"I Am Sure That They Use My PROM Data for Something Important." A Qualitative Study About Patients' Experiences From a Hematologic Outpatient Clinic

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“I am sure that they use my PROM data for something important”

A qualitative study about patients’ experiences from a hematologic outpatient clinic

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The authors have no conflicts of interest to disclose

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This project was funded by The Danish Cancer Society and Zealand University Hospital.
Background: Patient Reported Outcome Measures (PROM) in clinical practice have the potential to contribute to and support shared decision-making processes by giving voice to patient concerns during consultations. However, the perspectives of patients diagnosed with chronic hematological cancer on the use of PROMs are unknown.

Objective: To describe how patients diagnosed with hematological cancer experience participating in a randomized PROM intervention study, including initial invitation, completion of questionnaires, and outpatient clinic visits.

Methods: A qualitative conceptual framework guided the study, using Interpretive Description (ID) with a focused ethnographic approach to explore patient experiences with PROMs in applied practice. Analysis was inspired by Habermas’ social theory of Communicative Action.

Results: The analysis revealed three predominant themes of patient experiences: that PROMs were “In the service of a good cause”, “The questions are not really spot on”, and “PROMs are sometimes used for something” i.e. unknown to the patient.

Conclusions: The patients’ experiences were dominated by the perspective of the healthcare system, and by gratitude and imbalanced power relations. During completion of questionnaires, patients struggled to identify with items and the questionnaires were associated with low content validity. When visiting the outpatient clinic, patients reported that doctors and nurses rarely discussed patients’ PROMs.
Implications for Practice: This study contributes knowledge of patient experiences of the integration of PROMs in hematological outpatient clinical practice. Findings can guide further research and improve future implementation of PROMs.
“I am sure that they use my PROM data for something important”

A qualitative study about patients’ experiences from a hematologic outpatient clinic

Introduction

Most patients diagnosed with chronic hematological cancers require close follow-up at outpatient clinics from the time of diagnosis. At these visits, patients meet physicians and specialized nurses who monitor the illness, adjust the pharmacological treatment, and identify adverse effects, but additionally, physicians and specialized nurses should focus on rehabilitation, supportive care, and palliative care.1–3 A lack of attention to the need for such treatment and care may result in long-lasting psychosocial and physical effects1,3 that can negatively influence patient wellbeing3,4. Patients diagnosed with cancer may experience lack of control, increased risk of depression and anxiety, uncertainty, isolation, increased physical stress, or negative body image,5–8 and changes in relation to family, network, and work life.9 Consequently, identifying and meeting patients’ needs and expectations for rehabilitation, supportive care, and palliative care could benefit patients with a cancer diagnosis.3,10

An increased awareness of the importance of including patient preferences in clinical care and soliciting their perspectives11 has resulted in the use of Patient Reported Outcome Measures (PROM).12,13 A PROM is defined as a health outcome directly reported by the patient who experiences it, usually through a series of questions about health, quality of life, or functional status associated with the care or treatment the patient has received.14 Research within oncology indicates that implementing PROMs in clinical practice could improve patient care and give voice to patient concerns, allowing them to contribute to decision-making between patients and health care professionals.4,15–18 Internationally, nurses advocate the use of PROMs as a routine part of clinical practice.19 However, empirical evidence supporting the benefits of the use of
PROMs is still lacking and to our knowledge, no studies have reported specifically on patient experiences when PROMs are integrated in hematological outpatient clinical practice. Such studies would help answer questions including: could the approach potentially be harmful, have unintended effects, or restrict the exchange between the health care professional and the hematological patients? Also, does use of PROMs truly empower hematological patients and give them voice?

**Objective**

The aim of this study was to investigate how patients diagnosed with hematological cancer experience participating in a randomized PROM intervention study, including invitation to participate, completion of the PROM questionnaires, and subsequent visits to the outpatient clinic.

