verringern könnten, was weitergehend untersucht werden müsste.

Nach der Erprobung in wenigen Teams veränderten wir zur verbesserten Durchführbarkeit, Akzeptanz und empfundenen Angemessenheit die Schulungen. Dabei wurde mehr Fokus auf die Interviewtechnik gelegt mit Integration der Themen in die Gespräche mit Patientinnen, Patienten und Angehörigen sowie die Nützlichkeit der PROMs für die Praxis [84]. Da bei der Implementierung in ganz Hessen dann ähnliche Probleme auftraten, scheinen diese Änderungen nicht ausreichend gewesen zu sein. Dies könnte mit der nur einstündigen Dauer der Schulungen zusammenhängen. Aufgrund des ausgefüllten Arbeitsalltags der SAPV-Teams konnten die Gruppenschulungen durch Mitarbeitende des Studienteams nicht länger dauern. In anderen Studien zeigte sich außerdem, dass die Nutzung dieser PROMs ein andauernder Prozess ist, der fortlaufendes Engagement benötigt [10, 48]. Die Anleitung und Schulung durch Kolleginnen und Kollegen der praktischen Palliativversorgung, wie es beispielsweise bei Kommunikations-Trainings für junge Ärztinnen und Ärzte in der Onkologie verwendet wurde, könnte hier ebenfalls hilfreich sein [28]. Von Professionellen in einer anderen Studie wurde dies positiv bewertet [14]. Vorteile dieses „peer-teaching“ sind ein ähnlicher Wissensstand und ähnliche Erfahrungen, wodurch die Inhalte praxisnah und in der „Sprache der SAPV“ vermittelt werden könnten. Für die nachhaltige Anwendung sollte den SAPV-Mitarbeitenden daher eine dauerhafte Unterstützung mit Peer-Support angeboten und die Kooperation der SAPV-Teams gefördert werden.

Die Übertragbarkeit auf andere Regionen ist gegeben, sofern sich die Versorgungsstrukturen und -organisation ähneln. Die Arbeitskultur und Historie einzelner Leistungserbringer sind dennoch zu adressieren [56]. Für eine nationale Implementierung des Verfahrens zur Darstellung der Versorgungsqualität bietet das NHPR eine gute Grundlage. Bei der Implementierung in mehreren SAPV-Teams ist zu bedenken, dass in Hessen bereits geeignete Strukturen für ein solches Vorhaben vorlagen [42]. Die flächendeckende Versorgung mit Zusammenschluss aller SAPV-Teams im SAPV Fachverband Hessen e.V. hatte sichergestellt, dass alle SAPV-Teams gemeinsam an der Studie teilnahmen und hat die Kommunikation, Organisation und Implementierung erleichtert. Die Datenerhebung zur Identifizierung der zentralen Themen könnte zusätzlich für das Thema Qualität aus Perspektive der Betroffenen sensibilisiert und die Teilnahmebereitschaft der Professionellen erhöht haben. Es ist daher zu empfehlen, eine ähnliche Vernetzung auch in anderen Regionen schaffen. Für die Vernetzung der SAPV-Teams, Schulungen und fortlaufende Weiterentwicklung inklusive EDV-Umsetzung werden entsprechende zeitliche und monetäre Ressourcen benötigt.

Das Verfahren ist nicht auf die SAPV von Kindern und Jugendlichen (SAPV-KJ) übertragbar, da sich die Versorgung in Hinblick auf deren Belange, die vorherrschenden Krankheitsbilder, die Einbindung der Familie und der praktischen Versorgung unterscheidet [27]. Die Anwendung von PROMs mit Selbsteinschätzung ist Kindern ab dem Alter von fünf Jahren möglich, wenn hierfür angepasste Fragen und Skalen verwendet werden [17]. Eine afrikanische Studie entwickelte inzwischen eine PROM für Kinder und Jugendliche (C-POS, Children's Palliative Care Outcome Scale) [66]. Für die Qualitätsdarstellung in der SAPV-KJ ist weitere Forschung notwendig.

Wie erläutert konnte die Erhebung und Darstellung der Bedürfnisse von Angehörigen noch nicht akzeptabel, angemessen und durchführbar in die tägliche SAPV implementiert werden. Hier bedarf es weiterer Forschung zu validierten und möglichst international einheitlich angewandten Instrumenten für diesen Zweck.

Bisher ausstehend ist die Längsschnittanalyse der erhobenen Daten im Hinblick auf die Vollständigkeit der Daten. Da die PROMs nur einen Bestandteil des Verfahrens zur Darstellung der Versorgungsqualität darstellen, müssen bei der umfassenden Betrachtung auch Struktur- und Prozessdaten sowie die regelmäßige, stichprobenartige „Befragung von Betroffenen“ (Abbildung 1) berücksichtigt werden. Für die nachhaltige Weiterentwicklung ist es außerdem wichtig, dass die Anwendenden dies mitgestalten können, indem beispielsweise Auswertungen entsprechend ihres fachlichen Interesses konzipiert werden [14]. Um zu erforschen, wie die langfristige Anwendung tatsächlich umgesetzt wird, empfiehlt sich eine Prozessevaluation in den SAPV-Teams inklusive qualitativer Erhebungen. Hierdurch können notwendige Anpassungen in der Anwendung und unterstützende Maßnahmen abgeleitet werden. Hierbei sollte die Perspektive der Patienten, Patientinnen und Angehörigen auf die Anwendung ebenfalls berücksichtigt werden.

3.4 Schlussfolgerungen

Die implementierten PROMs und PCOMs zur Darstellung der patientenzentrierten Ergebnisqualität stellen einen wesentlichen Baustein zur Evaluation der Versorgungsqualität in der SAPV dar, weil hiermit das subjektive Erleben der Patientinnen, Patienten und Angehörigen in den Vordergrund gerückt wird.

Die Anwendung kann in den Arbeitsalltag der SAPV integriert werden, Professionelle fühlen sich aber teilweise unwohl in der Anwendung und haben Bedenken, dass Patientinnen, Patienten und Angehörige hierdurch belastet werden könnten. Für eine nachhaltige Anwendung müssen diese Bedenken adressiert werden: Professionelle sollten den Nutzen für die tägliche Arbeit erfahren und die Qualitätsdarstellung verstehen. Hierdurch können Ängste verringert, Motivation und Wohlbefinden in der Anwendung gestärkt und durch verbesserte Compliance die Datenbasis für Forschung und Praxis verbessert werden.

Es handelt sich hierbei um einen dauerhaften Prozess, der monetäre und zeitliche Ressourcen braucht. Unterstützend ist dabei die Nutzung der Instrumente in der Teamkommunikation, transparente, regelmäßige Auswertungen, fortlaufende Schulungen, Peer-Support und die Vernetzung von SAPV-Teams.

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5 Anhang

5.1 Publikation 1

Seipp H, Haasenritter J, Hach M, Becker D, Ulrich L-R, Schütze D, Engler J, Michel C, Bösner S, Kuss K (2021) How can we ensure the success of specialised palliative home-care? A qualitative study (ELSAH) identifying key issues from the perspective of patients, relatives and health professionals. Palliat Med 35(10):1844-–1855. doi:10.1177/02692163211026516

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How can we ensure the success of specialised palliative home-care? A qualitative study (ELSAH) identifying key issues from the perspective of patients, relatives and health professionals

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Abstract

Background: Specialised palliative home-care supports patients with life-limiting diseases in their familiar surroundings. The number of palliative care teams and patients being cared for is increasing worldwide. To assess and improve quality, it is needed to understand, how specialised palliative home-care can be provided successfully. For this purpose we examined the views of all involved stakeholders.

Aim: To identify the issues that patients, their relatives and involved health professionals view as important in ensuring the success of specialised palliative home-care.

Design: We used a qualitative design based on participant observations, interviews and focus groups following the principles of a Grounded Theory approach.

Setting/participants: All specialised palliative home-care teams ($n = 22$) caring for adults in Hesse, Germany, participated. We conducted participant observations ($n = 5$), and interviewed patients ($n = 14$), relatives ($n = 14$) and health professionals working in or collaborating with specialised palliative home-care ($n = 30$). We also conducted focus groups ($n = 4$) with health professionals including a member check.

Results: Successful specialised palliative home-care needs to treat complex symptoms, and provide comprehensive care including organisation of care, involving relatives and addressing issues of death and dying. Sense of security for patients and relatives is key to enable care at home. Care delivery preferences include a focus on the quality of relationships, respect for individuality and the facilitation of self-determination.

Conclusions: Consideration of the identified key issues can help to ensure successful specialised palliative home-care. Knowledge of these should also be considered when researching and assessing quality of care.

Trial registration: German Clinical Trials Register DRKS-ID: DRKS00012421; http://www.germanctr.de.

Keywords

Palliative care, home care services, quality of health care, needs assessment, qualitative research, grounded theory

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What is already known about the topic?

- Specialised palliative home-care enables patients to die at home and supports patients and their relatives in this situation. It aims to promote quality of life and self-determination, but it is not clear how to achieve these aims.
- Quality assessment helps address the needs of patients and their relatives and fosters patient-centred care. By evaluating the quality of care, it also reveals potential for improvement.
- As specialised palliative home-care focusses on the needs of patients and their relatives, their perspective is essential in any assessment of quality of care.

What this paper adds

- Successful specialised palliative home-care needs to address the treatment of complex symptoms. It further needs to offer comprehensive care that includes organisation and coordination of care, involves relatives and addresses issues of death and dying.
- To enable care and dying at home, a sense of security for patients and relatives needs to be promoted.
- Preferences in how care is delivered comprise a focus on the quality of relationships, respect for individuality and the facilitation of self-determination.

Implications for practice, theory and policy

- The results help specialised palliative home-care teams to recognise and address needs. Improved understanding of what constitutes successful palliative home-care can ensure care is patient-centred.
- Both, service providers and policymakers, should take the identified issues into account when planning and organising specialised palliative home-care.
- The identified issues should be considered when researching the quality of specialised palliative home-care. They form the basis to develop a method of quality assessment that is adapted to this specific setting and considers the perspectives of those involved.

Introduction

The aim of palliative care is to enhance quality of life in patients with life-limiting diseases.[1] Specialised palliative care provides extensive support to those with complex needs who require a specially qualified team.[2] Evidence shows that most patients would prefer to die at home, and specialised palliative home-care helps patients to continue living at home.[3,4] In Europe, more than 2500 teams provided specialised palliative home-care in 2019.[5] Worldwide trend shows an increasing number of palliative care teams and patients cared for, which raises the question of how successful care can be provided and assessed.[6]

Quality assessment promotes patient-centred care and helps to address patient needs.[7] Furthermore, it is gaining increasing attention from those responsible for allocating resources.[8] A variety of outcome assessment tools in palliative care exist. They focus on different target groups like patients, relatives, health professionals or the healthcare system and cover different domains, that range from symptoms to spiritual needs.[9,10] Some initiatives like the Australian Palliative Care Outcomes Collaboration[11] and the Outcome Assessment and Complexity Collaborative[12] focus on comprehensive approaches to evaluate palliative care. It is recommended to use validated outcome measurement tools, that include patients as well as relatives, are appropriate for the setting they are used in, and cover all relevant aspects of care.[7]

In order to improve and to assess the quality of specialised palliative home-care, it is crucial to know which issues influence quality in this setting. Studies indicate that beyond symptom control, further complex issues like security and the organisation of everyday life contribute to successful palliative home-care.[13] Previous studies have examined the views of different stakeholders concerning successful care: Patients and relatives value provision of appropriate resources, reliability and partnership, as well as security and continuity.[14] For the bereaved, the consideration of their own capacity for care, the preparation, presentation and support after death, as well as professionalism combined with humanity are relevant issues.[15,16] Health professionals also describe beside anticipation, commitment and flexibility that the teams' capacity and communication promote successful care.[17,18] However, no previous study with focus on specialised palliative home-care incorporated all perspectives combined. Other studies focussed on successful care for patients with specific diseases.[19–21] But for a broad-based quality assessments aiming at including every case, the approach should be independent of the underlying disease.

Because patients and their relatives are in the focus of care, their perspective is decisive on which issues are relevant for successful care. Integrating the opinion of health professionals enables a comprehensive view across individual cases. Research is needed to understand what successful specialised palliative home-care means to all directly involved stakeholders, particularly to patients and their relatives, regardless of the underlying disease.

The ELSAH-study ('Evaluation of Specialised Outpatient Palliative Care by taking the example of Hesse') aims to implement a set of measures that enables the evaluation of quality of care in specialised palliative home-care (work package I). The study protocol has been published elsewhere.[22] The qualitative study presented in this paper provides the basis for developing an outcome measurement approach. We undertook this qualitative research in order to comprehend what constitutes successful specialised palliative home-care in the opinion of all involved stakeholders. This article follows the consolidated criteria for reporting qualitative research (COREQ).[23]

Methods

Study design

Aim of this study was to comprehend what constitutes successful specialised palliative home-care in the opinion of patients, their relatives and involved health professionals. We used a qualitative design based on the principles of Grounded Theory. We considered an inductive design appropriate in understanding the perspectives of those involved.[24,25]

Setting

The study took place in the state of Hesse, Germany, where all specialised palliative home-care teams are members of the Professional Association of Specialised Palliative Homecare and provide state-wide care.[26] We invited all teams providing care to adults ($n = 22$) to participate. In Germany, all statutory health insured persons with non-curable, progressive, life-limiting diseases are eligible to receive specialised palliative home-care when they have complex symptoms and associated care requirements that can be met in the outpatient setting.[4] The interprofessional palliative care team includes nurses, physicians and sometimes other professions like psychologists and social workers.[27] They provide outpatient care in familiar surroundings in cooperation with other health care providers, including a 24 h on-call-service.[28] Mean duration of care lasts about 20 days (median 11).[29]

Sampling

All participants had to be at least 18 years old, to speak German fluently, and to provide written informed consent. To be eligible, patients had to be receiving specialised palliative home-care. Sampling was purposive and followed the principles of 'Theoretical Sampling'.[30] When analysis revealed, that relatives have an important role in specialised palliative home care, we contrasted this information by recruiting people living alone to examine their perspective. Furthermore we enhanced inclusion of non-oncologic patients, because our sample included many patients with oncologic diseases.

Health professionals either worked in, or collaborated (hospice service coordinators, chaplains, general practitioners) with specialised palliative home-care. We sampled them by considering their profession, experience of palliative care, team location and team structure.

Recruitment

We contacted health professionals by phone or email. If they were interested in participation, we sent study information. Specialised palliative home-care team members provided patients and relatives with study information. If potential interview partners allowed us to contact them, we called them by phone, gave further information, answered questions and made an appointment. The patients themselves or specialised palliative home-care team members proposed relatives. As no prior relationship with the participants existed, we introduced ourselves and explained that we were researchers. We stopped recruiting, when no new themes emerged from data and data saturation was esteemed to be achieved.

Data collection

Data collection took place from May to November 2017. Every participant received study information written and orally, and consented in a written form. After data collection, participants in the interviews and focus groups were asked to complete a form requesting demographic information.

Interviews

We interviewed health professionals, patients and relatives in order to gain insight into the perspectives of those involved.[31] Two experienced female health researchers (HS, KK) conducted face-to-face semi-structured interviews. In case both, a patient and relative participated, the patient decided whether interviews should be conducted separately or jointly. We asked interviewees to describe their experiences and what successfulness in specialised palliative home-care means for them. We developed semi-structured interview guides for interviews with health professionals, and another one for those affected. We adapted them to suit the interviewee and combined them in jointly conducted interviews (Supplemental Material A). We used them flexibly and carefully navigated difficult issues, while providing the participants with the opportunity to present their main concerns.[32]

We audio-recorded the interviews and wrote additional field notes. The interviews were transcribed verbatim following commonly used standards using f4transkript, and pseudonymised.[33,34] The transcripts were not returned to the participants.

Participant observations

We (KK, HS) undertook participant observations in specialised palliative home-care teams by accompanying team members throughout the working day. We focussed on interaction between health professionals, patients and relatives to understand how specialised palliative home-care is conducted in practice.[35,36] The health professionals introduced the researchers and explained the study. We paused observation, if persons were unwilling or unable to consent, or if health professionals did not estimate observation appropriate. We wrote field notes during car rides or breaks and completed them directly after the observation. The observation reports contained detailed descriptions of situations, interactions, conversations and the researchers' views.

Focus groups, member check

We conducted focus groups with specialised palliative home-care team members to facilitate the discussion of different perspectives and experiences. Based on the results of interviews and participant observations, we developed a topic guide with focus on how successfulness is incorporated into daily work and how it could be assessed (Supplemental Material B).

