

Heart Failure Education of African American and Hispanic/Latino Patients: Data Collection and Analysis

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Abstract

Heart failure is a global epidemic with debilitating effects. People with heart failure need to actively participate in home self-care regimens to maintain good health. However, these regimens are not as effective as they could be and are influenced by a variety of factors. Patients from minority communities like African American (AA) and Hispanic/Latino (H/L), often have poor outcomes compared to the average Caucasian population. In this paper, we lay the groundwork to develop an interactive dialogue agent that can assist AA and H/L patients in a culturally sensitive and linguistically accurate manner with their heart health care needs. This will be achieved by extracting relevant educational concepts from the interactions between health educators and patients. Thus far we have recorded and transcribed 20 such interactions. In this paper, we describe our data collection process, thematic and initiative analysis of the interactions, and outline our future steps.

1 Introduction

Heart failure (HF) is defined as “a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill or eject blood” (Hunt et al., 2009). Approximately 5 million Americans currently live with this condition. In the United States, minority communities have a higher mortality rate than Caucasians (Roger, 2013; Toukhsati et al., 2019). This has been attributed to multiple factors like genetic variations, access to quality healthcare, socioeconomic conditions, health behavior, lower health literacy among others. However, some of these risk factors can be mitigated (Der Ananian et al., 2018; Tucker et al., 2011). For example, a patient with access to personalized educational material is better equipped to identify and address his self-care needs resulting in increased compliance

and better health outcomes (Alberti and Nannini, 2013).

Self-care is “a naturalistic decision-making process by which individuals make choices about behaviors that maintain physiologic stability and the response to symptoms when they occur.” (Riegel et al., 2004) However, this process can be rendered ineffective when the patient has a limited understanding of the disease. Furthermore, most self-care materials available outside the hospital are catered towards the White Caucasian educated population, and thus lack cultural nuances to assist patients from minority communities (Barrett et al., 2019; Hughes and Granger, 2014; Lee et al., 2011). This has resulted in poor heart self-care regimen in minority communities (Howie-Esquivel, 2014).

Therefore, we intend to develop a dialogue agent that can provide medically reliable and culturally sensitive self-care information to discharged African American and Hispanic/Latino HF patients, and help mitigate the health disparities observed among them. In this paper, we talk about our first step towards building the agent i.e. collecting the data (since there is no publicly available dataset) and analyzing it. We used topic modeling to identify core educational concepts and analyzed the data for initiative, i.e., who takes the conversational lead. Not surprisingly, educators take more initiative, however the portions in which the patient has control are more important to uncover what patients may ask of a dialogue agent.

We also tried to evaluate the interactions for cultural competency. However, existing tools such as Cross-cultural counseling inventory (LaFromboise et al., 1991) and the Multicultural counseling inventory (Sodowsky et al., 1994) focus on provider’s knowledge and do not evaluate patient educational materials. Therefore, with the help of content experts in our team, fundamental concepts of cross-cultural care (empathy, respect, and curiosity), and

focus groups (Bobo et al., 1991; González-Lee and Simon, 1987), we will manually identify culturally relevant topics and model the dialogue agent accordingly as part of our future work.

2 Related Work

In the 1960s, ELIZA was the first Natural Language Processing (NLP) based chatbot which facilitated a dialogue between humans and machines. Since then, multiple advances have been made in artificial intelligence and NLP resulting in the evolution of dialogue agents. They have transitioned from accepting very restricted user input (answers to multiple-choice questions only) to processing full sentences and providing medically reliable information (Laranjo et al., 2018).

Multiple randomized control trials have established the efficacy of dialogue agents in health-care settings as well (Bickmore et al., 2013a,b; Lovell et al., 2017). They have been successfully used to promote a healthy lifestyle, increase adherence, or provide adjunct psychotherapy among other uses (Laranjo et al., 2018). Technology-based interventions have been used to assist HF failure patients for quite some time. Most of these interventions are catered towards remote monitoring and medication management (Hughes and Granger, 2014). CARDIAC (Computer Assistant for Robust Dialogue Interaction and Care), a conversation assistant for chronic HF patients was designed to collect both objective and subjective information from the patients (Ferguson et al., 2009). Similarly, DIL, another conversation agent was designed to help HF patients to transition from hospital to their homes by motivating them to follow a healthy lifestyle and maintaining medication adherence (Moulik, 2019). To our knowledge, there is no existing culturally sensitive dialogue agent designed to assist minority communities with their heart failure self-care needs.

3 Data Collection

We recruited three health educators to conduct HF education of AA and H/L patients in both the inpatient and outpatient clinics of our university. We plan to collect 40 HF education sessions, half with AA patients and half with H/L patients. We have recorded 20 interactions so far, 18 with AA patients and two with H/L patients; of these 20 patients, 8 are males and 12 females. One of the barriers to recruiting H/L patients is how our hospital iden-

Patient: Yeah, I don't, I don't do the frozen meal.
Educator: Okay.
Patient: I was basically doing the uh, vegetables.
Educator: Okay.
Patient: Frozen vegetables,
Educator: They should be fine.
Patient: Yeah.
Educator: But... but, but I do want you to start looking at those nutrition labels.
Patient: Okay.
Educator: And look for something that says less than 5%.
Patient: Okay.
Educator: So, the other thing we always want you to do is, um, of course take all your medicines like you're supposed to.
Patient: Which I didn't do last night.
Educator: Okay.

Figure 1: Excerpt from a conversation

20 transcripts			
	turns	sentences	words
Educator	116.90	205.45	2281.10
Patient	108.40	131.20	849.50
Total	225.30	336.65	3130.60

Table 1: Distributional analysis of the conversations

tifies them; additionally, since at the moment we focus on English as the language of interaction, we exclude H/L patients if the interaction is conducted in Spanish. Lastly, H/L patients comprise only 20% of our hospital population; this is less than half of the AA patients (45%). The remaining 35% comprises 10% Asian American, and 25% Caucasian and others.

