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ORIGINAL ARTICLE

PRO-ONKO—selection of patient-reported outcome assessments for the clinical use in cancer patients—a mixed-method multicenter cross-sectional exploratory study

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Abstract
Purpose Cancer patients frequently suffer from multiple symptoms often impairing functional status and health-related quality of life (HRQOL). A comprehensive assessment including patient-reported outcomes (PROs) is recommended to enable individualized supportive care. However, PRO assessments are still not part of routine clinical practice. Therefore, this project aimed to compile an item pool from validated assessment instruments to facilitate the use of PROs for clinical decision-making in oncology clinics.
Methods This qualitative dominant mixed-method cross-sectional exploratory study was carried out in four centers and comprised two stages. Stage I: Six interdisciplinary focus groups were conducted to choose questionnaires meeting particular clinical requirements. Stage II: Adult patients with heterogeneous cancer diagnoses, receiving in- or out-patient treatment were asked to participate and complete the chosen questionnaires (participation 71/74). Resulting PROs were compared with clinical records. Health care professionals (HCPs) and patients rated the usefulness for routine clinical practice.
Results The European Organisation of Research and Treatment of Cancer (EORTC) QLQ-C30 and Distress Thermometer were chosen for screening and M.D. Anderson Symptom Inventory (MDASI) and EORTC single items for monitoring. Comparison of $n = 88$ PRO assessments with clinical records showed consistent documentation of side effects like fever and emesis. Symptoms like fatigue, sadness, or sleep disturbance were not documented regularly in the medical records but captured by PRO assessments. Patients and HCPs judged the chosen questionnaires and electronic data collection as useful.
Conclusions Future studies should examine how PROs can complement or substitute routine documentation in order to achieve standardized assessment and documentation during the treatment process in different settings and examine possible benefits for patients.

Keywords Patient-reported outcomes · Cancer · Quality of life · Screening · Monitoring · Supportive therapy

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Introduction

Cancer patients often suffer from multiple disease- or treatment-related symptoms like fatigue, disturbed sleep, pain,

nausea, lack of appetite, and numbness. Symptoms and functional impairments can lead to distress or reduced health-related quality of life (HRQOL) [1] and might limit treatment options [2]. In order to apply individualized supportive measures, it is essential to assess occurrence and severity of symptoms and side effects. Studies showing differences between professional assessments like the Common Terminology Criteria for Adverse Events (CTCAE) [3] and self-assessment [4] indicate that professional assessment is not reliable enough. Patient self-report is more sensitive and tends to identify symptoms earlier [5]. Aiming for comprehensive assessment, standardized measures have been developed to capture patient-reported outcomes (PROs). PROs are defined as information obtained directly from patients regarding their condition [6, 7]. The use of PROs for pharmaceutical studies is strongly recommended [8, 9], and the integration of patient-reported outcome measures (PROMs) in routine clinical practice is the focus of international research [6, 10, 11]. Snyder et al. confirmed that PROMs developed for research are suitable for clinical practice [12]. Recent reviews show that the inclusion of patients' perspectives by means of PROMs can improve communication, symptom management, and patient satisfaction during therapy [11, 13]. Studies also examined the possible benefits of PROMs in clinical decision-making and care [14–17]. Electronic data collection is feasible and accepted by patients and health care professionals (HCPs) [18, 19]. Computer adaptive testing allows the individualized application of PROMs [20]. Meanwhile, the use of PROMs is recommended in treatment guidelines to supplement clinical assessments [21–23]. However, despite this encouraging research, the standardized use of PROMs is still not part of daily clinical routine. Guidelines recommending specific instruments and standardized treatment pathways for clinical application in different settings are still missing. Therefore, HCPs might be unsure about how to use PROMs and how to react to reported problems [24]. Recent reviews examined implementation factors and barriers that should be addressed to facilitate successful implementation of PROMs [25–27]. Goals of data collection, measurement points, scores requiring the clinicians' attention, and treatment pathways should be specified to integrate PROMs in clinical decision-making [25, 28]. Resources must be available to offer adequate supportive measures [29], and HCPs should be offered training on how to use and interpret PROMs and how to respond to reported difficulties [24, 26, 30]. Because clinical settings are dynamic and complex, the successful selection and implementation of PROMs depends on careful planning, joint consent, and respect for the needs of all involved parties [25]. International research groups (Patient-Centered Outcomes Research Institute (PCORI), International Society for Quality of Life Research (ISOQOL), and Assessing the Symptoms of Cancer using Patient-Reported Outcomes (ASCPRO)) recommend selecting instruments for clinical application based on specific clinical questions and resources [6, 9, 31, 32]. Following these recommendations, the aim of this study was to choose PROMs that are suitable and feasible for routine use in German oncology clinics, taking into account the perspectives and preferences of patients and HCPs.

