"We can still talk to the patient!" - Negotiating the narrative power of patient reported data

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Abstract. Patient Reported Outcome data (PRO data) are standardized questionnaire data on patients' own experience of their health and quality of life increasingly collected on digital platforms as part of treatment trajectories. In Denmark, national efforts are being put into developing questionnaires tools for meaningful clinical use of such data in cross-sectorial clinical pathways. PRO data is among other things seen as a way to enhance patient involvement by focusing the clinical encounter on "what matters to patients". With increased datafication of healthcare, some see the power of the irreducible patient narrative set aside for quantified, standardized and thus reductive representations of the patient – PRO data potentially being a case in point. Rather than assuming such reductionism, in this paper I will explore empirically how health professionals engaged in developing PRO-tools enact the relationship between PRO data and more complex, narrative representations of the patient. Based on fieldwork in the national Danish initiative engaged in choosing and developing PRO-tools for heart-rehabilitation, I will suggest that PRO data is both enacted as an illumination of the patient narrative, a substitution for the narrative and an inhibitor of the narrative. The tensions between different enactments call for further reflections on the role of PRO in emergent digital health infrastructures.

In recent years, great efforts have been put into making patient involvement more systematic and clinically relevant and the concept of Patient Reported Outcome data (PRO data) has gain significant success as useful both in and beyond the clinical encounter. PRO data is data registered by the patient in (online) standardized questionnaires and in the Danish context defined as: "data on the

patients' health status, physical and mental health, symptoms, health-related quality of life and functional level" (PRO-danmark.dk – my translation). Health policy makers, clinicians, and patient advocates increasingly see access to patients' individual assessments of their health and the effects of treatment as a necessary source of knowledge about the individual patient case as well as about the overall outcome of healthcare system (Black 2013). Research has shown that clinicians rarely ask patients about all the issues that they might find to be problems (Sprangers & Aaronson 1992) and asking more systematically for patients' own assessments and needs with standardized questionnaires has been shown to be positively correlated with clinical outcomes (Basch et al. 2017). Coupling such arguments for more clinical patient-involvement through data with a parallel promotion of more organizational involvement of patients experiences of outcomes as a better steering mechanism for healthcare systems, has made PRO data an extremely popular field of exploration when pursuing more patient-centered and efficient health system configurations.

However, the hype around PRO data should be seen in relation to a broader datafication of healthcare (Hoeyer 2016) in which the patient increasingly is datafied including the more subjective, intimate and everyday aspects of disease. However, with increased datafication of healthcare some see the power of the irreducible patient narrative set aside for quantified, standardized and thus reductive representations of the patient (Lyon 2007; Lupton 2012). In their paper entitled "Electronic Health Records and the Disappearing Patient" Hunt et al. (2017) describe, how the increased influence of the electronic health record in the everyday clinical encounters demands evermore standardized data points on the patient for documentation, billing and quality monitoring purposes. This, they argue, has pushed aside the clinical conversation and attention to the patient's individual narrative: "[EHR] seems to be obstructing clinicians' authority to direct consultations based on their knowledge, and is all but erasing patients as individual persons from the clinical encounter, replacing them with a digital representation as the object of care" (ibid; p. 404). The concept of "the data double" has also been put forward by scholars as a way to suggest that the real, embodied patient is being separated out from and made secondary to an artificial and de-humanized representation in data (Haggerty and Ericson, 2000; Lyon, 2007). However, as Grew and Svendsen has shown in their exploration of the increased datafication of heart patients, the experiences of knowing the patient and knowing oneself with data in healthcare arrangements may be more ambivalent, as the "real" patient and the patient-with-data cannot be easily separated to begin with (Grew & Svendsen 2016). Still, they also call into attention the frictions between data and personal story that may arise in the clinical encounters: "In many situations, there is no discrepancy between data and the embodied patient, and the use of data goes smoothly. In some situations, however, data become dominant and patient testimonies are marginalized,

generating experiences of being secondary to data and not belonging in the clinic." (ibid; p. 84). However, might PRO data be different, taking into consideration that they concern subjective aspects of having and living with disease? Prainsack argues, that we should still be critical in assessing their ability in supporting, what Prainsack has called a "deep" patient-centeredness (Prainsack 2018): "Meaning cannot be ascertained by handing out questionnaires to patients about what matters to them and what they believe in. Knowing what is important to patients, and supporting them in making decisions that are meaningful to them and their significant others, requires that patients are treated by people and in institutions that know them, see them and listen to them." (Ibid, p. 156). The use of data does not by definition stand in opposition to knowing, seeing and listing to patients. Rather the specific configurations of tools, infrastructures and practices may or may not afford a sensitivity toward "what matters to patients". Therefore I am in this research interested in exploring, how health professionals negotiate data vis a vis the patient narrative while being engaged in developing what is presented as patient-centered PRO tools.