We organised a final focus group in March 2018 that involved a member check to discuss whether our results were representative of the stakeholders' perspectives.[37] For this we invited all team members that had previously participated in interviews or focus groups. We presented our methods and findings and encouraged the participants to discuss them.[38] Two or three of us (HS, KK, SB, JH) moderated each of the focus groups and afterwards reflected the discussion in written field notes. The discussions were videotaped.

Data analysis

According to the principles of Grounded Theory, we undertook data collection and analysis simultaneously.[39] Based on the findings, we reviewed and adapted the samples, as well as the interview and focus group guides (Supplemental Materials A and B) for new emerging issues. By using inductive open coding supported by MAXQDA 2018 software, each analyst (HS, KK, JH, CM) coded the first three interviews, field notes and observation reports.[40] We discussed the coding trees (Supplemental Material C) until consensus was reached. We continued separately and regularly discussed axial coding in team meetings.

In a first round, we used MAXQDA 2018 to code the videos of focus groups thematically.[40] We then discussed all sequences in the research group (HS, KK, JH, SB), and created knowledge maps in a similar way to the method used in Focus Group Illustration Maps.[41] We used this method in order to guide the focus on the participants' core concepts. Identified key sequences were transcribed verbatim.[34]

We triangulated the findings of interviews, focus groups and participant observations by complementing the findings (method triangulation).[42] Finally, we identified key issues using selective coding. As a last step, we conducted the member check focus group. We transcribed the member check verbatim to capture discussions in detail.[34] Then we reviewed our findings by discussion in the research group until consensus was reached to broaden analysis by investigator triangulation.[42]

Ethical considerations

We communicated with the caring health professionals before and after contact to patients and relatives to inform about potential incidents.[22] The whole study team is experienced in care and research on vulnerable groups, has undergone training, and was offered supervision. The study was approved by the Ethics Committee of the Faculty of Medicine, Philipps University Marburg (27-04-2017; ref. 34/17).

Findings

Study sample

We interviewed health professionals (*n* = 30), patients (*n* = 14) and relatives (*n* = 14). One of the relatives was bereaved, as the palliative patient had died 3 months earlier. Two patients and two relatives withdrew before the interview because of health deterioration. The interviews with patients and relatives lasted 23–85 min (mean 44; SD 15.8) and took place at the patients' homes, while interviews with health professionals lasted 27–98 min (mean 55; SD 18.5) and were carried out at their workplaces.

We conducted the five participant day-observations in different teams, and performed 16 home visits overall. Four of the visits were not included in the data analysis because patients were not able to provide their consent. A total of 13 participants attended the three focus groups, which lasted 77–115 min. Seven nurses and one social worker gave feedback in the 94-min member check focus group.

Characteristics of all participants are classified by method and shown in Table 1. Table 2 presents more detailed

Table 1. Characteristics of patients, relatives and health professionals (HPs), ordered by method.

Method	Participant observations			Interviews			Focus groups	Member check
Participants	Patients	Relatives	HPs	Patients	Relatives	HPs	HPs	HPs
Number of participants; *n*	12	10	32	14	14	30	13	8
Gender; *n* (%)								
Female	8 (66.7)	5 (50)	22 (68.7)	8 (57.1)	9 (64.3)	22 (73.3)	10 (76.9)	8 (100)
Male	4 (33.3)	5 (50)	10 (31.3)	6 (42.9)	5 (35.7)	8 (26.7)	3 (23.1)	0
Age; years; Mean (SD)	n/a	n/a	n/a	65.5 (±12.5)	61 (±15.3)	52 (±9)	49.5 (±6)	54.5 (±8.9)

n/a: not applicable; HPs: health professionals; SD: standard deviation.

Table 2. Detailed characteristics of interviewed patients and relatives.

Participants	Patients	Relatives
Number of participants; *n*	14	14
Main diagnosis; *n* (%)		
Cancer	12 (85.7)	n/a
Cardiovascular disease	2 (14.3)	n/a
Family status; *n* (%)		
Married/living with partner	9 (64.3)	12 (85.7)
Single	2 (14.3)	1 (7.1)
Divorced	1 (7.1)	0
Widowed	2 (14.3)	1 (7.1)
Relationship to patient, *n* (%)		
Spouse or life partner	n/a	7 (50)
Child	n/a	2 (14.3)
Sibling	n/a	2 (14.3)
Parent	n/a	1 (7.1)
Grandchild	n/a	1 (7.1)
Bereaved spouse	n/a	1 (7.1)
Frequency of contact to patient; *n* (%)		
Every day	n/a	13 (92.9)
4–6 days/week	n/a	1 (7.1)
Nationality; *n* (%)		
German	13 (92.9)	13 (92.9)
Turkish	1 (7.1)	1 (7.1)

n/a: not applicable.

characteristics of interviewed patients and relatives, and Table 3 the characteristics of health professionals.

Key issues contributing to successful palliative home-care

We identified six key issues contributing to successful specialised palliative home-care: The main issues were (1) treatment of complex symptoms, (2) comprehensive care and (3) a sense of security. Related issues describing care delivery preferences were: (4) a focus on the quality of relationships, (5) respect for individuality and (6) facilitation of self-determination. Figure 1 presents a model showing how specialised palliative home-care can successfully achieve its aims in this setting. We illustrate our findings with pseudonymised quotations, which we have translated into English.

Treatment of complex symptoms. Health professionals characterised the *treatment of complex symptoms* as a key issue. Patients and relatives shared their view:

> *Well, the most important thing to me is not to be in pain. I'm not afraid of dying but I'm afraid of being in pain or whatever, in my dying days. That's what I'm really terrified of. (1102P, patient, male, interview)*

Study participants throughout the sample described the treatment of complex symptoms as a broad issue made up of physical, mental and emotional aspects.

> *So, what they give is also emotional support. [. . .] It's easy to talk about your fears, too. That's how they really support you. I mean, for me now is the time; it's not like I can say: "I'll be cured tomorrow." It's more like I'm heading straight towards death. (1312P, patient, female, interview)*

Professionals specified that 'treatment' means providing the greatest possible relief in accordance with the patients' will. It establishes trust between the patients, their relatives and the specialised palliative home-care team. It also provides room to take care of other issues that are relevant for patients and their relatives. Observations showed that physical symptoms are often addressed first, then team members initiated an emphatically relaxed conversation, to address other issues.

Comprehensive care. Participants also attached great importance to *comprehensive care*. This consists of the organisation of care, satisfaction of the patients' social and spiritual needs and consideration for the needs of relatives.

Organisation and coordination of care, revealed in narratives and observations, included networking with collaborating health professionals, involving further care providers (e.g. home-care services, home-care hospice services, chaplains) and the provision of medication and medical supplies.

Patients and relatives expressed relief at not having to deal with such concerns, and health professionals regarded it as their responsibility:

Table 3. Detailed characteristics of health professionals (interviews, focus groups, member check).

Method	Interviews	Focus groups	Member check
Number of participants; *n*			
SAPV team members	21	13	8
Collaborating HPs	9	n/a	n/a
Profession; *n* (%)			
SAPV nurse	15 (50)	8 (61.6)	7 (87.5)
SAPV physician	5 (16.7)	3 (23)	0
SAPV social worker	1 (3.3)	1 (7.7)	1 (12.5)
SAPV psychologist	0	1 (7.7)	0
General practitioner	2 (6.7)	n/a	n/a
Home-care hospice service coordinator	4 (13.3)	n/a	n/a
Chaplain	3 (10)	n/a	n/a
Work experience, mean years (SD)			
SAPV team members (experience in SAPV)	5.8 (±3.4)	5.3 (±3.6)	8.3 (±4.6)
Collaborating HPs (experience in palliative care)	9.3 (±7)	n/a	n/a
SAPV team location*; *n* (%)			
Urban	7 (33.3)	3 (23.1)	1 (12.5)
Suburban	5 (23.8)	7 (53.8)	4 (50)
Rural	9 (42.9)	3 (23.1)	3 (37.5)

n/a: not applicable; SAPV: '*Spezialisierte ambulante Palliativversorgung*' or specialised palliative home-care, in Germany; HPs: health professionals.
Note. Home-care hospice services in Germany provides voluntary psychosocial support.
*Only specialised palliative home-care team members.

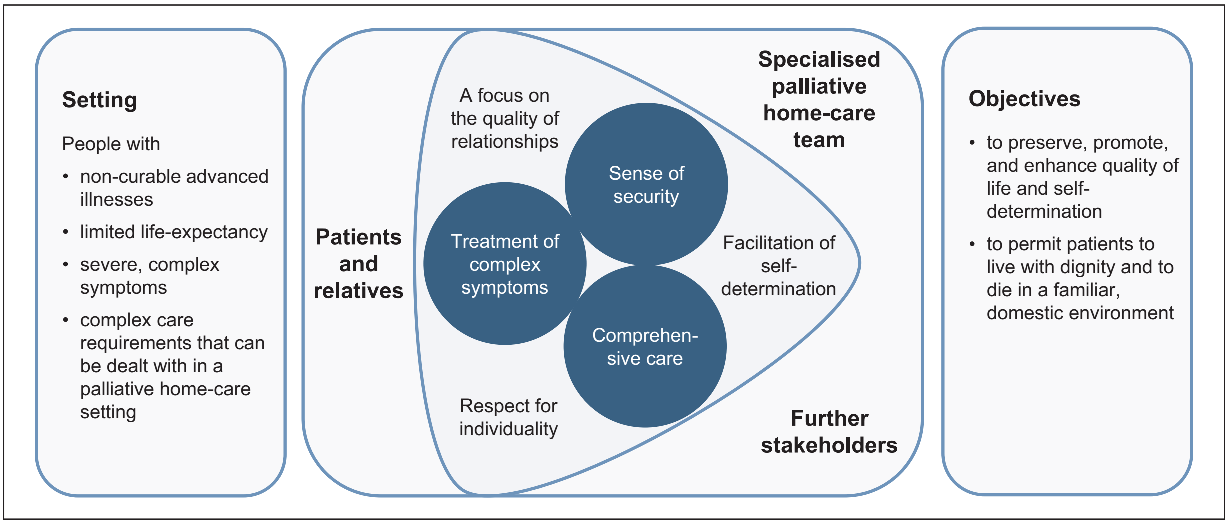

Figure 1. ELSAH model of successful specialised palliative home-care.
Setting and objectives as described in the directive of the Federal Joint Committee of Germany (G-BA).[4]

> *Basically to be with them on their journey. To make plans. To provide care. To accompany them. To coordinate. To help them with organisational things. [. . .] That is very, very important. Ultimately, the symptoms. [. . .] Everything else, that's what really helps! [. . .] That is . . . that is what you really notice (sighs) a feeling of relief; that it takes a load off the mind [of the patient] to say: 'I do not have to worry about that'. (1706E, SAPV physician, male, focus group)*

In addition to talking about dying and death in the near future, some patients and relatives raised spiritual topics and patients' worldviews. Health professionals addressed these topics sensitively during observed home visits, and adapted the conversation to the reactions of patients and relatives. They considered such issues as a relevant issue to handle the palliative situation:

> *It's more about, also finding out what gives him strength; what gives him hope. What his view of nature is, of the world outside. . ., to try to find out a bit about what gives him a feeling of courage, what is perhaps able to strengthen him, despite knowing that life is drawing to an end. (1507E, SAPV nurse, female, interview)*

During the home visits observed, the well-being, concerns and needs of the relatives were always included, either by asking them directly or by wrapping it up in conversations. Almost all participants emphasised that care for relatives is an essential element of successful palliative home-care. On the one hand, relatives make it possible for patients to die at home, on the other hand, they are personally affected. Some of them described their fear of the actual process of dying and the time afterwards. Accordingly, specialised palliative home-care team members said that part of their work was to provide stability in such a situation.

> *Quite often there are situations - with some patients - when we go there and spend more time with the relatives than the patient, because they need more attention. But that can help you to manage the whole situation better. (1512E, SAPV nurse, female, interview)*

Sense of security. Most participants described a *sense of security* as a key issue in successful specialised palliative home-care. It provides the basis for care in the familiar surroundings and can be strengthened by five aspects:

Firstly, the teams' round-the-clock availability, in person and on the phone, was considered important to patients and especially to relatives. While home visits, health professionals strongly encouraged patients to call if needed, to reduce anxiety. Those affected appreciated the fast and uncomplicated response in case of need, and regular contact even in stable periods.

> *And so I was always lying awake at night thinking: 'If something happens now, what are you going to do?' And now I know: 'Okay, if something happens, you can call palliative care!' And that's a relief to me. Now I can sleep again! (1306A, spouse, female, interview)*

Secondly, health professionals characterised anticipation of needs and precautionary actions as providing a sense of security. This involves consideration of how diseases and symptoms are likely to progress, possible emergencies, overburdened relatives, alternative care locations, explaining the care network and recommending medical supplies. Patients and relatives particularly appreciated consideration of organisational issues.

Several patients and relatives said that being empowered to act in emergencies and deal with everyday matters created a sense of security. Health professionals illustrated how empowerment makes dying at home possible.

Fourthly, observations showed that the health professionals become acquainted with all cases in team meetings. Patients and relatives described relief at knowing the team members, and knowing that they were aware of their needs and desires.

> *And I have people around [. . .] that know me, my situation, my living situation; that are able to judge what's going on, and to involve me: What is now the right thing to do? You know? (1316P, patient, female, interview)*

Expertise in medical topics as well as in interacting with terminally ill persons and their relatives is the fifth aspects of providing a sense of security.

A focus on the quality of relationships. Participants in all groups mentioned the importance of focussing on the '*quality of relationships*':

> *On the subject of QUALITY: One crucial quality of our work that distinguishes it from other work is that we enter into relationships, into personal relationships. [. . .] Despite the professionalism, nevertheless. [. . .] That means I am here as a person, me and you, not just in the role [of a professional; author's note]. In my opinion, successful palliative care hinges on the quality of relationships. It doesn't have to be a relationship to all ten team members or whatever, but there have to be moments when personal relationships to certain individuals exist, under the professional umbrella. (1705E, SAPV physician, female, focus group)*

Patients and relatives appreciated the attitude of the specialised palliative home-care teams. They said they felt they were treated with respect and dignity, and taken seriously.

> *I don't just suffer pain - my prolonged disease caused a load of other illnesses to develop. Not to mention what it has done to my soul. That's where we also need support, companionship or just somebody beside you that takes you seriously. And who feels for you. [. . .] And that's what I noticed, [long pause] that these eight weeks [in specialised palliative home-care; author's note] (-) it was an incredible relief to enjoy feeling and discovering that I am alive again. (1101P, patient, female, interview)*

While observed home visits, the specialised palliative home-care team members showed empathy and adapted their behaviour to the patients' mood. The professionals reasoned that this enables them to identify what matters to patients and their relatives:

> *You need to establish a kind of trusting relationship with the patient in order to find out about particular problems that are not visible at first sight. In some way or other, in some conversation or other - that's how you get there, through detours. And so you have to develop a certain sensitivity. (1502E, SAPV nurse, female, interview)*

Respect for individuality. Health professionals mentioned respect for individuality as another key issue. The individual wishes are constantly enquired, as the needs and desires of individuals vary:

> *That they really find their own way. That is success. And in case of SAPV, there is often one banal objective: 'To make it*

> *possible to die at home.' It's written everywhere, but sometimes it's not the right place, right? [. . .] We had a woman with little children, who said: 'They can see a lot, but they don't need to see everything. I want to come to your palliative care unit and die there!' So, this 'successful for whom' is one thing, but the other thing is: What does it mean to facilitate the individual way and to take relatives' needs into account? I think that's the real challenge! (1705E, SAPV physician, female, focus group)*

When asked to describe what quality of life currently means to patients and relatives, a variety of answers are provided: for example, relief from symptoms, to be at home, mobility, independence, a normal everyday life or participation in a social life. That supports the professionals' view of individual needs and aims. Patients and relatives that talked about the individuality of care welcomed it:

> *No rigid pattern was offered to me, but a willingness to consider my susceptibilities. And that really is a great help. (1316P, patient, female, interview)*
>
> *–and to create the conditions where support is possible. (1317A, life partner, male)*
>
> *Yes! Yes! (1316P)*
>
> *To makes things possible. And not to offer standard solutions. That is an important difference. (1317A)*

Facilitation of self-determination. All participants said that acting in accordance with the will of patients and relatives is necessary for success. This became apparent in participant observations, when health professionals informed in detail about possible treatment, made a recommendation, but also followed the patient's will when the patient disagreed with their recommendation. Some patients wished to make decisions themselves, while others appreciated sharing decision-making with the health professionals.