Materials and methods

The study was approved by the local ethic committees and registered DRKS00005337. Reporting of the study follows the STROBE statement [33].

Study design

The study comprised a qualitative dominant mixed-methods design [34] with two stages and was carried out in four centers between March 2013 and May 2014. Methods included focus groups, application and analyses of PROMs, analysis of medical records, and semi-structured interviews of patients and HCPs.

Stage I aimed to explore the needs of HCPs concerning additional assessments of PROs and to select appropriate instruments. Stage II was designed to examine acceptance, feasibility, and possible benefits of the selected PROMs for clinical application from the perspectives of patients and HCPs.

Method stage I

HCPs (physicians, nurses, and others, e.g., social workers) from the participating centers were informed about the study and invited to participate in interdisciplinary focus groups. A convenience sample of HCPs volunteering to participate was included. The interview guide is shown in Table 1. Following the assessment of routine documentation and the collection of clinical issues, preselected instruments covering these issues were introduced and the perceived pros and cons discussed. The discussions were recorded, transcribed, and analyzed following the procedure of qualitative content analysis [35]. The summarized results were approved by the participants.

Method stage II

Eligibility criteria stage II

Adult patients with heterogeneous cancer diagnoses receiving in- or out-patient treatment in the participating centers were eligible. Three groups of patients were recruited based on treatment setting, the leading clinical issue, i.e., screening or monitoring, and the use of PROM: group A: hospitalized, screening of HRQOL $n=45$; group B: hospitalized, monitoring of symptoms $n=30$; and group C: out-patient treatment, assessment of symptoms and supportive care needs $n=25$.

Table 1 Guideline for interdisciplinary focus groups

Step 1	Relevant clinical issues and requirements of involved professions
1.	*Which issues are already covered sufficiently by routine documentation?* (e.g. assessment of pain by 10 pt. NRS, assessment of oral mucositis by CTCAE …)
2.	*Which additional clinical issues are important and should be assessed patient reported?* (e.g. fatigue, distress, anxiety, loss of appetite …)
3.	*When and how often do we want do assess?* (e.g. screening following admission, monitoring under treatment or both)
4.	*Who wants to know what, when and why?* (e.g. physician wants to know patients perception of numbness and tingling, nurse wants to know patients perception of quality of sleep …)
Step 2	Available treatment paths and resources
5.	*What happens as a result of the assessment? Which treatment options can be offered to burdened patients?*
Step 3	Summary of issues, introduction of instruments fitting the collected requirements
6.	*What are the pros and cons of the available instruments considering the needs of patients and HCPs and the resources required including data collection and treatment options?*
Step 4	Decision on which of the existing instruments are most suitable

Recruitment

Physicians introduced the study to eligible patients as research aiming to improve assessment in clinical routine. They obtained written informed consent and defined group allocation according to the leading clinical issue. As different questionnaires were used for the groups, patients were allowed to participate up to three times during the treatment trajectory provided their group allocation had changed.