**Methods**

**Design**

This study took place at a specialized outpatient clinic at the hematological department of a university hospital in Denmark. The physical environment for the outpatient clinic consisted of a large waiting room, ten consultation rooms allocated for physicians, and two nursing sections, each with the capacity to treat ten patients side by side and simultaneously, leaving little physical space or privacy for patients. Furthermore, the outpatient clinic included a reception area where patients checked in on arrival and scheduled future appointments. Patients were assigned a permanent primary physician at the outpatient clinic but not a primary nurse. Visits with physicians were estimated to last 20 minutes, inclusive of the physician’s preparation and documentation time, leaving approximately 12-15 minutes allocated to direct contact with
patients. Timespan for nurse visits varied depending on the appointment and the patient’s specific circumstances. Some nurse visits lasted 30 minutes while others lasted several hours or a day, depending on the treatment, e.g. subcutaneous injections, blood draws, or blood transfusion. Patients diagnosed with chronic hematological diseases require a plan for their next visit since such conditions require close follow-up for early identification of potential changes. These circumstances allowed physicians and nurses to plan patients’ appointments long-term, which worked well with the need for the systematic collection of PROMs.

**Multimethod Project**

The present study is a qualitative study that is part of a larger multimethod project, which is defined as “studies that include the use of more than one method of data collection or research in a research study or set of related studies”. The overall aim of the project was to explore different aspects of how PROMs were integrated in the follow-up care of adult patients diagnosed with chronic hematological cancer. A flowchart of the multimethod project is available in Figure 1.

The larger project includes a randomized controlled trial (RCT), from which the patients participating in the present qualitative study were recruited. The RCT included patients diagnosed with chronic hematological cancer who had completed their initial cancer treatment in the department and had been transferred to the outpatient clinic for further follow-up. Some patients did not require treatment and were moved directly into a follow-up plan at the time of diagnosis. Patients were included for a two-year period and randomized into three study groups:

- Group 1, PROM data were available to the nurses and the physicians in the electronic medical record system.
- Group 2, PROM data were not available to the nurses and the physicians.
Group 3, a control group that followed the departments’ standard procedures, i.e., patients were not asked to complete a PROM.

PROM questionnaires 4-25 (Table 1) were accessible to patients in Groups 1 and 2 electronically by PC, tablet or smartphone. Patients unable to complete questionnaires electronically were offered the opportunity to complete the PROMs in paper form one week before the visit and return them in a pre-paid envelope. The PROM data from the paper forms were then entered into the electronic medical record system for Group 1 participants. Participants were informed about the randomization groups by letter and phone, and those in Group 2 were encouraged by the project managers to discuss and reflect upon their PROM answers with the nurses and the physicians, as they were told that PROMs were not available to these professionals. After randomization, the patients and their primary physician were informed into which group the patient had been randomized. The nurses were not individually informed about patients’ randomization group, since there was no system of assigning primary treating nurses. Therefore, nurses only knew PROMs were available if the data appeared in the electronic medical record system when working with a patient. The physicians and nurses met patients from all three groups.

Nurses and physicians at the department were offered one-hour information sessions regarding the purposes and design of the multimethod project prior to when the study began. Similar content in a newsletter was produced and circulated via e-mail to all nurses and physicians.