> *It's not that I was forced to undergo some therapy or other, but rather that a piece of advice is given and discussed by different people. And later on, they have a look to see whether I react positively to the idea [. . .]. We talk about that and then discuss the degree to which it's good or whether something else would be better, you see? (1312P, patient, female, interview)*

Health professionals further described it as their duty to enable patients and their relatives to give informed consent. Fittingly, patients and relatives appreciated it when members of the specialised palliative home-care team provided comprehensible and satisfactory information:

> *Because of cancer? No idea! I can talk to people about flu, a cold, or something like that, everybody can. But not about this! These are things you hear about, but that don't affect you! In the personal sphere, nobody! And then the palliative care team came. How they talked to us, explained things to us, the developments. REALLY! Like in 'Loewenzahn', the children's television show . . . in a way a child could understand! Even in the true sense, they were responsive to a child! My nephew. Six years old. They really think of everything! (1404A, sibling, male, interview)*

Discussion

Main findings

We identified six key issues that contribute towards successful specialised palliative home-care from the perspective of patients, relatives and the involved health professionals. Participants revealed that *treatment of complex symptoms, comprehensive care* and a *sense of security* were key issues, and they wanted specialised palliative home-care to be delivered with *a focus on the quality of relationships, respect for individuality* and *the facilitation of self-determination*. Consideration of these key issues enables the objectives of specialised palliative home-care to be achieved: promotion of quality of life and self-determination at the end of life.[4]

It is obvious that these key issues are highly interrelated: for example, the quality of relationships, respect for individuality and patient-centred care are preconditions for the provision of appropriate treatment for complex symptoms and comprehensive care. Simultaneously, the effective treatment of complex symptoms and comprehensive care necessitate respect for individuality and the facilitation of patient-centred care, which, in turn, improves the quality of relationships. A sense of security is created when all issues are taken into consideration. Appropriately, a meta-ethnography concluded that a sense of security is key to meeting the needs of those affected because feeling secure provides people with the space to use their remaining time for things that matter to them.[43] The relevance of sense of security is induced by the home-care setting. Although a 24-h on-call service is provided, team members cannot always be on site immediately, especially in rural areas. Additionally, other studies also showed that factors unrelated to care, such as financial worries, also influence sense of security.[44] Here, the diversity of needs to gain a sense of security becomes clear, so that the response must be adapted to the individual situation. The importance of particular key issues can differ between cases, so that for successful care all issues should be considered, but it could turn out that there is no need for action.

As palliative care is complex,[45] good care requires more than the consideration of physical, psychological, social and spiritual wellbeing.[46] We found that by providing comprehensive care, specialised palliative home-care can stabilise a situation involving complex and individual needs. Prior studies confirm the importance supporting relatives because this enables 'the home' to continue functioning and prepares relatives for continuing their lives.[47,48] This supports the view that the health care system could also benefit from comprehensive care as it would lead to a reduction in follow-up costs.

To strengthen individualised and comprehensive care it can be useful to increase inclusion of other professions like psychologist or social workers in the specialised palliative home-care teams.[49] Other studies have shown that also leadership, education, teamwork and communication influence team capacity and therefore affect ability to provide successful care.[50] A mutual team approach, in which every team member knows the patients' and relatives' situations and needs, was also mentioned in an earlier study.[47] Networking with other health care providers can facilitate successful palliative care, but in practice implementation it is difficult due to informal collaborations and different perspectives.[51]

Our study revealed that personal relationships play an important role in the provision of successful specialised palliative home-care. In a Swedish study, patients and relatives describe it as a precondition for self-determination.[14] Also, interaction and communication are described as necessary to the organisation of everyday life and therefore for promoting quality of life.[52] Because trust needs time to grow, specialised palliative home-care needs enough time to address the needs of patients and relatives, and should heed early integration.[53] This constitutes, why specialised palliative home-care can only be standardised to a certain degree, but rather needs flexible approaches.[17]

Strengths and limitations

Recruiting patients and relatives via the specialised palliative home-care teams may have resulted in more positive feedback, because they rely on the team for continued care. To counteract this, interviews with patients and relatives were conducted without presence of team members and the study team emphasised their obligation of secrecy.

We did not explore elements of non-successful specialised palliative home-care, because recruitment via the caring teams was not suitable for this purpose. However, our rich findings imply that the opposite of the described findings implicate non-successful care. Another study confirmed that neglecting patients' needs and attaching little importance to the quality of relationships inhibit the success of palliative home-care.[14]

The setting of specialised palliative home-care in Hesse could have overestimated our findings, because as members of the Professional Association of Specialised Palliative Homecare of Hesse all teams engage in common quality assurance procedures.[54] It can be assumed that particularly interested health professionals have agreed to participate, but by sampling them by diverse experience of palliative care, team location and team structure, we included a variety of health professionals from different teams.

We involved only one bereaved person, because specialised palliative home-care formally ends with decease of the patient, so that the teams do not accompany mourning of bereaved. To reduce recall bias, which can change the memory of the bereaved over time, we decided to involve mainly persons during care.[55] Although relatives in the 55–69 years age group most frequently care for family members, more younger and older participants as well as more unmarried participants could have been involved.[56] We included mostly persons with cancer diagnoses, which corresponds to the majority of palliative patients in Germany and Europe being cancer patients.[2,57] Our predominantly female sample fits to the mainly female healthcare workforce and to the predominantly female informal caregivers.[56,58]

Although, we conducted participant observations for just 5 days, we included many participants from different groups in various situations. We strengthened our research by integrating different groups in our study, triangulating our methods of data collection and conducting a member check.[42] Data collection and analysis in our interdisciplinary team facilitated the interpretation of results.[36]

Implications

To the best of our knowledge, our study is the first to develop a comprehensive framework that has been adapted to the specific setting of specialised palliative home-care based on the views of all directly involved stakeholders, and especially patients and relatives. Similarities to other studies suggest our results are transferable to other regions where specialised palliative home-care for adults is provided. Because care conditions, and the role of relatives in paediatric specialised palliative home-care differ, transferability to paediatric specialised palliative home-care is limited, and needs further research.[59]

Taking the key issues into practical consideration can help meet the needs of patients and their relatives. In our study, all participants mentioned the same issues, indicating that health professionals endeavour to provide patient-centred care. Their efforts could be supported by using tools for quality measurement regularly. Moreover, improvements in team performance could be facilitated by evaluating their work with a focus on quality of care.[17] Further research is needed on how different professions and actors in care influence successful palliative home-care and how collaboration networks can be promoted.

Both, service providers and policymakers, should therefore take into account the identified issues when planning and organising specialised palliative home-care. For the evaluation of quality, an assessment system is needed that considers the key issues from the perspectives of those involved, and especially of patients and their relatives. Further research is needed on how best to translate the issues into practice.

Conclusion

Patients, relatives, members of specialised palliative home-care teams and collaborating health professionals described six issues that are important to the success of specialised palliative home-care: The *treatment of complex symptoms, comprehensive care* and a *sense of security*, as well as *a focus on the quality of relationships, respect for individuality* and *the facilitation of self-determination*. Policymakers and service providers should consider these issues when planning, delivering and evaluating specialised palliative home-care.

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Author contribution

MH, SB, LRU and JH devised this project and secured project funding. HS, KK, JH and SB collected, analysed and interpreted the data and wrote this draft of the paper. MH and DB supported the recruitment of participants and prepared the study team for and supervised them in dealing with terminally ill patients and their relatives. CM, JE, DS, MH and DB assisted in the analysis and interpretation of data. All authors revised the paper and approved the final version. Authorship follows ICMJE recommendations.

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: MH and DB manage the Professional Association of Specialised Palliative Homecare in Hesse. SB, JH, KK, HS, LRU, DS, JE were employed as researchers at the universities of Marburg and Frankfurt. All authors declare that there were no conflicts of interest.

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Research ethics and patient consent

The study was conducted according to the Declaration of Helsinki. It was approved by the Ethics Committee of the Faculty of Medicine, Philipps University Marburg, Germany on 27th April 2017 (ref. 34/17). It is registered in the German Clinical Trials Register (http://www.germanctr.de, DRKS00012421), which is the primary WHO-acknowledged trial register in Germany. All participants gave their written informed consent before inclusion in the study. Consent form and other relevant information will be provided to participants on request.

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Data management and sharing

To protect the participants’ privacy, no original data can be released, but online supplemental material on data collection and analysis is provided.

Supplemental material

Supplemental material for this article is available online.

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5.2 Publikation 2

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RESEARCH

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Integrating patient- and caregiver-reported outcome measures into the daily care routines of specialised outpatient palliative care: a qualitative study (ELSAH) on feasibility, acceptability and appropriateness

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Abstract

Background: The use of patient-reported outcome measures (PROM) and caregiver-reported outcome measures can raise the patient centeredness of treatment and improve the quality of palliative care. Nevertheless, the everyday implementation of self-report in patients and caregivers is complex, and should be adapted for use in specific settings. We aimed to implement a set of outcome measures that included patient and caregiver self- and proxy-reported outcome measures in specialised outpatient palliative care (SOPC). In this study, we explore how the Integrated Palliative Outcome Scale (IPOS), IPOS Views on Care (IPOS VoC) and the Short-form Zarit Caregiver Burden Interview (ZBI-7) can be feasibly, acceptably and appropriately implemented in the daily care routines of SOPC.

Methods: Five SOPC teams were trained, and used the outcome measures in daily practice. Team members were mainly nurses and physicians. To investigate their feedback, we used a multi-method qualitative design consisting of focus groups with SOPC-team members ($n = 14$), field notes of meetings and conversations with the SOPC teams. In an iterative process, we analysed the findings using qualitative content analysis and refined use of the outcome measures.

Results: We found that integrating patient and caregiver outcome measures into daily care routines in SOPC is feasible. To improve feasibility, acceptability and appropriateness, the resulting burden on patients and relatives should be kept to a minimum, the usefulness of the measures must be understood, they should be used considerately, and administration must be manageable. We removed ZBI-7 from the set of measures as a result of feedback on its content and wording.

Conclusions: SOPC-team members have reservations about the implementation of PROM in SOPC, but with appropriate adjustments, its application in daily care is feasible, accepted and perceived as appropriate. Previous to use, SOPC-team members should be trained in how to apply the measures, in the design of manageable processes that

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include integration into electronic documentation systems, and in ongoing evaluation and support. They should also be taught how useful the measures can be.

Trial registration: May 19th, 2017, German Clinical Trials Register DRKS-ID: DRKS00012421.

Keywords: Palliative Care [MeSH], Home Care Services [MeSH], Quality of Health Care [MeSH], Needs Assessment [MeSH], Qualitative Research [MeSH], Patient Outcome Assessment [MeSH], Patient Reported Outcome Measures [MeSH], Routinely Collected Health Data [MeSH]

Background

In Germany, just as in other countries, specialised outpatient palliative care (SOPC) is available for patients with life-limiting diseases and complex needs, who would prefer to receive treatment in an outpatient setting [1]. Multidisciplinary teams care for patients at their places of residence, e.g. at their homes, in order to promote patients' self-determination and quality of life [2]. SOPC teams provide comprehensive care, including physical and psychosocial care, and also take relatives into account, who themselves often provide informal care.

Patient-reported outcome measures (PROM) and caregiver-reported outcome measures have proved their worth in palliative care and they are being increasingly used in practice [3]. On a patient level, they help identify and address patients' unmet needs [4], while on a provider level, their use permits case-by-case evaluation of care, and on a policy level, they allow care to be monitored [5]. Previous research has shown that the implementation of patient-reported outcome measures (PROM) is complex and needs to be adapted to the specific setting in which it is used [6, 7].

To take into consideration these complex needs, there are multiple frameworks that aim to support this work. The Consolidated Framework for Implementation Research (CFIR) implies that beyond the characteristics of the intervention, also the inner and outer setting, the implementation process as well as individuals influence successful implementation. [8] Proctor et al. emphasize that the exploration of implementation outcomes is key to understand how implementation can be successful. They describe conceptually distinct outcomes, which can be relevant in the evaluation of an implementation. They include, among others, the stakeholders' view on acceptability, appropriateness and feasibility [9].

The study presented in this paper is part of the ELSAH-study ('Evaluation of Specialised Outpatient Palliative Care by taking the example of Hesse'). The aim of ELSAH is to ensure that all SOPC teams in Hesse, a federal state in Germany, implement measures that enable the evaluation of quality of care in SOPC (work package I) by focusing on outcome measures from the perspective of patients and relatives [10]. Data collected before our study were based on the National Hospice and Palliative Care Registry and comprise mainly data on structure and process quality, symptoms, and treatment and support needs from the perspective of health professionals. Patients' and relatives' perspectives were barely considered at all [11]. We are striving to integrate tools into existing documentation and analysis structures to ensure their sustainable implementation and use. The study has already enabled us to identify topics that contribute to providing successful care from the perspectives of those involved [12]. Based on these findings and an overview of the literature on outcome measures used in palliative care, we have put together validated tools to a set of measures [10] that are designed for use in a palliative care setting and that can help support the team in their work [13]. The set of measures is based on the Outcome Assessment and Complexity Collaborative (OACC) suite of measures [14] and includes, amongst others, the Integrated Palliative Outcome Scale (IPOS) [15], and IPOS Views on Care (IPOS VoC) [16]. As a previous phase of the study showed that family members play a central role, we have further included the Short-form Zarit Caregiver Burden Interview (ZBI-7), which is also recommended for use in palliative care [17].

A further study has highlighted patients' appreciation of the use of IPOS in a SOPC setting on the basis that it resulted in the adaptation of care to meet their needs [18]. Another study has examined the views of patients, informal caregivers and health professionals on the use of the OACC suite of measures across different palliative care settings [13]. The authors of that study recommend its stepwise implementation under consideration of the available organisational infrastructure, the teams' motivation, the rationale for use, and training in the skills required to apply such tools in practice. The findings of further studies that the implementation of the targeted outcome measures is feasible in a specialised palliative care setting for inpatients cannot automatically be transferred to the SOPC setting, as the needs of patients, the organisation of care, and the extent of family involvement, all vary in this setting [19–21].

We intend to establish the implementation of such outcome measures in all Hessian teams for use in routine care, and to publish our results elsewhere. For this small-scale implementation study before the larger rollout in all hessian SOPC-teams, we followed proctor's taxonomy of three implementation outcomes and applied the them to our study as follows [9]:

1. Feasibility: Extend to which the use of the outcome measures is feasible in SOPC.
2. Acceptability: Perception among SOPC team members that the use of the outcome measures is agreeable, or satisfactory.
3. Appropriateness: Perceived fit or relevance of the use of the outcome measures in SOPC for use in daily work and for presenting the quality of care.

Methods

Aim

The aim of this study was to explore whether implementing the IPOS, IPOS VoC and ZBI-7 outcome measures in the daily care routines of SOPC is feasible, acceptable and appropriate.

Setting

The study took place in Hesse, a federal state of Germany with about 6.3 million inhabitants. Adult German SOPC-patients mostly suffered from cancer [22]. SOPC can be prescribed by outpatient physicians or hospital physicians [23]. SOPC team members are physicians, nurses and sometimes social workers and psychologists. All 25 SOPC teams in Hesse are members of the Hessian Professional Association of Specialised Palliative Homecare and have a common strategy of collecting standardised data and analysing them regularly in order to improve quality [24, 25]. The teams use electronic documentation systems (EDS) for data collection, but not all from the same software provider.

Sampling

We included five of the SOPC teams that provide care to adults in the state of Hesse. We purposively sampled the SOPC teams for team location (rural and urban locations), and the use of differing EDS, to address software-related issues with regard to the expansion in all hessian teams. The SOPC teams knew the research team from a previous phase of the study [12].

Design

In line with Proctor's recommendations to explore these implementation outcomes, we used a qualitative design including the direct involvement of stakeholders [9]. The multi-method qualitative design included focus group discussions, the researchers' written field notes of all conversations and meetings with the SOPC teams, as well as field notes of feedback from SOPC-team members to the research team about the use of the measures (face-to-face, per telephone, or per e-mail). To examine integration into daily care, we applied an iterative process, which included testing their use in SOPC, collecting feedback from health professionals, adjusting the process depending on the feedback, and examining the effect of the adjustments [26].

Table 1 shows the outcome measures we used in this study, including content, target population and respondents, as well as information on when and which versions were used.