Exclusion criteria stage II

Patients lacking sufficient knowledge of the German language, suffering from severe dementia, or patients whose medical condition did not allow participation were excluded.

Data collection

Patients were asked to complete the questionnaire chosen in phase I, as determined by their group allocation. PROs were collected via tablet PC with automatic scoring and graphic printouts (Quality-of-Life Recorder, www.ql-recorder.com) in two centers and with paper and pencil in two centers. In subsequent semi-structured interviews, patients were asked to rate the questionnaire with respect to comprehensiveness, wording, and usefulness to inform HCPs about their condition. Patients were also asked to give their personal definition of HRQOL. These definitions were collected in order to further examine appropriateness of the selected instrument by comparing whether relevant issues were covered. The individual PROs were compared with medical records. Results were then presented to nurses and physicians ($n = 29$) who were asked to judge the usefulness of the applied PROMs for routine clinical practice.

In addition, socio-demographic and medical data of participating patients were recorded.

Data analysis

Qualitative data were transcribed, and qualitative content analysis was performed to summarize and categorize the issues [35].

In addition to individual scores, descriptive quantitative analyses of the collected PRO were performed using SPSS V.18.

Qualitative data from stages I and II and quantitative descriptive analyses of the collected PRO were summarized and discussed with the clinicians to interpret the data and evaluate feasibility, acceptance, and possible benefits of the selected PROMs for clinical decision-making, screening, and monitoring purposes.

Results

Stage I: focus groups

Participants and focus groups

Altogether, six focus groups were conducted in four centers (hematology-oncology ($n = 2$), surgery, and radiotherapy). Thirty-nine HCPs participated (nursing staff $n = 19$, physicians $n = 10$, medical technicians $n = 3$, psycho-oncologists $n = 3$, social worker $n = 1$, pastoral worker $n = 1$, nutritional consultant $n = 1$, nursing researcher $n = 1$). The discussions lasted between 45 and 90 min. All focus groups reached consensus by mutual agreement regarding the selection of measures.

Results of focus groups

Content analysis of the focus group transcripts resulted in five major categories: first, needs for additional assessments;

second, reasons for decision on instruments; third, doubts concerning the application of PROMs; fourth, benefits of the application of PROMs; and fifth, requirements for the application of PROMs.

Analyses of the focus group discussions showed that HCPs' needs for additional assessments differ considerably depending on the scope of actual routine assessments and available resources. They revealed doubts concerning the application of PROMs, e.g., burden on HCPs ("more work") and patients. HCPs suggested that "instruments should be precise and short," documentation should not be "just for the record," and further diagnosis should take place by personal in-depth interviews and examinations when indicated. They requested options to react if problems were reported. HCPs valued the potential of electronic data collection and graphic representation of the results. The major categories and subcategories are summarized in Fig. 1. Results concerning the choice of instruments are reported in connection with the first major category in the following paragraphs.

Needs for additional assessments

This major category comprises four subcategories.