**Qualitative study**

This study was guided by a qualitative conceptual framework using Interpretive Description (ID) with a focused ethnographic approach to gain knowledge about patients’ experiences. ID is a qualitative research methodology with an inductive analytic approach, aligned with a
constructivist and naturalistic orientation to inquiry. This strategy endeavors to ensure the logic of qualitative research within the health sciences to ensure academic credibility while also allowing for methodological flexibility. The aim of ID is to generate knowledge relevant for the clinical context of applied health disciplines by answering practice-oriented questions that are grounded in nurses’ own epistemological foundations. ID acknowledges the theoretical and practical knowledge that researchers bring to a project, structured by distinctive features to ensure credibility: scaffolding the study, framing the study, strategizing a credible study, entering the field, constructing data, making sense of data, and conceptualizing findings. The study team engaged in an ID research network with monthly meetings to present the research, discuss the methodology, challenges and weaknesses, and address specific questions or problems. ID also encourages borrowing from the spectrum of available design techniques, as appropriate to the nature of the research question. Therefore, with inspiration from classic ethnography but with a rationale of study limitations in clinical practice, a focused ethnography, inspired by Knoblauch, was chosen to support the data production process. Focused ethnography is characterized by focusing on specific situations where individuals are involved in relationships (i.e. patients and health care professionals) in a field that may be viewed as fragmented or separated from society. Here, the focus was on hematological patients who had been randomized to participate in a new PROM intervention, and their experiences.

The fieldwork included: a) participant observations, focusing on the interactions between the health care professionals and the patients during consultations in the outpatient clinic, and b) individual interviews with patients regarding their experiences with participating in the study, answering questionnaires, and participating in outpatient consultations afterwards.

**Focus and patient participants**
Six women and ten men were purposefully selected to reflect intervention group, sex, and age (Table 2). Their ages ranged from 68 to 86 years. In addition, patients were selected to reflect the totality of the outpatient clinic’s nurses and physicians to represent possible differences incidental to patients’ experiences with diverse clinicians.

Patients gave consent to participate at the time of inclusion and again at the time of their visit, including permission for the researcher to observe consultations and to participate in follow-up interviews. No participants declined participation at this stage. Most patients were accompanied by a relative (Table 2), all of whom were the participants’ partners. During the field observations and interviews, relatives participated in the patient meetings with nurses and physicians. They could observe, engage, ask questions and offer input, but no relatives were observed involving themselves in questions or conversations regarding the PROMs.

**Data collection**

Fieldwork took place between May 2017 and June 2018. Twenty visits were studied: 10 visits where participants only visited their physician, two consultations where participants only visited a nurse, and four occasions when participants first met a physician and then a nurse (the latter were held separately with no disclosure between the professionals, therefore these visits counted as eight separate visits). The duration of visits varied from eight minutes to five hours (Table 2). After the consultations, participants (and relatives, if any) were interviewed about their experiences using a semi-structured interview guide with descriptive, structural and contrast questions. Each interview lasted 20 to 45 minutes; in total, eight hours of interviews with patients were recorded. The guide for observations and interviewing was adjusted after study team discussions before proceeding with new rounds of field observations. Field notes were taken during observations and collected afterwards with reflections concerning the
Interviews and observations were digitally recorded, anonymized, and transcribed into text.

**Ethical considerations**

The multimethod project (ClinicalTrials.gov identifier NCT03056469) was approved by the Danish Data Protection Agency (associated with Journal no. 2008-58-0020) and the National Committee on Health Research Ethics approved the study with no reason for further ethical review. The ICN Code of Ethics for Nurses and the Danish Health Act was followed. Patients gave written consent to participate in the project. Participants are referred to by pseudonyms constructed by the first author, with ‘P’ for patient followed by an individual number.

**Data analysis**

The conceptual framework was inspired by German sociologist and philosopher Jürgen Habermas’ critical theory. In particular, concepts about system and lifeworld, strategic and communicative actions, and the operationalization of power were referred to.\(^{35,36}\) Habermas defines lifeworld as the environment of competencies, practices, and attitudes represented in one's cognitive horizon. It is the lived realm of informal, culturally-grounded understandings and mutual accommodations.\(^{35,36}\) Data collection and analysis were initially guided by the research question. However, as the process of data collection and interpretation evolved, the focus of observations, the questions, and the data collection all became more data-driven. Data were analyzed using ID, including the following phases\(^{27}\):

1. Comprehending data by coding
2. Synthesizing meanings
3. Theorizing relationships
4. Recontextualising data into findings

Analysis was conducted on the transcribed textual data. Transcribed interviews, observations and field notes were uploaded to the qualitative software program NVivo™ with data grouped to each participant in cases with affiliations. NVivo 11™ was used to ease the work process in regard to the large amount of data, linking different kinds of data sources and facilitating replication by making procedures explicit and transparent. As ID does not prescribe a rigid process, the analysis was guided by a qualitative content analysis process which aimed to categorize and identify characteristics responsive to the research question.

