Patient-reported outcomes and psycho-oncological screening in hematology: a practical example of routine electronic monitoring

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Summary Patient-reported outcomes (PROs) have gained increasing importance in oncology. PROs can supplement medical treatment with important information about the patient's quality of life (QoL), which is typically assessed using standardized questionnaires. PROs capture the symptomatology and functional impairments as perceived by the patient without further interpretation by another party. In this article, we describe how routinely assessed electronic PROs (ePROs) at the outpatient unit of the Department of Hematology Innsbruck complement the Austrian Myeloma Registry (AMR) and clinical routine. There is a broad body of literature showing that ePRO assessments can supplement patient–physician

contact and help focus communication on clinically relevant issues that matter for the patient. Based on ePRO results, physicians can initiate clinical action such as referring patients to psycho-oncological treatment. Electronic PRO assessments might facilitate communication between healthcare providers among themselves but also between healthcare providers and patients, and make it possible to incorporate the patients' point of view into treatment in a standardized way. The example depicted herein demonstrates how ePRO assessments can be integrated and used in routine monitoring and for psycho-oncological screening.

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Introduction

In recent years, treatments for hematological cancer have achieved prolonged survival and have shifted the patients' quality of life (QoL) more and more into focus [1–3]. Among other self-reported health concepts, QoL can be assigned to the umbrella term of patient-reported outcomes (PROs), which in turn can be defined as all health outcomes directly reported by the patient without any interpretation by a second party. PROs are typically assessed using standardized questionnaires measuring patients' symptoms and functioning (physical and psychosocial domains). PRO data can help patients and physicians decide which treatment options to pursue and allow meaningful insight in the patient's health status over the whole course of the disease. Such standardized integration of the patient perspective can supplement the medical assessment of the patient's state of health. Studies have shown that healthcare professionals (HCPs) often undervalue symptoms and functional impairments in patients' QoL [4, 5]. PROs can provide added value for the patient–physician relationship and may even increase survival time as initial studies have shown [6, 7].

How are PROs assessed?

PRO assessments are typically used in clinical studies or in routine care monitoring. On a basic level, PROs on QoL are either broad instruments applicable to a general population, or specific instruments validated for certain groups (e.g., disease groups like cancer). Usage of generic PRO tools like the EQ-5D or the Short Form Health Survey (SF-36) permits a comparison across different disease groups. However, those questionnaires do not cover disease-specific domains and symptoms that may be relevant to patients. In most cases, using a cancer-specific measurement is advisable, as those more precisely measure issues relevant to oncological patients. One of the most widely used PRO measures is the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) [8–10], developed by the EORTC Quality of Life Group, which can be supplemented using disease-specific modules for different types of cancer. Other cancer-specific PRO tools are the PROMIS-Cancer measures by the National Cancer Institute (NCI) or the Functional Assessment of Cancer Therapy – General (FACT-G). Depending on the focus of the assessments, the PRO measure should be selected carefully [11, 12]. Additional specific questionnaires can be used to assess particular domains of interest such as the need or indication for psycho-oncological treat-

ment, e.g., Distress Thermometer [13] or Hornheider Screening Instrument (HSI) [14].

While in clinical studies the results of PRO measures are often analyzed after conducting the study, requirements for PRO usage in clinical routine are different. Research has shown that the integration of PRO results into the clinical workflow benefits from instant scoring and comprehensive PRO result presentation [15, 16]. This can be accomplished with electronic patient-reported outcome (ePRO) data collection. Using PCs, tablet-PCs or smartphone devices, patients can report on PRO measures. Directly after completion, HCPs can review the results and tailor the clinical encounter to the patient's responses. Compared to paper–pencil data collection, ePRO data collection has been shown to improve data integrity and reduce missing data in clinical trials [17] while offering the same validity [18].

Why assess PROs in oncological care?

Assessing PROs offers a variety of benefits in the clinical setting. PROs can systematically assess relevant symptoms and side effects that may be relevant to treatment. The PRO results, especially when collected electronically, can help HCPs gain a quick and comprehensive impression of the patients' perceived health. Review of the results may lead to clinical exploration of the data or initiate clinical action. For example, for the EORTC QLQ-C30, thresholds for clinical importance are available indicating a high possibility for clinically important problems in a patient's QoL [19]. These thresholds can be used for symptom screening in clinical practice. Well-validated and established PRO tools like the EORTC QLQ-C30, combined with interpretation guidelines such as normative data or thresholds for clinical importance, allow the comprehensive and systematic assessment and interpretation of patients' QoL. Due to the broad assessment focus of standardized questionnaires, different sensitive domains (like fatigue, sexuality) are addressed which are otherwise less likely to be picked up during consultation [20–22]. At the same time, a wider variety of topics can be covered in the consultations if PRO results are used because PROs can cover a broad range of QoL domains [23, 24]. Another welcome effect is that PRO results can support focused dialogue between HCPs and patients, as they give an indication on which topics or QoL domains merit in-depth discussion [20]. Even though more topics are picked up and discussed, the time spent with the patient during consultation remains the same [20, 24]. Focusing patient-relevant issues and evaluating patient priorities can support shared-decision making in therapy which in turn can increase treatment satisfaction and adherence in patients [24–26].