1. Screening of newly admitted patients for QOL issues
   HCPs agreed on the need for HRQOL assessment following admission to hospital care in order to aid treatment decisions. "Before I think about third line therapy, I want to know how the patient perceives his or her quality of life." The Functional Assessment of Cancer Therapy (FACT-G) [36] and the European Organisation of Research and Treatment of Cancer (EORTC) QLQ-C30 V. 3.0 [37] were discussed. The EORTC QLQ-C30, which captures cancer-specific patient-reported HRQOL with respect to symptoms and functioning during the last week, was preferred by HCPs.
2. Screening for the need for psycho-oncologic support
   Several recommended instruments which can identify patients who require psycho-oncological counseling were discussed [38]. HCPs expressed concern that in-depth questions might trouble the patients and that they might not be able to cope with patients' reactions on their own. Therefore, the Distress Thermometer (DT) [39] as a short and easily applicable instrument was chosen.
3. Monitoring of in-patients undergoing treatment
   For monitoring patient-reported symptoms and side effects during hospitalization, HCPs at two centers preferred the 0–10 numeric rating scale (NRS) of the M.D. Anderson Symptom Inventory (MDASI) [40]. HCPs at one center preferred the four-step Likert scale of the EORTC symptom-related questions. Although the application of single items from EORTC questionnaires to capture and monitor symptom intensity has not previously been validated, it was decided to pilot-test this option in phase II. A list of $n = 25$ single items presumed relevant by the participating HCPs was comprised in order to gather patients' and HCPs' appraisals of clinical usefulness. Nineteen of 25 items were not part of the standard documentation in this center. The items were selected from the following questionnaires: QLQ-C30, QLQ-STO22, QLQ-FA13, QLQ-BR23, QLQ-CR29, and QLQ-OV28 [http://groups.eortc.be/qol/].
4. Screening and monitoring of out-patients
   For outpatients, HCPs wanted screening and monitoring of symptoms and assessment of supportive needs. In order to avoid burdening patients by using several instruments, the newly developed supportive-care-needs-assessment for patients with cancer (FU-T) was chosen. The FU-T refers to the previous week and comprises six domains covering symptoms and functioning, psychosocial strains, resources, personal aims, and requests regarding aftercare. Perceived intensity and perceived burden are assessed separately by visual scales representing the traffic-light system (red = high, yellow = medium, and green = none). The FU-T is currently undergoing final validation [41].

Stage II: clinical testing

Participants

Seventy-one patients participated (approached: $n = 76$; recruited: $n = 74$; withdrawal due to reduced health: $n = 3$). Group allocation of $n = 17$ patients changed during the course of their treatment (e.g., screening followed by monitoring), so that they were eligible to participate twice ($n = 16$ group A and B, $n = 1$ group B and C). Participants were aged between 26 and 84 years (Mean: 61.3; SD: 11.2) and 70 % were living with a spouse. Further socio-demographic and medical data are summarized in Table 2.

Group A: screening of hospitalized patients Thirty-five newly hospitalized patients were screened for HRQOL-related issues with the EORTC QLQ-C30 in three centers. Descriptive quantitative analyses show considerable inter-individual differences and are summarized in Table 3.

The Distress Thermometer (DT), which was completed by $n = 10$ patients, showed inter-individual differences regarding perceived distress (mean: 5; min.: 0; max.: 8; SD 3). Anxiety and sorrow were marked by 7/10 patients and sadness by 6/10 patients. All other issues were marked by four or less patients. One patient requested a pastoral worker.

Group B: monitoring of hospitalized patients Symptom intensity was measured by EORTC single items in one center