Data from informants was reviewed several times, starting with a brief coding, followed by a second and deeper coding to critically appraise relationships and conduct a summary of informants. At this stage, each consultation was categorized as to whether PROM was used in consultations or not.

Finding patterns and themes was a more creative process, as working in the software program at this stage seemed to limit the options for exploring the data in depth, potentially leading to premature conclusions or interpretations. Therefore, nodes or potential zones of interest or thematic crossover, quotations and sequences were printed on paper and grouped vertically across informants in categories and emergent themes. The analysis process was characterized by synthesizing meanings and theorizing relationships across data, wherever potential relationships within the data became apparent. At this stage, questions were constantly asked about the textual content from the transcripts to stimulate a critical appraisal, such as “What do I see?” and “Why do I see that?” This process led to a final categorization structure and a conceptualization of thematic patterns concerning patients’ experiences when PROMs were integrated in their follow-up. The last phase was to re-contextualize these findings, which is reported below.
Findings

The analysis revealed three themes: PROMs were said to be “In the service of a good cause”, “The questions are not really spot on” and “PROMs are sometimes used for something”. All quotes were translated from Danish to English and translations were agreed on by the study team. Below, “all participants” indicates all 16, “most” indicates 9 to 15 participant individuals, “some” indicates 3 to 8, and “a few” is less than 3.

“In the service of a good cause”

Through analytic processes, the theme “In the service of a good cause” was explored and separated into two subthemes: “Contributing to research” and “Paying back”; both were predominant themes of participants’ experiences with the new PROM intervention. These findings represent situations where patients narrated viewpoints regarding the study invitation period.

“Contributing to research”

This subtheme was found to be an underlying premise for study participants. All 16 stated the importance of and motivation for their participation in research, and their willingness to contribute to research, including developing the system. The patients felt they contributed to a larger cause and thus they were not critical of the use of their PROMs.

I said yes to participate because…well…I do not know…[laughing]…I got the impression that it would be wrong not to participate when I was asked. However, to answer the questions is absolutely no problem. It is easy and does not take a long time. For many years I was a teacher in computer skills so I find that easy. (P15)
Some patients thought that completing the PROMs was an evaluation that could help the clinic or future patients, and did not perceive the assessment was intended to benefit their own treatment or condition.

“Paying back”
This sub-theme touches on how participants had feelings of gratitude toward the department for their treatment and potentially prolonged lives. Having the opportunity to give something back that the hospital regarded as meaningful was important to them. Some of the participants connected their reflections on this issue to concerns regarding how much longer the department would keep them in the system despite their advanced age or progression of their illness. “I sometimes wonder, how long a time are you going to give me this very expensive treatment (EPO), I mean…I am an old man and what does the society get from me anymore…” (P3)

“The questions are not really spot on”
This theme revealed participants’ retrospective reflections about completing the PROMs. The interpretation flowed into two subthemes: “Do these questions concern me?” and “Answering questionnaires was not easy”.

“Do these questions concern me?”
Participants completed the same PROMs before every visit at the outpatient clinic and were not able to see their previous responses. This seemed repetitive and did not allow for reporting new developments they experienced in their lives. Some directly suggested that changing PROMs (e.g. instead of completing a new one from scratch each time) would be more suitable to assess their current condition, implying lack of item relevance and content coverage.
I did not know if my physician got my answers or if this study was running concurrent. I guess it is some huge and broad research with control groups and everything…someone must use it for something. I think the questions are silly. Take me for an example, my spine is collapsed and I have pain in my shoulders and hip. Then you ask if I have pain. I answer yes. Nevertheless, this has nothing to do with my leukemia. You will catch something wrong. (P16)

During the field study, most participants explained that they were struggling to identify with the questions, and the issues did not relate to their situation or disease (P5, P6, P9-11, P15, P16). In the interviews, several participants related that the questions had nothing to do with their situation or hematological disease and their disease and the visit.

