Patient responses to daily cardiac resynchronization therapy device data: A pilot trial assessing a novel patient-centered digital dashboard in everyday life

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BACKGROUND Heart failure (HF) is a growing public health problem in the United States. Implantable cardiac resynchronization therapy (CRT) devices reduce mortality and morbidity, and remote monitoring (RM) of these devices improves outcomes. However, patient RM adherence is low, due in part to lack of access to their RM data. Providing these data to patients may increase engagement, but they must be appropriately tailored to ensure understanding.

OBJECTIVE The purpose of this study was to examine patients' experiences interacting with their RM data through a novel digital dashboard as part of daily life.

METHODS In this mixed-methods pilot study, 10 patients with implantable CRT defibrillators were given access to a patient-centered RM data dashboard, updated daily for 6–12 months. Pre- and post-health literacy, engagement, electronic portal (MyChart, Epic Systems Corporation) logins, and RM adherence were measured; system usability scores were collected at exit; and dashboard views were tracked. Exit interviews were conducted to elucidate patients' experiences.

RESULTS Participants (100% white; 60% male; age 34–80 years [mean ± SD: 62.0 ± 13.4]) had adequate health literacy, increased MyChart logins ($P = .0463$), and nonsignificant increase in RM adherence. Participants viewed their dashboards 0–42 times (mean 14.9 ± 12.5). Interviews revealed participants generally appreciated access to their data, understood it, and responded to changes; however, questions and concerns remained regarding data interpretation and visualization.

CONCLUSION Preliminary findings support potential future integration of a CRT RM data dashboard in the daily care of HF patients. With appropriate informational support and personalization, sharing RM data with patients in a tailored dashboard may improve health engagement.

KEYWORDS Biventricular pacing; Cardiac implantable electronic devices; Consumer health informatics; Data transparency; Heart failure; Left ventricular pacing; Patient engagement; Patient portal; Personal health record; Remote monitoring

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Introduction

Heart failure (HF) is a growing public health problem in the United States, with approximately one-fifth of Americans over age 65 years expected to have HF by 2050.[1] Heart failure with reduced ejection fraction (HFrEF) comprises approximately one-half of this population.[1] Adults with HFrEF are increasingly more likely to receive a cardiac implantable electronic device (CIED) with cardiac resynchronization therapy (CRT) capability,[2] which reduces mortality and improves quality of life when biventricular pacing is >92%.[3] Clinical guidelines advise remote monitoring (RM) of CIEDs,[4] as early intervention for reduced pacing is critical for reduced hospitalizations and improved survival.[5,6] However, RM adherence remains low. Data suggest that of the approximately 50% of HF patients on RM, one-half utilize it <75% of the time,[7] although some studies report higher adherence rates.[8]

Typically, RM data are periodically aggregated for clinicians to interpret. Advances in technology are allowing providers to make timelier care decisions informed by more comprehensive data.[9] However, patients still lack widespread

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KEY FINDINGS

- Adults aged 34–80 years who had heart failure with reduced ejection fraction were able to navigate a digital dashboard populated daily with their remote monitoring (RM) data, including percent left ventricular pacing, and take appropriate action.
- The experience of viewing the dashboard in daily life exposed challenges to interpreting the data and questions about the device and its function that did not necessarily arise in previous user-centered design sessions.
- There was a significant increase in patient portal use during the trial compared to 6 months before the trial, suggesting that providing patients with a dashboard of RM data may have had an impact on engagement with health technology.

access to their RM data and report a desire to receive more information and faster feedback.[10,11] Digital technologies, such as mobile phone applications and electronic health record (EHR) patient portals, show promise for engaging patients in self-management involving RM data,[11–14] including elements such as biventricular pacing that, when monitored daily, may allow for earlier identification of worsening heart function, irrespective of symptoms, and, thus, earlier intervention.[6] Despite benefits of daily monitoring,[5] not all existing RM systems allow for daily transmission.[14]