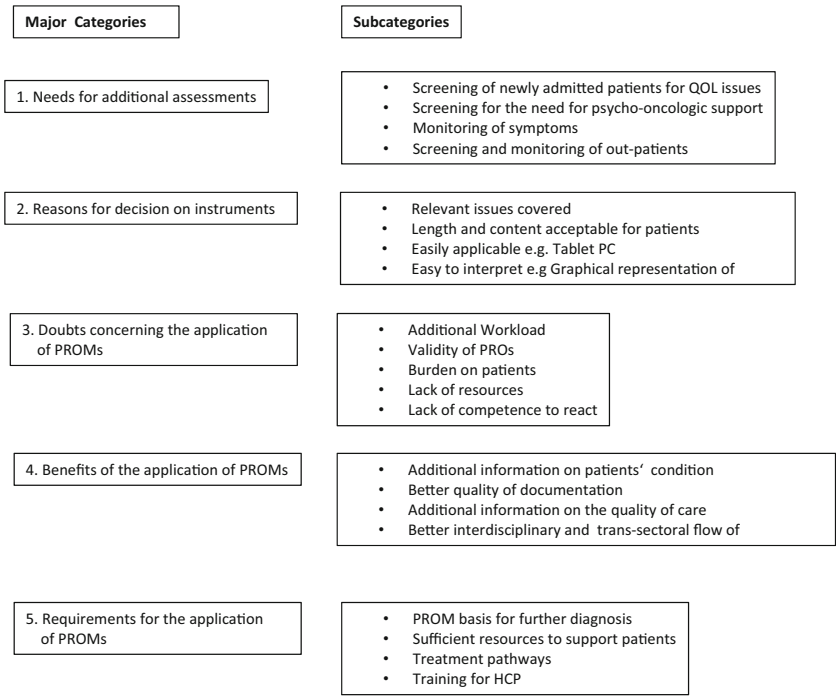

Fig. 1 Summary of major categories and subcategories derived by content analysis of the focus groups (stage I) and interviews with HCP (stage II)

($n=8$) using paper and pencil and by the MDASI in two centers using electronic data collection via tablet PCs ($n=10$ radiotherapy, $n=10$ hematology). Descriptive quantitative analyses show large variations in symptom occurrence and intensity. An example of computed results for an individual patient is shown in Fig. 2, and results of the MDASI are summarized in Table 4.

Group C: screening and monitoring of out-patients Few of the $n=25$ outpatients who completed the FU-T reported symptoms of high intensity (pain 4/25, fatigue 4/25, depression 3/25, loss of appetite, nausea and trouble sleeping 2/25, and diarrhea 1/25). Patients used the open question and reported additional symptoms, e.g., mucositis, skin reactions, and cramps. With respect to their general situation, 13/25 patients reported burden on family and friends, 9/25 worry about relapse, 5/25 felt they could contribute nothing to their cure, and 5/25 reported financial problems.

Patients' definitions of quality of life

Patients' replies to the question "What does quality of life mean for you?" were categorized. Main categories comprised:

1. Well-being and symptom control: "health," "vitality," "feeling well also at home," "being able to eat what I like," "that the illness is bearable," and "to live without pain - which I haven't for years"
2. Daily functioning: "being able to cope with everyday chores," "independence," "gardening," "shopping," "not being bedridden," and "being able to make plans"
3. Relations with others: "friends and family" and "peace at home"
4. Finances: "to be able to afford what I want" and "fixed income"
5. Finding and maintaining purpose: "to reach small aims - large goals and dreams are long gone"
6. Being cared for: "here in the clinic everyone cares for me and is friendly"

These categories match the items of the EORTC QLQ-C30 except finding and maintaining purpose and being cared for.

Patients' appraisal of the questionnaires

In general, patients rated the use of questionnaires as useful to inform HCPs about their condition: "So they know what to do." Electronic data collection via tablet PC was well accepted. All questions were well understood. Some patients needed explanations regarding the interpretation of the scales and the recall period especially when their condition was changing day by day. "What do you mean: last week or now?" Patients regarded questions about side effects like loss of appetite, nausea and vomiting, mood, enjoyment of life, and relations with others as most important. They criticized standardized questions regarding physical functioning, e.g., EORTC QLQ-C30 item 1: "Do you have any trouble taking a long walk?" or MDASI core item 16: "work including work around the house," for patients whose physical condition was obviously reduced.

With respect to the intervals at which PROs should be collected, patients reported that symptoms should be assessed

Table 2 Characteristics of participating patients ($n = 71$); values are numbers (percentage) unless stated otherwise

