

Focus on the Successes: The Conflict between the Goals of “Data Science” and What Patients Want from Conversational Robots in Healthcare

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ABSTRACT

This position paper explores the conflict between the goals of data science and the actual needs of patients in healthcare settings, particularly in the context of conversational user interfaces (CUIs) and large language models (LLMs). The paper argues that while data science aims to improve human decision-making through data analysis and visualization, in contrast patients (especially those with chronic illnesses like dementia) may find real-time data insights depressing rather than helpful. The paper presents evidence from ongoing research on conversational robots for people living with dementia (PLwD), highlighting the patients’ preference for data that focuses primarily on their successes in maintaining their language abilities, rather than overall data that may *accidentally* highlight their decline due to chronic illness. The authors call for more research on how to best utilize conversational data from CUIs (e.g. conversational text, speech biomarkers, etc.) to create user interfaces that increase motivation in healthcare users with chronic illnesses.

CCS CONCEPTS

- **Human-centered computing** → **Natural language interfaces**;
- **Computing methodologies** → **Natural language processing**;
- **Computer systems organization** → *Robotics*.

KEYWORDS

Conversational User Interface (CUI), Large Language Model (LLM), Healthcare, User Interface, Robots, Data Science

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1 INTRODUCTION

What is data science exactly, and what is it intended to accomplish? There are many ways to answer that question, but perhaps the simplest way is to say that it intends “to improve human decision-making”. That of course demands we have data available to help with such decisions. There are several methods to accomplish that using data from many different sources/technologies, but one method that has become increasingly popular is to utilize data from conversations with people, both human-to-human as well as human-to-machine, given that conversation is a natural/easy form of human communication. The latter type of conversations between human and machine can be defined as conversational user interfaces (CUIs), which can be deployed on smartphone mobile apps, robots, chatbots, websites, and so forth [10, 15].

One obvious area we might try to improve decision-making would be human health and/or healthcare [8]. Human health after all is greatly impacted by the choices that people make every day regarding their lifestyle and environment, and when sick, affected by their choices as a patient, such as adhering to prescribed treatments. Furthermore, clinicians (doctors, nurses, etc.) also make many decisions that affect human health [3]. Those decisions are based on things like medical knowledge and current data, but are also mediated by the conversations that occur between patients and doctors, as well as patient families [16]. Nowadays, those conversations themselves are another source of data we can utilize (conversation text, speech biomarkers, etc.), especially with the rise of large language models (LLMs). All of which makes for a rich data environment for CUIs that are integrated with data science techniques, e.g. machine learning/deep learning (ML/DL), in the healthcare domain.

The question exists though as to what combining data science with CUIs (e.g. conversational robots) may offer to patients in a healthcare setting, beyond what they might get from just having the conversation itself [21]. **That is the question we intend to consider in this position paper, taking the stance that the goals of data science may in fact be in direct conflict with what patients actually would want from CUIs.** As evidence, we use initial results from our own research on developing conversational robots for people living with dementia (PLwD) [18] and illustrate some surprising findings from user testing of user interfaces designed to show data visualizations of those conversations to PLwD. We add to that evidence from others’ research, and end by clarifying our position on these questions and what it implies for future research on CUIs for healthcare.

2 THE GOAL OF DATA SCIENCE IN HEALTHCARE

First, we should briefly clarify what the goals of data science are more specifically in healthcare. If you look at the data science literature coming out of academia, the focus of most of it is on the “cool things” we can do with real-time data to improve healthcare efficiency and/or to make recommendations to doctors and patients [1, 6, 14, 20]. **There is a clear assumption that the data itself holds some value to patients** ... that is just a matter of how we analyze and/or visualize it for it to reach its true potential (aka insights). As such, that assumption leads to the primary goal of data science in healthcare being *extracting the value* out of the data to provide to users (e.g. patients, doctors). Primarily, we focus here on using conversational data downstream after analysis (e.g. speech biomarkers) to improve patients’ health choices and informing clinician decisions, though we can also consider the case of discussing the user’s pre-existing medical information during the conversation. Both cases overlap in making the same above assumption.

Even the literature that focuses on using data science for “patient-centered care” falls along the above lines (despite its more humanistic approach), with a clear undercurrent that there is meaningful value in data that will somehow impact/change how people think about their own bodies and the choices they make regarding their health [3, 8, 22]. However, that discounts the psychological constructs that affect how humans think about their own health, especially when it comes to chronic illness or long-term health outcomes that are harder for individuals to assess. **To illustrate that more simply:** most people know they shouldn’t drink too much alcohol or smoke or binge watch tv shows on the couch instead of going to the gym, yet many of those people still do those things ... even some scientists.

The choices people make about their own health are not always so logical or rational or even “data-driven”, but rather driven by many other factors. That suggests that the above assumption about the inherent value of data needs to be examined more closely. For our purposes here, we look at it from the angle of emerging CUIs in healthcare, as well as the data that can be derived from such conversations.

