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Towards Automated Evaluation of Patient Centered Care—Assessing the Potential of Electronic Health Records

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Abstract. Providing patient centered care is a crucial element of high quality care. It can be defined as a responsive way of caring for and empowering patients, embodying compassion, empathy, and responsiveness to the patient's needs. The aim of this study was to assess the potential of using EHRs as information source in the development of tools for assessing PCC. An annotation guide following the Person-centred Practice Framework proposed by McCance and McCormack was developed for the purpose of this study. Twenty patients' documents were manually annotated, resulting in 539 expressions. All dimensions of the framework were covered in the documents, with 61.3% of expressions describing the activity of engaging authentically with the patient. The results of this study indicate that electronic health records are one potential source of information in automated evaluation of patient centered care, however more information is still needed on how to interpret this information.

Keywords. Patient centered care, electronic health records

1. Introduction

Patient centered care (PCC) has always been a cornerstone of high-quality nursing [1]. Today the value of delivering PCC to improve health outcomes and patient satisfaction is widely recognized within all areas of health care [1,2], being an integral part of high-quality health services [3]. PCC can be defined as a responsive way of caring for and empowering patients [4], linked to attributes such as compassion, empathy, and responsiveness to the patient's needs [3]. Ways to evaluate PCC are numerous, with the majority of approaches focusing on surveying or interviewing patients and

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professionals, or on observing clinical encounters. These methods are costly, time-consuming, and difficult to implement as part of routine care [5].

The potentials of utilizing electronic health records (EHR) in assessing aspects related to practice have been established within nursing research [6]. In their practice, nurse managers use EHRs to monitor nurse-sensitive quality markers, but they report a lack of tools to extract the information they need [7]. Previous studies indicate that, combined with artificial intelligence methods such as natural language processing, secondary use of EHR data would benefit automated evaluation of quality of nursing care components [8]. However, the utilization of free text EHR data in evaluating PCC is still lacking [9].

The aim of this study was to assess the potential of using EHRs as information source in the development of tools for assessing PCC. For this purpose, we developed and pilot tested an annotation guide for labeling expressions related to PCC. The guide could be utilized in collecting expressions to be used in training a machine learning model to automatically evaluate PCC from EHRs. The pilot was a manual annotation of EHRs from cardiac care units.

2. Methods

This was a retrospective descriptive pilot study using EHR data obtained from a cardiac center of a hospital district in Finland. All EHR entries made for patients (n=1852) admitted to the center in January 2020 were collected, including all free-text entries Provided by healthcare personnel caring for the patient. The data were extracted from the data lake by a data scientist and organized randomly as numbered text documents. The sample of 20 patient's documents used in this pilot study were selected using random sampling.

To guide the manual annotation of the EHR data, an annotation guide was constructed by conducting a systematic literature review using PubMed (Medline), CINAHL (Ebsco) and Cochrane -databases. The review resulted in eight research articles describing the use of EHRs in identifying aspects related to PCC. The organization of the literature was guided by the Person-centred Practice Framework proposed by McCance and McCormack. Examples of PCC extracted from EHRs were derived from the articles and categorized under five activities of PCC, i.e., (1) engaging authentically, (2) sharing decision-making, (3) working with patients' beliefs and values, (4) being sympathetically present and (5) providing holistic care [1]. The data analysis resulted in further dividing these categories into subcategories explored in chapter 3.

Using the annotation guide, the manual annotation of the EHRs data followed deductive content analysis methods [10]. Words or phrases describing PCC were annotated on the documents following the annotation guide. These were then collected and arranged to a spreadsheet for further analysis.

To ensure trustworthiness, all writers contributed to the data extraction in developing the annotation guide. Additionally, the manual annotation of the EHRs data was performed by two researchers. The reporting of this research followed the Standards for Reporting Qualitative Research (SRQR) checklist [11].

The study was conducted in compliance with The European Code of Conduct for Research Integrity guidelines [12]. The data used in this study was processed following the Regulation (EU) 2016/679 of the European Parliament and of the

Council and Data Protection Act and the Finnish decree on patient records (298/2009). All data was pseudonymized and managed following a confidentiality agreement, obliging the data access and storage solely using the servers of the hospital district. The study belongs to the Smart Health Care Leadership and Management programme at the Department of Nursing Science at the University of Turku, holding an ethical approval statement (9/2020) issued by University of Turku Ethics Committee for Human sciences (Health Care Division) and an administrative approval (J14/20) by the hospital district.

3. Results

20 patients' documents were annotated in this study. Half of the patients were male (n=10), with an average age of 72, 9 years (SD 9, 6). The total number of extracted expressions from the EHR's was 539, of which 429 were derived from nursing and 108 from physician notes.