Characteristic	$N = 71$
Age years (MW, SD)	61,3;(11,2)
Sex	
Female	32 (45)
Male	39 (55)
Family status	
Living alone	21 (30)
With partner	50 (70)
With adult children	4 (6)
With underage children	7 (10)
School education	
Main school	38 (54)
Secondary school	22 (31)
A level	11 (16)
Education	
University level	11 (16)
Vocational training	59 (83)
Not qualified	1 (1)
Profession	
Retired	44 (62)
Employed	17 (24)
Unemployed	6 (9)
Freelance	3 (4)
Missing	1 (1)
Cancer site	
Hematological	25 (36)
Gastrointestinal	13 (18)
Gynecological	11 (16)
Head and neck	7 (10)
Lung	7 (10)
Prostate, bladder, and testes	4 (6)
Brain	2 (3)
Other	2 (3)
ECOG performance status	
0 without restriction	10 (14)
1 slight restriction, not able to work	42 (59)
2 <50 % of day in bed	11 (15)
3 ≥50 % of day in bed	0
Missing	8 (11)
Comorbidity (min. = 0; max. = 10)	
Circulatory	45 (63)
Endocrine, nutritional, and metabolic	24 (34)
Digestive	16 (23)
Urogenital	15 (21)
Musculoskeletal	8 (11)
Immunological	5 (7)
Neurological	4 (6)
Alcohol dependency	4 (6)
Mental and behavioral	2 (3)
Pulmonary	2 (3)

more frequently than functioning and global HRQOL: "quality of life should be assessed, so that emotional problems can be detected," "at the beginning, in the middle and at the end of treatment," or "once a week, - but I want to give my consent before, otherwise it upsets me." Some patients were wavering between the need to communicate concerns in order to get support or to suppress their needs: "I think it is important, but I do not want to be reminded." Many patients brought up that HCPs should act upon the information they gather from patients and address the concerns raised in any assessments.

Comparison with clinical records

Clinical records of participating patients were checked to see whether symptom-related items of the EORTC QLQ-C30 rated "quite a bit" and "very much" or items of the MDASI rated >3 or items of the FU-T marked yellow or red were represented. Clinical records showed consistent documentation of complications like fever and side effects like emesis, mucositis, diarrhea, and pain. Symptoms captured by PRO assessments like sadness, loss of appetite, fatigue, trouble sleeping, and dry mouth and functional restrictions were not documented regularly in the medical records.

Appraisal of potential clinical benefit by HCPs

HCPs of the surgical department stated that most symptoms reported by patients were "normal" for their condition and known to the team. Documentation would therefore focus on

Table 3 Patient-reported health-related quality of life measured with EORTC QLQ-C30 (total: $n = 35$; radiotherapy: $n = 10$, hematology: $n = 10$, surgical ward: $n = 15$)

EORTC QLQ-C30 last week	Number	Min.	Max.	Mean	SD
Functionality					
Physical function	35	7	100	62	30
Role function	34	0	100	58	36
Cognitive function	35	17	100	61	24
Emotional function	35	17	100	81	21
Social function	35	0	100	62	39
Symptoms					
Fatigue	35	0	100	48	29
Nausea and vomiting	35	0	100	20	31
Pain	35	0	100	32	36
Dyspnea	35	0	100	36	39
Insomnia	35	0	100	44	41
Appetite loss	35	0	100	38	41
Constipation	34	0	100	14	29
Diarrhea	35	0	100	10	24
Financial problems	34	0	100	10	22
Global health-related quality of life	35	17	100	50	18