PRO in Denmark: PRO for cross-sectorial heart-rehabilitation

Under the auspices of the Ministry of Health and managed by the Danish Health Data Authorities a national PRO initiative has since 2017 been seeking to initiate and support widespread and cross-sectorial use of PRO in Denmark. A central task for the PRO office is to select and/or develop nationally certified PRO-tools for a still undecided number of clinical areas to be made accessible to health professionals and health managers through a central 'PRO bank'. Central to its task is also to ensure a functional national it-infrastructure for sharing PRO tools and PRO data across sectors. The work is highly collaborative, where questionnaires are selected and developed with the involvement of patients, health professionals, patient associations and those responsible for national clinical quality databases. The work of selecting and developing PRO tools for cross-sectorial heart rehabilitation was planned in the beginning of 2018 and in August approximately 40 participants – mainly physicians and nurses from hospitals and municipalities across the country – participated in the first of 4 clinical coordination groups aimed at selecting and developing a national PRO tool to support the rehabilitative care given to heart patients. Parallel with these meetings a group of patients also meet in four workshops to discuss their perspectives on PRO and specifically to inform and reflect the decisions made by the group of primarily health professionals in the clinical coordination group. In this paper, I have limited myself to mainly analyzing the observations made in the clinical

coordination group. The participants in these workshops had very diverse experiences with PRO data - from not having worked with such tools and data at all to already having extensive experiences with specific tools for research or quality monitoring purposes. Also, they came from a number of different sectorial, organizational, professional and regional contexts with – which became evident in the workshops – very different practices and experiences. Nevertheless, the workshops can be regarded as an important space for the initial negotiation and scripting of the national PRO tool – a standard which will have implications for clinical encounters in future cross-sectorial heart rehabilitation.

Methods

During the fall of 2018, I did participant observations in eight workshops arranged by the Danish Health Data Authorities: Four half-day workshops for heart-patients and four whole-day workshops for clinicians. In addition I had informal conversations with the chair and project manager and consultants from the health data authorities and included written material such as mail correspondence and power point shows. The fieldwork is part of a larger assemblage ethnography (Wahlberg, 2018) studying the emergent PRO data assemblage in the Danish context (see also Langstrup 2018). I wrote extensive field notes during and shortly after the workshops and analyzed the material thematically.

Results

PRO data as illumination

"PRO is the patient's own illumination of his/her condition and situation – without the health professionals' interpretation" (my translation). This quote is taken from a slide with the caption "Why PRO is a good idea", which was presented by a consultant from the health data authorities to the participants at three of the four clinical coordination meetings on heart rehabilitation. The slide also shows a human figure illuminated by four sources of light each with a caption: "the record"; "test results"; "the consultation", and "PRO". The slide also says PRO as a source of information should be added to "give the patient more insight into and influence on his or her treatment" and "to complement the knowledge the health professionals have about the situation and condition of the patient [...]". Throughout the four clinical coordination workshops, PRO is promoted as data, which can illuminate the perspective of the patient. A doctor, in

a small promotional movie shown to participants, says "PRO is openness" and describes how PRO data has helped him get to talk with patients about issues like depression and anxiety – issues he would not normally have the time – or the nerve – to get around to talk about. Here and elsewhere, the traditional consultation is depicted as a limited space with very limited time – and PRO as a way to expand this space and the conversation between the clinician and the patient by asking the patient to consider "what is important to me" in advance with the questionnaires. The clinicians at the meetings are very positive toward this version of PRO: "Patients feel that these tools can help them get better at verbalizing how they are feeling", one physician with PRO experience argues.