Supporting patients with CIEDs undergoing RM requires a holistic approach to enhance quality of life.[15] Recent works demonstrating the feasibility of sharing these data with patients suggest that type, amount, and modality are highly personal, and the data require explanation, relevance, and personalization to be meaningful and actionable.[16–19] However, these works have not provided patients a specific data element on which to take action and instructions for doing so. When evaluating new technologies, it is important to conduct research naturistically to determine context and usage within daily life,[20] and a small sample is sufficient to identify most major usability problems.[21] Thus, we designed this pilot study to evaluate a novel, digital, patient-facing RM data dashboard, created from preferences identified in previous user-centered design sessions.[19,22]

Our study explores the potential of sharing daily RM data with individuals with HFrEF and a cardiac resynchronization therapy–defibrillator (CRT-D), assessing their experiences using the dashboard on their own time over several months. Before the study, these individuals did not have direct access to their RM data. We included access to daily percent left ventricular (LV) pacing values, an RM datapoint with high importance for CRT-D functioning, as well as instructions for what actions to take if pacing decreased. The primary goals of this pilot study were to gain insight into individual patients' interpretations of device data and visualizations and their responses to RM data in daily life, and to contribute these insights to an emerging field of health data sharing that ultimately aims to design and implement technologies to further engage patients safely and effectively in self-management.[16,23–25]

Methods

Design

This mixed-methods pilot technology trial is the culmination of 3 previous study phases reported elsewhere.[19,22] In this trial, participants received access to certain CRT-D RM data in a digital dashboard through a link accessible in MyChart (2019; Epic Systems Corporation, Verona, WI), an EHR patient portal. Data collection included surveys, measurement of patient portal and dashboard use, RM adherence data, and semistructured interviews.

Setting and sample

The study was conducted at a mid-size, not-for-profit health system in the Midwestern United States. The device clinic provided a list of patients with Biotronik CRT-Ds (Biotronik SE & Co. KG, Berlin, Germany), which are uniquely able to transmit RM data daily.[5,14] Researchers screened for adults (age $\geq$18 years) with a history of HFrEF and CRT-D for $\geq$60 days, using Biotronik Home Monitoring (automatic daily surveillance via a mobile wireless RM system) for $\geq$5 weeks. Ten participants were enrolled, which required 16 months due to the limited number of patients meeting inclusion criteria (for further details, see adapted CONSORT[26] diagram in Figure 1).

Dashboard

The digital dashboard included datapoints, visualizations, and labels informed by preferences of similar participants in previous study phases.[19,22] The default view included 5-week average percent LV pacing, depicted as green (>92%), yellow (85%–92%), or red zone (<85%) (Figure 2). Daily percent LV pacing was available as a bar graph (Figure 3). Additional data included remaining battery life; average heart rate; number of episodes (ventricular therapy: antitachycardia pacing or shock); reminders of HF-related symptoms to monitor (eg, water weight gain); and rotating health tips.

Procedure

After providing written informed consent, participants completed a survey and received verbal instructions and a take-home packet from the research nurse coordinator on accessing and navigating the dashboard, as well as the actions to take if in yellow zone (watch for symptoms indicative of worsening heart condition) or red zone (contact the clinic). Participants were sent a MyChart message containing a link to their dashboard, which they accessed at will for 6–12 months. If the 5-week average percent LV pacing