All the 20 recordings were transcribed by a professional transcription service. An excerpt is shown in Figure 1. We should note that in some cases, a third person (a caregiver, like a spouse) is present, and the conversation may involve both patient and caregiver, or be mostly between the educator and the caregiver. While transcribers did a good job, they failed to capture linguistic practices and choices of patients (vernacular speech) and converted it to standard English: for example, ‘gonna’ was transcribed as ‘going to’. Given our focus is on cultural sensitivity, such linguistic practices are of great importance to us, and therefore, the transcripts were revised again to make sure that exactly what was said is recorded.

The average length of an interaction is about 15 minutes. Table 1 presents the average number of turns, sentences, and words per conversation over these 20 HF education sessions. A turn refers to a complete unit of speech and can consist of multiple sentences. Therefore, it makes sense that


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----- Control: Patient -----
Patient: Yeah, I don't, I don't do the frozen meal. (assertion/command)
Educator: Okay. (prompt)
Patient: I was basically doing the uh, vegetables. (assertion/command)
Educator: Okay. (prompt)
Patient: Frozen vegetables, (assertion/command)
----- Control: Educator -----
Educator: They should be fine. (assertion/command)
Patient: Yeah. (prompt)
Educator: But... but, but I do want you to start looking at those nutrition labels. (assertion/command)
Patient: Okay. (prompt)
Educator: And look for something that says less than 5%. (assertion/command)
Patient: Okay. (prompt)
Educator: So, the other thing we always want you to do is, um, of course take all your medicines like you're supposed to. (assertion/command)
----- Control: Patient -----
Patient: Which I didn't do last night. (assertion/command)
Educator: Okay. (prompt)

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Figure 3: Example conversation showing utterance type and control transfer.

prioritized *children* in their discussion (*family* was also in the top 20 categories), whereas for educators neither of them were even in the top 25 categories. *negative_emotion*, *shopping*, and *party* were in the top 20 of educator categories, therefore can be considered similar to patient categories where they are in top 15. Lastly, *giving*, *business*, and *cleaning* categories were more common in educators. This is because *giving* relates to the term ‘give’ which educators used frequently to provide information such as ‘give you a followup appointment’, ‘give you a phone number to call’, ‘give you medicine’. *Business* relates to terms such as ‘need’, ‘work’, and ‘company’, which, similarly to *giving*, was used to inform patients about different companies offering low sodium salt, what they need to do upon discharge, and to educate them about how medications work. *Cleaning* is in the top categories because it relates to the term ‘water’ which can be considered a partial duplicate of category *water*.

Initiative analysis focuses on the distribution of turns based on the person taking the lead in the conversation. A person takes the lead/initiative when he/she contributes to the conversation (e.g., by asking a question) instead of only answering the questions or responding with fillers (such as ‘okay’, ‘umm’). In turn, when a speaker takes initiative, the control of the conversation transfers to that speaker and remains with the same speaker until the other speaker takes initiative.

We classified a given turn as a question, prompt, or assertion/command where: a question tries to elicit information, a prompt doesn’t express any propositional content, an assertion states facts, and a command intends to instigate action (Walker and Whittaker, 1990). We used the rules below to automatically annotate the turns:

- Question: if the turn ends with a question mark (?)
- Prompt: if a turn consists only of words ‘uhhuh’, ‘okay’, ‘ok’, ‘yeah’, ‘umhmm’, ‘right’, ‘oh’, ‘umm’, ‘uh’, ‘hmm’, ‘umumm’, ‘ummm’, ‘alright’
- Assertion/Command: everything else

We didn’t separately annotate command and assertion as we were more interested in the number of questions and prompts by the educators and patients; additionally, it would be hard to distinguish them using simple rules.

The rules for control transfer used by us are shown below (Turn type: Controller):

- Assertion/Command or Question: speaker unless response to a question
- prompt: hearer

Figure 3 shows the excerpt from Figure 1 marked with utterance type and control transfer. The utterances with type *assertion/command* indicate speaker initiative. On analyzing the transcripts, we found that on an average per conversation, educators asked 26 questions and produced 17 utterances with prompts as compared to 3 questions and 39 prompt utterances by the patients. As a consequence, an educator held the initiative for about 95 turns per conversation, whereas the patient did for 51 turns; the control lasted for about 5 turns on average in the case of an educator as compared to patients who only held control for 2 turns on average. These observations about patient/educator interactions have also been confirmed by an expert we have consulted with, Dr. Kishonna Gray from Department of Communication and Gender and Women’s Studies at University of Illinois Chicago.

We hypothesize that, even if few, the turns where the patient takes control are important for the development of the dialogue agent: in fact, we envision this dialogue agent as an assistant that the patient will have to interact with on their initiative, rather

than a system that operates as a health educator per se. Next, we will extract the topics from the turns where the patients have control since those are probable topics of discussion. We also plan to conduct focus groups with 10 self-identified AA and 10 H/L patients to gain insight into their lives post HF diagnosis and evaluate the acceptability of a dialogue agent to discuss HF. We believe talking to individuals with HF outside the hospital environment can help solicit questions that do not appear in the recordings or existing literature.

5 Conclusions and Future Work

In this paper, we discussed our data collection process for heart failure education conversations between educators and African American or Hispanic/Latino patients. We analyzed 20 transcribed recordings and found that the most common topic of discussion was food. Patients also discussed family and children frequently. Though mostly educators took the lead, we will extract topics where patients take control to build a dialogue agent that can answer patient queries effectively. We will also use insights from these interactions to inform the questions for the focus groups which we will conduct in the future.

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