

How to Represent the Patient Voice in the Electronic Health Record?

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Abstract. There is an agreement among patients, professionals, as well as leaders, and governance that person-centered care (PCC) is central to care quality. PCC care is a sharing of power to ensure that the answer to: “What matters to you?” drives care decisions. Thus, the patient voice needs to be represented in the EHR to support both patients and professionals in the shared decision-making process and enable PCC. The aim of this paper is therefore to investigate how to represent the patient voice in an EHR. This was a qualitative study of a co-design process with six patient-partners and a team of healthcare personnel. The result of the process was a template for the information needed to represent the patients’ voice in the EHR based on three questions: “What is important for you right now?”, “What matters to you in your life?”. “What do you want your care team to know about your history?”.

Keywords. Person-centered care, what matters to patients, digital work-tool

1. Introduction

Patients, professionals, leaders of care delivery organizations, and governance alike consider person-centered care (PCC) as central to care quality [1]. Yet there is a significant gap between the rhetoric of PCC and the frontline delivery of PCC. The call for PCC is more urgent now than ever, as system demands on professional conduct leave little room for the enactment of PCC. Professional burnout is rising [2], and patient concerns are lost amid conflicting and rigorous requirements regarding documentation, cost-control, and adherence to guidelines, procedures, and standards. Ironically, the triad of PCC, integrated and proactive care (PIP-care) is thought to be synergistic, and key to the very outcomes systems are seeking [1]. Thus, improving PCC remains a high-level goal, both because it is the right thing to do, and because it is linked to improved patient, professional and system outcomes [3].

“PCC care is a sharing of power to ensure that the answer to: “What matters to you?” drives care decisions. Patients and professionals work together, within the constraints set by the care system, in a care process to achieve goals that are meaningful to the person.” [4]. While most interventions on PCC have focused on educating patients and professionals, little attention has been given to the information support directed at

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professionals. In the typical outpatient visit, the professional makes decisions on diagnosis and treatment based on the case history, the EHR information, and the clinical exam in the span of 10-15 min. The majority of patients > 60 years are multimorbid, in which case it is even more difficult to get a good understanding of the patient's challenges within the time limits. In addition, there are documentation and communication tasks to serve administrative needs.

In such a time-constrained context, spending time on an interview on the challenging topic of "what matters" to the patient, seems almost unreasonable. Yet, omitting this information may lead to interventions that are misunderstood, poorly adapted to patient circumstances, in contradiction to patient beliefs, or a burden of treatment that is unsurmountable [5, 6]. Especially in cases of complex multimorbidity, rigorous application of guideline recommendations may be disruptive and overwhelming [7]. The sum of these issues leads to loss of patient adherence, and a waste of time and resources spent [5, 6].

Thus, it is important that the patient's voice is represented in the electronic health record (EHR). This can increase clinician awareness and improves the clinicians' opportunity to tailor care to the unique patient. There is, however, a gap of knowledge on how to design a user interface and presentation of the patient's voice in the EHR, which can support both patients and professionals in the shared decision-making process and thereby lower the barrier to patient-centered care.

Our aim was therefore to investigate patient and professional views and suggest how to represent the patient voice in an EHR.

2. Methods

This paper is based on data from a qualitative co-design process with six patients with complex and long-term health problems and next of kin, hereafter named patient-partners, and a team of healthcare personnel working according to the PIP principles [1], in the Patient-Centered Team (PACT) [8]. Data from the patient-partners was collected through semi-structured interviews lasting up to 2 hours and two full-day workshops. The topic for the data collection was how the patient's voice, in terms of needs, values and preferences could be presented in an EHR to support collaboration and person-centered care for patients with complex long-term care needs. We also collected data through a series of four workshops with the PACT professionals. We focused on how to elicit necessary information and document it most efficiently. The workshops were audio-recorded, and summaries were written afterward. In addition, we did two full-day observations of PACT in clinical practice. The data was analyzed thematically in an iterative process aiming to provide a template for the information needed to represent the patient's voice in the EHR [9]. The template content was also discussed within the research group, and with the patient-partners and PACT in several iterations before we arrived at a final template.

3. Results

3.1. The Patient-Partners

The patient-partner wanted to make their health and life stories available for healthcare personnel involved in their services. They envisioned a digital summary of the key events of their health and life journey in form of a text or a video. The summary should enable professionals to see the patient as a whole person “*not just a bundle of diseases*”, and as a starting point for meetings between the patients and healthcare personnel.

The patient-partners underlined that their social life, relationship, networks, and role in society shape the way they live with one or more diseases. Therefore, the EHR must focus on more than diseases, tests, and diagnoses. They wish to be understood as individuals in terms of how they cope with their conditions in their everyday life. “*It is important that doctors and nurses know what you have in your ‘backpack’*” (patient partner).

Another reason for wanting a summary was to avoid having to repeat their story again and again. For multi-morbid patients who have a long complex medical history and/or have lived a life with various other types of challenges and traumas, it is stressful to continuously repeat their stories, especially traumatic experiences. A summary might avoid the reopening of old wounds and reduce the stress of remembering salient details for each new provider.

