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Use of patient-reported outcomes in outpatient settings as a means of patient involvement and self-management support - a qualitative study of the patient perspective

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Abstract

Rationale, aims and objectives: Patient-reported outcomes (PROs) are being implemented in clinical practice across different healthcare settings with varying purposes. Involving patients in reporting outcomes may increase their attention to symptoms and thereby support their self-management. The aim of the present study was to describe patients' experiences with a web-based PRO system where patients complete a PRO questionnaire at home or in the outpatient clinic prior to a consultation. Moreover, the study aimed to explore how PROs influenced the interaction between patients and clinicians during the consultation.

Methods: Through participant observations of 9 consultations and 12 semi-structured interviews with patients after the consultation this interpretive description study explored patients' experiences with the PROs system. The PRO included self-assessment on health-related quality of life, symptoms and wellbeing. Patients who visited the outpatient clinic at the Department of Renal Medicine at Aarhus University Hospital in the Central Denmark Region in February and March 2014 and in March and August 2015 were invited to participate. We used a convenience sampling approach to recruit patients who had completed at least two PRO questionnaires.

Results: The analysis revealed rudiments of PROs in clinical practice leading to an increased understanding of their chronic disease, patient-centred communication and an additional focus on psychosocial problems. However, the operational application of PROs in the outpatient clinic and also patient attitudes were substantial and crucial barriers for PROs as methods to achieve patient involvement and self-management.

Conclusion: The use of PROs in outpatient consultations may support patients' self-management by (a) encouraging patient-centred communication in the consultation, (b) legitimising talk about psychosocial problems and (c) increasing patient understanding of their disease. Yet, implementing PROs in clinical practice does not *automatically* involve patients and support their self-management. We suggest supplementary clinical initiatives to strengthen patient involvement and securing benefit from PROs.

Keywords

Chronic illness, outpatient setting, patient activation, patient-centred care, patient-centered communication, patient empowerment, patient engagement, patient involvement, patient perspectives, patient-reported outcomes, person-centered healthcare, psychosocial care, self-care, self-management

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Introduction

Globally, patient involvement in healthcare is high on the political and clinical professional *Agendum*, not only because patients themselves are calling for more

involvement [1-2], but also because of legal requirements [3,4] and clinical ambitions [1,5]. Although studies of patient involvement have shown promising results, it remains a challenge to maintain these positive effects in daily clinical practice [6,7]. Patient involvement has been

reported to be more of an aspiration than a programme of action and the reality lags behind the rhetoric [8]. Patient involvement is not the ultimate goal of clinical practice, but rather a means to support patients' self-management. Self-management refers to the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition [9]. Self-management support is the assistance caregivers provide to patients with a chronic disease to encourage decisions that improve health-related behaviours and clinical outcomes [10].

A patient-reported outcome (PRO) is defined as "a measurement based on a report that comes directly from the patient about the status of a patient's health condition without amendment or interpretation of the patient's response by a clinician or anyone else" [11]. PROs may be used at a group level in research and quality improvement and at individual patient level to support clinical decision-making and ensure optimal efficient use of resources [12]. This study focuses on PROs at individual patient level. In recent years, PROs have been implemented across different healthcare settings aimed at increasing the level of patient involvement [13-16]. PROs seek to ascertain patients' views of their symptoms, their functional status and their health-related quality of life (HRQoL) [13,14,17,18]. The use of PROs can be an incentive to a patient-centred communication between patients and clinicians where the patient's view and opinion regarding his or her health is valued [19-21]. According to a conceptual framework proposed by Epstein and Street, patient-centred communication influences the quality of the encounter between patients and clinicians by fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, sharing decision-making and supporting patient self-management [22].

Communication as well as information exchange between patients and clinicians on topics such as emotional functioning, HRQoL and sensitive issues, including sexual dysfunction, has been shown to improve using PROs [23]. Implementing PROs into clinical practice potentially allows patients to actively participate in their own care [24-26]. Furthermore, studies indicate that management of symptoms may be improved by PROs in routine clinical practice and increase symptom-related actions by both patients and clinicians [23], which is consistent with a better patient self-management.