Table 1 Patient reported outcome measures used in this study

Measures	Integrated Palliative care Outcome Scale (IPOS) [15]	IPOS Views on Care (IPOS VoC) [16, 28]	Zarit Caregiver Burden Interviews (ZBI-7), 7-Item Version [17, 29]
Target population	Patients	Patients	Informal caregivers
Content	Ten questions covering the main problems, including physical, psychological, and spiritual problems, and practical concerns	Four questions on quality of life, and requesting an evaluation of the influence of the palliative care team on the current situation	Seven questions on the burden of care on informal caregivers
Respondents	Patient self-reporting or proxy-reporting by relatives or staff	Patient self-report	Relative self-report
When the measures were used	On admission, after about 5–10 days, and at ≥ 3 further appointments; at least once during further care, and when changes occurred	On admission, after about 5–10 days, and at ≥ 3 further appointments; at least once during further care and when changes occurred	On admission; at least once during further care
Version	Validated German Versions [30]	Own translation into German	7-item version recommended for palliative care; translation into German based on a German version validated for dementia care [31]

a) Initiation: preparation and team training

We started the implementation in one team and gradually added the other four. We presented and discussed the study plan in preparatory meetings (JH, HS, KK) with members of two of the SOPC teams. All team members were invited to participate in training sessions (held by HS, KK) at the teams' offices. We explained the different measures to the teams, and talked about content, aims, how to use them with the respondents in practice and benefits of the outcome measures in practical care. We gave the teams case folders containing information on the measures. We started using the paper-based version in order to be able to adjust the case folder flexibly, and to allow for written comments. We collected the changes and entered them into the existing electronic documentation system (EDS) at a later date to prevent unnecessary programming. The teams started using the measures in daily practice immediately after the training meeting.

b) Application in daily practice and support

SOPC-team members handed the paper-based measures to patients and their informal caregivers and asked them to complete the forms either alone, or with the assistance of a SOPC-team member. Afterwards, they collected the completed forms. We encouraged the SOPC-team members to contact the study team in case of questions, comments, and problems arising from the use of the measures. Evaluation meetings were arranged when there was a need to discuss matters face-to-face. We wrote field notes on all telephone calls and meetings for preparation, training and evaluation. Field notes were taken of the date, team, type of contact, content, and the researchers' comments [27].

c) Evaluation: focus groups

Two of the three researchers (HS, KK, JH) conducted focus groups with two of the SOPC teams to gain insight into their experiences and to collect suggestions on the use of the tools (Additional file 1: A: focus group topic guide) [32]. We wrote field notes during the focus groups, and transcribed relevant passages of the audio files verbatim [33].

Analysis

To analyse feedback from the health professionals, we used an iterative process for qualitative content analysis [34, 35]. For this purpose, we imported all field notes and audio files from the focus groups and entered them into MAXQDA 2018 software. We also triangulated all field notes and focus group data [36, 37]. We predefined codes according to our research interest and prior knowledge from data collection, and we added inductive codes for topics emerging from the data [35]. We (HS, KK, JH) discussed all emerging topics at all stages of data collection and identified those that were relevant. We adjusted the process accordingly and discussed major decisions at conferences with the whole study group until we reached a consensus.

Ethics, data protection

All SOPC teams represented by the Professional Association of Specialised Palliative Homecare in Hesse agreed to participate in the ELSAH-study. Participants in focus groups gave their written informed consent for audio recording before they began. SOPC-team members obtained patients' and caregivers' written consent to complete the measures for research purposes. The study was approved by the Ethics Committee of the Faculty of Medicine, Philipps University Marburg (05–04-2018; ref. 47/18).

Results

Sample

Participating SOPC-teams

All five invited SOPC teams agreed to participate, and all team members applied the outcome measures. The teams all had about 20 members of staff, of which about 60% are nurses and 40% physicians. Four teams started by using the paper version and switched to the software version later. The fifth team started using the software version directly. Four teams used the same EDS, which about 80% of the hessian SOPC-teams use. One team used another EDS. We met twice for preparation, eight times for training and four times for evaluation purposes. Table 2 presents the course of the study from April 2018 to January 2019 for each team.

Focus groups

The two focus groups took place at the SOPC teams' offices. We invited all team members of Team 1 and Team 3 to participate, but some did not work that day or work-related matters prevented their participation. Table 3 shows characteristics of the focus groups and their participants.

Feasible, acceptable and appropriate use of the measures

We identified problems in the overall usage of the outcome measures and in the use of specific measures, but found solutions and refined the process accordingly. We present each issue below, and provide feedback on particular measures. We illustrate our findings with pseudonymised quotations from the focus groups, which we have translated into English. Issues arose for all methods of data collection, but not necessarily for all participants.

Table 2 Timeline of study

	Team 1 (urban)	Team 2 (rural)	Team 3 (urban)	Team 4 (rural)	Team 5 (urban)
April 2018		Preparation			
May	Training/Start (P)				
June		Training/Start (P)		Preparation	
July	Evaluation		Training/Start (P)		
August	Focus group	Evaluation	Evaluation	Training/Start (P)	
September					
October		Evaluation	Focus group		
November		Training (S)	Training (S)		Training/Start (S)
December				Evaluation	
January 2019	Training (S)				

Training (P) Training beginning with paper-based version, *Training (S)* Training beginning with software version

Table 3 Characteristics of focus group participants

		Focus group 1 (Team 1)	Focus group 2 (Team 3)	Total
Number of participants; n		7	7	14
Duration; minutes		120	36	-
Gender; n (%)	Female	6 (85.7)	4 (57.1)	10 (71.4)
	Male	1 (14.3)	3 (42.9)	4 (28.6)
Age; years	Mean (Min, Max)	48.4 (34, 61)	40.1 (27, 52)	44.3 (37, 61)
Profession; n (%)	SOPC nurse	6 (85.7)	5 (71.4)	11 (78.6)
	SOPC coordinator	1 (14.3)	0	1 (7.1)
	SOPC physician	0	1 (14.3)	1 (7.1)
	SOPC social worker	0	1 (14.3)	1 (7.1)
Work experience in SOPC; years	Mean (SD)	3.3 (1.4)	5.9 (4.7)	4.6 (3.6)

SD standard deviation

Avoid overburdening patients and relatives

Acceptability and appropriateness were limited, when SOPC-team members feared to burden patients or relatives and to harm the quality of relationship by the use of the measures. Most SOPC-team members said they feared overburdening patients and relatives by asking them to complete forms and discuss sensitive topics, which was something they thought might be an additional and unreasonable burden in the palliative situation.

> *I think that for OUR patients - both for patients and their relatives – it's often asking too much of them. They find themselves in a life-limiting situation, they are often completely stressed out, especially the relatives, so that it's difficult for ME to give them something extra on top … that they have to fill out [...]. My personal opinion is that if our patients are doing well enough to occupy themselves with such a questionnaire, then I would rather they spend their time differently, use it for something else, namely with each other. (1728E, female nurse)*

Some health professionals were afraid of weakening their relationships with patients and relatives by allowing the outcome measures to dictate the care they provided, rather than focussing on what the patients actually required. Others, on the other hand, saw advantages in using the measures, and promoted their use.

Understanding their usefulness

All types of data collection showed that understanding how useful the measures are is key to being accepted and to be perceived appropriate by SOPC-team members. Some team members doubted the need to measure quality out of principle on the grounds that the patients provided them with direct feedback on the quality of care anyway. Others said they could not imagine how use of the outcome measures could result in improvements to care.

> *They're all issues that are familiar to us! Why should we document it all? We do it, and we enter the information into [our documentation software]. But*

> *why? Why do we have to do all that as well? (1722E, female nurse)*

Some participants had reservations about the validity of the assessments. They argued that they could be biased by the fact that patients were dependent on their SOPC teams and suggested asking bereaved relatives instead. Some SOPC-team members further presumed that analyses of aggregated data would be biased because assessments were not always obligatory, on the assumption that some SOPC-team members would skip assessments they considered unnecessary. It became obvious in a focus group that several SOPC-team members used the measures because they felt they were required to, but that they took no further interest in the results.

Some SOPC-team members raised the question whether it was really possible to measure quality of care in this way because patients' health generally deteriorated until they ultimately died. Participants further feared that it would be impossible to show any development in care, especially in cases of short duration.

> *Can you arrive at a correct result by doing this? [...] The situation of our patients won't, won't get any better. It will get worse and worse and worse and then you won't get any positive answers. (1727E, female nurse)*

SOPC-team members were afraid that misinterpretation of data could lead to harassment, or be used to force them to provide care in a specific manner.

> *What I, personally, am really worried about is that we get modules, and we are told what to do with our time: 'Home visits shouldn't take more than half an hour. You can get rid of this and get rid of that.' No, you can't! And then we won't talk about ´SOPC´ anymore, or about quality. (1723E, female nurse)*

Participants also wanted to understand the usefulness of the outcome measures and suspected that this would increase their motivation to use them.

> *I want to understand it. And I'd like to feel convinced that it is something that it makes sense to participate in on the basis of my own understanding that it could work. (1722E, female nurse)*

We therefore revised the training to focus more on usage and usefulness. One topic in these meetings was the potential for improvement that the outcome measures offered in individual cases, and their usefulness in daily practice, for example in visualising care and communication processes in a team. We further discussed the importance of measuring quality in the healthcare system, and spoke about the weight attached to data sovereignty to reduce fears of misuse. The use of aggregated data to achieve internal quality improvements and to help explain quality of care to external audiences were further topics of the meeting.

Enable sensitive use

Sensitive use promoted feasible use and strengthened acceptance among SOPC-team members. Some SOPC-team members felt uncomfortable handing out questionnaires and reading out the items word-for-word. In their opinion, some topics should be adapted to each individual, with use of the questionnaires generally requiring empathy. For the same reason, they thought it was wrong to use them at a predefined time point.

> *The other thing is that things happen when it's their turn to happen. My problem is that when I feel as though; when I continue talking and touch a sore spot, then I have reached a point when it's time to stop [the survey]. And I have to work that out myself. No questionnaire can judge that. (1723E, female nurse)*

To ensure the survey is used with respect for sensitive topics, we encouraged SOPC-team members to integrate the patients' self-reported views into conversations, to abstain from using the question's exact wording if necessary, thus relying more on the patient's narrative. Participants described this as being difficult to begin with, but added that it became easier over time.

> *So, when I have filled out the form like that [in conversation], then I generally did it by devoting part of the conversation to the questions, but what I never did was to read them out loud, so to speak, and use the exact wording, you see? [...] Then things went ok. (1729E, male physician)*

We also left it to the professionals to decide if and when it was reasonable to broach a specific topic at a certain time. We therefore avoided arranging predefined time points for self-report, but instead made the default to ultimately assess every topic when the information was collectible, at the very least in the form of a proxy-report. Topics that are relevant in a particular case should nonetheless be reviewed regularly, even when the situation changes, for example because of deterioration in health. Participants said this was feasible for them:

> *When we've built up a relationship of trust in the course of our work, then when we strike up a conversation, it sometimes happens in passing that you end up being able to tick a box. [...] That is the way to do it. (1729E, male physician)*

Manageable administration

Manageable administration was key to a feasible implementation and influenced the acceptance of use. Most SOPC-team members said that handing out paper-based forms to the patients and relatives, explaining and asking them to fill them out, collecting them afterwards, and analysing the results was a major effort:

> *And before every home visit you have to think about it: Ah yes, there's a questionnaire of the patient's, what do I have to take with me? (1727E, female nurse)*

It became clear that previously planned integration into the electronic documentation system was necessary because SOPC-team members considered it more practical:

> *If I have this question in my [documentation software] and I answer it then, when it's relevant [...] then everything's ok and I can do it. But not when I have to it at a specific time (1723E, female nurse)*

SOPC-team members further outlined that self-report was not possible for all patients. The reasons they described for non-participation were health deterioration, language barriers, and cognitive and psychological impairment. Participants said that short periods of care resulting from, for example, death, or a change in the place care is provided, complicate the use of measurement tools.

> *It struck me that we had [...] a lot of patients suffering from dementia, or who were so weak, ill, or whatever, and close to death that it was not really possible to do more than fill out the symptoms via proxy-report. I noticed that we were very often not in a position to answer interesting questions like 'What has been worrying you?' (1729E, male physician)*

SOPC-team members appreciated the involvement of relatives when measuring outcomes, as they are also affected. Nevertheless, they said that relatives could not always make assessments because of language barriers, cognitive and psychological impairment, or because they were not involved in providing care. SOPC-team members also said they could not provide information on all topics via proxy-reports, pointing out that while they are able to assess some topics such as physical condition, they considered it presumptuous to comment on psychosocial subjects such as 'quality of life':

> *I don't think proxy-reporting is really possible at all. I cannot presume to judge how someone felt three days before we took part in care. (1728E, female nurse)*

In consequence, we encouraged SOPC-team members to handle the items more flexibly and to alternate between self- and proxy-reporting. Patient-reported outcomes remained our first choice, but if it was not possible or reasonable, the measures could be still assessed by relatives acting as proxies (second choice), or health professionals as a third possibility. When SOPC-team members said they were unable to answer, we provided the response option 'not assessable' for every item of the proxy-report version.

SOPC-team members said patients, relatives and health professionals sometimes differed in their views. They considered this as interesting from a care perspective, so we included a marker to indicate who had reported the item in the electronic documentation.

Feedback on specific measures

SOPC-team members confirmed that the content of the measures was relevant to the topics of care under investigation. IPOS' main problems and symptoms were accepted and perceived appropriate and feasible, but the formulations of the other items were considered inadequate and difficult to understand. SOPC-team members were divided over if IPOS VoC was appropriate and acceptable, but most reported of limited feasibility. ZBI-7 was neither assessed appropriate nor acceptable. Detailed feedback and adaptions relating to the specific measures are described in Table 4.

Discussion

Main findings

For the feasible, acceptable and appropriate integration of patient-reported and caregiver-reported outcome measures into the daily care routines of SOPC, the burden of its use on patients and relatives must be kept to a minimum. Furthermore, the usefulness of the measures must be clearly explained, care must be taken when broaching sensitive subjects, and administration should be manageable.

Comparison of findings with those reported in the literature

Avoiding burden on patients and relatives was a major concern for SOPC-team members in our study. It is also an issue that is addressed in another study and reflects a common assumption in society that research into palliative care can be burdensome [38]. But it is preferable to permit patients and relatives to participate in care design, in research, and in quality improvement [39]. Evidence exists that both severely ill patients and their relatives are able to express their opinions on the quality of care [40]. Patients and relatives generally appreciate the chance to participate, provided they are not overburdened by their

Table 4 Feedback and adaptation of measures used

Measures	**Integrated Palliative care Outcome Scale (IPOS) [15]**	**IPOS Views on Care (VoC) [16, 28]**	**Zarit Burden Interview (ZBI) [17]**
Feedback relating to the measure	The HPs said that IPOS covered relevant topics of care, and that when patients were able to complete a written questionnaire, filling in the self-report form did not cause problems The HPs explained that questions on being at peace, feeling anxious, or being worried about the illness or treatment, and whether their families and friends had been anxious or worried, required trust before they could be broached. They feared that the relationship between patients and HPs could otherwise be impaired, and that it might stress patients and relatives if such issues were raised at the wrong time The HPs regarded the question on whether patients felt at peace as causing the greatest problems. They reasoned that in their opinion hardly any patient can be at peace when receiving palliative care. They also said that they felt uncomfortable asking the question directly, as it was not formulated in the way they would like it to be	The HPs appreciated the focus on quality of life, as they considered it to be a relevant topic The HPs reported that multiple applications per case were rarely possible because of deteriorating health or because care periods are often too short for repetition. They assumed that this meant developments would not be identified when using this outcome measure. Some HPs felt it sounded like they were fishing for compliments when they asked patients if they thought '*the palliative care team is making a difference to how things are going*' and expected no objective answers, for as long as they were providing care to the patients	The HPs valued the focus on the relatives when measuring outcomes, as they reckoned their needs are a relevant aspect of successful care. They also thought it made sense that the ZBI requires relatives to reflect on their own situation Nevertheless, the SOPC teams rejected use of the measure in practice. They told us that relatives had been outraged by questions on whether providing care had caused them to lose control of their lives, as they felt caring is a natural duty that they wanted to fulfil Furthermore, HPs thought using the measure was unsuitable because family caregivers' answers could burden the patients, e.g. when they are asked whether the patient affected '*relationships with other family members or friends in a negative way*' They also criticized the measure for not providing the differentiated feedback that would be helpful in practical work
Adaptation	We established the parallel use of self-reporting (written and oral) and proxy-reporting, whereby self-report was preferred. We further added the possibility to integrate topics into general conversation We avoided arranging predefined times, and suggested addressing the main problems/concerns and symptoms during the first assessment, and the other topics as soon as possible. The decision on what was appropriate was always made by the HPs	We changed the application from mandatory in all cases to voluntary, and for use when SOPC-team members considered it to be suitable We additionally integrated IPOS VoC into regular postal evaluations, which is another part of the ELSAH set of measures and will be described in another publication	We removed ZBI-7 from our set of measures. Instead, we developed and implemented a questionnaire for relatives that was based on the IPOS VoC patients' version

HP health professionals

health condition or the demands of the study [39]. Kane et al. found that comorbidities complicated the use of IPOS in an inpatient palliative care setting, but did not necessarily overburden patients [41]. Creating a research culture through early communication and the request to participate in research can reduce the stress caused by deteriorating health [38]. Analogously, it is safe to assume that early explaining to patients and relatives how and why measures are used can help reduce stress.