Most questions are not relevant to me…If I need help to shower, going on toilet, personal care…that is not relevant so it is easy to answer. Questions are not relevant to whether my treatment helps me or not because there is no question about that. It is all about my general condition…mostly useful to assess if I can get my treatment. However, someone must think this is relevant to me, so I just continue… (P16)

My feet hurt a lot, but I am sure that has nothing to do with my hematological disease…So what should I answer? I also think that it is a problem that I cannot see what I answered last time…It makes it hard for me to indicate if it feels better or worse than last time…Some of the questions I did not want to answer at all – but I had to…(P13)
Some patients even experienced a sense of alienation, as the questions seemed developed for others:

The questions in the questionnaire sound like they are made for very sick people and I am not like that at all. So of course I will answer, but does it make any sense? Or maybe I am not sick enough to participate? (P11)

_Completing PROMs was not easy_

Some patients expressed that it was difficult to answer the questions in the PROMs due to practical issues with the paper form or technical problems with the electronic version. Practical problems could be related to the instructions for the paper form, which were not intuitive for some patients:

I think there are so many questions and different instructions. Sometimes I am told to mark with a circle [around the response categories] and sometimes I am told to mark with a cross. And then I feel that you ask me the same questions several times and I am afraid to write something wrong that could influence my treatment here. (P5)

Few participants who completed the paper version of the PROMs had difficulty with their completion since the PROMs were accompanied with detailed instructions. One described not understanding the instructions in the electronic system and did not complete any PROMs because of being locked out by the electronic system.

Others expressed that they found it hard to make a decision about which response category to choose. They felt there was a lack of response options that would allow them to be more precise in their replies. Another problem reported was that questions were unclear or irrelevant to the point that answering was not possible:
Well…I think that it is hard to answer some of the questions...For instance, the question if I found my last visit here useful. What am I supposed to write…I actually do not know if my consultation has helped me or not – I would suppose [it is for] you to know that? (P12)

Another challenge participants reported was technical issues related to internet connections, mobile phones or problems with internet browsers. However, the paper form was also found to be difficult for some:

“You see I do not have an internet connection because I cannot use it. Can’t you just call me on my phone and ask me the questions? Going to the letter box is not easy for me either because it is so far away.” (P7)

“**PROMs are sometimes used for something**”

During the participant observations, no patients were seen to use or include their PROM responses in their dialogues with the professionals. However, one patient described that the completion of the PROMs had made him and his wife reflect further on their situation:

“Sometimes we [participant and his wife] talk about the questions and what did I answer last time…or sometimes this reminds me something that I should ask the nurse.” (P13)

Another participant explained how she always prepared for the visits by writing a list of questions that had emerged since the last visit. These were not related to her PROM answers. Prior to one particular visit, she had prepared seven questions on a post-it note. This patient seemed very satisfied with that visit because it had focused on issues that were important to her:

I always have this list on my table at home…Whenever a question or doubt comes up in my mind, I write it down…I am the one who is sick and I need explanations so I bring this with me when I see my physician. (P5)
Most participants experienced that their PROMs were not mentioned during the consultations and some felt insecure about whether the professionals used their PROMs. Some assumed that physicians and nurses would automatically incorporate the PROM data in the assessment of their condition. Participants did not expect to have a conversation about their answers or to get feedback on their PROM data during the consultations.