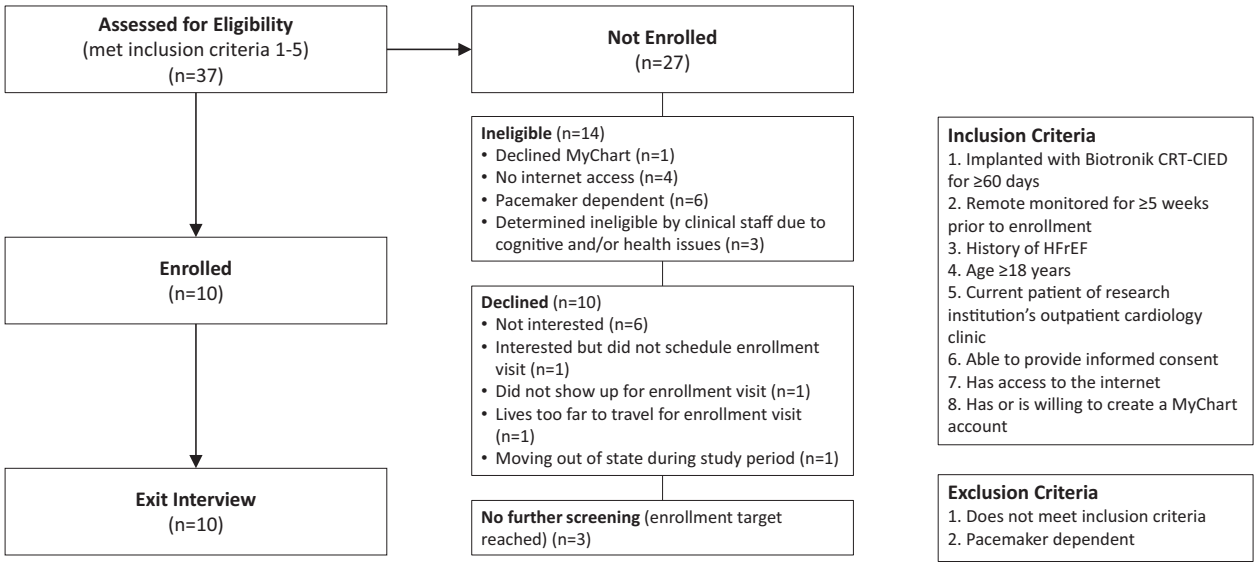

Figure 1 Study flowchart. Participant screening, enrollment, and completion of study, as well as a summary of inclusion and exclusion criteria. All participants received the dashboard for 6–12 months between enrollment and exit interview.

zone increased or decreased, the research nurse coordinator sent a short MyChart message to notify the participant. This message did not describe the change or instruct the participant to take any specific action, but simply stated that a change had occurred and reiterated that the participant could check the dashboard at any time. Figure 4 shows a visual representation of the research team's role in the study process.

