1. INTRODUCTION

Education materials and discharge instructions that are provided to patients when they are discharged from hospitals are usually created using a “one size fits all” approach. However, since the capability of a person to understand health content varies with several factors like his/her age, background, educational status, and medical history, majority of the patients might not be able to benefit from such a generalized document. Studies have shown that patients’ perspective is essential for patient education and that engaging the patients in their own care reduces hospitalizations and improves the quality of life [Riegel et al., 2011]. Motivated by the results from these studies, we plan to generate personalized hospital-stay summaries for patients. In this abstract, we will give an overview of our work in progress: the factors based on which we plan to proceed with personalization and our ideas for incorporating these information into our summaries.

2. BACKGROUND

Our framework for generating personalized summary builds upon the modules that were developed during the earlier phases of our research (see modules labeled as ① and ② in Figure 1). Module ① identifies the medical concepts present in the physician and nursing documentation for a patient and explores the relationship between them [Di Eugenio et al., 2014]. In module ②, desired concepts are extracted and a metric is used to decide whether a medical concept needs to be further simplified or not. For those concepts that are identified as Complex, definitions are extracted from three knowledge sources: Wikipedia, Wordnet, and the Unified Medical Language System (UMLS). The definition that is ranked lowest (i.e. simplest) by our metric is selected and is provided to the user along with the summary [Acharya et al., 2016].

Related work: Seminal work on personalizing health document focused on producing customized patient education materials by using a manually created knowledge base. [Gatt et al., 2009] use hand-crafted ontologies to generate customized documents for nurses, family, and friends of the patient admitted to Neonatal Intensive Care Unit (NICU). Our work is inspired from the PERSONAGE system [Mairesse and Walker, 2011], which is a parameterizable language generator that takes the user’s linguistic style into account and modifies the system’s linguistic style accordingly.

3. APPROACH

We plan to customize our summaries according to the health literacy of the patient and their motivation to participate in taking care of their own health. We also want to include other patient-specific information like their socio-emotional status, preferences, and needs so that patients are encouraged to read and understand the content of their discharge summaries.

3.1 Features guiding personalization

1) Health literacy: Statistics show that only 12% of US adults have proficient health literacy and over 77 million people have difficulty with common health tasks like following medical instructions or directions on a prescription drug label [HHS, 2008]. There are three assessment tools that are primarily used for measuring health literacy: Test of Functional Health Literacy in Adults (TOFHLA), National Assessment of Adult Literacy Survey (NAALS), and Rapid
Estimate of Adult Literacy (REALM). TOFHLA is used for measuring the capacity of a patient to comprehend hospital documents, while NAALS evaluates the patient on the clinical, prevention, and navigation domains of health. We plan to use REALM, which a 66-itemed word recognition and pronunciation test. Based on how correctly a participant pronounces the words present in the test, a score is provided. This score indicates whether the literacy level of the patient is of ‘third grade or below’, ‘fourth to sixth grade’, ‘seventh to eighth grade’, or of ‘high school’ level.

2) Patient’s familiarity with the health issue: Patients who have been suffering from a health issue for a while are known to be familiar with some of the basic diseasespecific terminologies. We plan to use this information to refine our insights about the terminologies that need to and do not need to be explained.

3) Patient Activation Measure (PAM): PAM is a metric that can be used to quantify the motivation of a patient to participate in taking care of his/her own health [Hibbard et al., 2004]. It consists of 13 items that are grouped under four developmental stages. In the first stage, people believe that patient role is important but are overwhelmed and unprepared to play an active role. People in the second stage have necessary knowledge for self-care but appear to lack the confidence for self-management. In the third stage, people know how to handle symptoms and prevent further problems; while in the fourth stage, people are able to maintain the lifestyle change even during the times of stress. Identifying the stage in which a patient currently is will help us in deciding the amount and type of information that should be provided to the patient.

4) Patient’s perspective: Since we are interested in generating patient friendly summaries, we need to take into account the kind of sentence structure and terminologies that patients would prefer reading. In addition, we also want to correlate the PAM scores of the patients with the content they discuss and the complexity of the vocabularies they use. For this purpose, we plan to conduct interviews where patients will describe their health issues as well as their experiences before and after being diagnosed. They will also be asked to answer the PAM questions.

3.2 Incorporating personalization features

In our earlier work, we had developed a metric for identifying medical concepts that need to or do not need to be further simplified. This metric (represented by module 2 in Figure 1) uses the score returned by a linear regression function and sets several thresholds to categorize a concept as Simple or Complex. In order to incorporate the information regarding the health literacy of the patient and his/her familiarity with the health issues, we plan to fine-tune our existing metric by introducing additional thresholds. This refined metric will then assign the patient to a specific category, depending upon which decisions about whether or not a particular term needs to be explained will be made. The summaries produced after introducing these features will be evaluated by nurses and patient advisors and the thresholds will be refined if needed.

Inferences from the patient interviews and the guidelines provided by the developers of PAM will be used for deciding on the various attributes that can be tuned for customizing the summary.

4. CONCLUSION

In this abstract, we discussed about our ongoing research on generating personalized hospital-stay summaries for patients. We built upon the framework for exploring concepts and the natural language generation pipeline that were developed previously. We discussed about different features that will guide our personalization process and our plans on integrating these features into our existing framework. The next steps in this research will be to finalize the parameters for personalizing the summary and to find the mapping from PAM scores to the values of the attributes.

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6. REFERENCES