The value of PROs as opposed to clinician assessment is emphasised by well-documented discrepancies between patients with chronic kidney disease, for example and healthcare provider assessments of problems and severity of symptoms [27]. A systematic review published in 2012 of randomized trials regarding electronic symptom reporting between patient and provider describes 29 different PRO systems. The review concluded that the capacity of these systems to support self-management interventions was likely to be particularly promising in terms of (a) patient satisfaction and health benefits, for example, improved quality of life and reduced symptoms and (b) improved resource utilisation [28]. A systematic review published in 2013 on the impact of routine collection of PRO data provided strong evidence that well-

implemented PROs improve patient-provider communication and patient satisfaction [19]. However, the review also concluded that the evidence of the impact of PROs on changes regarding patients' self-management, improved health outcomes and health behaviour was weak and that definitive conclusions on the impact of PROs are not yet available [19].

In summary, reviews of existing empirical research indicate that the patient perspective has received little consideration when it comes to PROs in clinical practice and as a means to support patients' self-management. The few available studies on the subject demonstrate that patients experience the use of PROs in clinical practice as valuable [26,29]. A smaller evaluation study on the experiences of patients with epilepsy of a web-based PRO system found that PRO led to an increased understanding of their disease in some patients [26]. A feasibility study published in 2010 on patient participation, PROs and self-management in patients with long term conditions [29] found that patients anticipated several advantages by using PROs. Completing the questionnaire and reflecting on the answers helped these patients to identify their main challenges. However, due to the feasibility design of the study, it is not possible to conclude whether or not the use of PROs has clinical impact on patients' level of self-management.

The aim of the present study was to describe patients' experiences with a web-based PRO system used in follow-up of patients with chronic kidney disease in an outpatient clinic at a Danish university hospital. Moreover, the study aimed at exploring how the PRO system influenced the interaction between patients and clinicians during the consultation.

Methods

To explore the impact of patient experiences and the PRO system on the consultation, we conducted an ethnographic field study using interpretive description (ID) as the overriding research approach. The field study comprised participant observations during outpatient consultations and individual semi-structured interviews with patients after the consultations. ID is an inductive, flexible research strategy to generate knowledge relevant within a clinical context [30]; in this case how patients with chronic kidney disease experience the PRO in outpatient follow-up.

Using theoretical scaffolding rather than a fixed theoretical framework and drawing pragmatically on elements of the classic methodologies grounded theory, ethnography and phenomenology, ID intends to gain a deeper insight into and understanding of human experiences within their natural context [30,31]. ID intends to develop a comprehensive interpretive description that can provide clinical practice with a research-based choice of action [30].

Setting

The fieldwork took place in February and March 2014 and in March and August 2015 in the outpatient clinic at the Department of Renal Medicine at Aarhus University Hospital where the web-based PRO system AmbuFlex/pre-dialysis was implemented in September 2013. Patients fill in a PRO web-based questionnaire at home before the visit or in the outpatient clinic prior to the consultation. It was applied in the outpatient clinic on the initiative of a consultant. At the start time of the study, 34 patients had filled in the AmbuFlex/pre-dialysis questionnaire and at the time of the last interview, 396 patients had completed the questionnaire. The group of referred patients included adults with chronic kidney disease, though not yet in dialysis treatment. The aim of AmbuFlex/pre-dialysis was to increase the quality of the consultation, to support patients' self-management [32] and thus to strengthen the focus on the patient as an active partner. PRO results were presented graphically to clinicians using the usual electronic health record system and could thereby be used as a tool in the consultation to support a patient-centred dialogue and identify important symptoms and problems in collaboration with the patient.

Sampling

Patients using AmbuFlex/pre-dialysis were referred to and included in the system by a nephrologist at the outpatient clinic. The inclusion criteria for the present study were patients referred to AmbuFlex/pre-dialysis who had completed at least two PRO questionnaires. We sampled the participants consecutively by convenience.

Data collection

The first author conducted the fieldwork, apart from 3 interviews conducted by a research assistant. Participant observations were carried out during the consultations where the researcher would take field notes. During the observation, the researcher focused on (a) how the PRO affected the interaction between the patient and the health professional; (b) how the PRO was articulated by both the patient and the clinician and (c) how much focus the PRO was given by both the patient and the clinician. The interviews took place in research facilities at the clinic after the consultation and were audiotaped. A semi-structured interview guide was developed and adjusted concurrently with data collection and analysis in accordance with the ID method. Data saturation was reached after 9 participant observations and 12 interviews.