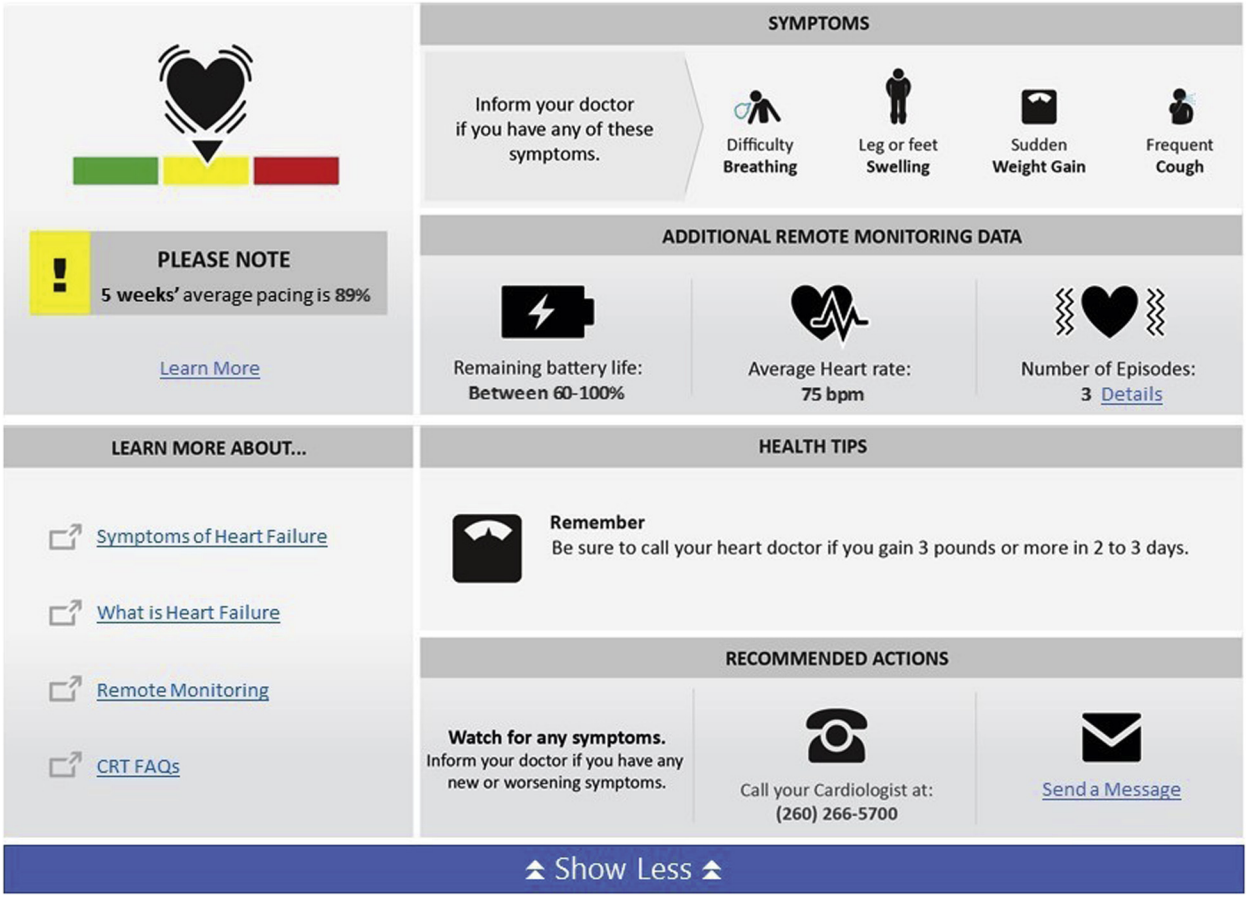

Figure 2 Patient-facing dashboard. A novel, patient-facing cardiac resynchronization therapy–defibrillator data dashboard featuring a 5-week average percent left ventricular (LV) pacing zone; here, the percent LV pacing is in the yellow zone (between 85% and 92%).

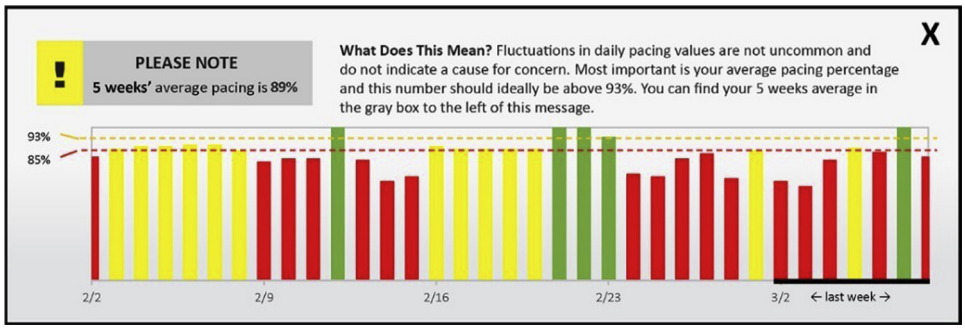

Figure 3 Daily percent left ventricular (LV) pacing over 5 weeks. The daily percent LV pacing values (5-week look-back) were available through a link from the full dashboard. Each bar is 1 day, and the color represents the percent pacing for that day.

Additionally, if participants missed >2 consecutive days of RM, we contacted them by phone to troubleshoot potential transmission issues. This was done for quality assurance purposes (ie, so participants could continue to receive their data as intended by the study). Participants completed surveys and interviews and received $40 debit cards at enrollment and exit. All study procedures were conducted in accordance with the Declaration of Helsinki and approved by the Parkview Health Institutional Review Board.

Measures

Participant characteristics

A survey with sociodemographic items and questions about technology use was administered at enrollment. Demographics and health information also were collected from Epic medical records.

Health literacy

The 6-item Newest Vital Sign (NVS),[27] which uses a nutrition label as a prime, was used at enrollment and exit to measure health literacy.[27] Correct responses were totaled, with 4+ considered adequate.

Patient engagement

The 12-item Altarum Consumer Engagement (ACE) measure assessed engagement at enrollment and exit.[28] The ACE uses a 5-point Likert-type response set (1 = strongly disagree, 5 = strongly agree) composed of 3 dimensions (Cronbach α): navigation (0.66), commitment (0.85), and informed choice (0.82).

