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Healthcare professionals' perspectives on assessing selected patient-reported outcome measures in specialist palliative care institutions: a multi-country mixed-methods study

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Abstract

Background Despite the growing significance of patient-reported outcome measures (PROMs) for various purposes, including economic evaluations, implementing them effectively in palliative and end-of-life care settings remains a challenge. This study aimed to identify barriers and facilitators to PROMs data collection in inpatient specialist palliative care settings and to assess data collectors' applied perspectives on four relevant PROMs.

Methods We conducted an explanatory sequential mixed-methods study, including an online survey ($N=29$) and qualitative interviews ($N=12$) with healthcare professionals and researchers from eleven countries. These participants had direct experience with PROMs data collection in specialist palliative care settings, either as part of the international *iLIVE* project or the Austrian *PallPROMS* study. The aim was to identify opportunities for optimising clinical care and other assessment purposes in the future. We conducted a descriptive analysis of the survey data and a thematic analysis of the qualitative data.

Results The main reflected factors were patients' very limited ability to self-complete PROMs and the optimal timing and duration of assessments. Opinions on the usefulness of different PROMs varied significantly according to the role of the participants. Overall, setting-specific PROMs assessing symptom burden were preferred to more generic quality-of-life/wellbeing measures. Identified barriers and facilitators related to five themes: patient-related factors, data collection processes, PROM type, staff perceptions and organisational factors. Findings also highlighted better information and training needs.

Conclusions Prioritising care-relevant tools and carefully planning data collection, with main barriers addressed, can significantly increase the successful implementation of PROMs collection in specialist palliative care institutions. Since the preferred PROMs are not directly suitable for health economic evaluation, it is crucial to explore mapping alternatives for this purpose.

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Background

Patient-reported outcome measures (PROMs) are commonly used in research and clinical practice to monitor health status, assess treatment and care effectiveness, and evaluate the impact and value of interventions [1–3]. With the increasing population needing palliative care and rising healthcare budget constraints, evaluating the costs and patient outcomes of these services and interventions is becoming even more crucial [4–7].

However, palliative care lacks a gold standard PROM, resulting in the concurrent use of various instruments that address different aspects of the patient experience and serve different stakeholders [3, 8–10]. In general, two types of PROMs can be distinguished: generic and disease- or context-specific PROMs. Generic PROMs cover general aspects of health and can be used across different populations, whereas disease- or context-specific PROMs relate to a specific group of conditions [11]. Both types of PROMs have advantages and disadvantages, and there is currently no consensus on which type of PROM is most appropriate for use in palliative care [12]. The EuroQol-5-Dimensions-5-Levels (EQ-5D-5L) is the most commonly used generic preference-based health-related quality-of-life measure to inform health economic evaluations, especially for the calculation of quality-adjusted life years (QALY) [13, 14]. However, there is an ongoing debate about whether the QALY-framework adequately measures the impact of end-of-life interventions [12, 15, 16]. As an alternative to generic measures, context-specific preference-based measures may be utilised, although not many are available for palliative care. One example is the ICECAP Supportive Care Measure (ICECAP-SCM), which adopts the capability approach to assessing broader wellbeing at the end-of-life [17]. In clinical practice, PROMs have positively affected patients, providers and care processes [18, 19]. Their increased use in palliative care, as recommended by the European Association for Palliative Care [20, 21], can help identify unmet patient needs and treatment effects, supporting patient-centred care and symptom management [10]. The Integrated Palliative care Outcome Scale (IPOS) [22] and Edmonton Symptom Assessment System (ESAS) [23] are commonly used for this purpose. These context-specific PROMs primarily focus on symptom evaluation [20, 24, 25], thus potentially overlooking other relevant aspects of care and are not directly suitable for informing value assessment in economic evaluations.

Regardless of the purpose for collecting PROMs, implementing them in palliative care clinical practice is a complex endeavour that requires a tailored approach [21]. This appears to be particularly challenging in settings where patients' complex palliative and end-of-life care needs are addressed through a holistic approach. The feasibility of implementing PROMs in specialist palliative care units has been explored in Austria and Germany, albeit with low participation rates (13–25%) [26, 27]. In contrast, the reported participation rate for patients receiving outpatient cancer care ranged from 76% in the USA [28] to 93% in Norway [29]. Hence, gathering further international insights from stakeholders experienced with PROMs assessment is crucial to understand context-specific barriers and facilitators inherent in their use and to learn about experiences with PROMs in the specialist palliative care settings. Consequently, these insights will inform the planning of future implementation efforts [20, 21, 30]. To date, many studies on implementing PROMs in palliative care [20] have primarily focused on outpatient settings [31] or one specific clinical PROM, such as the IPOS [22]. Few studies have focused on specialist palliative care units, and those that have are often limited in scope, focusing on only one PROM [32], a specific geographical and cultural region [32], or a particular patient group (e.g., patients with end-stage organ failure in hospital or oncology settings) [24]. Moreover, they typically do not address the barriers and facilitators to implementation.

In two cohort studies, the international *iLIVE project–Live well, die well* and the Austrian *PallPROMS* study, various PROMs (ICECAP-SCM, EQ-5D-5L, IPOS and ESAS) were assessed in specialist palliative care institutions (see Fig. 1; Table 1). *iLIVE* was designed to provide an in-depth understanding of the experiences, concerns, expectations and preferences of patients in the terminal phase of their lives using PROMs for research purposes [33], while *PallPROMS* aimed to determine whether available context-specific PROMs could provide reliable and valid information for the purposes of routine patient care, quality assurance, (economic) evaluations and the planning of services in specialist palliative care units in Austrian hospitals [26].

In this mixed-methods study, we first aimed to identify and evaluate the main barriers and facilitators to data collection of four selected PROMs in specialist palliative care settings, based on experiences from the *iLIVE* and *PallPROMs* cohort studies conducted in 12 countries. Second, we aimed to assess variations in our findings across professional roles and geographical locations. Third, we intended to use our findings to draw conclusions for optimised future implementation of PROMs