I have not felt that it was necessary to mention it [the PROMs] to physicians or nurses…I just complete the questionnaires…and I assume that someone takes care of it and takes action if needed…I do not know if my physician sees it…I guess she does? (P11)

Only one participant (P13) reported that his physician talked about his answers to the items in the PROMs during the visits observed, but this situation did not contribute to a better discussion of what was important to the participant.

Today was the first time that my physician was so concrete about my answers…normally she just repeats some of my answers. She might think the areas she chooses are important but is it not always what I feel is most important. (P13)

My physician was wondering why my breathing difficulties had increased. And well, I do not know what I had answered the last time but maybe something was changed. (P15)

This analysis has resulted in the conceptualization of three overall themes, all interconnected. First, participants experience that they contribute to a good cause by completing PROMs. They also reported that the content of the PROMs they were asked to complete were not highly relevant and did not cover all the constructs of importance to them. Moreover, participants
reported that they were certain that their PROM data was used for something relevant, either for research or as background information for their appointment. Only one mentioned that the completion of the PROMs was used to reflect on his situation. The process and themes are summarized in Figure 2.

**Discussion**

Despite the fact that well-known PROMs\(^2\) were used in the multimethod project, most patients in this study found that the questions did not resonate with their personal experiences and some patients experienced that they were forced to complete irrelevant items in order to complete the questionnaire. Other studies have also shown that using a well-known PROM is no guarantee of the PROM’s high content validity or adequate measurement properties.\(^1\) A recent review of PROMs strongly recommends that the target group be involved during the selection or development of the PROMs.\(^3\) Lack of patient involvement may have consequences for how well the questionnaire reflects patient perspectives, which in turn may affect the scope of how beneficial the use of PROMs can be. Another perspective on patients’ perceptions of PROMs has been found in a similar study that identified major challenges and concluded that PROMs may be of benefit to patients: however, the way in which PROMs are linked with the health care team is essential to patients’ experiences.\(^4\) This argues that patients’ experiences are, among other factors, dependent on nurses’ and physicians’ use of PROMs,\(^5\) a factor primarily absent in our study. Most of the patients in this study completed the PROMs because they were convinced that it would contribute to a good cause or because they felt indebted to an institution for expensive treatments. Similar findings have been found in previous studies, which have described that some patients diagnosed with cancer participate in research because they feel motivated to provide potential benefits to future patients or to possibly contribute to finding a cure for
cancer. Other studies have described this as a “moral duty to participate in scientific research.”

Finally, it was a significant finding that all the participants expressed high satisfaction even though their PROM responses were not discussed during visits in the outpatient clinic. Rather, their expectations were met, these being the monitoring of their illness status and adjustment of pharmacological treatments by a physician they knew and had confidence in. Previous research has shown that cancer patients expect different types and amounts of disease information depending on their type of cancer, the extent of disease progression, and their unique personal life circumstances. A study of acute myeloid leukemia patients’ expectations, for example, demonstrated that patients wanted basic information about their diagnosis, extent of disease, and treatment duration, while they were less inclined to want additional information, such as survival and remission rates, chemotherapy details, and subtypes of their leukemia.

From a critical theoretical perspective, patient experiences reported in the present study can be viewed as representing what happens when a patient’s lifeworld perspective meets the system-world at the hospital. Ideally, PROMs should improve patient care and give voice to patient concerns, and visits with a physician or nurse should reflect equality, consensus and shared decision-making. In this study, adding PROMs to the formalized process between patients and health care professionals did not change the communicative space or allow the patients’ lifeworld perspectives to influence communication and decisions, what Habermas refers to as the “discourse ethics.” Rather, the patient-professional relation was dominated by measuring and treating the illness based on science, and operationalized in practice as instrumental actions and result-oriented decisions, aiming for efficiency.
Habermas stresses the importance of keeping a balance in power and limiting the system from taking over: ideally, the patient’s lifeworld re-captures (or maintains) space for communicative action and therefore the individual experiences greater social freedom. Applying PROMs to clinical practice represents a systems-approach toward more person-centered care. In this study, such an approach did not seem to enable the patient’s lifeworld or facilitate person-centered care; instead, signs of indirect power were seen, for instance when participants reported feeling alienated, obliged to give something back to the system, fearful that they were too old to deserve treatment, or fearful that without participating the treatment would stop because the medication was too expensive. Seen from this theoretical perspective, the system dominated the PROM process from invitation through participation, and from completion of the questionnaires through to the visits at the outpatient clinic.