System usability

At exit, participants rated the dashboard on the 10-item System Usability Scale (SUS), which assesses ease of use, consistency, complexity, and learnability of a computer system.[29] The SUS uses a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree) for alternating positive and negative statements (alpha = 0.91). Higher scores indicate higher usability, and 70+ is generally considered acceptable.

MyChart logins

MyChart logins for 180 days pre- and post-enrollment were captured through Epic's reporting tools.

Dashboard views

Number and date of dashboard views per participant were captured with Google Analytics (https://marketingplatform.google.com/about/analytics/).

RM adherence

RM adherence (percentage of completed transmissions) was calculated from RM logs. The number of RM days started 180 days before enrollment, or with the participants' first transmission. Epic and MyChart records were accessed to count messages and calls to participants.

Changes in percent LV pacing

These data, which were populated into participants' dashboards, collected from RM logs.

Exit interviews

A researcher (RA) led participants through semistructured individual interviews, which explored understanding, perceptions, and experiences during the study and included a walkthrough of their dashboard. Interviews were audio recorded and transcribed.

Data analysis

Quantitative

Summary statistics were calculated for patient characteristics, surveys, MyChart logins, dashboard views, and RM adherence. Paired sample Student *t* tests were used to examine changes from enrollment to exit.

Qualitative

Researchers analyzed transcripts in 2 phases. The first phase, in which 3 researchers (MF, AC, RP) coded common ideas that emerged across participants, revealed the complexity of lived experiences and the importance of context in assessing dashboard feedback. Guided by these observations, four researchers including the interviewer (SW, AC, CD, RA) further unraveled the complexity of these individual

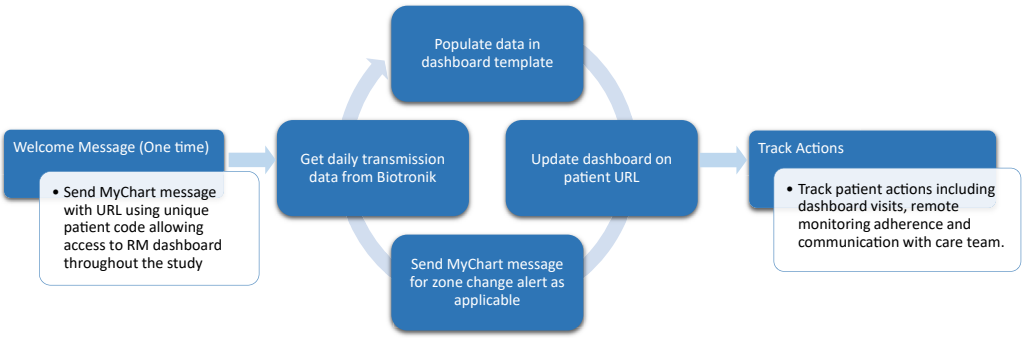

Figure 4 Research procedure for updating dashboards and tracking activity. Researcher activities for retrieving daily transmission data, uploading it to the dashboard, and notifying participants of changes in percent left ventricular pacing. RM = remote monitoring; URL = uniform resource locator.

experiences, remaining open to emerging concepts. Applying the constant comparative method,[30] they coded 4 of 10 transcripts using open and *in vivo* coding to develop an initial codebook, comparing new data and modifying and reiterating on codes until consensus was reached (4 meetings). Two researchers (AC, CD) applied the codebook across the remaining 6 transcripts, meeting 8 times to achieve consensus and collaboratively summarize findings.

Results

Participant characteristics

Participants were 100% white; 60% male; and age 34–80 years (mean ± SD: 62.0 ± 13.4 years). Time since implant ranged from 64 to 1896 days (mean 336 ± 560.8). Full participant characteristics are listed in Table 1.

Quantitative

Health literacy, patient engagement, and system usability

All participants demonstrated "adequate" literacy on the NVS at both enrollment and exit. Average ACE scores at enrollment and exit were "medium" for informed choice (13.9 ± 3.1 and 14.4 ± 4.5, respectively), and "high" for navigation (17.8 ± 1.7 and 18.8 ± 3.3, respectively). Commitment score averaged "low" at enrollment (15.9 ± 3.5) and "medium" at exit (17.8 ± 1.7); however, a paired Student *t* test comparing these scores was not significant (t 1.62; df 9; $P = .14$). Mean SUS score was 76.5 ± 11.0, indicating acceptable usability.