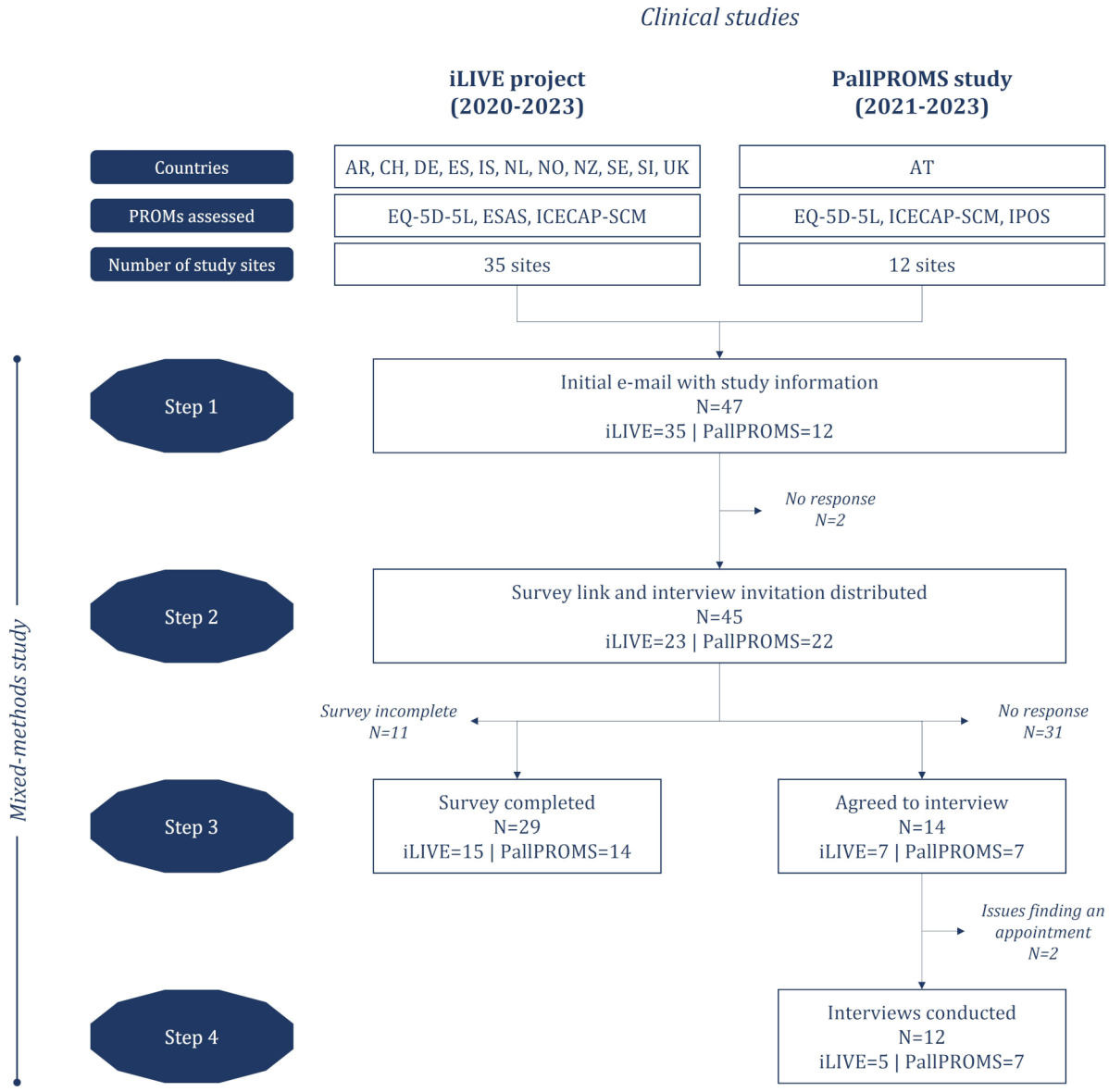

Fig. 1 Study design and recruitment overview
Legend to Fig. 1: AR = Argentina, CH = Switzerland, DE = Germany, EQ-5D-5L = EuroQuol 5 Dimension 5 Levels, ESAS = Edmonton Symptom Assessment Scale, ES = Spain, ICECAP-SCM = ICECAP Supportive Care Measure, IPOS = Integrated Palliative care Outcome Scale, IS = Iceland, NL = (The) Netherlands, NO = Norway, NZ = New Zealand, SE = Sweden, SI = Slovenia, UK = United Kingdom

data collection for care, evaluation and research purposes in the specialist palliative care setting.

Methods

Study design

The study was a pragmatic, explanatory sequential multi-country mixed-methods study [34] following the case study framework [35] to build a comprehensive understanding of the issues that are associated with PROMs assessment in specialist palliative care settings as experienced in the international *iLIVE* project (11 countries) and the Austrian *PallPROMs* study (one country). We conducted an online-survey and follow-up qualitative semi-structured online-interviews [36] to explore the survey results in more depth. Participants were healthcare staff with primary responsibility for patient care (e.g. medical doctors, nurses, psychologists) and clinical research staff with primary responsibility for clinical studies (e.g. research nurses, doctoral and postdoctoral researchers) who all had direct involvement in PROMs collection in the *iLIVE* or *PallPROMs* studies. The results from our online survey informed the subsequent interviews, following the approach of *integration through building* [35].

Table 1 Overview of the quality domains of the PROMs used

Collected PROMs and their domains			
EQ-5D-5 L	• Mobility • Self-care	• Usual activities • Pain/discomfort	• Anxiety/depression
ICECAP-SCM	• Having a say • Being with people who care about you	• Physical suffering • Emotional suffering • Dignity	• Being supported • Being prepared
IPOS	• Pain • Shortness of breath • Weakness/lack of energy • Nausea • Vomiting	• Poor appetite • Constipation • Sore or dry mouth • Drowsiness • Poor mobility • Anxiety in patient	• Anxiety in relatives • Depression • Feeling at peace • Sharing feelings • Receiving information • Practical problems being addressed
ESAS	• Pain • Tiredness • Drowsiness • Nausea	• Lack of appetite • Shortness of breath • Depression • Anxiety	• Wellbeing • Other problem • Location of pain

Legend to Table 1:

Abbreviations: PROMs = patient-reported outcome measures, EQ-5D-5L = EuroQol 5 Dimensions 5 Levels, ESAS = Edmonton Symptom Assessment System, ICECAP-SCM = ICECAP Supportive Care Measure, IPOS = Integrated Palliative care Outcome Scale

We reported following the Standards for Reporting Qualitative Research (Additional file 1) [37]. Our study is in the exploration and preparation phase of implementation, following the EPIS (Exploration, Preparation, Implementation, Sustainment) framework [38].

Setting and population

Our eligible study population comprised individuals directly involved in PROMs data collection within specialist palliative care settings with at least six-months experience, either as part of the local study teams in the international *iLIVE* project (35 sites) or the Austrian *PallPROMS* study (12 sites) (Fig. 1). There were no specific a priori exclusion criteria based on age, gender or professional background given the highly multidisciplinary nature of specialist palliative care. Relevant information was included in the study information sheet and collected in the initial part of the survey to prevent invalid participation. Further information about the *iLIVE* and *PallPROMs* cohort studies is reported elsewhere [26, 33].