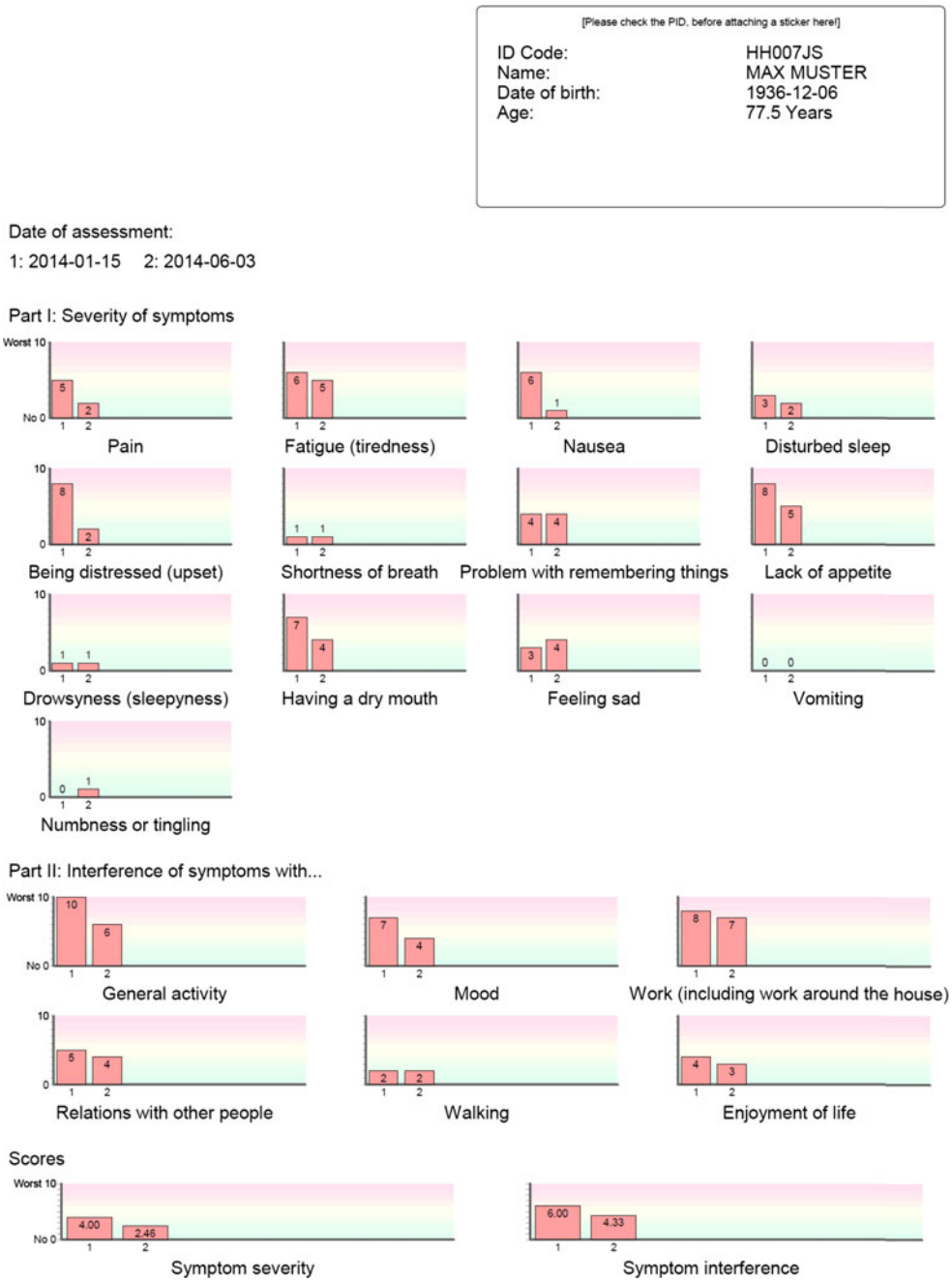

Fig. 2 Example of computed results for an individual patient of two measurements MDASI

serious side effects and complications. However, additional assessment of HRQOL was rated useful during follow-up and aftercare to judge whether additional supportive measures were indicated and treatment goals could be achieved. HCPs of the other participating centers rated the additional information about symptoms and functional restrictions obtained by PRO as a useful addition for screening and monitoring and thus beneficial for clinical decision-making: "If I know the patient suffers from emotional problems, I can refer her to a psycho-oncologist" and "physical as well as psychological aspects are important to indicate where patients perceive unsolved problems." On the basis of obvious gaps between patient-reported symptom intensity and clinical assessment and documentation, issues of validity and the importance of communication with patients about their perceptions were discussed. Additional information on the patients' condition and especially the graphic display of computed results were considered useful for treatment decisions and to facilitate the flow of information between HCPs and the different wards and clinics involved during the course of treatment. In addition, presented with summarized group data, HCPS considered the use of PRO assessments and the selected instruments to be beneficial to provide complementary information on the quality of care and symptom control.