MyChart logins and dashboard views

The average number of MyChart logins significantly increased from 37.4 ± 41.8 in 180 days pre-enrollment to 60.8 ± 63.7 in 180 days post-enrollment [t(9) = 2.31; $P = .0463$) (Table 2). Dashboard views ranged from 0–42 (mean 14.9 ± 12.5). Of the 9 participants who accessed the dashboard, 5 demonstrated decreased frequency of views over time.

RM adherence

RM adherence increased from 85% before enrollment to 91% during the study (increase of 7.06%). Table 3 lists the percent change per individual, as well as the number of phone calls for missed transmissions.

Changes in percent LV pacing

Three participants had changes in pacing zone during the study; 2 were in the red zone and were followed-up with the clinic as instructed. Table 4 lists 5-week average percent pacing values at enrollment and exit and changes in zone per participant. Participant P01 returned to the green zone within a week of exit interview.

Qualitative

Familiarity with technology

Three participants (P01, P03, P05) were new to MyChart. Participants accessed MyChart from smartphones, computers, and tablets. In exit interviews, no participants expressed difficulty using the portal or accessing the dashboard. "The neat thing about being able to check, you know, on the computer, it gives you that peace of mind" (P09).

Table 1 Participant characteristics (N = 10)

Age (y)	62.0 ± 13.4
Male sex	60
White, not Hispanic or Latino	100
Body mass index (kg/m^2)	38.1 ± 7.8
Diabetes	50
Coronary artery disease	20
Hypertension	60
Private insurance/Medicare	80/20
High school, GED/trade, some college/college graduate/postgraduate	30/10/40/20
<$40,000/<$60,000/<$100,000	40/40/20
Retired/full-time/part-time/unemployed	50/30/10/10
Household: Spouse or partner/lives alone/independent senior living	70/20/10
Computer use: Average/very good/good/poor/very poor	50/40/10/0/0
Internet use: Average/very good/good/poor/very poor	50/40/10/0/0

Values are given as mean ± SD or percent.
GED = General Education Development.

Table 2 MyChart logins during 6 months pre- and post-enrollment, and dashboard views during the study

Participant (sex/age [y])	MyChart Logins (during the 6 mo before and 6 mo after enrollment)			Time in study (months link active)	Dashboard views (during each participant's study period; length varied)	
	Pre-enrollment	Post-enrollment	Change		Total visits	Visits per month
1 (F/61)	2	20	+18	10.6	7	0.66
2 (M/69)	24	47	+23	11.0	13	1.18
3 (F/64)	1	22	+21	10.3	22	2.14
4 (M/80)	16	46	+30	7.3	31	4.25
5 (M/46)	2	37	+35	8.3	42	5.06
6 (F/59)	127	224	+97	7.1	15	2.11
7 (M/34)	62	33	−29	6.6	4	0.61
8 (M/65)	52	76	+24	6.1	10	1.64
9 (M/73)	78	99	+21	6.3	5	0.79
10 (F/69)	10	4	−6	6.2	0	0.00
Average	37.40	60.80	+23.40	8.0	14.90	1.84

F = female; M = male.

Frequency of access

Five participants (P05–P09) described looking at the dashboard less frequently over time. Some noted that the lack of change in their data disincentivized continued, frequent checking.

P02 implied being too busy to check the dashboard regularly, and P10 did not use it at all. Both expressed in the exit interview that they should have checked more. P10 noted, "I don't always understand this kind of stuff. I guess that's why maybe I pass over it."

Understanding/interpreting the dashboard

In general, patients understood the stoplight metaphor. "Green is good. Green means go. And if it's yellow I've got a concern and red, hey this is serious" (P04).