Pinto et al. also found that health professionals fear that deteriorating symptoms may mask any improvement. They further fear that financing could depend on results [13]. Training and better understanding may reduce such fears, discourage health professionals from overprotection and gatekeeping, and promote their motivation to use PROMs by explaining how the results can be useful in practice [42]. Besides practical training in using the measures and explaining the rationale behind their application, it is therefore important to show their potential to improve quality on a micro, meso and macro level. At the same time, limitations should be addressed. Practical exercises and ongoing training would enable their use to be sustainable, and may also harmonize handling by different health professionals [19]. Howell et al. therefore suggest ongoing case-related education sessions and peer learning, combined with comprehensible reports on collected data [43]. A systematic literature review shows that most studies provide no guidance on how to react to problems [44].

In other studies, health professionals also have shown scepticism about the validity and reliability of the measures because of differences in the way they are handled in practice, e.g. by rewording in the interviewed self-report, or via proxy-reports [45, 46]. Although independent self-reports are preferable, it is also reasonable to interview them when it is necessary to reduce burden, or when patients are unable to participate [47]. Clapham et al. found that the incidence of self-reported symptom distress depends on the disease, and the urgency of needs, and that it is more common in an outpatient setting than an inpatient setting [48]. This reinforces our view that self-report in outpatient settings is feasible. As we found that the parallel use of self- and proxy-reporting can lead to interesting results in practical care, it should also be considered.

Furthermore, by demonstrating empathy when broaching sensitive topics, health professionals can reduce burden and scepticism. A predefined framework ensures comparability and orientation, but a successful SOPC approach requires flexibility and the ability to adapt to individual needs and situations [12]. Health professionals in other studies also feared that the use of PROMs may reduce the quality of relationships, but they also found that PROMs can result in open conversations and help patients raise topics of personal relevance [46].

As fixed time points caused feasibility problems, we decided to assess each topic upon inclusion in care, and to review them regularly when situations change. More guidance on when to use outcome measures may support health professionals and further improve comparability across services. An international expert consensus workshop therefore recommended the use of the 'Phase of Illness' to standardize time points for data collection, but it also emphasized that exceptions should be possible, depending on the patient's situation [49]. Bausewein et al. also said guidance can promote manageable use [50].

The need to document outcome measurements electronically is obvious. However, the question of what is a successful implementation also arises. Indeed health professionals in other settings also appreciate electronic documentation [42], and possibly even more so in an outpatient setting. In contrast to the inpatient setting, travelling to patients' homes, and taking along paper involves greater administrative effort. A current review on the use of PROMs in oncology has identified lack of time as a barrier to use [51]. In outpatient palliative care, the time available for home visits is limited, and as health professionals meet patients less frequently, they must react immediately or wait until the next home visit.

According to a systematic review, having a coordinator in the team that is responsible for all implementation processes can facilitate successful implementation [6]. This aspect did not emerge in our study because the SOPC-team leaders automatically assumed the role of facilitator. When several SOPC teams are implementing measurements in parallel, it can be assumed that overarching coordination facilitates implementation.

The OACC suite of measures has been used in various studies. Similar to the feedback on IPOS in our study, health professionals in the inpatient setting struggled most with questions on psychosocial and family issues. Nevertheless, missing values decreased over the course of time [19]. We would expect ongoing training and familiarisation to improve the situation further.

Whereas the use of ZBI in our study was considered inappropriate and burdensome, another study found it to be appropriate [13]. This may be because our German translation had not been validated for use in palliative care. This has now been carried out for another study, and indeed translation problems were evident in the first version, and the measure was only recommended for use after translation adjustments [52]. As shown in feedback from our participants, Seibl-Leven et al. assumed the ZBI would lead to conflicting emotions and problems with loyalty. This is because relatives are asked to describe the burden caused by their ill relatives [53], which may be more relevant when relatives play a central role in the provision of care in an outpatient setting. Replacing the ZBI still seems to make sense. In the meantime, the OACC recommends the additional use of two questions for caregivers that are similar to the version we developed based on IPOS VoC [47].

Strengths and limitations

In this study, we examined feedback from health professionals, but did not directly seek feedback from patients and caregivers. Health professionals may not have accurately reflected patients' attitudes, but their views on how patients might feel are a first approximation.

The study is limited by our gaining feedback from health professionals without observing them in action. Participant observations could have provided the opportunity to obtain practical insights [54].

As revisions had already been made when later teams were included, the intensity of collaboration and feedback from health professionals from different teams varied. To broaden our findings, we purposively sampled SOPC teams based on team location and documentation methods, and thus incorporated a variety of working conditions, attitudes, team structures and contexts. Although only a sample of SOPC team members participated in the focus groups, additional field notes meant all health professionals had opportunities to provide feedback. To get a deeper understanding of health professionals' views, we triangulated our field notes in with focus groups. We conducted the focus groups in two SOPC teams, but did not combine members from different teams, although this might have made the discussion more diverse [32].

The Professional Association of Specialised Palliative Homecare in Hesse represents all SOPC teams in Hesse and is at the same time a research partner in this study. This may have biased our research, but the fact that we focussed on real-world implementation that will continue after the end of the study may have motivated health professionals to promote integration and provide honest feedback.

Implications

Some of the aspects we identified were similar to those in studies in other settings. However, we also uncovered problems relating to the greater administrative effort and involvement of relatives in outpatient settings. This may help others avoid the difficulties we faced in our study. Furthermore, the collaboration between researchers and practitioners helped foster mutual understanding and is in our view to be recommended in other settings. Our findings are transferable to similar outpatient settings, but may be of limited use in SOPC care for children, as collaboration between health professionals, child patients and their families differs from the care of adults [55].

In routine specialised outpatient palliative care, patient- and caregiver-reported outcome measures provide a good basis from which to strengthen patients' and relatives' impact on care. Data collected using the described measures has not yet been analysed statistically, so testing on a larger sample was still pending at the time of this study. Routine data collection should also include the use of further regular, detailed surveys of patients and relatives receiving care, as well as surveys of bereaved relatives. In a further step, we will present a comprehensive concept on how to improve the quality of care in SOPC, which will build on the results described here [10].

Over the short term, implementation requires time and resources for training, integration into documentation systems and technical equipment, but additional work on data collection, administration, support and ongoing training is also necessary over the long term [7, 44, 56]. Benze et al. found high adherence of patients with advanced cancer in the use of a smartphone application in the outpatient setting [57]. More research is needed on how electronic PROM can be integrated into the outpatient palliative care setting through the use of, for example, web-based tools. Additional financial support is required to expand the use of PROMs in SOPC.

Conclusions

The feasible, acceptable and appropriate integration of patient and caregiver outcome measures into daily care routines encourages their use. In this study, we found that although reservations about their implementation in a SOPC setting exist, appropriate adjustments can ensure their application in everyday care. For integration to be feasible, acceptable and appropriate, the burden on patients and relatives must be kept to a minimum, participants must understand the usefulness of the measures, empathy is required when exploring sensitive issues, and administration must be manageable. Implementation of the measures requires resources, especially for practical training, explaining the usefulness of the measures, designing manageable processes that include integration into electronic documentation systems, and for ongoing evaluation and support.

Abbreviations

COREQ: Consolidated criteria for reporting qualitative research; DRKS: German Clinical Trials Register (‚Deutsches Register Klinischer Studien'); CFIR: Consolidated Framework for Implementation Research; EDS: Electronic documentation systems; ELSAH: Evaluation of Specialised Outpatient Palliative Care by taking the example of Hesse; HP: Health professional; IPOS: Integrated Palliative Outcome Scale; IPOS VoC: IPOS Views on Care; OACC: Outcome Assessment and Complexity Collaborative; PROM: Patient reported outcome measure; SD: Standard deviation; SOPC: Specialised outpatient palliative care; ZBI: Zarit Burden Interview; ZBI-7: 7 Item Short-form Version of Zarit Burden Interview.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-022-00944-1.

Additional file 1: A. Focus group topic guide (translated into English). **B**. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist.

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Authors' information

SB, JH, KK, HS, DS, JE, CP were employed as researcher fellows at the universities of Marburg and Frankfurt. MH and DB manage the Professional Association of Specialised Palliative Homecare in Hesse. All authors declare that there were no conflicts of interest.

Authors' contributions

MH, SB, and JH devised the project and secured project funding. HS, KK, and JH collected, analysed and interpreted the data. SB, JE, DS, MH and DB assisted in the analysis and interpretation of data. HS wrote the draft paper. MH and DB supported the recruitment of participants, and supported the cooperation with the SOPC teams. All authors revised the paper and approved the final version.

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Availability of data and materials

As the data may provide enough information to allow teams or participants to be identified, no original data will be published. The focus group topic guide and COREQ checklist [58] are provided as supplemental materials:
Additional file 1.pdf.
A. Focus group topic guide (translated into English)
B. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Declarations

Ethics approval and consent to participate
The study was conducted according to the Declaration of Helsinki. It was approved by the Ethics Committee of the Faculty of Medicine, Philipps University Marburg (05–04-2018; ref. 47/18). All participants gave informed consent before inclusion in the study.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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5.3 Publikation 3

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RESEARCH **Open Access**

State-wide implementation of patient-reported outcome measures (PROMs) in specialized outpatient palliative care teams (ELSAH): A mixed-methods evaluation and implications for their sustainable use

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Abstract

Background: Such patient-reported outcome measures (PROMs) and patient-centered outcome measures as the Integrated Palliative Care Outcome Scale (IPOS), Phase of Illness, and IPOS Views on Care (IPOS VoC), facilitate patient-centered care and help improve quality. To ensure sustainability, implementation and usage should be adapted according to setting. When settings involve several distinct teams that differ in terms of views and working practices, it is more difficult to integrate outcome measures into daily care. The ELSAH study aimed to learn how health professionals working in specialized outpatient palliative care (SOPC) viewed the use of these outcome measures in daily care, and what they express is needed for successful sustainable, state-wide application.

Methods: We used a parallel mixed-methods design involving three focus groups ($n=14$) and an online-survey based on normalization process theory ($n=76$). Most participants were nurses and physicians from 19 SOPC-teams in Hesse, Germany. We used a triangulation protocol including convergence coding matrices to triangulate findings.

Results: The majority of health professionals were able to integrate the outcome measures into their working lives and said that it had become a normal part of their day-to-day work. To ensure their sustainable integration into daily care, the motivation and concerns of health professionals should be taken into consideration. Health professionals must clearly recognize how the measures help improve daily care and quality evaluation.

Conclusions: To implement the outcome measures in a number of teams, it will be necessary to take individual team characteristics into account, because they influence motivation and concerncs. Further, it will be necessary to offer opportunities for them to engage in peer support and share information with other teams. The sustainable use of outcome measures in SOPC will require continuous support within each team as well as across teams. When several distinct teams are working in the same setting, a cross-team coordination unit can help to coordinate their work efficiently.

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Background

In palliative care, patient-reported outcome measures (PROMs), patient-centered outcome measures and caregiver-reported outcome measures enable patients' and families' needs to be recognized and addressed [1]. Evidence that their use improves patient-relevant outcomes is growing [2]. Further, their use allows quality of care on a provider level to be improved through case-by-case evaluation and by monitoring care on a policy level [3].

In palliative care, a variety of outcome measures exist. Some focus on specific domains e.g. on physical, social, spiritual or cultural domains [4]. Some consider special target groups like patient, relatives, health professionals or the healthcare system [5]. The European Association for Palliative Care (EAPC) recommends to use validated outcome measures, that include patients and relatives, and cover all relevant aspects of care [1]. Initiatives like the Australian Palliative Care Outcomes Collaboration (PCOC) and the Outcome Assessment and Complexity Collaborative (OACC) developed comprehensive approaches to evaluate palliative care [6, 7].

The implementation of outcome measures is complex and needs to be adapted to the setting in which it is used [8]. The Consolidated Framework for Implementation Research (CFIR) implies that successful implementation must take characteristics of the intervention, the implementation process, the individuals, as well as the inner and outer setting into account [9]. Implementation in a broad setting involving different healthcare professionals presents an additional challenge because of differing backgrounds, views, management and working practices. Nevertheless, a degree of standardization and guidance helps promote fidelity and improve data quality. This condition must be fulfilled if benchmarking and national and international care comparisons are to be possible [1].

Health professionals' views must be taken into consideration if usage is to be sustainable. In a similar study, a negative attitude of health professionals to quality measurement reduced the chance of successful implementation [10]. Previous research has also shown that participants may refuse to use PROMs if they feel not to have enough time and training for use [11, 12]. Lind et al. found a general feeling of fatigue followed changes to routines in various palliative-care settings [13]. Implementation research has shown that if staff do not feel that a task is appropriate to their job responsibilities, rejection and reduced fidelity may result [14]. Implementation frameworks can help organize tasks and improve implementation [15]. Normalization Process Theory (NPT) focuses on the work that needs to be done to implement, embed, and sustain practices in different contexts. For this purpose, the theory considers the four core constructs coherence (how health professionals make sense of a new practice), cognitive participation (relational work to redesign the work), collective action (to sustain use), and reflexive monitoring (how the health professionals appraise the impact on work) [16]. This theory is therefore particularly suitable for studying the normalization of change in the work of teams, and considering the perspectives of involved health professionals. Therefore, NPT has been widely used in research to evaluate and understand implementation processes [17, 18].

Specialized outpatient palliative care (SOPC) provides comprehensive care to patients with life-limiting diseases and complex needs in their familiar surroundings [19]. The aim of our ELSAH study ('Evaluation of Specialized Outpatient Palliative Care by taking the example of Hesse') was to implement outcome measures in all SOPC-teams in Hesse, Germany. Before our study patient records were based on the German National Hospice and Palliative Care Registry and, although including data on structure and process quality, symptoms, treatment and support needs, they barely considered outcomes from the perspective of patients and relatives [20]. To find out more about day-to-day care and include a quality assessment from their perspective, we added patient-reported and caregiver-reported outcome measures [21].

In a first step, we examined key features of successful care from the perspective of patients, relatives and health professionals. We found that 'treatment of complex symptoms, comprehensive care and a sense of security, as well as a focus on the quality of relationships, respect for individuality and the facilitation of self-determination' [22] are relevant topics that need to be covered. On this basis, we assembled a set of validated outcome measures, which is based on the Outcome Assessment and Complexity Collaborative (OACC) suite of measures [6]. The set of outcome measures includes the Integrated Palliative care Outcome Scale (IPOS) [23], Phase of Illness [24], and IPOS Views on Care (IPOS VoC) [25]. In the next step, we examined the feasibility, acceptability and appropriateness of these outcome measures in a sample of five SOPC-teams. We found that they should be used considerately in order to minimize the burden on patients and relatives, and ensure their administration was manageable. It was also important that participants understood that the measures were useful [26].

However, it is not yet clear how the sustainable implementation of these outcome measures can take place in a broad SOPC setting involving different healthcare professionals, backgrounds, views, management and working practices. Because the health professionals are the ones who use the outcome measures, and their attitudes influence sustainable use, their perspective is decisive. Therefore, we evaluated the state-wide use of these outcome measures in daily care from the perspective of health professionals in this study.

Methods

Aim

We aimed to understand how health professionals working in SOPC viewed the use of outcome measures in daily care, and to determine what they express is needed for successful sustainable, state-wide application. We assumed that the implementation and application of outcome measures in daily care is a complex, dynnamic, and intersubjective process [27]. Therefore, we chose to use normalization process theory (NPT) as an explanatory framework in order to investigate embedding into routine care and to gain an insight into participants' experience of implementation [16].

Design

We used a parallel mixed-method design. Althought we first conducted the qualitative focus groups and then a semi-structured online-survey, we analyzed them in parallel due to organisational reasons [28]. We considered mixed-methods appropriate and used an online survey to gather information on the views of professionals, and focus group discussions to understand participants' views in more in depth [29]. We followed Mixed Methods Article Reporting Standards (MMARS) (supplemental material A) [30].

Setting

We gradually implemented the outcome measures in daily care from November 2018 to June 2019 via the electronic documentation systems (EDS) of 19 SOPC-teams caring for adults in Hesse, Germany. In a further three teams, implementation could only take place after data collection due to delayed software adaptation. Hesse is a federal state in Germany containing rural and urban areas and about 6.3 million inhabitants [31]. In total, 22 SOPC-teams provide state-wide care for adults. Teams mainly include nurses and physicians, but in some cases also involve psychologists and social workers. All SOPC-teams belong to the Professional Association of Specialized Palliative Homecare in Hesse, which collects standardized data in order to improve quality of care [32].

