



Using cardiac implantable electronic device data to facilitate health decision making: A design study

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ARTICLE INFO

Article history:

Received 3 February 2017

Received in revised form

22 September 2017

Accepted 22 November 2017

Available online 4 February 2018

Keywords:

Patient empowerment

Design requirements

Focus group

Cardiovascular disease

Chronic heart failure (CHF)

Personal health record (PHR)

Cardiac resynchronization therapy-cardiac implantable electronic device (CRT-CIED)

ABSTRACT

For some individuals who live with chronic heart failure (CHF), cardiac implantable electronic devices (CIEDs) offer lifesaving therapy. Remote monitoring data from CIEDs are transmitted on a routine schedule for highly trained clinical staff to review. However, the remote monitoring data and clinical interpretations are not directly accessible to patients. Hence, people living with CIEDs are not able to reflect on their health data, let alone take any health action based on relevant data buried in their electronic health record (EHR). Prior research has shown that properly timed and tailored health data through a personal health record (PHR) can enable individual decisions about health in novel ways. However, in order to be effective, patients' needs must be well described before designing a tailored intervention. This study is an early investigation into ways in which complex CIED data can be harnessed to guide the health decisions of individuals living with CHF. To understand these information needs, we conducted four focus groups (N = 24) comprised of adults living with CHF (who were undergoing remote monitoring of their CIED data) and their informal caregivers (spouse or adult child). Focus group participants shared preferences for on-demand and personalized push message education. Through our analysis, we identified specific elements of device data and delivery design that can help promote reflection on changes in disease progression and CIED function over time. In this paper, we describe design ideas for the delivery of tailored CIED data and education that supports patient-level decision making.

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1. Introduction

Patients with chronic heart failure (CHF), who have impaired cardiac function, often benefit from cardiac resynchronization therapy (CRT). This lifesaving therapy is delivered through a device

directly implanted in the patients' heart, improving CHF symptoms and reducing mortality (Shea and Sweeney, 2003). These cardiac implantable electronic devices (CIEDs) collect data about cardiac function, life-threatening rhythm disorders, and device performance while automatically delivering treatment. Data from CIEDs are routinely transmitted to specialized cardiac rhythm clinicians who are responsible for following up with patients when changes in therapy are required (Burri and Varma, 2013; Kalahasty et al., 2013). However, currently, transmitted CIED data are not directly accessible to most patients (Campos, 2017; Daley et al., 2015; Marcus and Weaver, 2012; Skov et al., 2015). This contributes to patient frustration and anxiety due to the inability to access their own health information (Campos, 2017; Daley et al., 2015; Marcus and Weaver, 2012; Skov et al., 2015). Although research shows that sociotechnical solutions (e.g., glucose monitoring devices,

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physical activity trackers, wearable sensors, and monitoring patches) have been successful in supporting people living with chronic health conditions such as diabetes and heart disease (Mamykina et al., 2006; Randriambelono et al., 2015; Smith et al., 2007; Swan, 2012a,b; Kelsey, 2013), there is a paucity of research focused on the needs of patients with CIEDs (Daley et al., 2015; Denning et al., 2010; Skov et al., 2015).

Providing meaningful information from CIED transmissions may allow patients with CHF to reflect and take important health-related action (e.g., checking for other symptoms and/or calling the clinic for an adjustment in therapy). Previous research found that providing properly tailored health data should be considered as a mean to activate individuals (Ball et al., 2007; Klasnja and Pratt, 2012; Pagliari et al., 2007). However, simply providing data to patients (e.g., via a personal health record (PHR)) will not automatically result in improved patient engagement or health outcomes (Toscos et al., 2016; Ancker et al., 2015). For instance, CIED reports contain hundreds of data elements (from complex electrical heart rhythms to device battery life and lead status – both data types and amounts of data); thus, provision of data to patients must be carefully designed to be accessible and engaging without being overwhelming. Prior research suggests patients prefer to be presented with a sub-set of essential and easy to understand data that will not overwhelm them (Longo et al., 2010), but this requirement is yet to be translated for the delivery of CIED remote monitoring data.

Both the human-computer interaction (HCI) and human factors engineering (HFE) approach to patient-centered design require an understanding of users' needs (Holden et al., 2016; Krist and Woolf, 2011; Srinivas et al., 2016) before sharing CIED data with patients. Hence, in this study, we aimed to understand patients' experiences and needs around CIED data delivery and education to support patient decision-making.