Some participants were confused by the daily pacing visualization (Figure 3). P04 was pacing at 100% for the entire study and, thus, assumed the green bars represented a successful daily transmission and the red dotted lines (93% and 85% cutoffs) related to his pacing data. "I've never seen a green bar that didn't go clear to the top…so I thought the green bar was always gonna be full." P01 had similar confusion. At exit, her 5-week average was 88%, but she stated, "I know you want me at 93% and I'm doing 85?" in reference to these lines. A few participants also expressed residual confusion of what exactly "pacing" meant, in a clinical sense.

No patients expressed difficulty reading the data visualizations for battery life, heart rate, or episodes, although some had mild difficulty interpreting. For example, P10 could identify her heart rate but was unsure whether it was high, low, or normal.

Although educational information was provided, P05 wished it was clearer and more actionable. "I did get an email saying…my overall was in the yellow. …I emailed them and I'm like, well what does this mean? And they're like...refer to the information we gave you. And it's like…I don't know what I did with that, you know? It would have been nice to have it like right there, have access to it in terms of clicking on [a] link. Okay, so if you're in the yellow and you're in this range, this is what this means."

Taking action on the data

Participants generally understood the instructed actions to take if their pacing dropped below green. P01 and P02 called

Table 3 Remote monitoring adherence pre- and post-enrollment and number of phone calls to participants during the study due to missed transmissions

Participant (sex/age [y])	Pre-enrollment period			Post-enrollment period			Percent change	Calls
	Days	Transmissions	Adherence (%)	Days	Transmissions	Adherence (%)		
3 (F/64)	180	88	48.9	180	150	83.3	70.3	4
5 (M/46)	112	91	81.3	180	178	98.9	21.7	0
2 (M/69)	180	146	81.1	180	168	93.3	15.0	5
9 (M/73)	35	34	97.1	180	180	100.0	3.0	0
6 (F/59)	92	92	100.0	180	178	98.9	−1.1	2
1 (F/61)	180	172	95.6	180	166	92.2	−3.6	3
4 (M/80)	97	97	100.0	180	168	93.3	−6.7	1
8 (M/65)	145	137	94.5	180	155	86.1	−8.9	0
10 (F/69)	35	35	100.0	180	159	88.3	−11.7	2
7 (M/34)	68	64	94.1	180	136	75.6	−19.7	10

Abbreviations as in Table 1.

Table 4 Changes in percent LV pacing (5-week averages) from enrollment to exit interview

Participant (sex/age [y])	Five-week average percent LV pacing at enrollment (t = 0)	During study				Five-week average percent LV pacing at exit interview
1 (F/61)	98%	3.8 mo* (91%)	4.3 mo (84%)	11.6 mo† (86%)		11.7 mo (88%)
2 (M/69)	97%	3.4 mo (92%)	6.3 mo (84%)	10.5 mo (85%)	11.6 mo (94%)	12.1 mo (95%)
3 (F/64)	100%	No threshold crossing				11.4 mo 99%
4 (M/80)	100%	No threshold crossing				7.5 mo 100%
5 (M/46)	100%	5.1 mo (92%)		6.0 mo (94%)		8.6 mo (99%)
6 (F/59)	100%	No threshold crossing				7.4 mo (100%)
7 (M/34)	100%	No threshold crossing				6.8 mo (100%)
8 (M/65)	100%	No threshold crossing				6.2 mo (99%)
9 (M/73)	100%	No threshold crossing				6.5 mo (99%)
10 (F/69)	100%	No threshold crossing				6.3 mo (100%)

LV = left ventricle; other abbreviations as in Table 1.
*Number of months during the study and at exit interview denote the time point that percent LV pacing (5-week average) was collected.
†Occurred after this participant's cardiac resynchronization therapy–defibrillator was explanted and replaced with a pacemaker.

the clinic upon noticing their pacing had decreased. They and P04 (who noticed missing data due to transmission issues) also reported discussing data with providers at appointments. P01's device had "an over-sensing issue," ultimately leading to its replacement. "They were talking at that point about what they wanted to do…and in the meantime, my pacing was dropping, but [my doctor] said not to worry about it." P02, who "had difficulty finding exactly what pacing percentage meant," mentioned his lowered pacing at a checkup, and ultimately his device was adjusted. He explained, "I better understood, because I felt no different." P08 showed his doctor the dashboard, but his doctor was unfamiliar with its format and this study. P06–P09 all stated they would hypothetically call their doctor or the clinic if their pacing worsened.