Sampling and recruitment

Participants were recruited using a purposive sampling approach, aiming to include at least one participant from each of the 11 *iLIVE* countries and from each of the 12 *PallPROMS* centres in Austria. Following a waiver for formal ethics approval from the institutional ethics committee, an initial survey invitation was distributed via email within the *iLIVE* and *PallPROMS* consortium/collaborators mailing list between August 2022 and January 2023. Upon initial expressions of interest, a password-secured survey link was sent to 45 collaborators via email, who were encouraged to complete the survey themselves if they fulfilled the inclusion criteria, or were asked to forward the link to eligible local study team members. In addition to the survey link, the email included a detailed information sheet about the survey, an initial electronic consent statement for completers (integrated at the beginning of the online survey), and information about the planned follow-up interviews with request to indicate interest and availability via a separate email. Interested individuals were provided with an information sheet that included the purpose of the interviews, the process, the compliance with the General Data Protection Regulation and the right to withdraw at any time without consequences. To ensure that participants understood the information, they were given the opportunity to ask questions at any time, and at the beginning of the interviews, time was specifically allocated for participants to ask questions. To assure anonymity, no identifiable information such as name, age or gender was collected as part of the survey. Separate written consent was obtained from all interview participants prior to their interviews.

Data collection

The survey (Additional file 2) consisted of non-randomised questions exploring barriers and facilitators regarding reliable PROMs data collection, the effects of PROMs data collection on routine practice of specialist palliative care institutions, and the experiences with different PROMs for potential monitoring and actionability purposes (e.g. symptom management). Developed by the authors, the survey was based on a previous systematic literature review [39] and preliminary findings from ongoing projects. After internal revision, external review by colleagues not involved in this study or the *iLIVE* and *PallRPOMS* projects, and piloting with four volunteering local study team members (two from *iLIVE* and two from *PallPROMS*), the questionnaire was finalised and distributed via *SoSci Survey*, as outlined above [40].

A semi-structured interview guide (Additional file 3) was developed by the authors based on the survey findings. The interview guide was piloted during the first interview to assess its clarity and relevance, making necessary adjustments based on participant feedback. ES, a public health PhD candidate with prior training and experience in leading qualitative interviews, conducted all of the interviews using *Webex* virtual meeting software. She was supervised by CF, a senior post-doctoral researcher with several years of qualitative research experience, who also took part in the first interview to assure quality. Frequent meetings between ES and CF to discuss interview contents ensured confirmability [41, 42]. The interviews were conducted online due to the geographical distance of the participants, and participants were informed about the required technology in advance [43]. Interviews were either held in English (*iLIVE* participants) or in German (*PallPROMs* participants). The virtual meeting was recorded and the audio and video material saved to a secured local institutional server. In addition, ES took paper-based notes during the interviews to help with checking the transcripts.

Data analysis

Survey data were analysed descriptively using frequencies and means to allow a clear and transparent presentation of results without over-interpreting statistical significance. Wilcoxon-Mann-Whitney tests, as they are suitable for small sample sizes and ordinal data, were used to assess differences in preferences for PROMs and their effects on patients and clinical care between respondents involved in direct clinical care and those who had patient contact solely for research purposes. These groups were based on data collectors' roles within the *iLIVE* or *PallPROMS* study. For the group 'involved in clinical care`, ward nurses, ward doctors, *PallPROMS* study coordinators and principal investigators who were clinicians actively involved in clinical care during data collection were included. Analyses were conducted in IBM-SPSS-Statistics-version-27.0 [44] and Microsoft Excel.

The interviews were transcribed verbatim, providing a word-for-word reproduction of the interview, by a contracted external professional service. The external service followed the transcription guidelines for a simple transcript according to Dresing & Pehl [45]. This includes the exclusion of filler words to provide concise and readable transcripts. The transcripts were quality-checked and revised by ES, and participants were offered to read and check the transcripts for accuracy [46]. Identifiers (e.g., country) were not deleted or altered in the transcripts as only the author team had access to the data. Following the thematic analysis according to Braun & Clarke [47], transcripts were reviewed and text segments deductively coded into themes based on the interview guide. Then, they were inductively coded into further themes or subthemes [47]. The transcripts were initially coded by ES, the codes double-checked by CF, and themes discussed and classified into respective implementation levels [20] following review by all authors. The initial and final theme-maps are presented in Additional file 4. To ensure trustworthiness throughout the thematic analysis, we followed the step-by-step approach by Nowell and colleagues [42] including strategies such as peer debriefing to enhance the credibility, transferability, dependability and confirmability [41, 48, 49]. All steps of the thematic analysis took place using MAXQDA 22 [50]. Quotes included in the manuscript were translated from German to English, if necessary.

The results from the online survey and interviews were *integrated through narrative*, following the *weaving approach* [35]. The presentation of our results was guided by the structure of the online survey. Specifically, the topics from the online survey were used as headings, online survey data were reported and each section supplemented with detailed insights from the qualitative data analysis.

Results

Participants

Overall, 29 participants from 11 countries completed the survey (*PallPROMS*: $n = 14$; *iLIVE*: $n = 15$) between December 2022 and January 2023. Participant characteristics are summarised in Table 2. Comparative analysis of the responses between those with direct involvement in clinical care ($n = 13$) and those without ($n = 16$) are presented in Table 3. Distributions differed between *iLIVE* and *PallPROMs* participants. Between January and March 2023, 12 participants from six countries had a further in-depth interview (Table 2). The interviews lasted on average 35 min (17–55 min).

The qualitative analysis revealed five overarching themes with 13 subthemes (Table 4). The following sections present the results of the online survey, complemented by detailed findings from the qualitative analysis of the interviews.

Experienced barriers and facilitators regarding reliable PROMs data collection

COVID-19 pandemic

Among *PallPROMS* participants, mainly ward-internal staff, seven encountered challenges attributable to the COVID-19 pandemic. This proportion was higher among *iLIVE* participants ($n = 13$), especially among external study research staff. A quote illustrates the experiences:

> *Ward staff were stretched to the limit, due to staff absences due to illness and COVID-19 testing and the heightened level of intensity of caring for patients*