Table 4 Patient-reported symptom severity and symptom interference measured with the MDASI

	Number	Min.	Max.	Mean	SD
MDASI symptom severity last 24 h ≥1 (NRS 0–10)					
Pain	20	0	6	2	2
Fatigue	20	0	10	3	3
Nausea	20	0	8	1	2
Insomnia	20	0	10	2	3
Worries/grief	20	0	9	3	3
Dyspnea	20	0	10	1	2
Memory problems	20	0	8	1	2
Appetite loss	20	0	8	2	3
Dizziness	20	0	7	1	2
Dry mouth	20	0	9	3	3
Depression	20	0	10	3	3
Vomiting	20	0	6	1	2
Numbness/tingling	20	0	10	1	2
MDASI symptom interference last 24 h ≥1 (NRS 0–10)					
General activity	18	0	10	4	3
Mood	20	0	8	2	3
Work (including work around the house)	14	0	10	3	4
Relations with other people	20	0	6	1	2
Walking	20	0	10	3	3
Enjoyment of life	20	0	10	2	3

Discussion

This exploratory mixed-methods study aimed to select PROMs meeting the requirements of both clinicians and patients. The qualitative dominant mixed-method design allowed for the exploration of clinicians' needs regarding PROMs, including choice of appropriate instruments, evaluation by clinical application, and comparison of individual and group data. Results show that the selected instruments and electronic data collection are appreciated by patients and HCPs. Descriptive analyses of the group data showing large inter-individual variations confirm the importance of individual assessments. Comparison of individual data with standard documentation showed that the selected PROMs captured symptoms of medium and high intensity and functional restrictions that were not documented in the clinical records. Concordant with other studies, the graphic display of the results was appreciated by HCPs [42]. During the focus groups, HCPs discussed their attitude towards PROMs and individual and organizational facilitators. Barriers to the successful implementation of PROMs were revealed and addressed [6, 25, 26, 43]. Subsequent comparison of PROs with clinical records triggered discussions with the participating HCPs about the validity of PROs and the importance of communication with patients about their perceptions. These discussions confirmed the relevance of these issues when training HCPs in the use of PROMs prior to implementation [24]. HCPS considered the use of PRO assessments and the selected instruments to be beneficial for screening, monitoring, symptom control, and the flow of information. Quantitative data were considered useful to provide information on the process and quality of care throughout the treatment trajectory.

The main limitations of this study are the small number of participating centers and the small and heterogeneous sample of patients limiting the generalizability of these findings. During the course of the study, the significance of institutional differences, ward- and clinic-specific documentation standards, and resources for the choice of PROMs became evident. Therefore, although the chosen instruments were approved by HCPs and patients in the participating centers, we do not claim generalizability. Successful implementation of PROMs for clinical applications is influenced by settings, dynamic systems, and individuals and has to be supported by all parties involved [25]. Therefore, rather than recommend specific tools, we would recommend the use of interdisciplinary focus groups to select appropriate PROMs in each setting. By applying this method, we demonstrated that it is possible to choose appropriate instruments within an acceptable time frame and address the issues considered most important by all involved parties. The results of the subsequent pilot-testing served to focus clinical issues and to foster decisions with regard to the targeted application of PROMs in clinical practice.

Future efforts should focus on international collaboration to incorporate the broad international experience in PRO

assessments, treatment pathways, and education in order to facilitate the implementation of PRO in clinical routine and thus further improve patient-centered care.

Compliance with ethical standards

Conflict of interest The work was funded by a grant of the Wilhelm-Roux program of the medical faculty of the Martin Luther University Halle-Wittenberg. The authors state no conflicts of interest related to the work of this study. The authors have full control of all primary data that can be reviewed if requested.

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