2. Background

2.1. Implanted device for patients with CHF

Many patients who have CHF with reduced ejection fraction are at risk for sudden cardiac death from fatal arrhythmias (Epstein et al., 2008). Implantable cardioverter defibrillators (ICDs), one type of CIED, are implanted in the chest wall with wires attached to the heart. These wires detect lethal arrhythmias and deliver high-energy and life-saving shocks when patients are at risk of sudden cardiac death (DiMarco, 2003). Some patients with heart failure require CRT, a more advanced technology, that restores normal electrical activation of the right and left ventricles, thereby improving CHF symptoms and reducing mortality (Shea and Sweeney, 2003). These treatments have been combined into the CRT – cardiovascular implantable electronic device (CRT-CIED), which provides carefully timed electrical stimulus to the cardiac muscle (pacing) to simultaneously activate the right and left ventricles. This simultaneous activation of both sides of the heart improves the heart's pumping ability and effectiveness. As a result of this therapy, patients have experienced fewer hospitalizations, less procedural cost, an increased lifespan, and an overall improved quality of life (Iyengar and Abraham, 2005). Between 2002 and 2010, a total of 374,202 patients received CRT-CIED treatment (Sridhar et al., 2016).

To ensure that patients with CHF receive the most benefit from undergoing CRT-CIED, it is imperative to monitor the percent of ventricular pacing (Jentzer and Jentzer, 2011). Patients treated with CRT-CIED experience deterioration in left-ventricular (LV) performance when the percent synchronized ventricular pacing drops below 93% (Koplan et al., 2009). Therefore, clinicians monitor LV

pacing to identify subthreshold values. Typically, clinicians use wireless remote monitoring, which transmits data from the CRT-CIED to the clinic via a variety of technologies. Remote monitoring reports are sent to the clinic for routine monitoring and appropriate intervention (Burri and Varma, 2013; Kalahasty et al., 2013). Remote monitoring has increased efficiency for healthcare providers, improved patients' quality of care and decreased mortality (Crossley et al., 2011; Guédon-Moreau et al., 2012; Landolina et al., 2012; Watanabe et al., 2013). However, clinicians can be overwhelmed by the volume and complexity of CIED data coming into their patients' electronic health record (Ajami and Bagheri-Tadi, 2013; Levine et al., 2014), which might interfere with the communication of important information to the patient (Petersen et al., 2012; Slotwiner et al., 2015). If patients were able to access this data in a meaningful way, they could augment the current process that requires clinician review before patient notification. Therefore, one possible benefit of sharing transmitted data with patients is a shorter time interval between deterioration of LV pacing and related adjustments in CRT-CIED.

2.2. Patient access to health data

In prior research investigating patients' opinions on remote monitoring, patients reported not receiving their cardiac function data or any indication of deterioration or improvement (Campos, 2017; Daley et al., 2015; Marcus and Weaver, 2012; Skov et al., 2015). For these patients, not having access to one's own health data can cause anxiety and frustration (Campos, 2017; Daley et al., 2015; Marcus and Weaver, 2012). Additionally, devices have limited utility without tailored data delivery to promote meaningful use of data, reflection and action (Abedtash and Holden, 2017).

Prior research has shown that patients with CHF have difficulty interpreting physical symptoms and making determinations about appropriate actions pertaining to specific symptoms (Mickelson et al., 2016; Srinivas et al., 2016). Artifacts (e.g., pillboxes and medication lists) and strategies (e.g., rules of thumb, relying on others) exist that may support patients with CHF in decision making and taking an action (Cornet et al., 2017; Mickelson and Holden, 2017). However, there are still barriers to access and use of these artifacts and strategies, such as patients' biomedical conditions, knowledge deficit, and usability of the artifacts (Holden et al., 2015; Mickelson et al., 2015). One way to encourage patients to take action is to transform data into understandable information (Meyer et al., 2014) and include directions for necessary actions (Swan, 2012a,b).

Features of technological decision support tools have proved beneficial for the following health-related concerns: *diabetes* (Mamykina et al., 2016a,b; Mamykina et al., 2006; Mamykina et al., 2008; Toscos et al., 2012a,b), *cancer* (Patel et al., 2012), *physical activity promotion* (Consolvo et al., 2008; Lin et al., 2006; Toscos et al., 2011), and *sleep behaviors* (Choe et al., 2011; Choe et al., 2015). In this previous work, scaffolding patients' thought processes with relevant information for health conditions promoted reflection. For example, parents of children with diabetes were presented with a trend report of blood sugar values along with a list of potential explanations for the low blood sugars that the child was experiencing overnight (Toscos et al., 2012a,b).

Building on these studies, our research is novel in its focus on patients with a CRT-CIED and its related complexities. For one, the nature of a CRT-CIED is quite different from other health monitoring technologies in that CRT-CIEDs are embedded, "in-the-body" versus other wearable sensing technologies (e.g., continuous glucose monitoring devices, GCM, for individuals with diabetes) that are "on-the-body". Second, these CRT-CIEDs can deliver a lifesaving (Shea and Sweeney, 2003) shock at any moment that

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