However, illumination and extended dialogue may not be without its problems. Getting to know more about the patient's emotion and everyday life can be "heavy", and not all the participants found every patient narrative set in motion in a clinical encounter equally relevant: "Patients want to talk about a lot of things. We cannot talk about everything!" (Physician). Another physician says: "Not all patients are equally clever. If the patient controls everything [that is talked about, ed.], then we lose our justification for taking up their time" (Heart surgeon), suggesting that it is the clinician, who has the expertise to know what is relevant and irrelevant to address in the clinical encounter. Moreover, some of the participants fear that more rich accounts of patients' lives, concerns and needs produce new demands for clinical action that in reality are not actionable or not a medical concern to begin with. In a discussion about whether to add an item in the questionnaire tool about sleep, a cardiologist reflects: "Sleep! But what the hell am I to do about that with my cardiology expertise? […] We should not ask about things that we just leave unattended, then patients will be very disappointed". The possibility of referring the patient to someone with expertise in sleep is suggested as the obvious solution by other participants. Regarding issues that might be brought up, but are seen as irrelevant for treatment – in this case their relationship status, which statistically may be predicative for their outcome – a physician jokingly asks: "Maybe we should find them a partner? Refer them to a dating app?".

PRO data as substitute

However, PRO is not just introduced by the health authorities as a tool for starting and enhancing a dialogue – it can also be a tool for focusing the dialogue or substituting it altogether. PRO data is produced by patients answering questions at home in advance of a clinical encounter, and it is standardized and can be presented to the clinician in advance as a color-coded overview of the patient's concerns (issues encoded as red, yellow or green when rated on severity). However, the calculability of the data also makes it possible to sort patients and prioritize services accordingly. In the clinical coordination workshop, this usage

of PRO data is referred to as "visitation". Here PRO data could be a substitute for a clinical encounter and thus for the patient narrative. The issue of automation, substitution and prioritization is a delicate matter throughout the workshops. On the one hand, using the data to substitute redundant or time-consuming dialogues is supported by some physicians: "PRO is smart. We can use it to sort our patients. It is more rational! The resources can be allocated to where I need them" a physician argues. "We are getting more and more patients! We need to prioritize […] Who should be seen by us, and who shouldn't. Some patients drive a very long way!" (physician). Here the possible substitution of a clinical encounter with screening through PRO data is seen as a way to curb raising demands and avoid wasteful care – also for the sake of the patients. On the other hand, the wish to engage more with patients and their individual concerns is by most participants seen as the main purpose – not to rationalize visits. The ambivalence toward the use of PRO data becomes particular evident in discussions about a paper-based dialogue-tool promoted by a participating nurse. This tool does not record any data, but as the nurse argues: "It signals, "We are interest in you as a patient!". It helps us get away from the biomedical model! It is important to be met very openly and not as a category in a questionnaire". However, in the workshops PRO is differentiated from such more unsystematic and 'analogue' approaches which are deemed inappropriate with reference to their incalculability: "The dialogue-tool might be important for conversations, but it isn't an instrument that can measure anything" (chair of the workshop, physician). This indicates that even if dialogue is the central purpose, data should be produced for several purposes, not just supporting the patient recounting their narrative.

However, using the data algorithmically for deciding who should be seen and how shouldn't is opposed by the majority of participants and also by powerful stakeholders in the cardiology arena beyond the meetings: "We are skeptical because it has been linked to cost-reductions, wanting to cut some consultations". "We are not ready to use it as visitation support, deciding whether to see the patient or not. We still want to see the patient" (Cardiologist referencing conversations she has had with the Cardiological society between workshops). The hesitation toward substitution of clinical conversations with patient also surface in other discussions: "There shouldn't have to be a PRO questionnaire before every meeting – it doesn't make sense! It is still a clinical task talking to patients! We have to be very critical when considering what we are committing ourselves to. People and trajectories are different." (Physician). At a different occasion, the same physician forcefully exclaims: "We can still talk to the patient!". The issue whether PRO data is supplementing or substituting the clinical conversation is professionally touchy as many of the participants see "talking to the patient" and getting to know their problems and concerns as their core task and competence as clinicians. When asked about his thoughts on PRO at the first workshop a physician laconically answers to the amusement of the

participants, "Sounds like a good idea. Asking patients questions and acting on their answers". He obviously felt, that this was at the core of what he already did.