Compared to other recent PROM studies, our findings differ. A recent Danish study concludes that PROM-based follow-ups allow for greater possibilities for patients self-management, and that patients experienced consultations as being more relevant and personal when PROM were used.\textsuperscript{47} Another study found that PROM-driven visits may facilitate a more comprehensive assessment leading to prompt identification and tailored management of needs; furthermore, participants highlighted how the selected PROM prompted them to think about the full spectrum of their needs, resulting in needs and concerns being raised that they would not have identified previously.\textsuperscript{48} A hypothesis about the difference between the two studies and the present study may be the difference in contexts or that the PROMs used in the studies had high content validity, as it was developed directly for the target group, whereas the PROM used in the present multimethod project was generic.\textsuperscript{49} Finally, neither patients nor key staff were involved in the development of the PROMs in this project.
**Strengths and limitations**

In terms of validity\textsuperscript{38} and credibility,\textsuperscript{26} the findings reflect an interpretive description of patient perspectives about being included in a new PROM intervention at an early stage of testing. The results are highly dependent on the current study set-up and the findings could be expected to vary depending on the departments and health care professionals’ experiences with PROM data, as it is known that implementing PROMs is a long-term process.\textsuperscript{50} During the study, the research leaders discussed ethical considerations regarding justification of the lack of use of PROMs as identified by the participants. However, the decision was made to continue the intervention and observations, as the intervention was considered safe and such experiences were important to explain challenges and guide future practice with PROMs.

In our recruitment and data collection, we aimed for depth and variety. However, participants may not have represented the general patient population seen in clinical practice; even though all patients who were invited agreed to participate, this sample lacked participation by young or middle-aged patients with cancer. It is important to underline that the findings in this study come from the early phase of the PROM intervention and that the approach is new to both patients and staff, as PROMs represent a paradigm shift within consultations in the hematological speciality.\textsuperscript{39} Further research in PROMs should therefore focus on the experiences of nurses and physicians and how they perceive and use PROMs in clinical practice.\textsuperscript{19}

**Conclusion**

In this study, we found that participants struggled with the content of the PROM questionnaires being used: they found some items irrelevant, and some themes and items were missing, as were some response options. Though the PROM data were rarely elaborated on by the nurses and physicians during patient consultations, the participants continued to complete the PROMs
because they were convinced that the data was either used for something useful, was in support of research, or because they felt indebted to the institution for their treatment.

The contribution of this report is the finding that patients diagnosed with hematological cancers do not necessarily experience the use of these particular PROMs as supportive of their individual trajectories or experience that it provides room for their lifeworld perspectives. An implication for future practice is that nurses and physicians need to be able to articulate PROMs as part of routine care provision, to support the goal of patients’ PROMs being incorporated as a valuable part of their personal trajectories.
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Legends for tables and figures

Table 1. Facts and Considerations About the PROMs Used in the Multimethod Study

Table 2. Participants Included in the Qualitative Study

Figure 1. Flowchart of the Multimethod Project "PROMS Integrated in the Follow-up of Patients. Diagnosed with Hematological Chronic Cancer"

Figure 2. Flowchart of the Introduction (Green), Process (Blue) and Findings (Grey) for the PROM Intervention. Phases of Patients’ Experiences Linked to Activities.
### Rationale for the choice of PROMs used
The multimethod project was established to develop a holistic approach to patient care by increasing focus on supportive care, improved communication, and increased patient involvement during meetings at the outpatient clinic. The multimethod study aims to integrate PROMs in clinical practice as guided by the Danish National Guidelines on cancer treatment. What influenced the decision to use generic questionnaires was mainly the target group. Hematological cancers are a heterogeneous group of chronic conditions with different trajectories and the PROM instrument was chosen to reflect patients with a variety of disorders, as PROMs should report to clinicians about patients’ health-related quality of life, patients’ functional status and patients’ symptom burden. Nurses and physicians were encouraged to incorporate PROMs, guided by the local guidelines, during follow-up meetings with patients diagnosed with chronic cancers.