Table 2 Descriptive information about the survey respondents and interviewees

	Online survey participants		Interview participants	
	***PallPROMS* (*N* = 14)**	***iLIVE* (*N* = 15)**	***PallPROMS* (*N* = 7)**	***iLIVE* (*N* = 5)**
Professional background[1]	n	n	n	n
Clinical researcher	1	9	-	3
Medical doctor working in palliative care	12	5	5	2
Nurse	-	1	1	
Psychologist	1	-	-	-
Missing	-	-	1	-
Direct involvement in patient care[2]	12	1	-	-
No direct involvement in patient care[2]	2	14	-	-
Years of experience with data collection in palliative care settings				
< 1 year	5	1	1	-
> 1–5 years	4	6	1	3
> 5–10 years	2	3	1	2
> 10–15 years	1	1	2	-
> 15 years	2	4	1	-
Missing	-	-	1	-
Data collection setting				
Palliative ward in a non-university hospital	11	2	5	1
Palliative ward in a university hospital	3	4	1	3
Other ward (i.e. oncology) in a non-university hospital	-	1	-	-
Other ward (i.e. oncology) in a university hospital	-	6	-	1
Hospice		1		
Patients' own home/home care	-	1	-	-
Missing	-	-	1	-
Country of data collection				
Argentina	-	1	-	1
Austria	14	-	7	-
Iceland	-	2	-	1
The Netherlands	-	2	-	1
New Zealand	-	1	-	-
Norway	-	2	-	1
Slovenia	-	2	-	1
Spain	-	1	-	-
Sweden	-	1	-	-
Switzerland	-	2	-	-
The United Kingdom	-	1	-	-
PROMs data collection period[3]				
0–3 months	2	-	1	-
4–6 months	2	-	-	-
7–9 months	4	1	1	1
10–12 months	4	1	2	-
More than 12 months	1	13	2	4
Missing	1	-	1	-

Legend to Table 2:

[1]This was categorised based on the participants' reported roles: *Clinical researchers* include study nurses, *iLIVE* study coordinators and researchers. *Medical doctors working in palliative care* include principal investigators, *PallRPOMS* study coordinators and ward doctors. *Nurses* include ward nurses and *psychologists* include the option other as this was the only response not suitable for other categories

[2]This was based on the role within the *iLIVE* or the *PallPROMS* study as reported in the online survey

[3]Reference date for the online survey respondents: 31 October 2022

during this time. There was no energy for anything 'additional' in their workload, such as time to screen and identify potential patients. It took a long time for energy to return. (iLIVE-survey-participant)

Data collection process and patient characteristics

On a Likert scale from 1 (not at all feasible) to 5 (very feasible), baseline assessment was considered less feasible in Austria (mode = 3) compared to iLIVE countries

Table 3 Differences between participants with direct involvement in clinical care (DI) and those without (NDI) in expected impact in routine clinical care

Effect on clinical practice	Group	*N*	Median	IQR	U	Z value	*p*-value
In-depth description of concerns or symptoms	DI	13	4	2			
	NDI	12	5	1	36	-2.506	**0.017**
Information exchange	DI	13	4	1			
	NDI	12	5	1	24	-3.164	**0.002**
Monitoring of disease progression	DI	13	4	2			
	NDI	12	4	2	39	-2.354	**0.027**
Patient communication	DI	13	3	1			
	NDI	13	5	1	30	-2.979	**0.004**
Personalized care management	DI	10	3	1			
	NDI	12	5	1	19.5	-2.814	**0.003**
Relationship with patients	DI	13	3	2			
	NDI	12	5	2	38.5	-2.232	**0.026**
Shared decision making	DI	13	3	0			
	NDI	12	4.5	1	17	-3.494	**< 0.001**
Effect on patients							
Interaction with health professionals	DI	12	3	1			
	NDI	13	4	1	39.5	-2.204	**0.029**
Interaction with family/friends	DI	13	3	1			
	NDI	9	4	2	31.5	-1.921	0.054
Feeling of loneliness	DI	11	3	0			
	NDI	10	4	2	32	-1.821	0.093
Feeling of pressure to fill in questionnaires	DI	12	4	2			
	NDI	10	2	2	50.5	-0.654	0.553
Feeling overwhelmed	DI	13	2	2			
	NDI	11	2	3	66	-0.334	0.769
Feeling of having a say	DI	13	3	1			
	NDI	12	5	1	26.5	-2.953	**0.004**
Feeling talkative	DI	11	3	1			
	NDI	9	4	2	33	-1.337	0.213
Sharing of concerns/symptoms	DI	13	4	1			
	NDI	12	5	1	20	-3.358	**< 0.001**
Preferences of PROMs							
PROM ranking general: EQ-5D-5L	DI	12	2	1			
	NDI	14	2	1	54	-1.703	0.153
PROM ranking general: ICECAP-SCM	DI	11	2	1			
	NDI	14	3	1	63	-0.869	0.494
PROM ranking general: ESAS / IPOS	DI	11	1	2			
	NDI	14	1	0	52.5	-1.701	0.152
Simplicity of interpreting PROM results: EQ-5D-5L	DI	10	3	2			
	NDI	15	4	1	54	-1.22	0.258
Simplicity of interpreting PROM results: ICECAP-SCM	DI	10	3	2			
	NDI	14	3.5	2	52.5	-1.051	0.298
Simplicity of interpreting PROM results: ESAS / IPOS	DI	10	3.5	2			
	NDI	15	4	1	50.5	-1.453	0.165
Usefulness delivery patient-centred care: EQ-5D-5L	DI	10	2	2			
	NDI	16	3	1	48.5	-1.771	0.074
Usefulness delivery patient-centred care: ICECAP-SCM	DI	10	2	2			
	NDI	16	2	1	58	-1.239	0.294
Usefulness delivery patient-centred care: ESAS / IPOS	DI	10	2	2			
	NDI	16	3	1	21	-3.318	**< 0.001**
PROMs capturing concerns, symptoms: EQ-5D-5L	DI	11	4	1			
	NDI	16	3	1	72	-0.856	**0.4**

Table 3 (continued)

Effect on clinical practice	Group	*N*	Median	IQR	U	Z value	*p*-value
PROMs capturing concerns, symptoms: ICECAP-SCM	DI	11	3	2			
	NDI	16	3	2	79.5	-0.445	0.721
PROMs capturing concerns, symptoms: ESAS / IPOS	DI	11	4	1			
	NDI	16	4	1	44	-2.405	**0.009**

Legend to Table 3:

DI = direct involvement in clinical care, NDI = no direct involvement in clinical care, IQR = Interquartile range, PROM(s) = patient-reported outcome measure(s)

Answer options of the respective questions:

- Effect on clinical care and effect on patients: 1 = negative effect, 2 = slightly negative effect, 3 = no effect, 4 = slightly positive effect, 5 = positive effect
- PROM ranking general: Ranks 1 to 3 (1 being the best)
- Simplicity of interpreting PROM results: 5-point Likert scale: not at all easy to very easy
- Usefulness for delivery of patient-centred care: 4-point Likert scale: not useful to extremely useful
- Questionnaires capturing concerns & symptoms: 5-point Likert scale: not at all comprehensively to very comprehensively

(mode = 4). However, follow-up assessment feasibility was similarly difficult in both groups (mode = 2). Barriers to baseline assessments included patients' declining health ($n = 20$) and reluctance to complete questionnaires ($n = 10$). The primary obstacle for follow-up assessment was patient death ($n = 14$) and overall declining health.