Ethical considerations

The participant gave written informed consent prior to enrolment. The study was approved by the Danish Data Protection Agency (Identification no. 2015-41-3912). According to Danish law, no particular ethical permission was needed for this study.

Data analysis

In accordance with ID, we performed data analysis inductively and concurrently with data collection and included memo writing, synthesizing, theorizing and re-contextualizing [30,33]. All interviews were transcribed *verbatim* by the first author. First, we immersed in the transcripts to identify themes and patterns. Next, we moved on to broad-based coding where meaningful segments of text were assigned conceptual codes. As the codes became saturated, we moved on to pattern coding where specific dimensions of patients' experiences of the PRO were clustered into recurring themes. We asked new participants to reflect and elaborate on these recurring themes.

In the analysis of the interview transcripts and the field notes, we extracted 2 thematic patterns that represent the potential of the PRO for self-management support. The first pattern represents the *PRO as facilitator*, illuminating how the PRO can encourage patient-centred communication in the consultation, legitimising a focus on psychosocial problems and by increasing an understanding of the patient's disease. The second thematic pattern represents *barriers for the PRO* and demonstrates how the very application of the PRO, lack of joint ownership and the patient's attitude can become barriers for the PRO as a method for self-management support. The sub-themes are illustrated with quotes from patient interviews.

Results

Study participants were 9 males and 3 females aged between 36 and 81 years (Table 1). In what follows the 2 thematic patterns are presented.

Table 1 Study participants

Participant no.	Sex	Age (Years)
A	Male	44
B	Female	36
C	Male	79
D	Male	55
E	Male	55
F	Male	35
G	Male	70
H	Male	40
I	Male	39
J	Male	81
K	Female	48
L	Female	68
Mean		54

The PRO as facilitator

The use of the PRO in the outpatient clinic had the potential to increase patients' self-management. Two of the participants found that filling in the questionnaire helped them get a better understanding of their disease. When reflecting on the symptoms presented in the questionnaire,

the patients became more aware about the link between specific symptoms and their disease. For one woman, the PRO helped her to separate disease-specific symptoms from other more general discomforts:

“I think about, well that’s why I feel this way. Because it (the questionnaire) asks about water retention in the legs and dizziness and cramps and all that. Then you think, well this has to do with the disease because you don’t always know. A lot of things can be wrong with you (laughs) and you don’t always know if it has something to do with the disease.” (Participant no. B)

This increased understanding of the chronic disease may improve patients’ ability to manage symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic disease.

Two of the participants experienced the PRO as a way to legitimise focus on psychosocial problems. They both found that the application of the PRO in the consultation made it possible to initiate discussions concerning issues that were not limited to results of blood tests or the medical treatment of their kidney disease. A young woman describes how she experienced this change in focus:

“Yes, they’re more aware of how we feel. Before it was mostly about the numbers; the numbers are very much in focus. But now they also focus on if I feel well.” (Participant no. B)

She remembers that a doctor, based on her answers in the questionnaire, had asked about her thoughts about the future and whether she was concerned about the future. This focus on psychosocial problems increased the participant’s ability to manage some of the psychosocial consequences the disease had on her life.

A young man was diagnosed with a depression immediately after he filled in the PRO. He had been feeling sad and without hope since he was diagnosed with chronic kidney disease, but he had never found the courage or opportunity to discuss these feelings with any health professionals. When the doctor, prompted by the patient’s PRO, took the time to talk to the patient about his psychological wellbeing it became clear that the patient had a clinical depression and treatment was initiated:

“It was good because there were some things that I didn’t say myself that he managed to dig out (..) instead of sitting and explaining in there and it’s not always sure that you can say everything in there (...). It was in this way he found out I had a depression.” (Participant no. F)

The participant felt grateful and was convinced that without the PRO he would still have been depressed.

Thus, the participants perceived that the PRO satisfied their need for talking about problems and concerns that were not strictly related to medicine or treatment. When implementing the PRO and thereby routinely asking about the patients’ wellbeing and their perception of their disease, the health professionals signal that these are important issues.