Engaging authentically with the patient was the most highly represented PCC activity with 329 (61.3 % of all) annotated expressions in the EHRs. It was portrayed using expressions describing the patient's voice (n=140, 26.1%) by narrating the patient's speech, for example "the patient told", "says it's bothering" and "according to the patient". It also included documenting the patient's perspective (n=139, 25.9%), i.e., care experiences, expectations, and desires with expressions such as "thinks it might be a good idea", "wants to go home" or "the patient feels that". Additionally, engagement was made evident by describing the patient's emotional state and feelings (n=42, 7.8%), with expressions including "contented", "calm", "in a good mood" and "seemingly stressed". The patient's personality was scarcely presented with eight annotated expressions (e.g., "talkative", "pleasant in contact"), and no expressions portraying knowledge of the patient as a person were annotated in this pilot study.

Shared decision-making between professional and patient (n=97, 18.1%) was represented as signs of patient autonomy (n=51, 9.5%), such as patient declining ("refused pain medication") or requesting care, treatments, or help ("asks to adjust the flow"). It also manifested as shared understanding or agreement between the patient and the health professional (n=27, 5.0%) as expressions describing agreements ("agreed, that the patient walks") and mutual understanding, or as participatory decision making (n=19, 3.5%) in the form of discussions ("discussed heart healthy nutrition", "thinking about other options"). No annotations describing provider support to patient's choices were made.

Working with the patients' beliefs and values was described in 90 annotations (16.8%). The annotated expressions did not entail direct mentions about a patient's personal religion, values, cultural beliefs or attitudes, but they described the patient's social role (n=49, 9.1%) with expressions depicting visiting family members and friends ("the husband was visiting") or communication between loved ones ("the patient phoned his wife"). They also described the patient's personal history and life cycle (n=41, 7.6%) including expressions related to living arrangements ("the patient is living alone", "the patient is living with his wife"), family relations ("the closest relatives are...") and employment situation ("the patient is still in work-life").

Being sympathetically present in the care relationship (n=15, 2.8%) was described as a caregiver's support to the patient with ten expressions (1.9%) ("encouraged the patient to get up") and as the physical and emotional presence of the care provider with five expressions (0.9%) (the nurse had a "long conversation with the patient", the nurse "soothed the patient"). No annotations describing connectedness between the caregiver and the patient or their family were annotated.

Providing holistic care was the least represented activity in the EHRs with six annotated expressions (1.1%). They described care tailored to a patient's individual needs (n=4, 0.7%), such as offering patient "food to suit their appetite" or care to maintain patient resources (n=2, 0.4%) with descriptions of providing tailored guidance to facilitate returning to leisure activities.

4. Discussion

The results of this pilot test indicate that EHRs show potential in evaluating subjective and straightforward aspects related to activities of PCC, such as the patient's perspective, patient's voice, expressions of autonomy and commonly known social roles. It was observed that the more complexity was involved in the studied activities, the less they were mentioned in the EHRs. These included notes portraying interconnectedness between the patient and the caregiver, information regarding the patient's personal beliefs or values and depictions of the patient's personality. The use of these expressions in documentation would, however, require careful consideration, as they might reveal information regarded as sensitive to the patient or contain objective and potentially stigmatizing information left open for interpretation by the reader.

EHRs have long been criticized for believing to dehumanize the patient by portraying them through their symptoms and metrics [13] and their use have raised concerns of having a negative impact on PCC [14]. The findings of this study found evidence that the documentation does entail elements of PCC, but not all aspects are adequately presented. A previous study reviewing PCC in nursing documentation stated that patient's involvement in decision making was not evident [15]. These findings suggest a need for developing documentation guidelines to better promote PCC, for example by increasing the use of active terms instead of passive ones when describing patient care, activities, needs or desires. Further research is warranted to establish the fine line of information needed for the caregiver to provide best possible PCC whilst considering patients individual preferences of openness to share their personal matters such as values, believes or socioeconomical status.

The results of this study validate the annotation guide in evaluating PCC from EHRs. Moving further, a larger study with bigger sample size is required to establish the data needed for developing an algorithm to automatically extract PCC-related terms for monitoring of trends in documentation. However, using EHRs as a data source increases the importance of evaluating them before and during their secondary use, as all dimensions of nursing care are shown not to be fully presented in EHRs [16]. Understanding and taking these deficiencies into account increases the usability of the acquired information. Future research should also focus on developing guidelines to facilitate the interpretation of this information, as well as explore the possibilities in using information normally left out in regular care.

Limitations of this study include the small sample size used for the pilot testing of the annotation guide, and a single center institution.

5. Conclusions

This study showed the potential of extracting expressions related to PCC from EHRs, as well as the possibility of using EHR information as one data source in automated evaluation of PCC. This study also validated the annotation guide developed for the purpose of this study. To move forward with developing a machine learning model to automatically evaluate PCC from secondary data, guidelines for using and interpreting PCC information should be established.

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