### Questionnaires
The PROMs used were: the Danish versions of the EORTC QLQ-C30 and the OEQ. The OEQ was translated, adapted and validated; the translation was tested for understanding and adjusted during two rounds with two independent focus groups, consisting of patients diagnosed with hematological cancers. The validation was guided by the “Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO)”.4

### Completing the PROMs
Patients were systematically asked to complete the two questionnaires at home one week before meeting their physician at the hematological outpatient clinic. The questionnaires were available to patients on the internet through a safe, encrypted internet connection. Participants completed the questionnaires on their own PC, tablet or smartphone, using a security code. Participants received a reminder by e-mail and SMS or telephone when the questionnaires were available. Additionally, in order not to exclude patients lacking internet access, a paper form was offered so that patients could complete the questionnaire at home and then forward it by mail to the department. 16 patients used the paper form. Data were collected and stored in a safe database. The PROMs were transferred into the electronic medical record system to be easily available to clinicians. When transferring the PROMs into the electronic medical record system, the EORTC QLQ-C30 was converted to a standardized short-form while the OEQ was transferred in full.

### PROMs in Denmark and internationally
The development of PROMs is flourishing in Denmark. PROMs were introduced in Danish health services around 2016, when the organization Danish Patients published a report that analyzed the potential of PROMs in the Danish context. Previously, PROMs were mainly used within the medical industry to assess the influence of medication. In 2017, the Danish state decided to elevate the development of PROMs to a national level and formed a steering group to support standardization and application of PROMs throughout the health care system. The steering group is in charge of standardizing PROM instruments and establishing guidelines as well as contributing to knowledge sharing on the use of PROMs. The establishment of the steering group has led to numerous initiatives, including application of PROMs in heart disease and cancer treatment; however PROMs are rarely implemented as part of routine care. Internationally, PROM development is moving towards ePROMs, real time data, and interactive instruments developed psychometrically to transform items during completion. Such remote monitoring systems facilitate real-time communication between patients and clinicians using remote symptom monitoring devices, which are used, for example, in cancer treatment settings.5

Abbreviations: EORTC, European Organisation for Research and Treatment of Cancer; OEQ, Outcomes and Experiences Questionnaire; PROMs, Patient Reported Outcome Measures; QLQ, quality of life questionnaire.
## Table 2. Participants Included in the Qualitative Study

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<th>Patients</th>
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Abbreviations: Min., minutes; No., number; PROMs, Patient Reported Outcome Measures.

Patients marked with a * were accompanied by a relative.
Figure 1. Flowchart of the Multimethod project "PROMS integrated in the follow-up of patients diagnosed with Hematological Cancer."

Rationale for RTC study groups: Group 1 completed PROMs, which were available to nurses and physicians aiming to evaluate the effect on supportive care initiatives and patient satisfaction. For Group 2, PROMs were not available to nurses and physicians, with the aim of evaluating the effect of supportive care initiatives based on the hypothesis that PROMs completion supports patients, helping them to raise issues with clinicians. For Group 3, the control group, patients did not complete PROMs, as this was not standard department procedure. In a forthcoming quantitative analysis article, the control group is compared to Groups 1 and 2, as they answer the same two questionnaires once, after two years’ inclusion.
Figure 2. Flowchart of the introduction, process) and findings for the PROM intervention. Phases of patients’ experiences linked to activities.