During participant observations, we observed one situation where the PRO contributed to a patient-centred

communication. The PRO of an elderly man prompted a nurse to start a dialogue about his increased fatigue. In the dialogue the participant told that he believes the increased fatigue was caused by circumstances in his home, because his wife suffered from dementia. During the dialogue, the nurse and the participant talked about possibilities for him to get some help in the home.

In an interview, a young man explained how his PRO led to the involvement of his relative. The participant remembered how the doctor, prompted by the patient’s PRO, involved the wife in a discussion about the participant’s wellbeing:

“He (the doctor) sat down and explained it all, also explaining to her (the wife) how I felt. It was nice. Then it was a little easier for her. Then I didn’t have to sit and explain it to her.” (Participant no. F)

Barriers for PRO

There were 3 kinds of barriers for PRO as a method to promote self-management support. The first was the very application of PRO in the outpatient clinic; the second was a lack of joint ownership and the last barrier was the patients’ attitude.

The participant observations and interviews revealed that the application of PRO in the consultation was minimal and sometimes even absent. Not all doctors read the PRO overview in the electronic health record during the consultation. Some of the doctors did open the PRO overview in the consultation, but did not turn the screen so the patient could see the PRO and thus prompt a dialogue by the PRO. Most of the participants were in doubt whether their PRO was applied in the consultation or not. When asked about how PRO was used in the consultation, an elderly man answered:

“Well ... (long break). I don’t really know. I don’t think he (the doctor) has talked about it (long break). Yes, maybe once when the doctor said it looked really nice but otherwise there was nothing.” (Participant no. C)

When asked about how the consultation had changed since PRO was implemented, the majority of the participants articulated that the consultation had not changed at all. They experienced no difference in the interaction, the communication or the content of the consultation. This indicates that PRO has not been applied adequately in the consultation. An elderly man was asked to consider the difference between consultations before and after implementing PRO:

“Do you remember how the consultations used to be?”

“Yes, sure but there’s no difference.”

“No?”

“I don’t really think so but maybe the doctor thinks something else. I also assume that it’s for his sake I have to fill it in.” (Participant no. G)

A woman who had filled in more than six questionnaires was asked to describe how her PRO was usually used in the consultation:

“I don’t really know (...) It’s never been used.” (Participant no. K)

Thus, the missing application of PRO in the outpatient clinic was a crucial barrier for PRO as a method to support patients’ self-management.

Most of the participant had not even considered the PRO to be a tool for them. None of them complained about filling in the questionnaire, but the general assumption was that the questionnaire was a working tool for the health professionals.

A younger man puts it very straightforward when being asked what he gained from PRO:

“Nothing! I don’t use it, well I fill in the questionnaire, I’d say, but I don’t use it for anything.” (Participant no. A)

Another elderly man did not find the questionnaire very useful either:

“Has it taught you anything (to fill in the PRO)?”

“Not at all!”

“No?”

“No, I just think it’s a waste of time to do it.” (Participant no. D)

When the participants were asked about the purpose of the questionnaire many of them assumed that PRO was implemented to collect data:

“Well, I was sort of told that now you had implemented this and it’s just as much for collecting eh data to be able to see how you develop (...). So I’ve just seen it as something they use on the long term - to see what happens, you know, if it goes up or down.” (Participant no. E)

Another participant thought of the PRO as a way of saving time for the doctor:

“You have to make sure to answer the questions otherwise the doctor has nothing to start from. It’s what they go by. I guess it’s also to save time for the doctor otherwise you could sit there and jabber for hours.” (Participant no. F)

This lack of joint ownership is a barrier for PRO as a method for self-management support. When participants feel no ownership over the instrument and do not experience any benefits, PRO ranks alongside blood test and blood pressure measurement and implies no personal reflection. This lack of reflection can be one of the reasons why PRO did not automatically lead to increased self-management in this study.

The patients’ attitudes were found to be an overall barrier for PRO as facilitator for patient involvement. The analysis of the interviews revealed that almost all of the participants obstructed PRO as facilitator for self-

management because of their attitude. It was clear that most of the participants did not even expect to participate actively in the consultation or be involved in decisions regarding their disease or treatment.