> *Between the baseline and the follow-up questionnaire, one month later, maybe the patient is more tired, more ill, more with some other problems. […] I'm not sure the number exactly, but we have a lot of dropout patients after the baseline questionnaire because of the progression of the illness. (iLIVE interview partner B3, medical doctor working in palliative care)*

Participants noted that the feasibility of routine PROMs assessment largely depends on patients' life expectancy. They estimated that a higher proportion of patients with a prognosis of at least six months (mean = 46%) could independently complete PROMs compared to those with a prognosis of one month (mean = 21%). More patients with longer prognoses could handle PROMs lasting over 15 min (mean = 65%) than those with shorter prognoses (mean = 14%).

Interviewees emphasised explaining the questionnaire content and data collection purposes to enhance participation. Some patients were motivated by potential care improvements, while others were driven by contributing to future palliative care quality improvements. Patients unaware of their prognosis or with unrealistic recovery expectations might benefit from end-of-life discussions alongside PROM completion. Cultural differences, such as language barriers or attitudes towards research, also affected participation.

> *It is a rural region. It is perhaps different in a large city. […] Science is not a priority for patients here. They come here and want to be cared for. (PallPROMS-interview-partner A4, medical doctor working in palliative care)*

Simplicity of individual PROMs

Most participants assessed IPOS or ESAS ($n = 24$) as easy and manageable, as opposed to ICECAP-SCM ($n = 16$) (Fig. 2a). Interviewees explained that the multi-part questions of ICECAP-SCM caused difficulties, patients wanted more flexibility in scoring and experienced problems distinguishing between answer options.

> *I think it's the way the questions are asked. […] the ICECAP, the way the questions are asked is very, very complicated. Every possible answer is two lines long. So that is, that is difficult. (PallPROMS-interview-partner A7, medical doctor working in palliative care)*

Timing of the assessments

The majority of the *PallPROMS* participants preferred a one-week or shorter interval between PROM assessments, while *iLIVE* participants preferred longer intervals, especially for ICECAP-SCM and EQ-5D-5 L. Interviewees noted minimal changes within one week and concerns about overburdening patients with frequent assessments. Asking for participation on the admission day was seen as overwhelming; participants preferred completion a few days after admission. Incorporating assessments into doctor's visits and anamnesis interviews was considered beneficial for regular assessments.

Assistance with PROMs completion

Participants reported patient self-completion rates ranging from 0 to 91% with a median of 21%. Physical limitations ($n = 22$) and difficulties comprehending questions ($n = 16$) were reasons for patients' inability to self-complete questionnaires. Interviewees elaborated that the

Table 4 Overview of barriers and facilitators for data collection of PROMs in specialist palliative care settings

Level	Theme	Subtheme	Barriers	Facilitators
Patient level	**Patient-related factors**	Patient condition	Uncertainty about disease progression in this patient population	Patients in earlier disease phases (in better health)
			Overburdening of patients	Brief assessments to reduce burden on patients
			Cognitive impairment/problems focusing	
		Patient awareness	Patient's ignorance of their prognosis	Patients understand meaningfulness of PROMs assessment
		Cultural differences	Language and cultural barriers (e.g. gatekeeping by family)	Culturally adapted and validated tools
			Unwillingness to participate	Higher educational degree or urban residency
Management level	**Data collection processes**	Person-assisted PROMs assessment	Time consuming	Possibility to explain questions increases completeness of data
			Data validity issues arising from differing person-assisted assessment methods	Patients enjoy the conversation
		Technology-supported data collection	Poses greater difficulty for most patients' self-assessments	Facilitates assessment for relatives and some patients
				Digitalised PROMs results give a comprehensive overview of health status
		Assessment moment	Difficulty to identify the ideal timing for data collection	Integration in anamnesis interview is possible
			Lengthy questionnaire makes it difficult to complete assessments in a single session[1]	
Management, health-care professional and patient level	**PROM instruments**	Content and characteristics of PROMs	Lengthy and repetitive questions[1]	Short and clear questions
			Sensitive topics without adequate emotional support	Symptom-related questions
		Simplicity of PROMs	Complex questions (e.g. too much text, too vague)	Precise instructions
			Several questions within a single item (ICECAP-SCM)	Same scaling within PROMs[1]
				Short reference time frame
		PROMs preference	ICECAP-SCM: answer options not comprehensive (Q1,2,5,6,7)	IPOS: easy to understand and short
			EQ-5D-5L: irrelevant question (Q3 'Usual activities')	ESAS: questions about symptoms
Management and health-care professional level	**Staff perceptions**	Effect on clinical care	No regular consequences based on PROMs results	Additional information on patients' concerns is considered helpful
			PROMs are considered to have zero clinical impact or added value	Enables discussion about patients' emotions
				IPOS/ESAS: helpful for symptom management
		Attitude towards PROMs	Concerns that PROMs lead to standardised procedures in routine clinical care neglecting patients' personal needs	Importance of health assessments/quality-of-care assessment in palliative care is recognised
			Concerns regarding benchmarking across institutions based on PROMs results	Structured approach to assessing patients' health/wellbeing helps inexperienced carers
Management level	**Organisational factors**	Staff resources	Lack of time	Person-assisted PROMs assessment
			Insufficient training on the use and benefits of PROMs	Adequate training on the use and benefits of PROMs
			Single person responsible for PROMs data collection	Established positive patient relationship
		Care settings	Acute care setting	Outpatient or home care settings
			Differences in data collection without explicit guidelines	Efficiently organised data collection to streamline the process

Legend to Table 4:

[1]The length of the questionnaire, repetitive questions and changes in scaling are due to the fact that several PROMs were asked in one assessment

Abbreviations: EQ-5D-5L = EuroQol 5 Dimensions 5 Levels, ESAS = Edmonton Symptom Assessment System, ICECAP-SCM = ICECAP Supportive Care Measure, IPOS = Integrated Palliative care Outcome Scale, PROMs = patient-reported outcome measures, Q = question

Fig. 2 a-c. Participants' preferences regarding patient-reported outcome measures
Legend to Fig. 2a-c: PROMs = patient-reported outcome measures. **2a**) reflects the answers to the question 26: *On a scale of 1 to 5, how easy would you find interpreting the results of the PROM questionnaires for clinical care (based on your experience with PROM data)?***2b**) reflects the answers to the question 28: *In your opinion, how useful could the PROM questionnaires you have been using in the iLIVE study be in facilitating the delivery of patient-centred care in the palliative and EOL care setting?***2c**) reflects the answers to the question 25: *Which one is your preferred PROM questionnaire for clinical routine care in palliative/EOL care settings?*

provided support ranged from basic assistance (writing/reading) to interview-like assessments or emotional support during completion. Although some patients enjoyed the interviews and wanted to share their stories, these were time-consuming. The interviewees raised data validity concerns when assistance was required and underscored the importance of assisted data collection being well-monitored. Clinicians may focus on pain scales due to their professional background. Relative-supported assessments were considered problematic for questions about psychosocial wellbeing as patients may hesitate to share their true feelings. Participants' opinions varied: Some expressed concerns about assisted assessments potentially biasing responses; others suggested that an approach combining self- and external assessment could increase the validity of information provided by patients. Self-assessment resulted in more missing data and patients were more likely to answer open-ended questions when assisted.