In the last few years, the first RCT studies were able to show concrete survival benefits of PRO usage in the oncological setting. Basch et al. [6] report on

advanced lung cancer patients using a weekly web-based symptom monitoring during routine care. In the usual care group, no ePRO monitoring was carried out. If a patient in the ePRO group deteriorated or showed specific symptoms, an HCP was notified and could update the treatment accordingly (e.g., schedule additional imaging). Patients in the ePRO monitoring group showed a median prolonged survival of 5 months compared to patients in standard care. Similar results were reported by Denis et al., recruiting advanced nonprogressive stage IIA (TXN1) to IV lung cancer patients at five French centers [7]. In their study, median survival was 22.5 months (ePRO group) versus 13.5 months (standard of care). The authors conclude that ePRO integration enabled more adequate and timelier provision of care and therefore prolonged survival. Early detection of and adequate response to side effects are known factors to reduce unplanned hospital visits and increase patients' therapy adherence [27]. Furthermore, patients in the study by Denis et al. also tolerated longer chemotherapy than patients in usual care, which could be another contributing factor.

ePRO data collection in the outpatient unit of the Department of Hematology Innsbruck

Since 2016, the Department of Hematology Innsbruck has been conducting standardized QoL assessments in cooperation with the Austrian Myeloma Registry (AMR, <https://www.myeloma-registry.com>) at the outpatient unit. The AMR incorporates clinical data of patients with multiple myeloma (MM) in multiple representative centers in Austria. In Innsbruck, the clinical data are complemented with ePRO assessments. So far, over 250 patients with MM have participated in the ePRO assessments in Innsbruck. Due to the successful integration and the perceived benefits for MM patients, another patient group, patients with chronic lymphatic leukemia (CLL), was added to the standard clinical monitoring in 2017. Since then, roughly 200 patients with CLL have participated. In total, more than 3200 ePRO assessments have been completed (January 2020). The implementation procedure and feasibility of the ePRO data assessments for integration into the AMR has been published elsewhere [28].

Patients with MM are included into the registry and routine QoL assessments are carried out by an ePRO facilitator (HCP responsible for the assessments). The EORTC QLQ-C30 [29] and the myeloma-specific module EORTC QLQ-MY20 [30] are used for patients with MM. For patients with CLL, the data are only utilized for routine clinical monitoring using the EORTC QLQ-C30 together with the EORTC QLQ-CLL17 [31]. All EORTC questionnaires are available in multiple languages, which allows non-native German speakers to choose their preferred language for completion. The assessments are carried out on a tablet at the

outpatient unit or using a web-based patient portal which patients can access from home. This ePRO approach is realized using the Computer-based Health Evaluation System (CHES, [32]) which captures the PRO data for the registry and simultaneously provides instant graphical representation of the patients' results. Healthcare practitioners can use the CHES to get a quick and informative overview of their patients' perceived QoL in the last week. Patients' results can be compared to previous assessments and/or to normative data from other cancer patients. This allows the tracking and longitudinal monitoring of patients QoL over treatment trajectory. The EORTC has recently published a guideline on ePRO implementation in research and practice [33]. The Graphical User Interface for the Department of Hematology was crafted in accordance with those guidelines (an exemplary representation of patients' results is shown in Fig. 1).

Psycho-oncological screening

A cancer diagnosis is often physically and emotionally burdensome for patients and can result in high psychosocial and emotional distress for the individual and/or family [34]. According to the literature, 20–50% of cancer patients are emotionally distressed [35, 36] or have psychiatric comorbidities during therapy [37]. Consequently, cancer treatment should be supplemented with adequate psychosocial support such as psycho-oncological treatment which can increase patients' QoL and decrease distress [38, 39]. For HCPs, it can be challenging to identify patients in need of support and referral to psycho-oncological services as many patients do not proactively report distress or seek help, and HCPs might lack specific training to identify distressed patients [40, 41]. Although cancer-specific questionnaires usually assess emotional functioning or distress, this does not suffice for the identification of patients in need of psycho-oncological support and treatment [42]. Therefore, treatment guidelines suggest the use of a routine psycho-oncological screening tool [43]. In August 2019, the Hornheider Screening Instrument (HSI) [14] was added to the ePRO routine monitoring at our unit. The original version of the HSI contains seven items assessing emotional strain, unmet information needs and disease burden in the family. A cut-off indicates patients who would likely benefit from psycho-oncological treatment. For the screening of psycho-oncological treatment needs at the Department of Hematology Innsbruck, the HSI is supplemented with five additional items on episodes of depressive mood or anxiety, previous psychological or psychiatric treatment, and patients' personal wish to talk to a psycho-oncologist. This results in a total of 12 items which has been shown to be feasible for screening purposes [44]. To keep response burden low, patients complete the HSI screening in 3-month intervals. In CHES, the HSI cut-off is linked to a graphical indicator (a blue