Part of the attitude was the patients’ experience of time being an important factor in the meeting with the health professionals. All of the participants articulated that time was an important issue. They all experienced the health professionals as being in a hurry and they were very aware that the time was limited and thought the consultation should end as quickly as possible. Even though the participant observation showed that the health professionals always ended the consultation by asking if the patient had any questions, some of the participants were afraid to take up too much time:

“I can say if something is the matter. They ask how I am and all but time is limited and it has to go fast.” (Participant no. B)

Furthermore, some of the participants perceived the outpatient clinic as a rigid and simplistic system, with no room for individuality. Three of the participants looked for the opportunity to add additional text in the questionnaire, because they felt that the questions did not capture all of their symptoms:

“I would maybe have liked that there were three lines where you could write, ok? But I was told then that is was on purpose that they weren’t there because nobody reads it anyway. As they say they would rather do tick, tick, tick (informant makes short sounds and shows with the hand how to make a check mark). It’s very square - that’s how the system is.” (Participant no. A)

All of the participants perceived the consultation as the health professionals’ domain. They expected the health professionals to take the lead and be responsible for the consultation. They did not expect to have any say about the content of the consultation or the prioritizing of the problems discussed during the consultation. An elderly man was asked about his role in the consultation:

“My role? I don’t think I understand. I don’t think I have a role really in the consultation.”

“No?”

“My role, no I really don’t know what that should be; I don’t do anything.”

“Who decides for instance what to talk about in there?”

“Well, the doctor I guess (...) but I don’t know what the nurse writes to the doctor, I haven’t got a clue.”

“When you have filled in the questionnaire and it has maybe made you think about some problems or stuff, then you have the possibility to say ‘hey, I would also like to talk about fatigue’”

“No, that is not possible for me if the doctor doesn’t mention it.” (Participant no. G)

A younger man puts it very clearly when he was asked about his role in the consultation:

“My role? Well, I just show up, give blood, get a new appointment and go back home again.” (Participant no. A)

An elderly woman had had this experience in the consultation:

“I once said to the doctor: I have lost my desire to life, but then the doctor said that I can’t do anything about that. Then I said, I just feel I have no energy anymore and the doctor said, well the thing about the energy, we can do something about that.” (Participant no. L)

This reaction from the doctor clearly signals that the purpose of the consultation is not to examine psychosocial problems, but only biological problems. What is interesting is that not many of the participants problematized the consultation being the health professionals’ domain. It seemed that this was what they expected.

Discussion

In this qualitative study, we found rudiments of PRO in clinical practice leading to an increased understanding of chronic kidney disease, patient-centred communication and an additional focus on psychosocial problems added to the conventional physiological one. However, the very application of PRO in the outpatient clinic, a lack of joint ownership and the patients’ attitude were substantial and crucial barriers for PRO as a method for self-management support.

Our study revealed that, in a few cases, PRO contributed to patient-centred communication among patients-clinicians and clinicians-relatives, respectively. Several other studies suggest that using PRO improves patient-clinician communication [34-36]. In a framework for assessing the effects of PRO, Santana *et al.* [37] suggested that in a situation where clinicians use PRO data to discuss and educate patients, the use of PRO may potentially enhance patient activation. According to this framework, patients are activated when they understand their role and have the knowledge, skills and confidence to be active. In our study we found that 2 of the participants experienced how PRO helped them get a better understanding of their chronic disease. When reflecting on the symptoms presented in the questionnaire, the patients became more aware about the link between specific symptoms and their disease. The aforementioned framework states that patient activation promotes self-management, which is consistent with the findings in our study. We found that the use of PRO increased a participant’s ability to manage some of the psychosocial consequences the disease had on her life, which is concordant with increased self-management. In this framework it is further proposed that improvement in communication may help clinicians to detect unrecognized problems. A potential effect of completing the PRO may be that patients more frequently talk about the issues with

the clinician and the clinician gains insight into the patients’ perspective [37]. This perspective is consistent with our finding that 2 of the participants perceived PRO as a way to legitimise a focus on psychosocial problems. These patients both found that the application of PRO in the consultation made it possible to initiate discussions concerning issues that were not limited to results of blood tests or the medical treatment of their kidney disease.