> *The challenge is [...] assisting the participant in the right way, not to be very leading. Of course, you can reframe the question sometimes and [...] it would have been better to assist people, sit by them, but that is quite time consuming. (iLIVE-interview-partner B2, research nurse)*

Opinions on technology-assisted data collection varied: *PallPROMS*-respondents were more critical, expecting no impact on feasibility ($n = 6$) or only benefit to data collectors ($n = 6$). Conversely, *iLIVE*-respondents expected benefits for data collectors ($n = 10$), those assisting with questionnaire completion ($n = 7$) and patients ($n = 6$). Some interviewees explained that patients may struggle

with tablets due to physical weakness while others saw tablet-based data collection and the digitally presented results as the only feasible method for routine PROMs assessment.

> *The IPOS is then displayed graphically and it is much more informative when you have the output graphically in front of your eyes as opposed to some piece of paper that is [...] not looked at again. So it would be important to digitalise this, then the added value would also appear more clearly. (PallPROMS-interview-partner A6, medical doctor working in palliative care)*

Impact of PROMs data collection on routine clinical care

Views on the impact of PROMs on clinical care varied by study context and level of involvement in clinical care, with the two being correlated (see Fig. 3; Table 3). Only half of the *PallPROMS* participants ($n=7$) indicated they would consider changing care based on PROMs, compared to the majority of *iLIVE* participants ($n=13$), who could envision altering medications ($n=10$), treatment goals, and giving personalised advice ($n=8$). Most *PallPROMS* participants expected routine PROMs to have little to no positive impact on clinical practice and potentially harm patient relationships, as patients might feel pressured to complete them. In contrast, *iLIVE* participants viewed routine PROMs positively for clinical practice and patient relationships. *PallPROMS* participants found PROMs less useful for patient-centred care and had more difficulty interpreting results than international participants (Fig. 3). These differences were also significant between those with direct clinical care involvement and those without (see Table 3). The in-depth interviews revealed varied views on the actionability of PROMs, with some questioning their usefulness and impact on clinical care.

> *Whether it can help with clinical care, I don't know. But in any case, you get further insights into the patient. And that can of course also perhaps change therapy decisions, diagnostic decisions or even nursing decisions. [...] But I don't know if it really makes a big difference, because we talk a lot with our patients anyway. (PallPROMS-interview-partner A2, medical doctor working in palliative care)*

According to international interviewees, PROMs provide structure to consultations and a systematic approach to gaining deeper insights into patients' symptom burden. Despite these positive aspects, there were concerns about PROMs in Austria. Clinicians were worried about standardising palliative care and comparisons with other wards. Furthermore, PROMs assessment would only be useful if the entire patient group could be included.

> *They really are a very vulnerable group of patients with very individual approaches. And, yes, we have been struggling for years or decades about how to determine quality in palliative care. It is very difficult to really bring this into standardised survey methods. (PallPROMS interview partner A4, medical doctor working in palliative care)*

Participants' experiences with the individual questionnaires

Figure 2c shows that ICECAP-SCM was the least preferred PROM while IPOS/ESAS were more popular. Fourteen participants experienced questionnaire items as challenging to discuss with patients (e.g. *Anxiety/depression* (EQ-5D-5L), *Emotional suffering* (ICECAP-SCM), *Sharing of feelings*, *Practical problems* (IPOS)). The interviewees explained that patients preferred answering symptom-related questions over questions on emotions or end-of-life arrangements. The latter were emotionally challenging, necessitating vital emotional support.

> *We see that patients find these ICECAP questions very heavy because they have to think about, 'Do I have enough dignity?' or 'Do I have enough having a say?' [...] it's easier to answer questions about do I have a symptom than how do I feel and how do I prepare when I'm going to die. (iLIVE-interview-partner B4, clinical researcher)*

Interviewees preferred short, specific questions and recommended a brief six to ten question survey, taking no more than 15 min. ESAS was suitable for most patients, but the *Usual activities* (EQ-5D-5 L) item was irrelevant for inpatients, and its visual analogue scale required extra explanations. Patients wanted more positive options in ICECAP-SCM questions and found the domains of *Physical* and *Emotional suffering* too broad. For clinical care, IPOS and ESAS were preferred due to their relevance to symptom management and immediate access to information. ESAS was also preferred due to its familiarity in some countries. In contrast, ICECAP-SCM and EQ-5D-5L addressed different issues, with EQ-5D-5L better suited for outpatients. ICECAP-SCM was least preferred due to its imprecision and complex responses.

Organisational factors

The qualitative analysis revealed key organisational factors in PROMs assessment. Support for PROMs in acute hospital settings is universally needed, but clinical staff often lack resources for these tasks. Feasibility could be enhanced by utilising alternative resources like students