We conducted a training meeting with every team on their premises before implementation. Topics were reasons for implementation, the content and practical use of the outcome measures, and organizational integration into daily care routines. After the training meeting the SOPC-team members applied the outcome measures in every case. Table 1 describes the outcome measures used.

Table 1 Outcome measures used

Outcome measure	Content	Target population	Application
Integrated Palliative care Outcome Scale (IPOS) [23]	Ten questions on the main problems, including physical, psychological, spiritual and practical concerns	Patients	Self-report (orally), proxy-report by relatives or HP (separately and/or alternatively)
Phase of Illness [24]	Five distinct phases of patients' and relatives' care needs, and the suitability of current care	Patients	Proxy-report by HP
IPOS Views on Care (IPOS VoC)—patients version [25, 33]	Four questions on the impact the SOPC-team had on patients' quality of life and their main problems	Patients	Self-report (paper version handed out to patients; EDS entry after completion)
IPOS VoC: Question (no.4) on quality of life	One question on how patients rate their overall quality of life	Patients	Self-report (orally), proxy-report by relatives or HP (alternatively)
Views on Care (VoC)- relatives' version[a]	Four questions on the burden on relatives and the impact the SOPC-team had had on their relatives	Relatives	Self-report (paper version handed out to relatives; EDS entry after completion)
VoC: Question on support provided for relatives	One question about whether the family caregiver felt the family was currently receiving enough help from their SOPC-team	Relatives	Self-report by relatives (orally), or HP (alternatively)

[a] developed as part of the ELSAH study based on IPOS Views on Care, unvalidated German version; HP = health professionals

For the self-report, the SOPC-team members included the items into the conversations. Because we found in a previous study that it needs tact to address sensitive topics, we did not arrange predefined time points for self-report, but made the default to assess every topic when the information was collectible [26]. If a self-report was not possible, e.g. due to deteriorating health, the health professionals asked relatives or completed proxy-reports themselves.

Data collection

Focus groups

Two experienced qualitative researchers (HS, KK) conducted focus groups to investigate SOPC-team members' experiences and suggested changes. We developed the focus group topic guide by including the NPT core constructs (supplemental material B). We brought members from different teams together in order to stimulate a discussion [34]. We sent an email invitation to our contact partner in every team and asked them to forward it to team members and to choose one to three team members, independent of profession, to participate in a focus group. We did not sample for specific characteristics, but included the people who had interest to participate (convenience sampling) [35]. Participants gave their written informed consent to participate, permitted a video recording to be made, and provided demographic data in a questionnaire. We wrote field notes on the researchers' thoughts directly afterwards.

Online survey

We used lime-survey [36] to conduct an anonymous semi-standardized online survey, based on the NoMAD (Normalization MeAsure Development) instrument [37, 38]. Together with other authors, the authors of the NPT, May and Finch, developed the NoMAD tool, which aims to understand participants' implementation experiences. This validated generic quantitative measure contains 43 items and has been used in numerous previous studies [39–41]. It includes statements related to the core constructs of NPT and asks participants to rate their agreement on a 5-point Likert scale (strongly agree to strongly disagree plus the option 'not relevant to my role' and the possibility to omit questions) [37].

In line with the developer's recommendations, we adapted NoMAD to suit our research interest by adding both an introduction and questions on participants' characteristics [38]. We further added a question on how relevant they considered each outcome measure and gave them the opportunity to add comments in free text (supplemental material C). We emailed a participation link to all team leaders, and asked them to forward it to all team members involved in using the outcome measures (convenience sampling).

Analysis

Focus groups

We transcribed and pseudonymized the audio recordings using MAXQDA [42]. May et al. presented several possibilities to analyze qualitative data in line with NPT [18]. We (HS, KK) used qualitative content analysis, and combined inductive and deductive coding using MAXQDA [43]. By setting the four core constructs of NPT (coherence, cognitive participation, collective action, reflexive monitoring) and their respective outcome measure as a-priori codes, we were able to link the content to the online-survey and identify issues associated with a specific measure. We discussed and added inductive codes and assigned them to the four core constructs of NPT after initial coding.

Online survey

As suggested by the authors of the NoMAD, we (HS, KK) used Microsoft Excel, version 2016, to analyze the online survey descriptively by looking at the response distribution and percentages [38]. We (HS, KK) used MAXQDA to analyze the free-text answers using qualitative content analysis [42]. We used the same coding tree, that we have elaborated for analysing the focus groups.

Mixed-Methods integration

We triangulated the findings of the focus groups and the survey on and interpretation level by using a triangulation protocol [44]. We created a convergence coding matrix for NPT core constructs and another convergence coding matrix for specific feedback on outcome measures. During the process, we examined the key quantitative and qualitative findings for convergences, dissonances, complementary information and silences, and developed an overarching conclusion for each component [44].

Deduction of topics requiring particular attention

In the analysis we identified topics, that reoccured in all NPT core constructs. We assumed that, from the participants' point of view, these issues need to be addressed if further use is to be successful. From this, we have deduced that these topics require particular attention for sustainable use of the outcome measures. Therefore, we present the deduction and the topics contents separately in this article.

Results

Study sample

We conducted three focus groups with n = 14 SOPC-team members. Five participants cancelled at short notice due to time constraints. Discussions took place in September and October 2019 in the rooms of an independent palliative association in Fulda and at the University of Frankfurt, and lasted about 105 min. The time between implementation and data collection was 3–10 months, depending on team.

The anonymous online-survey was conducted from November 20, to December 31, 2019. At this time the outcome measures had been used for six to twelve months. In the end, n = 76 complete data sets were available, and 104 hits were registered in total. Detailed results of the online-survey are presented in supplemental material C.

Participants' characteristics are shown in Table 2.

In the following, we present the general appraisal and results according to NPT. Subsequently, we show key themes requiring particular attention, including specific findings on outcome measures.

Appraisal of use in daily care

In the overall appraisal, about 69% of participants in the online-survey said the use of the outcome measures currently belonged to their day-to-day work. Participants that disagreed generally believed this would not be the case in the future (supplemental material C).

We present our findings according to the four core NPT constructs in Table 3. For each subject in the online-survey, we present a synopsis of online-survey results and focus group findings, provide a statement on the agreement between findings, and draw a conclusion. In Table 3, we also present a summary for each core construct of NPT.

Topics requiring particular attention

We found that four key topics recurred across all NPT constructs (Fig. 1). From the perspective of health professionals in SOPC these topics require particular attention if the revised documentation is to be used sustainably in daily care: 1) Daily care, 2) quality evaluation, 3) motivation and engagement, and 4) fears and concerns. We illustrate our findings using translations of pseudonymized quotations from the focus groups.

Daily care

Most participants knew the difference between the old and new documentation, but several participants (42%) did not see that the new documentation provided additional value in their practical work. Correspondingly, many participants (46%) did not feel the time for documentation was well spent.

> *The patient has always been taken into account to a great degree, but just not in the documentation. Now the documentation is written as if the patient really said all this, but everything is actually the same as before. (1738E, female nurse)*

Table 2 Characteristics of participants

		1st focus group	2nd focus group	3rd focus group	Focus group participants in summary	Online survey participants
Number of participants; n		5	3	6	14	76
Duration; minutes		107	105	103	315	-
Gender; *n* (%)	Female	5	2	5	12	58 (76.3)
	Male	0	1	1	2	14 (18.4)
	n/a	-	-	-	-	4 (5.3)
Age; years	Mean (Min, Max)	51.2 (48, 57)	47.3 (45, 50)	57.7 (52, 68)	53.1 (45, 68)	49.5 (31, 69)
Profession; *n* (%)	Nurse	5	3	4	12	42 (55.3)
	Physician	0	0	2	2	24 (31.6)
	Administrator	0	0	0	0	6 (7.9)
	Other[a]	0	0	0	0	4 (5.3)
Work experience; years	Mean (Min, Max)	5.6 (2, 10)	10.3 (9, 12)	7.8 (5, 11)	7.6 (2, 12)	6.6 (1, 15)
Geographic location; *n* (%)	Urban	0	2	3	5	22 (29)
	Suburban	3	0	2	5	28 (36.8)
	Rural	2	1	1	4	26 (34.2)

n/a = not available; [a] The following information was provided under 'Other': Team leader nursing (*n* = 3), Physiotherapist (*n* = 1)

Table 3 Convergence coding matrix for NPT core constructs

Subject	Synopsis of online-survey results[a]	Synopsis of focus group findings	Agreement between online-survey results and focus group findings	Conclusion
Coherence: **→ How do participants evaluate the informative value of the outcome measures?** **→ Is there a common understanding of the purpose behind them?**				
Differentiation between old and new documentation	82% agreed that they knew the difference, 3% disagreed (12% neither)	Differences are known, but sometimes confusion occurs as to which changes our study is responsible for	Convergence	Participants appear to be aware of the differences between the old and new documentation
Shared understanding of the aim/purpose in the team	43% considered a shared understanding to exist, 37% did not (12% neither)	Some participants said they use the documentation because they are required to. Others thought the items were of value in their daily work	Convergence	There does not seem to be a shared understanding of the aim/purpose
Potential value in practice	37% considered the outcome measures to provide added value in their work, 42% do not (20% neither)	Some participants valued changes such as new response options and new items. Others considered the previous documentation to be sufficient	Complementarity (which changes participants welcomed and comparison to previous documentation)	Several participants saw no added value in practice. This may be because they considered the previous documentation to have been sufficient
Identification with the topics	57% could identify with the topics, 30% could not (9% neither)	Most participants considered the topics to be relevant to care. There was more discussion about whether the outcome measures captured the required information	Complementarity (concerns related more to measures than issues)	Most participants identified with the topics. Those that said they could not seemed to struggle with the measures rather than the topics
Modified documentation revealed changes in quality	26% believed the quality of care could be evaluated this way, 53% did not (18% neither)	Some participants generally doubted that quality can be revealed in documentation, and said quality could only be seen in practical interaction. Most participants disagreed that outcome measures could depict reality but could imagine that outcome measures might provide an indication of care quality	Complementarity (doubt on principle, but not necessarily related to the measures used here)	The majority of participants doubted that quality could be revealed through the use of the documentation. Participants seemed to doubt whether outcome measures can provide a real representation of care, rather than want to criticize the employed measures
Concern about negative impact on specialized outpatient palliative care	43% were concerned, 24% were not (25% neither)	Some participants feared their data might be misinterpreted and lead to a poor assessment of their work, whether or not they did a good job in practice. They were also concerned that time taken for documentation took time away from patients	Complementarity (what concerns participants have)	Several participants feared such documentation might have a negative impact on specialized palliative home-care. They feared the documentation of poor health in their patients might have a negative impact on the evaluation of their work and result in less time for patient care
Time for documentation is invested wisely in quality of care/patient care	30% agreed that the time was invested wisely, 46% disagreed (21% neither)	Some participants thought time spent with the patient was particularly valuable and important for the relationship with him or her. For participants that saw no added value for practical care, documentation was simply extra work invested for external evaluation. Spending a lot of time on such assessments seemed to them to be counterproductive	Complementarity (explanation of why time is perceived as not being invested wisely)	Several participants did not feel that time taken for documentation was well spent in terms of quality of care. This seemed to be particularly true when they saw no added value for their practical work. For them, spending time on assessments seemed to be counterproductive, i.e. lead rather to a deterioration than an improvement in care
Summary on coherence: It became apparent that not all participants shared a common understanding of the purpose of the measures. Although participants could identify with the topics, they doubted whether documentation would benefit their practical work and feared poor evaluations and a negative impact on practical work. Coherence is limited by general doubts about whether quality can be depicted through the use of outcome measures				

Table 3 (continued)

Subject	Synopsis of online-survey results[a]	Synopsis of focus group findings	Agreement between online-survey results and focus group findings	Conclusion
Cognitive participation: **→ How do users engage in the use of the outcome measures?** **→ How do users develop a collaborative approach to using them?**				
Key people in the team encouraged the continuous use of the outcome measures	62% agreed that some people in the team encouraged use of the measures, 8% disagreed (16% neither)	All participants said that at least one person in their team was responsible for documentation and encouraged its implementation and continuous use. They generally also made up the focus groups	Convergence	In most teams, at least one person encouraged continuous use of the modified documentation
Key people outside the team encouraged their use	42% agreed that people outside the team encouraged their use, 18% disagreed (16% neither)	All participants described the staff of the Professional Association of Specialized Palliative Homecare in Hesse as key people outside the team that encouraged its use Some participants also named our study team as among the people encouraging the use of the modified documentation	Complementarity (who are the key people)	Some participants agreed that key people outside the team encouraged its use. The Professional Association of Specialized Palliative Homecare in Hesse and the study team were among those named
Knew how the documentation should ideally be used	83% agreed to knowing how the documentation should ideally be used 7% disagreed (5% neither)	Participants were familiar with the new documentation. However, it became obvious in discussions that details concerning its practical use and background were not completely clear. For example, they felt unsure how to address psychosocial questions	Complementarity (where insecurities prevail)	Although most participants felt they knew how the documentation should ideally be used, it became obvious that details were unclear
Theoretical examination of topics	86% agreed that they had dealt with the topics theoretically (5% neither, 4% disagreed)	Participants knew what had changed in the modified documentation, and most participants agreed that added topics played an important role in their work	Convergence	Most participants said they have examined the additional topics in the modified documentation
Motivation to use the documentation in practice	41% were motivated to use the documentation in practice, 38% were not (16% neither)	Participants explained that the overall workload linked to the documentation reduced their motivation. They felt that the modified documentation created additional work for health professionals because it contained more items. Participants also said team members became frustrated when it did not work as they had hoped in practice. The sharing of information among teams and team-related feedback were described as encouraging use	Complementarity (which factors influence motivation)	About the same number of participants agreed as disagreed to being motivated to use the documentation with patients. The overall burden of documentation as well as problems in its practical use may have reduced motivation. The sharing of information among teams and team-related feedback may increase motivation
Support for the modified documentation	29% agreed to support the documentation and 41% did not (25% neither)	Participants that expected use of the documentation to result in improvements were more likely to support and try to integrate it. Those that expected no improvements tended not to support its use and to want to undo the changes	Complementarity (influence of assumed benefit)	Participants were divided on support for the modified documentation. Those that expected benefits from it tended to support it and those that did not tended not to

Table 3 (continued)

Subject	Synopsis of online-survey results[a]	Synopsis of focus group findings	Agreement between online-survey results and focus group findings	Conclusion
Summary on cognitive participation: Support for cognitive participation varied. Key persons that encouraged use of the revised documentation and expected benefits from it supported a collaborative approach to using it. The assumed benefit is influenced by participants' theoretical understanding and perceived feasibility. Motivation for use was reduced by the overall burden of documentation and promoted by information sharing across teams and team-related feedback				
Collective action: **→ Is collective action employed to promote the use of the outcome measures?** **→ What factors hinder or promote the use of the outcome measures in day-to-day work?**				
Easy integration into day-to-day work	While 42% said they could integrate the modified documentation into their day-to-day work, 32% said they could not (18% undecided)	Participants described symptom documentation as easy to use. They explained that the documentation on psychosocial issues and the assessment of self- and proxy-reports caused problems. Further, the organizational integration of paper-based IPOS VoC in day-to-day care was regarded as difficult. Some teams developed internal standards to facilitate use of the documentation, e.g. on how often to use the modified documentation in order to create a routine. Others tried to facilitate use of the documentation by sending out assessment documents by mail or conducting them on the telephone	Complementarity (which measures caused problems, initiatives to improve these)	Several participants had problems integrating the modified documentation into their day-to-day work. They described problems with documentation relating to psychosocial issues, with self- and proxy assessments, and with the integration of the paper-based IPOS VoC. Some teams developed internal strategies to facilitate use of the modified documentation
Improvements in cooperation with team colleagues	18% agreed, but 50% disagreed that the modified documentation had led to improvement in cooperation with colleagues (26% neither agreed nor disagreed)	The participants described different ways of using the documentation in their teams. Some discussed the results in team meetings, and those that did particularly appreciated IPOS Phase of Illness and IPOS. Others did not discuss results with colleagues, but at least looked at the documentation before visiting patients. They explained that from their point of view the previous documentation had sufficed. Furthermore, they said information on patients was generally communicated orally rather than via documentation	Complementarity (the way the documentation was used in day-to-day care influenced whether advantages were seen)	Several participants disagreed that the modified documentation led to improvements in cooperation with colleagues. The use of the documentation in day-to-day care apparently differed, with those that used it appreciating IPOS Phase of Illness and IPOS for its impact on cooperation with colleagues. Those that did not already use the documentation in team meetings may have seen fewer advantages in terms of cooperation with colleagues. This may be why a minority recognized a positive impact on cooperation with colleagues
Improvements in the quality of relationships with patients and relatives	13% agreed, but 48% disagreed that the modified documentation improved the quality of relationships (28% neither agreed not disagreed)	Although most participants agreed that the topics are important, many emphasized that relationships are built during interactions with patients rather than via documentation. Some participants feared that the strict use of documentation might damage relationships and stressed that a sense of balance was necessary, especially with respect to IPOS psychosocial questions	Complementarity (Reasons why participants think the quality of relationships might suffer)	Only a few participants agreed that use of the modified documentation improves the quality of relationships. Reasons for this may have been that the participants considered relationship quality to be influenced more by interacting with patients than by documentation. Furthermore, they feared that the relationship could be damaged by strict application of documentation