A third reason was that the summary could be a more effective way of providing new professionals with the information they needed. In the relatively short consultations, the patient-partners experienced there was not time enough to both tell the story and present the current problem and medical examination. Hence, they were forced to focus on the current problem, which led to the omission of relevant information from their past.

Regarding the content of the summary, the patient-partners emphasized an overview of their history, but also included “What matters to you?”. By the latter, they meant the summary should outline what they valued in their life and wanted to focus on forward, both in the short and long-term, so that this could be considered in the healthcare plans. To make the summary, the patient-partners suggest some form of an asynchronous dialogue between the patient and healthcare providers to provide the care team with important health-related issues to focus on upfront of an appointment.

3.2. What is Important for Health Professionals to Work with Coordination?

The PACT team, in line with the patient-partners, also talked, about the benefits of having a brief summary of the patient’s status and history, the patient voice, for their work. They said that such a summary could be used as the basis of their methodology to ensure coordinated patient-centered care. They especially outlined the importance of identifying the patients’ goal by asking “What matters to you? to both understand what was important to the patient and to get to know their personal life history.” They translated this goal together with the patient, the next of kin, and other professionals into a plan of actions to help the patient to reach the goals.

To make the summary, the PACT team gathered information through dialogues with the patient and next of kin in addition to a thorough reading of the patient’s medical record from different EHR systems to get a full overview of the patient’s life. A member from PACT also stated “[We] have time to do the thorough reading because it is part of our methodology”. In their experience, other healthcare personnel working in traditional

hospital wards, outpatient clinics, homecare services, or the GPs did not have the time and resources to make such extensive summaries.

They also emphasized that outlining the patients' long-term goals was not a trivial task. In their experience, patients often focused on short-term goals such as getting well enough to go home and manage life on their own. Thus, they had to ask a set of different questions to get patients to talk about long-term life goals. They also experienced that they needed to gain the patient's trust to get them to talk about their lives and what was important for the future. PACT underscored the importance of outlining the actual voice of the patient, in their own words, not just healthcare personnel's observations and interpretations of the patient's situation and what would be best for them.

When asked about how the current EHRs represent the patient's voice, they said that there was a prompt addressing "What matters to you?" in the daily nursing document template at the hospital. However, this field was seldom used, being either deleted or empty, because routines for when to ask and update this question was lacking and how to address the answers they got. "*You cannot ask the patient what matters to you in the same frequent manner as you ask about pain or observing a wound or fluid balance*" (PACT member). They also noted that even if there was a note on "what matters to you", it often disappeared in the long list of documents that evolved continuously, and often it had no link to the actions taken.

3.3. The Template for Digitally Outlining the Patient Voice

The template content included prompts to patients/ professionals that outlined the type of information needed, to cover the salient points in the history according to the patient (past, question three), the current situation (present, question one), and the long-term goals (future, question two). The overall concern was to bring forward information that was pertinent to the shared decision-making process where patients and professionals both contribute.

The first question was "What is important for you right now?" The purpose was to ensure that the short-term needs of the patient were included. As shown above, the PACT team had the experience that these instant goals were most important for the patients in an ongoing care situation.

The second question was "What matters to you in your life?" The purpose of this question was to attend to the more long-term health-related but also overall life goals of the patient in addition to the immediate ones.

The third question was "What do you want your care team to know about your history?" The purpose of this question was to get a summary of the patient's former important health and life events that might impact current care decisions. These include both aspects of life events, and the case history which may include care gaps, unresolved challenges, and expectations not yet fulfilled.

4. Concluding Discussion

We found that the patient-partners, health care personnel, and the researchers agreed upon three prompts based on "what matters to you?" that guide the presentation of the patient voice in the EHR: 1) current wishes, 2) the long-term wishes and 3) the key elements of the case history according to the patient. This "tool" can contribute to a PCC, integrated and proactive care approach, based on the patient's own understanding and

goals for his own life. However, it is not enough to know “what matters” to the patient, the information should also lead to action. Goals can be translated into concrete action plans, which are in turn evaluated against the patient’s “what matters”. As the patient’s situation and goals may change, iterative review and update of “what matters” may also be necessary.

With a stronger presentation of the patient’s voice, we show how the patient’s answer to “what matters” can be a guiding principle for concrete treatment and follow-up. Further research should investigate how feedback loops from patients regarding patient goals may support improvements of general quality of care and outcomes.

Conclusion: The ‘patient’s voice’ is a prerequisite for shared decision-making and a person-centered approach but is currently missing in the EHR. Thus, the findings in this study can be used to remedy this situation by providing patients and professionals with a practical “tool” that raises awareness, supports implementation, and evaluation of meaningful goals for patients.

Limitations: The ‘patient’s voice’-approach is mainly feasible work in chronic disease, and not e.g. in acute conditions. It is also intended as something that can be used during a consultation to overcome issues like patients’ literacy. Still, some patients could be asked to complete these questions themselves, thus saving the clinicians some time while at the same time strengthening the patient’s voice.

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