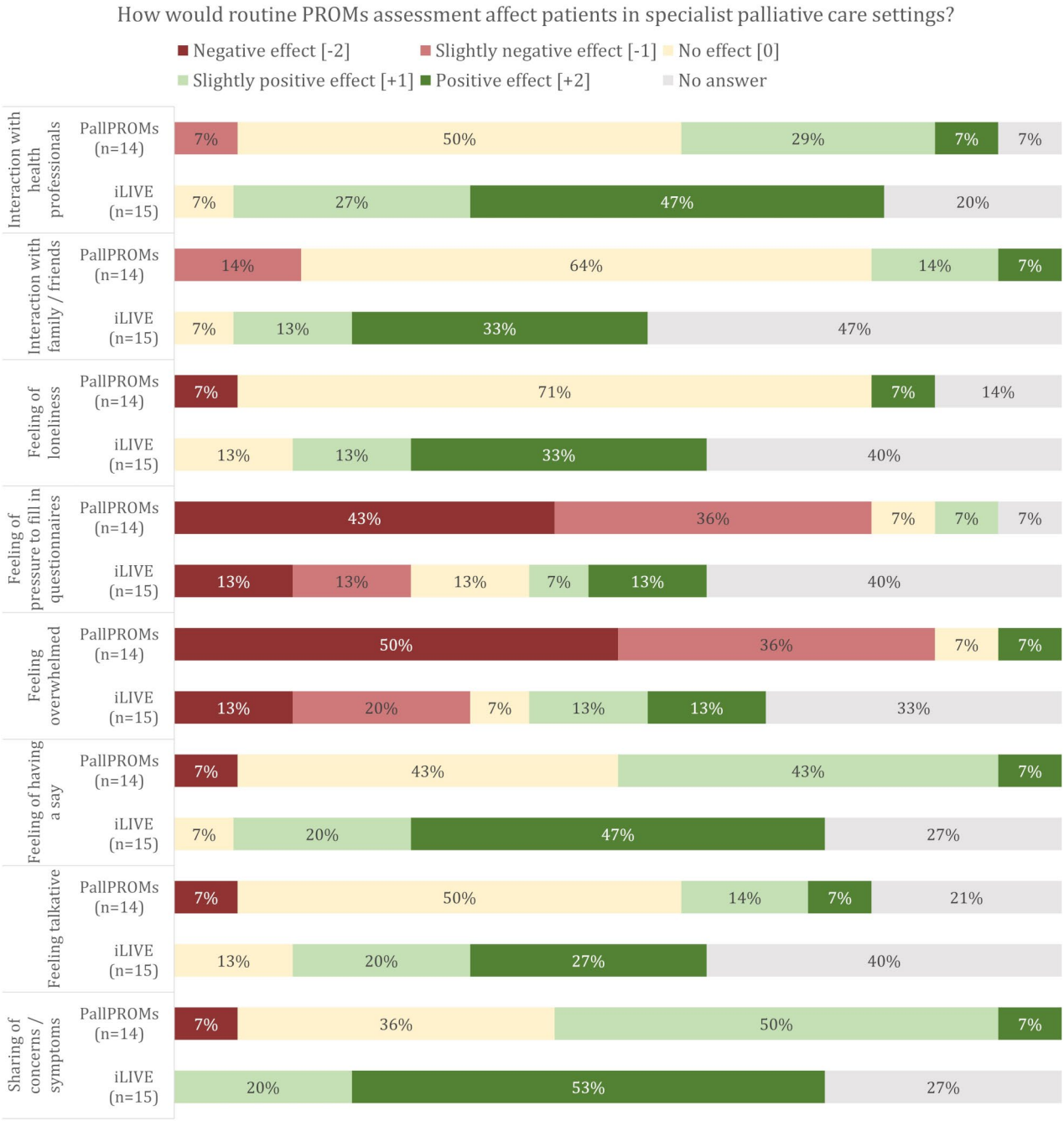

Fig. 3 Participants' expectations about the effects of routine PROMs data collection on patients
Legend to Fig. 3. PROMs = patient-reported outcomes measures

or volunteers. Strong patient-staff relationships increase patient participation and facilitate discussions on sensitive topics. Integrating PROMs assessment into routine workflows is critical for systematic implementation, and comprehensive training on PROMs' purpose and benefits is essential for healthcare professionals to effectively use structured tools in patient consultations.

This really needs these resources so that it can be carried out well. [...] Before you implement something like this in a department, you need targeted training to all employees so that they can grasp the underlying principles and purposes. (PallPROMS-interview-partner A7, medical doctor working in palliative care)

Interviewees noted that completing PROMs was easier for patients in earlier illness phases or in an outpatient or home-based palliative care setting compared to those with acute conditions in specialist palliative care institutions.

> *The patients who are mentally fit and who could perhaps fill this in very well, they always come with acute problems [...] I sometimes have the feeling that I cannot expect them to do this now. In the outpatient setting, where patients perhaps come for check-ups, I would find it easier. (PallPROMS-interview-partner A3, medical doctor working in palliative care)*

Discussion

Our study contributes to the literature on experiences with PROMs assessment across different organisational settings, disease areas but also geographical regions [21, 51]. We identified COVID-19-specific and general barriers and facilitators relating among others to data collection processes, patient characteristics, PROM simplicity, assessment timings, person- and technology-supported assessments, impact of PROMs data collection on routine clinical care, individual PROMs, and organisational factors.

Comparing our barriers and facilitators with those identified in previous studies demonstrates both universal as well as context-specific issues across different organisational palliative care settings such as home care or acute care. A systematic review of 31 studies identified a comprehensive overview of universal barriers and facilitators related to management, education, tools, and patient/carer levels [20]. In outpatient specialist palliative care, key factors were avoiding patient overburden, understanding PROMs' usefulness, and manageable administration [52]. In acute care, facilitators included person-centred care and quality improvements, while barriers were insecurity about using IPOS, integrating assessments into routines, and approaching severely ill patients [22]. While our study identified similar themes, we additionally found factors related to the patients' condition and awareness, data collection process, PROMs preferences (as participants assessed different PROMs) and staff perceptions specific to specialist palliative care institutions from a healthcare professionals' perspective.

Our findings show that it was especially difficult to address certain domains of PROMs when patients were unaware of their prognoses, leading to the necessity to initiate end-of-life discussions early. Given the high percentage of patients in specialist palliative care institutions who are unable to participate in PROMs assessments, proxy assessments may be necessary alternatives. Previous studies have found that proxy assessments are valuable when patients are unable to self-complete questionnaires due to cognitive impairments, particularly in inpatient settings and for those nearing end of life [53, 54]. For example, the Views of Informal Carers– Evaluation of services (VOICES) questionnaire employs a post-bereavement approach to collect data on the quality of end-of-life care from bereaved relatives, friends or carers acting as proxies, with a focus on service evaluation [55, 56]. A recent review on proxy- versus patient-reported outcomes concluded that despite the fact that there was a very limited number of new studies on the subject, proxy-completed outcomes should be viewed as a complementary perspective rather than a substitute for the patient's wishes and opinions [57]. Thus, proxy-reported outcomes should be used with caution because of potential discrepancies between patient- and proxy-completed outcomes [24, 57] and need further research regarding reliability and validity. Another potentially facilitating assessment method could be e-PROMs, however, but further research is needed from the patient perspective on e-PROMs [58] and how clinicians can use data from them to improve patient communication [59].