PRO data as inhibitor

Getting better, more patient-centered, systematic and more clinically relevant knowledge about the patient is the main argument for PRO data in the workshops. However, the risk that PRO will become an inhibitor for the clinical conversation and for allowing the patient to recount their illness narrative is also considered during the workshops. The standardization of the questions is seen as one challenge:

"During a break a couple of nurses discuss if PRO could imply new inequalities in access to treatment. Even if people get the same questions they will understand them differently. Nurse: "If a man from North Jutland answers, "I feel fine" it means something totally different from a man from Aarhus [big city] answering the same". The other nurses agree – this is something they can handle when they talk to people, but if they only get the data, they might not consider it." (Fieldnotes). This concern of inequality also related to language, as not all PRO tools are translated into all the languages spoken by patients: "We are so excluding toward patients who don't read Danish. […] We risk pushing them even further away." (Nurse). At another meeting, participants are again discussing if PRO could worsen inequality: "Answering a questionnaire, it is demanding. "Well, all in all I am doing okay". Then we get them into some it-system where it is registered that they are doing well. Then they will be referred to "no appointment"." The consultant comments, that the answers should not stand alone, but other participants are equally concerned: "A number of people will not answer because they feel that answering is an additional burden." (Physician).

At the very first meeting, the introduction of PRO is argued as the anti-dote to inattention to the patient: The chair of the workshops quotes a patient saying "Ten years ago you listened to us. Today you do not. You are too occupied with registration work". However, some participants are worried that this inattention will worsen with more PRO data to attend to: "I think it will be much worse with clinicians looking at their screens!" (nurse). Generally participants are worried about increasing data work in an already stressful clinical reality, looking more at screens and it-systems not working: "We will have to use time looking at it and doing something. We don't want to drown in data". The organizational and technological reality is thus seen as something that might corrupt the otherwise positive aspects of PRO inhibiting a more patient-centered dialogue with the patient.

Final reflections

The workshops ended with participants deciding on a 77 item questionnaire on a large range of issues ranging from symptoms over sexuality to mental health to given to patients at 3 to 5 different times during their treatment and rehabilitation trajectory. The questionnaire is to be tested during 2019 in a pilot study in a number of clinical practices across sectors. The participants also decided that the data collected should not be used to substitute any visits. The overall consensus was that PRO should be used to support the clinical dialogue. How this particular PRO tool will be used in practice is still an open question as is its actual implications for clinical encounters.

However, the analysis above does show that clinicians are actively trying to navigate between the different implications of datafication of the patient encounter. The participants in the four workshops actively engaged in discussing the purpose and use of PRO in cross-sectorial heart rehabilitation enacted PRO data as an illumination, a substitute and a potential inhibitor of the narrative of the patient. They generally supported the idea that data may enhance patient-centeredness by allowing for more nuanced accounts about what patients experience and need while dealing with severe heart problems. PRO data was here seen as a way to extend the clinical dialogue beyond the confines of the clinical encounter, supporting reflection and verbalization on the patient's part and giving legitimacy to talking about subjects otherwise easily neglected on the clinician's part. However, this primary enactment of PRO as a way to illuminate the patient's narrative rubbed up against the other enactments of PRO. These tensions concerned trade-offs between PRO data and clinical expertise; Trade-offs between the data-work implied with PRO data and having time to talk to and see the patient (Langstrup 2018); and finally, trade-offs between illuminating the narrative and raising demands (unrealistically or wastefully) for more care.

In one sense the analysis shows the seductive power of quantification (Merry 2016) of patient's intimate and everyday experiences of health problems. Participants were overall supportive of the ambition of using PRO as a way to ensure more systematic patient-centeredness in clinical practice and discarded the paper-based reflection tool for its inability to quantify and make calculable patients' reflections – even if dialogue was their stated primary goal. At the same time participants were also very cautious of the possible negative implications of increased reliance on a "data double" rather than the real patient in the clinical encounter. Knowing *about* patient through data rather than knowing *the* patient through "seeing them, and listening to them" (Prainsack 2018, p. 156) was something the participants were aware might be at stake and with this their professional expertise as interpreters of patient's narratives.

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