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Uncertainty Management among Older Adults with Heart Failure: Responses to Receiving Implanted Device Data using a Fictitious Scenario Interview Method

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Heart failure (HF) is a complex chronic illness that affects the older adult population, requiring medical therapy and day-to-day management to prevent worsening and exacerbation. Patients with HF are often treated with cardiac implanted electronic devices (CIEDs) which capture diagnostic and predictive parameters for HF. In this work we explore how patients would respond to receiving data from an implanted device, using a fictitious scenario interview method with 24 older adults with HF. We applied an uncertainty management lens to better understand how patients face uncertain outcomes and integrate novel data into their decision making. The findings provide insight into how patients would engage and respond to a technology which provides an indicator of their HF status from an implanted device.

INTRODUCTION

Heart failure (HF) is a complex disease that affects primarily older adults, requiring medical therapy and lifestyle modification. HF is often treated with cardiac implantable electronic devices (CIEDs). Devices are remotely monitored, capturing diagnostic data which may predict worsening heart failure (Hawkins et al., 2016). Currently, patients do not receive the data from their devices. There are hundreds of device data elements collected by the device, and transmission reports are complex and require a skilled electrophysiologist to interpret. Still, patient advocates have requested access to their data, sparking research into the technical feasibility and design of patient-facing technology which incorporates implanted device data. With the promise of diagnostic and predictive capabilities of device parameters, the relevance of providing patients with their data is even more significant. However, we are only beginning to understand how to design the functionality and presentation of the data, who would use and access their data, and the optimal ways to do this (Daley et al., 2017; Ghahari et al., 2018; Mirro et al., 2018). In a larger, cross-sectional study, we explored how patients with HF would make decisions about their health when presented with data captured by a CIED (Daley et al., 2018; Holden et al., 2018). The goal is to design a patient-facing application that can display device data to help HF self-management.

Heart failure management and prognosis are complex and uncertain, affecting patient quality of life (Chen, Kao, Cheng, & Chang, 2018). Therefore it may be useful to understand how patients manage uncertainty in order to design the presentation of new, unfamiliar data appropriately and how to help patients integrate this information into their

understanding. Uncertainty of illness theory (Mishel, 1988) proposes that people respond to unknown outcomes and day-to-day management of chronic illness by seeking or avoiding health-related information. Data can either cause anxiety or alleviate concerns, depending on the individual. We understand that HF self-care is a naturalistic decision-making process (Riegel, Dickson, & Faulkner, 2016), whereby people make decisions based on information available, their personal goals, previous experience, or other contextual factors (Lipshitz & Strauss, 1997). The current study explores how patients with HF manage uncertainty when receiving device data, and how they might incorporate the data in their decision making and self-care. In this study we address the question, **how do HF patients respond to receiving data about their heart from a device implanted in their chest?** Using a fictitious scenario interview method, we address this question with the goal of generating design implications for a novel, patient-facing technology.

METHODS

The current study employed interview-based cognitive task analysis (CTA) using a fictitious scenario prompt to explore decision making among older adults with HF. This study is part of a broader, cross-sectional study to explore how older adults with HF make decisions about their health and design a patient-facing technology prototype which incorporates device data to support HF self-care (Daley et al., 2018; Holden et al., 2018).

Participants were recruited from a large, not-for-profit hospital in the Midwest. Participants were adults over the age of 65, NYHA II-IV, with or without implanted devices, and

were invited to bring a support person (spouse, friend, or family member) with them to participate in the interview. Participants (HF patients and support persons) signed informed consent forms before any study activities. Two researchers conducted the interviews; one guided the prompts and one took observation notes. Participants were given a survey packet to take home at the end of the visit. Each participant (or dyad) received a \$20 Visa gift card. All study activities were approved by the hospital Institutional Review Board.

The fictitious scenario component took place in the second half of the interview. The interviewer presented a fictitious scenario to participants, asking participants to imagine that an implanted device, attached to the heart, could pick up data from the heart related to HF and send the data over the airwaves. In this scenario, the device would send a number from 1-10, where 10 was optimal and 1 meant something could be the matter. The interview began with the prompt: *Imagine you have this device, and one morning you receive a 9. What would your first thought be?* The interview followed a semi-structured interview guide to explore how participants would respond to readings, an increase or decrease in values, when they would want to receive readings, and other contexts; however, the interviewer followed the direction of the participants. The fictitious scenario component lasted approximately 30 minutes. All interviews were audio recorded and transcribed verbatim. The research team read two transcripts together and developed a codebook to code the remaining transcripts separately. The interview prompts served as a framework for the codebook, and codes were developed inductively using an iterative process, discussing discrepancies and new codes as they arose during weekly team meetings. After the codebook was complete, CD applied an uncertainty management lens to the set of codes, focusing on patient preferences or expectations for receiving the data and how participants responded to receiving implanted device data in the fictitious scenario.

RESULTS

Participants were 24 older adults with HF and mean age of 76.7 years (SD=6.5), White, 16 males, and 13 had CIEDs. Fourteen participants had a support person with them at the interview. The themes that emerged were related to desired (or expected) frequency of readings and responses to the readings: reflecting, questioning, seeking help, and self-monitoring.

