Patients' Perceptions of Heart Failure Through the Lens of Standardized Nursing Terminologies

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Abstract

The purpose of this study was to identify how frequently heart failure patients use nursing terminologies to describe their health. To create Concept Unique Identifiers, interview transcripts were processed using the Clinical Text Analysis and Knowledge Extraction System and matched to health-related terms from the Unified Medical Language System ontology. One-third of the health-related terms that patients used mapped to nursing terms. Findings suggest nursing documentation should be incorporated in the EHR for better communication.

Introduction

Effective communication between physicians, nurses, and patients is vital for patients to understand and engage in their self-care following hospitalizations. However, the use of different terminologies between physicians, nurses, and patients during hospitalizations can present a barrier to patients' comprehension of health information.[1] Our previous studies have shown the use of common terminology between physicians' and nurses' documentation is only around 21%.[2] Beyond the terminologies used by physicians and nurses when speaking to patients during hospitalizations, post hospitalization discharge summaries that inform patients of their self-care instructions often contain these terms that many patients find confusing. Although patients may be familiar with some of the physicians' terms, research has demonstrated that patients make multiple types of errors when interpreting medical documents.[3] Information on patients' use and understanding of nursing terminology is limited. These issues are particularly important for patients with heart failure (HF) because over 50% of HF patients do not have the required knowledge to understand their discharge instructions in order to take care of themselves at home.[4] This lack of understanding is a contributing factor that makes HF one of the most common cause of hospital readmission within 30 days after discharge.[5] The purpose of this study was to identify how often hospitalized patients with heart failure (HF) use terms that can be mapped to nursing terminologies, or their synonyms, when they describe their experiences with HF and health concerns.

Methods

As part of our larger research study (R01 CA225446-01), we conducted semi structured interviews with 21 patients (15 to 60 minutes, average 35 minutes) diagnosed with HF prior to their discharge from hospital. The research was approved by the IRB, participation was voluntary, and informed consent was obtained. The interviews, conducted by an expert in sociolinguistics, followed a narrative approach focusing on patient's perceptions, feelings, and experiences of their disease. Interviews were audio-recorded and transcribed. Transcripts were preprocessed to remove sections where patients introduced themselves and answered general questions as well as the interviewers' questions and responses. Then, the *Clinical Text Analysis and Knowledge Extraction System* (cTAKES) (http://ctakes.apache.org/) was used to process the remaining parts of the transcripts. cTAKES is a natural language processing system that turns health-related data extracted from unstructured text into structured data by mapping written words (e.g., "RA") to medical concepts (e.g., rheumatoid arthritis) based on standardized medical ontologies. cTAKES mapped the health-related terms patients used with the Unified Medical Language System (UMLS) ontology to extract the Concept Unique Identifiers (CUIs). UMLS is a comprehensive list of clinical concepts and terms from various controlled vocabularies that provides a mapping structure among vocabularies and enables linking the terms from various terminology systems (https://www.nlm.nih.gov/research/umls/).

Second, we counted how many times a CUI from the UMLS 2018 files occurred in our patient interviews. From the UMLS 2018 mappings of Nursing Diagnosis: Definitions and Classification (NANDA-I), Nursing Interventions Classification (NIC), and Nursing Outcomes Classification (NOC) structured terminologies, nurse related CUIs were identified. If the same CUI belonged to more than one category (e.g., C0043144 is both NANDA-I and NOC), we credited both terminologies due to the overlap. To be most inclusive of patients use of terms, we included health-related terms that were negated (e.g. "no chest pain" or "no weight gain").

Results

We identified a total of 2516 health-related terms in the 21 interview transcripts, 749 of which mapped to the standardized 3 nursing terminologies. Theses 749 nursing terms were classified as 45% NANDA-I, 2% NIC, and 53% NOC. On average patients used 120 health-related terms per interview with an average of 36 terms that mapped to nursing terminologies or their synonyms. Their use ranged per patient from 19% to 67% (average: 31.56%).

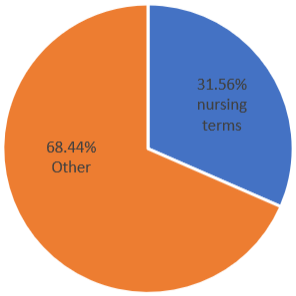

Figure 1. Percentage of health-related terms used by patients.

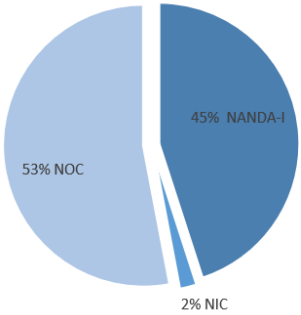

Figure 2. Percentage of nursing terms used by patients.

Discussion

We found that nearly one-third of the health-related terms used by patients mapped to nursing terms or their synonyms for diagnosis, interventions, and outcomes. The vast majority of the terms were either diagnosis or outcomes with very little use of nursing interventions terms. This is not surprising given that patients may not be focused or aware of the many interventions that nurses perform during their hospitalization. However, patients' understanding about the interventions performed by nurses (e.g. fluid management) in the hospital that will be shifted to the patient post hospitalization is vital to effective self-care. The high frequency of nursing terms or their synonyms in patient narratives and lack of nursing care documentation in Electronic Health Records (EHR) suggest an urgent need for incorporating interoperable nursing care information in patients' longitudinal record to avoid any potential for gaps in care or communication. Our future work will examine patient use of physician terms or their synonyms in patient narratives, but if nursing terms are commonly used more, using these terms to frame patient discharge instructions may be an effective way to improve the effectiveness of discharge instructions.

Conclusion

Patients are using nursing terms or their synonyms frequently when they describe their health. As national efforts to engage patients in their EHR, these terms must be in the patients' longitudinal record to increase patients' comprehension about their health and empower their involvement is self-care.

References

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