Our study also revealed that the very application of PRO in the consultation was minimal and sometimes even absent. This lack of use of PRO as a barrier for increasing patients’ self-management is consistent with findings in a study by Greenhalgh *et al.* [34] on how doctors refer to PRO in oncology consultations. The authors found that PRO was often not explicitly referred to by the doctors or patients. Furthermore, they found that high scores on the PRO were not explored further if the patient indicated they were not a problem or were not related to the disease or treatment [34]. This absence of dialogue about the patient’s perceived problems is problematic as it might reduce the patients’ motivation for filling in the PRO [35]. Greenhalgh *et al.* suggested that explicit mentioning of PRO in the consultation may strengthen opportunities for patients to elaborate on the problems, which could lead to an increase in the patient’s self-management. The authors furthermore suggest that doctors may not always know how to communicate about PRO [34]. None of the clinicians in the present study have been formally trained in using the PRO system or in communicating about PRO, which could be a reason for the missing application of PRO in the consultation. Santana *et al.* [35] additionally found that programmes teaching clinicians how to use and act on PRO in clinical practice are key steps in supporting patient engagement and participation in shared decision-making. Studies indicate that it is not only practical barriers as lack of training that is at stake when it comes to the health professionals’ role in enabling self-management by the use of PRO in clinical practice. A systematic review of qualitative research from 2014 found that barriers to implementing the use of PRO in routine clinical care included scepticism about the validity of patient self-reports, unfamiliarity with PRO, preferences for physiologic measures, lack of time and uncertainty [25].

Thus, the complexity of implementation might also be the cause of the missing application of PRO found in our study. Donaldson emphasises that if PRO is to have far-reaching effects on individualized healthcare, the adoption of the tool must be taken into consideration [38]. According to Donaldson, PRO has poor conditions when it is just an incremental and added task to standard care. He argues that if PRO should facilitate patient-centred care it would require new care models in which clinicians and administrative leaders take patient-centred care so seriously that PRO - not the patient visit - would be the centre of the model [38].

When the patients do not perceive PRO as a tool for them it is a barrier to patient involvement. Barnes *et al.* [39] identified several factors that are obstacles to progress of public participation. Lack of ownership and the perception of health professionals are key barriers for patient participation. Our study revealed an attitude in

almost all of the participants that obstructed PRO as a facilitator for self-management and most of the patients did not expect to be involved or active in the consultation. This is consistent with Eurobarometer's qualitative study on patient involvement [1]. In the report it is indicated that patient involvement, in the sense of having patients at the heart of the healthcare process, seems poorly understood by many patients [1]. The report states that patient involvement sometimes is interpreted as something clinicians do to patients rather than something patients do themselves and concludes that patients' attitude, lack of knowledge and awareness are the barriers to patient involvement [1]. A report from King's Fund [8] stated that the reason for the slow progress of patient involvement is the fact that involvement is challenging. Involvement challenges vested interest and established ways of doing things and amongst other things, patient involvement requires patients themselves to think about their health and care in different ways [8].

So it seems that dialogue about the patients' PRO in consultation is difficult and the health professionals may not know how to initiate a discussion based on the PRO. A dialogue about the patients' PRO is of vital importance, though [40,41]. If PRO should reach its full patient involving potential it must give rise to a dialogue about the patients' views of their symptoms, their preferences and their wellbeing. Based on the above discussion about facilitators and barriers we suggest supplementary clinical initiatives to strengthen the patient involving benefits of PRO.

There are some limitations to our study. The sample size was limited, but there was reasonable variety in age among participants and a clear sense of data saturation within the research team. The participants were 9 males and only 3 females. This gender distribution is different to that commonly found among patients with kidney failure. Even though we did not find any gender-specific differences we cannot exclude that such differences might have been identified if more women had participated.

This research has only focused on patients' perception of PRO in clinical practice. In order to explore the mechanisms of actions related to PRO as a method for self-management support and involvement in healthcare, other perspectives should be explored. Thus, further research should both include other qualitative perspectives, larger samples and an attention to other entrants in the outpatient follow-up.

Conclusion

The use of PRO in outpatient consultations may support patients' self-management by (a) impelling patient-centred communication in the consultation, (b) legitimising talk about psychosocial problems and (c) increasing the patients' understanding of their disease. Yet, applying PRO in clinical practice does not automatically involve the patients and support their self-management. We suggest supplementary clinical initiatives to strengthen the patient involving benefits of PRO.

Acknowledgements and Conflicts of Interest

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