Concerning individual PROMs, our findings support previous research highlighting the importance of choosing a measure appropriate for the task [20, 21] and including domains relevant for palliative care patients of the respective setting. So far, none of the existing preference-based quality-of-life instruments captures all eight of the recently identified relevant domains (cognitive, environmental, financial, independence, physical, psychological, social, spiritual) for patients receiving specialist palliative care services [60, 61]. Generally, standardising outcome measures in palliative care is challenging due to the heterogeneous population [62, 63] and differences between inpatient specialist palliative care and outpatient care settings, necessitating further PROM refinement to align with the relevant quality dimensions across various healthcare settings. A potential alternative measure could be the SEIQoL (The schedule for the evaluation of individual quality of life), which assesses quality of life from the individual's perspective by allowing patients to identify and rate the areas of life that are most important to them [64]. However, it must be acknowledged that this measure, in its current form, is not suitable for economic evaluations. Similarly, while clinical measures like IPOS were preferred by clinicians, they also do not meet the requirements for economic evaluations. Practical alternatives for assessing health-related quality-of-life and wellbeing in specialist palliative care institutions that are also valid for quality monitoring and (economic) evaluations are crucial. Our findings suggest that it is highly unlikely for patients in need of specialist palliative care to complete two PROMs. Therefore,

mapping IPOS scores to capability or utility scores could be viable, but this requires validation.

The views on PROMs assessment were wide-ranging. We observed a considerable difference between *Pall-PROMS*- and *iLIVE*-participants, with the former viewing PROMs assessment rather negatively, and statistically significant differences between participants directly involved in clinical care and participants with patient contact only for research purposes. While some differences among healthcare professionals were also present in previous research [31, 58], the dissimilarities in our study may be due to differences in the projects: *Pall-PROMS*-participants were mainly clinicians collecting data at non-university hospitals and *iLIVE*-participants were mainly researchers collecting data at university hospitals. Another aspect to consider is the geographical variation in terms of cultural differences, different healthcare systems as well as different models of provision of palliative care [7, 65]. Cultural differences, such as varying attitudes towards research or palliative and end-of-life care [66, 67], may influence both patients' and data collectors' willingness to complete PROMs. While PROMs and their integration into healthcare are more established in certain countries participating in the *iLIVE* study, leading to a more positive attitude towards PROMs [68], Austria has yet to make significant advances in this regard [69]. Therefore, in countries where PROMs are less established, more evidence and training on their benefits are needed. General training on PROMs, including practical guidance, could be integrated into the professional education of future healthcare professionals or offered through existing short courses at various universities. Examples of universities offering such courses are located in Australia and the UK, where PROMs are already more widely integrated into healthcare. Additionally, ongoing support for implementing PROMs, tailored to the specific needs of individual teams, would be beneficial [53, 70].

Concerning organisational factors, the importance of staff resources and adequate training for data collectors are supported by previous findings [20, 30, 32]. Furthermore, acute settings were seen as a barrier because of more patients with poorer health, adding to the existing understanding that PROMs assessment is more feasible in outpatient or early palliative care settings [22, 31]. These organisational factors, related to care settings, may vary between countries, as the provision of palliative care is highly heterogeneous [7]. A crucial next step for future research would be to incorporate direct patient and family perspectives [71] on PROMs assessment in palliative care contexts.

Our study suggests that PROMs relevant to clinical care are likely to be effectively implemented in specialist palliative care institutions by addressing the identified barriers and facilitators. In addition to following implementation recommendations [20, 21], based on our findings we suggest selecting PROMs that take less than 15 min to complete, avoiding assessment on the day of admission, and allowing a week or more between assessments, depending on the specific PROM. These strategies aim to enhance feasibility and minimise patient burden during the assessment process. Furthermore, our study highlights the need for a tailored approach to PROMs in specialist palliative care settings compared to curative settings.

Strengths and weaknesses

The international scope of our study enabled us to engage participants from eleven countries, offering valuable insights from different stakeholder groups from the healthcare sector with varying contextual perspectives. Our explanatory mixed-methods approach supported a comprehensive, in-depth analysis by allowing the quantitative results to be explored in more detail, thus providing a greater understanding of the underlying factors [34]. Another strength of our study is the emphasis on specialist palliative care institutions, an area often overlooked in research. Our study has some limitations. The high workload in specialist palliative care units and COVID-19-induced personnel shortages made participant recruitment challenging, resulting in fewer participants than anticipated. The relatively small survey sample size may have limited the robustness of our findings, while the distributional sampling bias between the two cohort studies had clear influence on our comparative results. Nevertheless, studies with smaller sample sizes, particularly in specific populations or settings such as palliative/end-of-life care are common [63, 72] and remain valuable for exploratory insights [73]. The generalisability of our findings is also limited as per the underlying purpose of PROMs data collection in the given cohort study, though our identified barriers and facilitators align with previous research in other palliative care settings. Furthermore, the scope of our study did not allow the elicitation of the views of patients and relatives, although their views would have helped to understand the full range of experiences, and the barriers and facilitators to effective PROMs data collection in palliative care.

Conclusions

Our study identified several barriers and facilitators regarding PROMs assessment in specialist palliative care institutions, related to the data collection process, patient characteristics, impact of PROMs data collection on routine clinical care, individual PROMs, and organisational factors. The opinions towards PROMs assessment ranged from positive to rather negative underscoring the need for better training on their benefits. Our study highlights

the need for a tailored approach to using PROMs in specialist palliative care settings, including the use of PROMs that are relevant to clinical care and take less than 15 min to complete, and the avoidance of assessment on the day of admission. Due to the vulnerable patient population, alternative assessment methods such as proxy assessment would need to be explored as well.

Abbreviations

EQ-5D-5L	EuroQuol– 5 Dimensions– 5 Levels
ESAS	Edmonton Symptom Assessment System
ICECAP-SCM	ICECAP Supportive Care Measure
IPOS	Integrated Palliative care Outcome Scale
PROMS	Patient-reported outcome measures
QALY	Quality-adjusted life year

Supplementary Information

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Additional file 1: Standards for reporting qualitative research

Additional file 2: Online survey adapted for iLIVE participants

Additional file 3: Interview guide for the qualitative interviews

Additional file 4: Additional results to the thematic analysis: development of codes to themes

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Author contributions
CF and JS conceptualised the study. All authors developed the methodology and contributed to the data collection. ES carried out the analysis and the initial coding, CF provided support. ES and CF developed and refined the themes, JS provided support and all authors contributed to the interpretation of the findings. ES and CF drafted the initial manuscript, JS provided feedback and revision. All authors read and approved the final manuscript.

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Data availability
The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
The study did not require ethics approval (confirmed by the Ethics Committee of the Medical University of Vienna). Written informed consent for participation was obtained from all survey and interview participants. Participants were given detailed information about the study prior to their participation, including the purpose of the study, compliance with the General Data Protection Regulation and the right to withdraw at any time without consequences.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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