Survey	Monitoring	Info	Last Name	First Name	Date of Birth	Pat. ID	Diagnosis	Assessments	Last	Next	Flag	Delta	PO
	Klinik						C91.1- Chronisch...	2	16/03/2020		→		
	Klinik						C91.1- Chronisch...	4	17/03/2020		→		
	Portal						C90 - Multiples M...	12	13/03/2020		→	!	
	Klinik						C90 - Multiples M...	1	23/03/2020		→		
	Portal						C91.1- Chronisch...	4	06/03/2020		→		
	Portal	12	Lastname	Firstname	02/06/1950	Pat-ID-here	C90 - Multiples M...	2	27/02/2020	23/03/2020			!

a

b

c

Fig. 1 Exemplary PRO results. Different options for displaying PRO results are available: **a** the patient list with example patients, **b** longitudinal questionnaire results for an example patient's EORTC QLQ-C30, **c** longitudinal questionnaire results for the HSI showing the clinical cut-off and the patients

wish for psycho-oncological treatment. *PRO* patient-related outcome. *EORTC QLQ-C30* European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire, *HSI* Hornheider Screening Instrument

exclamation mark) in the patient overview, which makes it easy for HCPs to identify patients who might benefit from psycho-oncological treatment. The exclamation mark is displayed when patients exceed the HSI cut-off (regardless of whether they wish to see a psycho-oncologist) or when they express the wish to see a psycho-oncologist (regardless of whether they exceed the cut-off). Fig. 2 (adapted from [45]) displays the possible outcomes and resulting actions taken by the staff depending on the HSI results.

Between implementation of the screening in August 2019 and January 2020, 91 patients completed at least one HSI screening. Of those, 40 (44%) ex-

ceeded the cut-off during the first screening but only 5 (5%) wished to talk to a psycho-oncologist. This gap between experienced distress and expressed wish for psycho-oncological support is known from other studies, although normally less prominent (e.g., [46–48]). Proposed reasons for few patients expressing the wish to see a psycho-oncologist are the fear of social stigma, a lack of knowledge about psycho-oncology, a preference for self-help, and the belief that their own distress is not severe enough to merit intervention [46, 49].

Fig. 2 Pathways of clinical action due to psycho-oncological screening. Depending on the screening outcome of the Hornheider Screening Instrument (HSI), different clinical actions are executed. The blue exclamation mark is shown as an indicator of necessary clinical action for healthcare professionals. Adapted from Schäffeler et al. [45]

ePRO from the patients' perspective

The patient perspective on the PRO assessments is a critical factor for any implementation. Research suggests that how patients experience the assessments is connected to their compliance [50] and satisfaction with the PRO usage [51]. At our outpatient unit, patients with MM and CLL are approached in the clinic by the ePRO facilitator. They are asked to participate in the monitoring program and, in case of a MM diagnosis, to consent to data usage by the AMR. After providing informed consent, the patient is presented further information about the goals and procedure of the monitoring. Patients then fill in the questionnaires for the first time on a tablet computer in a designated room. Patients can choose their preferred or native language, which reduces misunderstandings and includes foreign-language speakers. Due to the multilingual assessments, ePROs can help bridge language-based communication gaps between patients and physicians as they provide an extensive assessment in various languages. During questionnaire completion, the ePRO facilitator is present and can assist patients who require support with the assessment. The assessment is usually carried out between the blood sampling and the appointment with the doctor. This ensures that ePRO results can be reviewed by the doctor before and during the consultation. After the first inclusion into the routine monitoring, regular assessments are carried out at

each subsequent visit at the outpatient unit. Assessment intervals differ with appointment frequency and can range anywhere between 2 weeks and 12 months.