Table 3 (continued)

Subject	Synopsis of online-survey results[a]	Synopsis of focus group findings	Agreement between online-survey results and focus group findings	Conclusion
Everyone in the team can use it according to instructions	71% agreed that everyone in the team could use the modified documentation, 18% disagreed (7% neither)	As use of the documentation is obligatory for all participants, they used it in practice and knew how to do so. Small misunderstandings and uncertainties became clear, e.g. on frequency of use	Convergence	Most participants agreed that everyone in the team could use the modified documentation in accordance with instructions
Sufficient support offered during implementation phase	63% agreed that support was sufficient during the implementation phase, 20% disagreed (9% were undecided)	Participants were pleased with the implementation and all teams commented favorably on the personal training and the opportunity to ask questions. Team leaders felt that explanations provided by the study team were better received than their own	Convergence	Most participants agreed that the support offered during the implementation phase was sufficient
Sufficient support is provided	60% agreed that sufficient support was provided at the time of the survey, 16% disagreed (17% were undecided)	Some participants wished for continuous support from the experts in the use of outcome measures, because they sometimes felt unsure about details or technical issues relating to the EDS	Dissonance	While most participants in the online-survey agreed that support was sufficient at the time of the survey, participants in the focus groups would have welcomed more continuous and more regular support from experts in the use of the outcome measures. This may be because several focus group participants were members of the management team and were contacted by colleagues when questions arose. They may therefore have perceived a greater need for support
Sufficient resources are available for use in everyday care	While 40% agreed, 30% disagreed that sufficient resources were available for use in everyday care (22% neither agreed nor disagreed)	Some participants said sufficient resources were available. Others felt that they did not have sufficient time. These participants emphasized the overall burden of documentation and that it had increased as a result of additional items in the modified documentation. Some participants described attempts to counter this by delegating organizational issues to one team member	Complementarity (Resources mainly related to time, strategies for improvement)	Participants were divided over whether sufficient resources are available for use in everyday care. Those who felt they did not have sufficient resources said they lacked time for documentation
The management team provides sufficient support	72% agreed that the management team provided sufficient support for use of the modified documentation, 7% disagreed (11% neither)	Some management team attended the focus groups, so the adequacy of their support was not discussed. They themselves said it was difficult for them to motivate their teams over time	Silence	Most participants agreed that the management team provided sufficient support in the use of the modified documentation. Members of the management team said they had problems motivating their teams over time

Summary on collective action:
Obstacles to collective action were the difficulty of integrating the documentation into day-to-day work and concerns about lessening the quality of relationships. The way the documentation was employed in day-to-day care had an influence on whether it was seen to be beneficial. Participants were divided as to whether enough support was provided and enough resources were available, but they agreed that their management teams provided sufficient support

Table 3 (continued)

Subject	Synopsis of online-survey results[a]	Synopsis of focus group findings	Agreement between online-survey results and focus group findings	Conclusion
Reflexive monitoring: **→ How do the participants view the outcome measures?** **→ What improvements did they suggest?**				
Awareness of reports / experiences of usefulness	26% agreed they knew of reports/experiences of usefulness, but 43% disagreed (24% neither)	Most participants said they did not know of any such reports, and were uncertain how the data was evaluated. Some were afraid that poor final values would be considered as signs of poor quality	Convergence	Most participants were not aware of reports/experiences of the usefulness of the modified documentation
Benefit for their own work	24% agreed, but 47% disagreed to seeing any benefit for their own work (24% neither)	With respect to the advantages of using the modified documentation, participants distinguished between their practical work and quality evaluation In their practical work, participants valued the IPOS Phase of Illness, the symptom items of IPOS, the five-point Likert scale and the response option 'not assessable'. Some participants did not see any improvement over the previous documentation. Some participants suggested that a clearer presentation in the electronic documentation system would help in their practical work Some participants did not understand how the documentation could help them evaluate their own work. They doubted whether an assessment could really be objective and said the proxy assessment might not be valid because of differing opinions among staff members. They also criticized patient self-assessments on the grounds that their condition could influence their assessment	Complementarity (differentiation between advantages in their practical work and in its use for evaluation purposes)	Participants were divided over the advantages of using the documentation in their own work. With respect to any advantages, they distinguished between their practical work and quality evaluation. Participants basically saw how their day-to-day care benefited but thought some items were difficult to integrate. They said it was difficult for them to understand how outcome measures could be used in quality evaluation
Fellow employees' agreement on usefulness	13% agreed, but 51% disagreed that their fellow employees thought the modified documentation was useful (22% neither)	Agreement among their fellow employees was not discussed in the focus groups	Silence	Most participants disagreed that their fellow employees thought the modified documentation was useful
Confidence that feedback will improve	59% said they were confident that feedback would improve the modified documentation, 14% disagreed (21% neither)	Participants emphasized that their motivation might deteriorate if the teams' feedback was not taken seriously. They trusted that their feedback would lead to improvement	Convergence	Most participants were confident that their feedback would improve the usefulness of the modified documentation

Table 3 (continued)

Subject	Synopsis of online-survey results[a]	Synopsis of focus group findings	Agreement between online-survey results and focus group findings	Conclusion
Ability to adapt use of the modified documentation to suit their own way of working	61% could adapt the application of the documentation to suit their own way of working, 17% disagreed (13% neither)	All participants knew it was possible to include the items in conversation. They reported, however, that the practical implementation was sometimes difficult. Furthermore, IPOS VoC was described as difficult to adapt to suit their own work methods	Complementarity (aspects causing problems adapting)	Most participants agreed they could adapt use of the modified documentation to suit their own work methods Integration into conversations and use of IPOS VoC were more difficult
Summary on reflexive monitoring Participants were divided over the benefits of using the documentation. They reported that it was basically useful in day-to-day care, but said some items were difficult to integrate. It was difficult for them to understand how outcome measures can be used in quality evaluation				

[a] values rounded; response options 'not relevant to my role' and 'no answer' not reported; response options 'strongly agree' and 'agree', as well as 'disagree' and 'strongly disagree' were combined to form one response

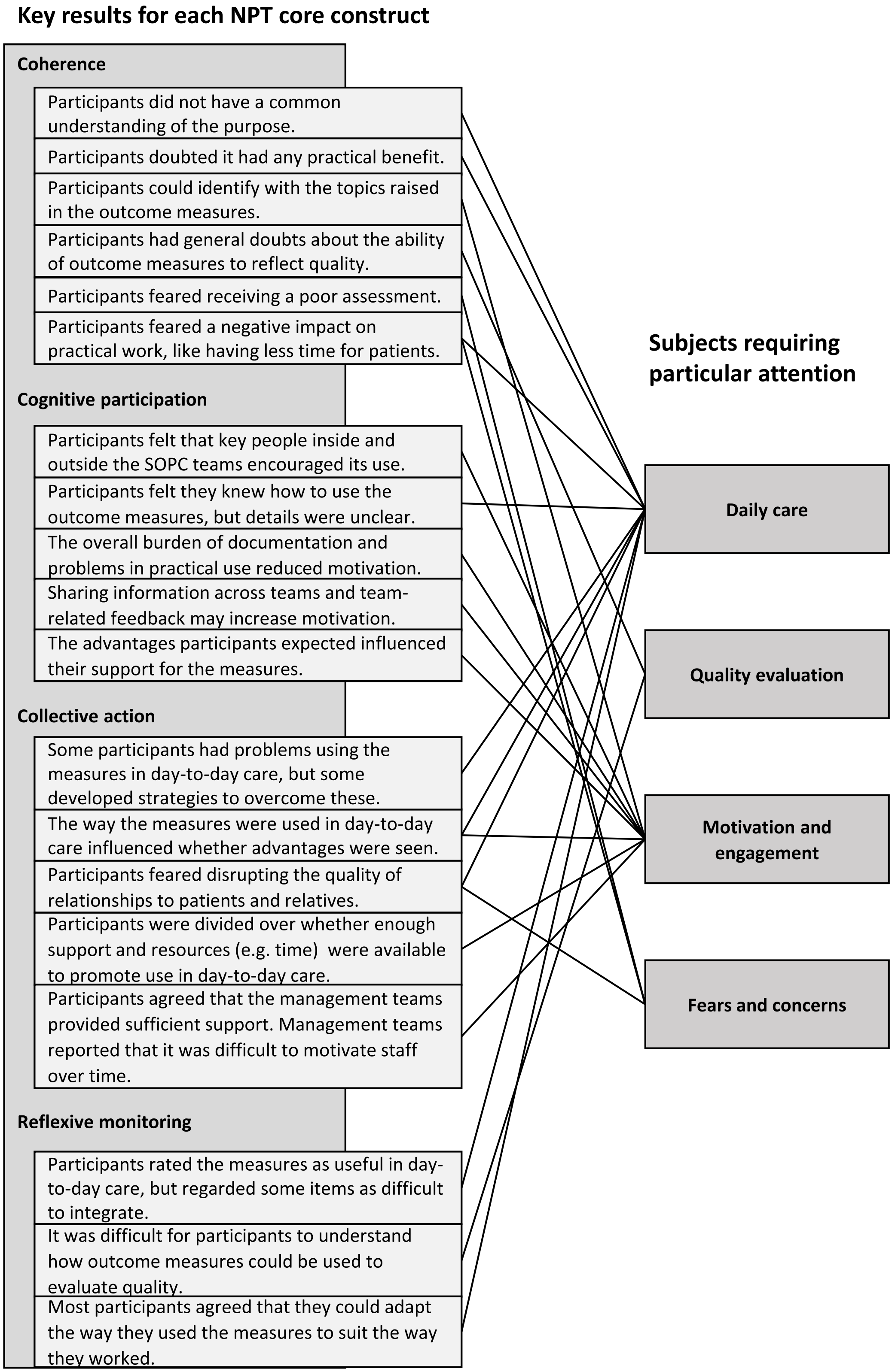

Fig. 1 NPT core constructs leading to four key themes

Most participants (71%) assumed, that everyone in their team could use the documentation in day-to-day care, but we found they had difficulties integrating it. Participants that felt they did not have sufficient resources at their disposal thought they had too little time for documentation.

Many participants (50%) thought the use of the outcome measures promoted cooperation with their fellow employees. While some mentioned the results in their team meetings, others did not look at them after entering the data. It became clear that not all participants knew how to integrate the results into their work, which may explain a lack of appreciation of their usefulness.

Quality evaluation

Many participants (53%) doubted whether quality could be evaluated through the use of documentation. This reflected a general concern whether outcome measures accurately reflected the actual care situation:

> *What I want to make comprehensible is that I can't use a table to illustrate the way a person is, the emotions a person has, the process of dying in a person, or how a person deals with an illness. (1738E, female nurse)*

Some participants struggled with the idea of an objective assessment. They criticized proxy assessments as having no validity because the assessment of health professionals can differ. They also criticized patient self-assessments on the grounds that patients' conditions might influence their assessment.

> *But isn't it again a bit of a subjective judgment that varies from one colleague to another, when we go through the symptoms and I assess something? [...] So I look-, and of course ask about pain, but of course I assess what he tells me in terms of the different categories. My colleague might see things quite differently. How coherent is the picture then? 1736E, female nurse)*

It became obvious that most participants (57%) could identify with the topics covered by the measures. However, many participants (43%) had no knowledge of reports or experiences of the usefulness of such measures, which may explain why they were sceptical about their usefulness.

Motivation and engagement

Only 41% of participants were keen to use the outcome measures in practice. Beyond the overall burden of documentation, the assumed benefit also influenced their engagement. Those that assumed care would benefit showed more interest in using it than those that did not.

Uncertainty in using the documentation in practice may also have had a negative impact on motivation. Most participants had dealt with the topics theoretically (86%) and felt they knew how the outcome measures should ideally be used (83%), but the discussions showed that some details were unclear. For example, they were particularly unsure how to address IPOS questions on psychosocial issues.

> *Yes, because how do I interpret the question, right? 'At peace with myself'. Hmm. I have cancer, shit, I'm going to die. How can you be at peace with yourself ... That's just an expression covering one, two questions, or three, four (laughs), that's actually something everybody has a hard time with, all of us. (1742E, female nurse)*

We found that sharing information across teams and team-related feedback helped motivate them. Most online-survey participants agreed that sufficient support was provided during implementation (63%), and at the time of the online-survey (60%), and they agreed that the management team provided sufficient support (72%). Nevertheless, participants in the focus groups wished for more continuous training and regular support from experts in the use of outcome measures.

Fears and concerns

Some participants (43%) expressed concern about a negative impact on care. They were concerned they would have less time for patients because they would have to invest time in completing the documentation. They also feared data might be misinterpreted, and that their work would be poorly evaluated, even though they were doing a good job in practice:

> *The Phase of Illness assessment, that's where the 'stable' bothers me. [...] But the thing is always: is he stable BECAUSE he has SOPC? [...] Stable actually means: does he still have an indication for SOPC? [...] And that's when I ask myself: will this be used against us at some point? If we use that in the evaluation for the [health] insurers, for the funding agencies, will that be used against us? [...] Is that stable at some point the time they say 'stable, stable, and you're providing SOPC!'? (1745E, female physician)*

Several participants (48%) denied that the use increased the quality of relationships with patients and relatives. Participants reckoned the quality of relationships depended more on personal interactions than outcome measurements. They also feared that the quality of relationships might deteriorate because patients might find some of the items upsetting:

> *But I find it very difficult to ask such questions because I'm then rather afraid that they might close themselves off completely. They are at home; we are already intruding on their intimacy, and so I think we should show a great deal of tact. (1744E, female nurse)*

Specific feedback on the outcome measures

Participants regarded IPOS, and Phase of Illness symptom documentation as most helpful in their day-to-day care. They struggled with the psychosocial questions asked in IPOS (anxiety, family anxiety, depression, feeling at peace, share feelings). Although most participants considered the content to be relevant to care, several participants found it difficult to integrate the questions into a conversation, and to classify the answers on the scale. Participants said it was often impossible to interpret answers to such questions at the beginning of care because trust first had to be built up before such topics could be addressed. These issues could therefore not be raised when care was only provided for a short period.

Some participants criticized the wording of the questions. They also said it was difficult for staff members to make proxy assessments and almost impossible with cognitively impaired patients. Most participants appreciated the usefulness of IPOS VoC in evaluating care, but not in their practical work. Detailed feedback on the outcome measures is presented in Table 4.

Discussion

Main findings

Overall, participants said that they had accepted the use of the outcome measures in daily care and that it had become part of their day-to-day work. However, participants expressed that sustainable integration into daily care will require that special attention is drawn to their usefulness in daily care, in quality evaluations, in motivating and engagement and appreciating the concerns of health professionals.

Comparison of findings with those reported in the literature

Feedback from participants in our study was heterogeneous, suggesting that the effectiveness of the implementation varied. While implementation worked well in some teams, this was not the case in other teams, suggesting that it is more difficult to implement in different teams than in individual teams. Top-down implementation might reduce the sense of accountability and possibly even lead to resistance when compared to bottom-up implementation [15]. Although the implementation by our research team was carried out in consultation with the Professional Association of Specialized Palliative Homecare in Hesse and thus with all SOPC-teams, it can be assumed that individual health professionals did not feel they had been included in the decision-making process.

In addition to the initial implementation, we found that the way the measures are used by the teams in daily care influences sustainability. Other studies found that supportive leadership and peer support facilitated the implementation and encouraged its further use [45, 46]. Bradshaw et al. said that the benefits need to be demonstrated in order to increase motivation and engagement and to promote and sustain a collaborative effort, adding that measures may otherwise be dismissed as pointless [47]. Another study agreed that good training and guidance is required in the use of PROM in care [48]. It became clear that training before and during implementation is not enough, but that continuous support, which should be adapted to the needs of individual teams, should be provided to users.