3 THE REALITY – EVIDENCE FROM OUR OWN RESEARCH

In our own ongoing recent research about developing conversational robots for dementia and accompanying mobile app user interfaces [18], one of the really surprising things we have found was that patients (both PLwD and their caregivers) were not all that interested in the real-time data or data insights, even if it was “actionable” from a purely data science perspective. Rather, during user testing (still ongoing, yet-to-be-published), patients reported that they actually **found the data “depressing”**. Their stated reason was that – given the long-term chronic health issue they are dealing with (in this case dementia) and the general downward trend in functioning and symptoms – that they didn’t want to see their gradual decline visualized on a screen. Specifically regarding CUIs, they also did not want their own spoken conversations written in text-form on a screen (e.g. subtitles), because it highlighted their speech mistakes as their language abilities declined.

In contrast, what patients with dementia wanted was only the parts of the data that focused on their successes in maintaining their language abilities, even if it was just a small day-to-day improvement in some particular language aspect, e.g. pragmatics (staying-on-topic during conversation). **For them, the power of data lies in the motivation that it can provide, because in their experience that is one of their greatest challenges.** As part of the ongoing study, we also conducted interviews with speech therapists who deal with dementia. During those interviews, they confirmed that finding from the PLwD users, pointing out that motivation was often something they implicitly worked on during in-clinic sessions with PLwD as part of overall therapy. The issue of motivation as a core component of CUIs also aligns with research coming out of other domains, such as office workers and their exercise habits [2].

However, that flies in the face of how we as scientists often think about data science in healthcare, particularly as we seek to leverage the data coming out of CUIs and conversational interactions to improve health outcomes. **The users we are designing these tools for are not data science “nerds” like ourselves**, but often quite the opposite. Thus, how they view data coming from CUIs, chatbots, and conversational robots as it pertains to their own health has a fundamentally different perspective that demands a shift in how we design those technologies for use in healthcare, as well as the technology’s accompanying user interface. Though our aforementioned study is still ongoing, these initial findings suggest we may be able to create specific guidelines towards that direction in the near future.

4 OUR POSITION

That brings us to our core position here: we still lack research on how to best utilize conversational data from CUIs and LLMs to create user interfaces that increase motivation in healthcare users with chronic illnesses (e.g. patients with dementia). That research needs to **examine how such conversational data can be both analyzed and visualized in a way that reflects how people with chronic illness think about their own long-term health**, which as mentioned above can sometimes be illogical or irrational from a purely data science view. Furthermore, the current assumption that data is inherently valuable for patients may turn out to be false, or at least not exactly what we expect. To move forward, more research is urgently needed to look at how data extracted from CUIs (e.g. conversation text, speech biomarkers, etc.) gets used *downstream* in healthcare when it is given directly to patients with chronic illness through patient-facing interfaces.

One may argue that personalization and customization could address some of the problems we mention in the previous sections, which is perhaps in partially true [12]. However, the reality is that this is not principally a matter of different preferences among users, but rather a conflict between how we frame the problem as scientists championing data and those using the data in a deeply personal way. It is principally a question of motivation in the face of an illness with no cure (i.e. a problem with no clear solution), and how data science can best contribute to that motivation in that sort of situation. That is a quite different question than building the most accurate model or improving some process by finding a faster

way to do it. The traditional data science benchmarks of efficiency, optimization, AUC scores, etc. have little bearing in this case, but rather the deeper philosophical question of what motivates people to keep going when there may be seemingly little left to gain. How might we measure that as data scientists, or think differently about the entire problem at hand?

Part of our position on this is derived from other CUI researchers who have been confronting similar issues from an entirely different angle. In particular, there has been a fair amount of recent literature looking at the “emotional experience” of interacting with a CUI or chatbot, by which we mean that users evaluate CUIs based on their own internal emotional state at the end of the conversation rather than any objective aspect (or measure) of the CUI. That research has looked at using intertemporal reflection exercises to help users “see” their future selves with dementia [11] and using concepts like “ikigai” to enhance personal meaning and self-worth [19], as well as the effects of increasing levels of gratitude in users toward themselves [13] and by deliberately making the CUI’s conversation style more “positive” [7]. Other research has focused on the underlying LLMs behind many modern CUIs in terms of trust, alignment, and transparency as that relates to the patient experience with them [4, 5, 9]. Conversations are inherently social after all, even if they occur with a robot, and so the emotional experience cannot be overlooked or discounted. Rather, that needs to be a separate consideration beyond saying the CUI or chatbot performs well in an objective metric sense (e.g. speech recognition accuracy, LLM latency, chat duration, etc.).

Of course, in this case we are focused on the accompanying user interfaces of CUIs and the health-related data that we present back to users downstream based on their conversations with the CUI, which is slightly different than the above research. **Yet it could be argued there is also an “emotional experience” of looking at the data derived from CUIs as well,** and there is research to suggest the way we design such interfaces affects user perceptions about themselves and their personal environment greatly [23]. Furthermore, there are of course ways to measure what is known as *intrinsic motivation*, and many existing scales for that including ones related to speech therapy [17]. All of which offers promise for future research.

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