Patients who are eligible to participate in an electronic PRO home monitoring (at least some internet usage, and no overt cognitive impairment) are introduced to our patient portal. Approval rates for the portal are high: most eligible patients agree to use the portal (79 of 88; 90%). Aside from questionnaire completion, the patient portal offers additional features for the patients. It provides reliable disease-specific information composed by the physicians and content which is dependent on patients' questionnaire results. Self-management tools are dynamically displayed for QoL domains if a threshold for clinical importance is reached [19]. The self-management tools consist of advice and instructions on how to handle disease- and treatment-related symptom burden (e.g. breathing exercise, dietary information), or contact information to relevant counseling sources such as psycho-oncology. Patients are recommended to view the self-help tools for domains in which they reached the predefined threshold. Moreover, patients can view their own results and compare them to reference data from other patients, a wish frequently reported by cancer patients [52].

ePRO from the physicians' perspective

Physicians entering the program for the first time are also introduced to the routine monitoring by the ePRO facilitator and are provided their own login data for the CHES system. Their account allows them to log into the CHES platform using just an internet browser at any time. Evaluation of the feasibility in our unit shows that the effort and burden of the ePRO assessments for physicians is low [28]. Typically, physicians are advised to review their patient's PRO results right before or during the consultation. They can choose just how much specific information they want to extract from the ePRO assessments: (level 1) inspect just a pie chart summarizing the results of all subscales of the three questionnaires and an indicator of change from the last assessment, (level 2) inspect the results for all subscales split by functions and symptoms, or (level 3) to check the specific answers a patient gave that led to the results at hand. This way physicians can adapt the amount of specific information to their needs. For instance, if the patients reported QoL did not deteriorate, it might be sufficient to just check the summarizing pie chart (Fig. 3). Otherwise, if the patient shows deterioration in some domains, the doctor can inspect the respective items and receive detailed information.

Routinely assessed PRO data can support HCPs in more easily adapting a patient-centered approach. Thresholds for clinical importance are used to identify QoL domains that might be clinically relevant [19]. If the threshold is passed for a subscale, it is likely that

Fig. 3 Levels of information depth and aggregation in the software. Information is most condensed on *level 1*: In the pie chart, *arrow* (delta indicator of change between the last assessments) and *psycho-oncology flag* (*exclamation mark* shown for psycho-oncological treatment indication) all questionnaires and subscales are aggregated. Subsequently, this level conveys the least specific information. *Level 2*: Health-

care practitioners can choose to explore the ePRO data in depth, by viewing the questionnaires' subscales and their trajectories. On this level, information is more specific. *Level 3* (highest information specificity): If even more detailed information is needed, the answers to items of a specific subscale can be viewed. *ePRO* electronic patient-reported outcome

the patient experiences clinically important problems in this domain. Physicians are advised to discuss those domains with the patient. The blue exclamation mark as an indication of a possible psycho-oncological treatment indication helps in the early recognition of patients who might benefit from further counselling and triggers adequate clinical action. Moreover, as the psycho-oncologists have access to the QoL data, they can obtain additional information on the health state of the patient from the PRO results before even meeting him or her.

Conclusion and future perspective

The outpatient unit of the Department of Hematology in Innsbruck successfully implemented the collection of ePRO (electronic patient-rated outcome) data on a regular basis to supplement the AMR (Austrian Myeloma Registry). This routine ePRO assessment should not stop at being a mere data collection, but gradually progress to enrich clinical care and research. Herein, we review the possible benefits of ePRO assessments in hematology and how routine ePRO screening can be used for psycho-oncological triage. In order to underpin the beneficial nature of

the structured use of ePRO data, follow-up projects will evaluate and analyze the routine assessment and associated care pathways like the triage of psycho-oncology treatment. A detailed analysis of clinical action initiated by healthcare professionals based on the psycho-oncology screening results may be used to gauge the benefit in treatment allocation provided by the screening. Another research focus on the use of the patient portal and the patients' opinion of the patient portal will help to identify both successful and useful functionalities as well as areas for improvement. To reinforce patients to provide their ePRO data upfront their appointment at the hospital, the use of the patient portal should bear additional incentives like adequate and feasible self-management tools or selected up-to-date medical information.

Take-home message

- Systematic patient-reported outcome (PRO) assessments in hematological patients are a sensible addition to standardized treatment monitoring.
- Patient-reported outcomes can enrich the patient-physician contact and help focus on clinically relevant issues that matter for the patient.

- This example of electronic PRO monitoring at the outpatient unit of the Department of Hematology Innsbruck shows that PROs can be a part of routine medical assessment.
- We demonstrate how PROs can be used for the screening of psycho-oncological treatment indication and referral.

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Conflict of interest B. Holzner and G. Rumpold have intellectual property rights of the software tool CHES. J. Lehmann, L.M. Wintner, M. Sztankay, W. Willenbacher, R. Weger, and W. Weyerer declare that they have no competing interests.

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