Sustainable motivation requires that results are interpreted and fed back to health professionals [46]. Our participants distinguished between benefits in their practical work and benefits in terms of quality assurance, but for its sustainable use it is important to understand both aspects. Use in daily care, e.g. in team discussions, may clarify the direct benefits in practical work and for individual patients. Similar to our findings, another study showed that health professionals appreciated the opportunity to recognize unmet needs through the electronic use of PROMs, but were also concerned that it could disrupt care delivery processes, especially when intimate questions were asked of patients with whom the duration of contact had been only short [49]. Other research, however, showed that psychosocial support is also possible on first contact [50]. On specific outcome measures, further feedback from our participants was in line with the results of similar studies [47, 51]. This shows the need for ongoing training, particularly on how to integrate the psychosocial questions of IPOS into daily care. Peers with experience of using the measures could regularly address issues surrounding integration and other problems in the team. By ensuring they were accessible to colleagues as low-threshold contact persons, they could also help train new staff. Cross-team information sharing amongst peers could improve the promotion of long-term, sustainable use. Implementation in several teams thus also offers opportunities for mutual support.

To enhance a good quality of nursing documentation, Groot et al. recommended to use familiar terms [52]. Following this recommendation, we used the term

Table 4 Convergence coding matrix regarding specific feedback on the outcome measures

Item	Quantitative results: online-survey results[a]			Qualitative findings: synopsis focus group findings and online-survey free-text response	Agreement between quantitative results and qualitative findings	Conclusion
	Mean (SD)	Median	Number of free text responses n (%)			
IPOS						
Main problems or concerns	7.1 (3.1)	8	10 (13.2)	Only a few participants commented on the main problems. They saw no problems in the responses and only suggested improvements in technical integration	Convergence	Participants regarded the main problems as relevant. The application did not cause problems in daily care
Symptom assessment (new: 'how it has affected' as opposed to 'severity of symptoms')	6.6 (3.1)	7	8 (10.5)	Participants rated symptom assessment as practicable and useful in their practical work. They said it was usually possible to ask about symptoms during a conversation, but that cognitive impairment complicated both the patient's self-report and proxy-assessments. Participants took into account whether their own assessment was consistent with the patient's self-report and considered this to be relevant to care. For the same reason, they welcomed the graphical representation of symptom trajectories Most participants welcomed the new questions asking about impairment caused by symptoms rather than about symptom severity. All participants appreciated the option to provide the response 'not assessable' when it was not possible to complete an assessment Participants were also concerned that symptoms often increased over the course of care and that this could be considered to reflect poor quality of care. Several participants were unsure how to deal with the final assessment because they were rarely present when patients were dying. They felt that both the assessment of the last contact and documentation after death were both biased. Most teams resorted to a default position of either documenting symptoms after every contact or at least once a week	Complementarity (Insecurity and concerns related to quality evaluation)	Participants considered symptom assessment to be relevant and useful in their practical work Some insecurity and concerns emerged with respect to quality evaluation

Table 4 (continued)

Item	Quantitative results: online-survey results[a]			Qualitative findings: synopsis focus group findings and online-survey free-text response	Agreement between quantitative results and qualitative findings	Conclusion
	Mean (SD)	Median	Number of free text responses n (%)			
Anxiety	4.4 (3.4)	5	16 (21.1)	Most participants agreed that this is an important issue in palliative care. Several participants did not think it should be asked this way, but should be addressed more tactfully Some participants considered the question unnecessary because they regarded it as normal to be afraid when receiving palliative care. Others valued the item because the question gave them the opportunity to start a conversation on the topic	Disagreement	While the relevance is rated as rather low in the qualitative results, qualitative findings showed that some consider the topic to be relevant but to be difficult to raise in practice
Family anxiety	4.5 (3.3)	5	14 (18.4)	Most participants agreed that this is an important issue in palliative care. Several participants did not think it should be asked this way, but should be addressed more tactfully Some participants considered the question unnecessary because they regarded it as normal that the family should be afraid when a relative is receiving palliative care	Disagreement	While the relevance is rated as rather low in the qualitative results, qualitative findings showed that some consider the topic to be relevant but to be difficult to raise in practice
Depression	4.7 (3.5)	5	12(15.8)	Most participants agreed that this is an important issue in palliative care. Several participants did not agree think it should be asked this way, but should be addressed more tactfully Some participants criticized the way the question was formulated	Disagreement	While the relevance is rated as rather low in the qualitative results, qualitative findings showed that some consider the topic to be relevant but to be difficult to raise in practice

Table 4 (continued)

Item	Quantitative results: online-survey results[a]			Qualitative findings: synopsis focus group findings and online-survey free-text response	Agreement between quantitative results and qualitative findings	Conclusion
	Mean (SD)	**Median**	**Number of free text responses n (%)**			
Feeling at peace	3.1 (3.2)	2	28 (36.8)	Many participants were upset by this question. They agreed that it is an important issue in palliative care, but did not agree that the question can be presented in this way Some participants rejected the idea that patients receiving palliative care could be at peace at all. Others feared the topic might upset patients Some participants said they integrated the subject into conversations, and hardly any participant asked this question as it was presented in the documentation. They also said that when the subject was raised, it often provoked questions as to what was meant by the term. They emphasized that this question requires a high level of trust, as they were concerned that the quality of the relationship with the patient would otherwise suffer. For these reasons, participants felt uncomfortable in asking this question	Disagreement	While the relevance is rated as rather low in the qualitative results, qualitative findings showed that some consider the topic to be relevant but to be difficult to raise in practice
Share feelings	3.6 (3.3)	3	11 (14.5)	Several participants did not think the question should be asked this way, but thought the subject should be addressed more tactfully. They also emphasized that not some patients did not wish to discuss this issue	Convergence	Most participants felt this topic had no relevance to care
Information needs	5.2 (3.5)	5	7 (9.2)	Some participants reported that this item sometimes raises new questions. Some explained that it is one of their tasks to provide information and that the question should therefore not be included in the patient's assessment	Convergence	Most participants felt this topic had no relevance to care
Practical problems	5.5 (3.4)	5	9 (11.8)	Most participants agreed that this is an important issue in palliative care. They said that practical problems should be discussed in great detail Some participants reported that affected patients often made unrealistic demands (e.g. desire for a night watch) and feared that this would have a negative impact on the evaluation	Convergence	Most participants felt this topic had no relevance to care

Table 4 (continued)

Item	Quantitative results: online-survey results[a]			Qualitative findings: synopsis focus group findings and online-survey free-text response	Agreement between quantitative results and qualitative findings	Conclusion
	Mean (SD)	Median	Number of free text responses n (%)			
IPOS Phase of Illness						
IPOS Phase of Illness	7 (2.9)	8	8 (10.5)	Most participants appreciated the use of IPOS Phase of Illness and reported that they used it when communicating within their teams. They appreciated the fact that it included the complexity of care in the quality evaluation Some participants feared the description of a phase as 'stable' might be misinterpreted. They feared it could be understood to mean the patient should no longer be eligible for specialized care, rather than that the patient is stable as a result of specialized palliative home-care	Convergence	Most participants considered this item to be relevant. Some participants feared misinterpretation
IPOS Views on Care						
Question on quality of life	6 (3.4)	6	12 (15.8)	Most participants considered this topic to be relevant. Some participants described this question as very intimate and criticized the way it was formulated Some participants felt the question was inappropriate because they assumed that the quality of life of palliative patients is inevitably poor. They reported individual cases in which patients expressed their dislike of the question. Some participants described the scale of 1–7 as too broad Others found it straightforward to ask this question or to address it in a conversation	Convergence	Most participants considered this item to be relevant. Some participants feared misinterpretation
Question on the relatives' support	5.5 (3.4)	6	10 (13.2)	Most participants considered this topic to be relevant. They said they asked the question regularly, and weaved it into their conversations. Some noted that the question could only be asked while care was being provided, although it was sometimes also relevant after death	Convergence	Most participants considered this item to be relevant. Some participants feared misinterpretation

Table 4 (continued)

Item	Quantitative results: online-survey results[a]			Qualitative findings: synopsis focus group findings and online-survey free-text response	Agreement between quantitative results and qualitative findings	Conclusion
	Mean (SD)	Median	Number of free text responses n (%)			
Patient's version as a whole	5.2 (3.6)	5	9 (11.8)	Most participants suspected it might be useful for evaluating quality, but only a few said they considered the results in their practical work Most participants feared that patients would not provide honest answers because of their dependence on the team. They therefore proposed integrating the questionnaire in an anonymous survey Participants reported that the questions were sometimes difficult for patients to understand because of the wording, so they sometimes filled out the questionnaires with the patients or presented the items orally Participants reported that it was a major effort for them to hand out the written questionnaires and collect them later	Complementarity (Different aspects within the relevance assessment)	Most participants considered the question relevant to quality evaluation, but did not use it in their practical work. They further reported difficulties approaching the subject
Relative's version as a whole	5.1 (3.5)	5	8 (10.5)	As in the case of the IPOS patient's version, participants criticized the effort involved and the lack of any usefulness of the responses in their practical work. However, they thought it would help in the evaluation of quality. They also mentioned the problem of patients' passing away before the questionnaires had been collected, making them unavailable for evaluation	Complementarity (Different aspects within the relevance assessment)	Most participants considered the question relevant to quality evaluation, but did not use it in their practical work. They further reported difficulties approaching the subject

[a] Question: 'How relevant to your work do you rate each of the questions/topics in the new documentation?'; response options for all questions: scale 0 (not at all)—10 (completely)); range 0–10; additional option to answer in free text

documentation in conversations with SOPC-team members about the outcome measures. Looking back, we realized that the term has negative associations and often worries health professionals because they do not see documentation as a supportive component of care, but rather as something separate. In further implementations, therefore other terms like patient- and care-relevant outcomes should be used, in order to underline the relevance for care and the patients and relatives and to strenghten the motivation for use.

We found concerns about negative consequences to be fundamental but related more to the health care system than to the outcome measures. For example, although the participants of our study considered the content of the outcome measure 'Phase of Illness' important, they also saw it as a potential threat. They were afraid the health care system might force them to exclude patients from SOPC, if the measure 'Phase of Illness' was recorded as stable. This critical attitude may result from our participants having dealt with quality assessment for some time, as this may have given them the impression that control by a higher authority (the health system), as reflected in more and more assessments, is increasing. Krawczyk et al. stated that health professionals rather focus on the micro- and meso-level in daily care, so the macro perspective needs to be explained to them [53]. Although this might reduce scepticism, individual teams may not have the resources to do this. A community of several teams could concentrate resources on key events and address these issues together. Further, internal benchmarking of teams within their community could enable best practices and areas of improvement to be identified, without producing fears of control [54].

Strengths and limitations

The use of normalization process theory helped us focus on the relevant aspects of integration into daily care. The mixed-methods design offered the opportunity to gain a multi-perspective insight [38]. If we had used a sequential design with the online survey first, we could have considered the results in the focus groups, but this was not possible for organizational reasons. However, the online-survey enabled low-threshold participation, and anonymous participation may have made it easier for participants to make critical statements. The focus groups allowed a deeper understanding of the participants' views.

For data protection purposes, we sent the invitations to participate to the team leaders and asked them to forward them to team members. Gatekeeping by the team leaders may therefore have influenced the results. Some participants could not participate because of their work obligations, or excessively long journeys to focus groups. In our focus group just two physiscians participated, but in total an adequate number of physicians could be recruited, so that the physician's perspective could also be integrated. Furthermore, we did not include patients in this evaluation phase. However, it became apparent that team members were strongly patient-oriented and tried to call attention to their needs.

Implications

We identified certain factors that may help promote the sustainable integration of PROMs and caregiver reported outcome measures in daily care. In addition to findings relating to the use of specific outcome measures, we also present measures that collaborating teams should use collectively. These results are probably transferable to similar home-care settings that are responsible for caring for adults. The transfer of results to the care of children and adolescents, or to inpatient palliative care, may be limited due to the differing needs of such patients and the different structure of their daily care [55]. We could only derive implications for a sustainable application from the feedback of SOPC-team members after a short period of application. Further research should focus on applying and evaluating strategies for sustainability and integrate the perspectives of patients and relatives.

The use of PROM as a basis for funding and accreditation has raised fears among our participants. They feared that, for example, higher compensation could be paid if the outcome measures were rated well and deductions could be made if they were rated badly. This should be carried out with caution, as stakeholders have differing interests and there is no clear evidence for its appropriateness in this regard [53]. However, we recommend internal use for comparisons with other teams and for internal quality assurance. Further research is needed on how results should be fed back to health professionals.

It became obvious that not all participants felt that the use of the outcome measures had or should become part of their day-to-day work. Previous research has shown that the relationship between implementers and users influences the success of an implementation. It may be helpful for similar implementation projects to make peers responsible for implementation, as their expertise may be better accepted than that of external staff [56]. Furthermore, it became clear that the measures should only be implemented over the long term, as the process is a continuous one that requires constant support and further development, along with appropriate resources.

Conclusion

The sustainable integration of outcome measures into daily care will require that particular attention is paid to responding to the motivation and concerns of health professionals and making them aware of the value of the measures in daily care and quality evaluation. Combining the implementation of PROMs in a number of SOPC-teams is more complicated than implementation in a single team because teams' specific characteristics must be taken into account and a comparable basis created. At the same time, combined implementation offers opportunities for mutual support and the pooling of resources. The provision of support by experienced peers within and across teams will enable concerns to be addressed and benefits in daily care to be explained on a low-threshold level. Centrally organized information sharing across teams is a suitable means of communicating the benefits of PROMs in quality evaluation, and, through the efficient use of resources, can help complex topics to be addressed. Both strategies can promote motivation and allay concerns. However, the task is ongoing and requires staff and time.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-022-01109-w.

Additional file 1.

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Authors' contributions

MH, SB, and JH developed the project and secured project funding. HS, KK, JH, and SB collected, analyzed and interpreted the data. HS wrote this draft of the paper. MH and DB supported the recruitment of participants as well as the implementation. JE, DS, MH and DB assisted in the analysis and interpretation of data. All authors revised the manuscript and approved the final version. Authorship follows ICMJE recommendations.

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Data availability

All online-survey data generated or analyzed during this study are included in this published article and its supplementary information files. As the focus group transcripts may provide enough information to allow participants to be identified, no original data will be published, but online supplemental material on data collection is provided.

Declarations

Ethics approval and consent to participate

Ethical approval was granted by the Ethics Committee of the Faculty of Medicine, Philipps University Marburg (05–04-2018; ref. 47/18). The study was conducted according to the Declaration of Helsinki. Focus group participants gave written informed consent before their participation. At the beginning of the online-survey, we provided information on the purpose, participation, contact details and data protection. Then participants had to give digital consent before taking part. No patients participated in this study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's note

5.4 Veröffentlichungen und wissenschaftliche Vorträge

VERÖFFENTLICHUNGEN

1. **Seipp H**, Haasenritter J, Hach M, Becker D, Schütze D, Engler J, Bösner S, Kuss K (2022) State-wide implementation of patient-reported outcome measures (PROMs) in specialized outpatient palliative care teams (ELSAH): A mixed-methods evaluation and implications for their sustainable use. BMC Palliat Care 21(1):216. doi:10.1186/s12904-022-01109-w
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5.5 Verzeichnis der akademischen Lehrenden

Meine akademischen Lehrenden an der Hochschule Fulda waren in alphabetischer Reihenfolge die Damen und Herren:

André, Stefanie; Bollinger, Heinrich; Börchers, Kirstin; Brückner, Hans-Jürgen; Brzank, Petra; Bunzel, Markus; Drewes-Kirchhoff, Anette; Eikenberg, Martin; Ernst, Christine; Gerland, Wilfried; Greß, Stefan; Güzel-Freudenstein, Gamze; Hahn, Daphne; Heberlein, Ilse; Heckenhahn, Silvia; Heinemann, Stephanie; Hintz, Elisabeth; Hofmann, Werner; Holst, Jens; Jäckel, Ariane; Kaiser, Guido; Kessler-Thönes, Tino; Klippert, Jürgen; Kreher, Simone; Kroke, Anja; Kümpers, Susanne; Lauckner, Eva-Maria; Lehmeyer, Anja; Leining, Ines; Liepe, Katharina; Niebuhr, Dea; Pallmeier, Heike; Reichelt, Angela; Rimbach, Astrid; Satola, Agnieszka; Scharpff, Nancy; Scheule, Rupert Maria; Schlott, Thilo; Schmelz, Ulrich; Schneider, Thomas; Schwegler, Gudrun A.; Seay, Ulrike; Siebert, Hendrik; Stegmüller, Klaus; Steinmetz, Edda; Weinbrenner, Christoph; Weißkircher, Janosch.

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