Theme 1: Desired (or expected) frequency of readings

Participants expressed that they wanted to receive readings frequently (more than once per day, such as every 15 minutes), on a limited basis, and variations between the two. Most participants (n=14) wanted (or expected) to receive a daily reading. In a couple of cases, participants who were enrolled in a telehealth program at the time of the interview implied that they would expect to receive readings once per day, because that is what they were used to in telehealth. A few participants expressed interest in on-demand data, for example if they were experiencing symptoms and wanted to

check the reading at the moment and to monitor changes. Others preferred to be less engaged in the device readings, and to receive information if necessary from their doctor.

Theme 2: Responses to the readings

There were four main categories in this theme: Reflecting, seeking information or help, questioning, watching and waiting, and listening to my body.

Reflecting (17 participants). Reflecting involved looking back on past behavior to try and understand the cause of the reading or reflecting on what could be done to bring the number up higher. Some participants used reasoning to justify a reading, such as attributing a drop in the value to a missed medication dose.

Questioning (9 participants). The theme of questioning emerged from participants' who said that they would call the device company or the clinic to verify if the reading was correct, or if there was an error, perhaps if the battery was low. This verification would be needed if the reading was lower than expected, or if the patient thought they had been doing better with their self-care than the number reflected.

Seeking information (13 participants) *or help* (18 participants). Most participants said that they would respond to a reading by seeking help, either by calling their doctor, going to the ER, or scheduling an appointment. The level of concern, depending on the reading and context in the prompts, varied among participants. For example, one participant said they would call their doctor if they received an 8, whereas another participant said they would call their doctor if the number was in the low range, 1-4. Others discussed the importance of how they were feeling (if experiencing symptoms, they would seek help regardless of the reading). However, a reading of 5, or a drop of 2 points were indicators for alert for several participants. About half of the participants would want to know what to do to get the number to go up or what to do in response to the number, and about one-third of participants wanted to know what specifically the device is measuring.

Watching and waiting (13 participants). This theme included the action of watching one's symptoms or watching the value or other values (such as blood pressure), when the reading is not perfect or has dropped. It also includes the response of "wait and see", resting and observing.

Listening to my body (5 participants). Some participants explained that they would pay close attention to how they feel, putting more value in how one feels over the actual number. A couple of participants said that if they were feeling ok or "normal", they would not pay attention to the reading.

DISCUSSION

The findings show that, using the fictitious scenario, participants proposed that they would want (or expect) to receive their device data at various intervals. Some participants expressed interest in having access to the data, knowing what the data involved and how to use it, whereas others described a more passive role and did not want to receive the data from the device and worry about messages.

These findings may reflect how patients manage uncertainty of illness (Etkind, Bristowe, Bailey, Selman, & Murtagh, 2017; Mishel, 1988). For some, data from the device may elicit anxiety about outcomes or inspire more questions and greater uncertainty, particularly when the data are coming from the device and not a human. In scenarios where participants questioned the reading, they explained that they would turn to the device company or trusted clinical expert for guidance and not necessarily trust the device information. For others, the data could help patients make sense of their condition and relieve anxiety.

Throughout the fictitious scenario prompts, participants assessed their situations by thinking through contextual factors such as whether they were experiencing symptoms, how their self-care regimen went the day before, or if they had pressing life demands and priorities as shown in the theme of reflecting. These factors impacted how they would integrate the device data into their decision making. Given the uncertainty and complexity of living with HF, health-related decision making involves situation assessment and context-based evaluation, technology should support patients' reflections and sense-making of their condition. As indicated by the findings, supporting information included what the device is measuring and/or knowing what to do in response to a reading. Thus, technology-based interventions to support self-care should be flexible to reflect individual needs and preferences for the type of informational support they require.

The fictitious scenario interview method allowed for an exploration of how HF patients would respond to data that are entirely new and may provide an indicator of HF status. For about half of the participants, imagining having an implanted device added another layer of imagination. This approach to CTA revealed patients' thoughts and reactions in a novel way, rather than asking patients to recount past stories and experiences. The findings offer novel insight into how people make decisions, as participants must rely on their real experiences to suppose what they would think and what they would do.

A limitation of this method is that asking people to imagine a scenario may be challenging for some more than others, and we cannot draw conclusions about what patients would do, only insights about what their thought processes might be. However, we believe the contribution is valuable and helps provide guidance for more robust designs of technology for field testing.

Implications for design

The study generated implications for design related to how patients manage uncertainty in decision making for HF self-care. Specifically, we suggest that technology-based interventions should:

- Support (rather than replace) human communication and connection (for trust and reassurance) in telehealth interaction
- Provide support for situation assessment in context of patients' lives

- Be flexible in terms of amount, type and frequency of data and information depending on individual needs

CONCLUSION

This study explored how HF patients respond to a fictitious scenario involving a reading from an implanted device, part of a larger effort to provide patients with CIED data to facilitate health-related decision making. The device parameters may predict worsening HF and therefore may be of value to patients in their self-care. The findings suggest that needs and preferences for receiving health-related data vary among individuals, and technology should support the amount, type, and frequency of information that aligns with how patients approach and manage uncertainty in their illness experience. Given the unknowns in the illness trajectory, technology that supports reflection, sense-making and the trust that patients have in relationships with clinicians is important.

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