P05 recognized the potential for improved care: "...Be able to call the doctor and go...I can see from what the device is telling me that…it's not functioning at what it's supposed [to]. This is what I'm feeling, you know? And then maybe be able to adjust meds...over the phone as opposed to getting into dire straits and then ending up in the ER with a huge bill."

Emotional reactions

Generally, participants' level of concern was contextually appropriate. Although most did not see the yellow or red zone during the study, they understood it should not cause extreme anxiety: "I wouldn't be running myself into the Emergency Room or anything like that" (P08). P03 did state that if her pacing zone was suddenly yellow, she would "probably panic, because it's been fine," but implied she could be reassured by her doctor, whom she trusted.

At exit, P07 had recently learned that his ejection fraction had not improved since receiving his device, even though his pacing zone was always green. He repeatedly expressed his frustration with this inconsistency. "…Looking at the graph-…I'm thinking everything's going excellent. Like because everything's green and there is no episodes recorded." "It was green every single time. I don't think it was under like 90-some percent like every single time and that made me think everything is getting better."

P05's appreciation for data access outweighed anxiety: "I'm used to seeing it in the green and it's like, okay it's fluctuated a little bit and...once in a while there's a yellow but all of a sudden I'm seeing the red and I'm going—What's going on? You know, should I be concerned? So just seeing it maybe caused a little bit of anxiety but being able to know what that means…[was] more just informational than causing, you know, alarm."

No other participants expressed negative feelings about having access to this data; in fact, some desired or had expected more. For example, P08, who noted that others may be overwhelmed, suggested an option to show more information if the patient wanted it. However, some were satisfied with the information provided, such as P09: "Really, I think it pretty much covers everything."

Connecting symptoms to data

Several participants wanted or attempted to connect their dashboard data to symptoms or events. For example, P01 and P06 experienced heart-related physical sensations and

wanted to see whether these corresponded with any changes in their dashboards. P06 also wanted to see whether the dashboard showed changes on days he was breathing heavily or felt he may be "doing too much." P03 felt reassurance that her pain and physical wellness did not seem to be related to shocks or changes in heart rate as per the dashboard. When P08 fell off a ladder and broke his collarbone, he checked the dashboard to confirm his device was still transmitting and he had not received a shock, and felt reassured that he was still pacing at 100%.

Before the study, P02 had connected his atrial fibrillation episodes to alcohol consumption and RM data communicated by his doctor prompted him to stop drinking alcohol. He wanted to use the dashboard to inform other self-care decisions and know "what possibly I was doing that might cause whatever problems were going on."

Discussion

Using implanted device data in daily life

Our study was the first to provide actionable daily RM data to individuals with CRT-Ds in a patient-centered digital dashboard with which they interacted on their own time. This pilot trial shows promising evidence in favor of further research and, ultimately, clinical use of similar tools to support an increasing population of adults with CIEDs. Adults across a wide age range (34–80 years) successfully engaged with the dashboard across the course of 6–12 months and reported no major usability issues. Although we did not empirically assess clinical burden, participants self-reported appropriate level of concern and responses to data, without excessive calls to the clinic or health care utilization. This aligns with related research that examined clinical burden from the provider's point of view.[18] However, several opportunities for further data sharing refinement and more extensive future research were identified.

Presentation of data requires personalization and education

Previous research suggests patients are satisfied with receiving RM data,[13,18] but it requires more explanation and personalization to be meaningful.[16,17] The participants in this study generally appreciated having access to their data, but several expected the dashboard to include more information than it was designed to provide, either in terms of the amount of data or its implications. Some attempted to connect how they were physically feeling with their data at a specific date or time. This may have been prompted by the instructions to watch for certain symptoms of worsening heart condition, particularly if the 5-week average pacing had dropped into the yellow zone. Clearer education regarding the lack of association between physical wellness and percent LV pacing on a more granular level, as well as the scope of the dashboard data in general, may have mitigated these unfulfilled expectations. Relatedly, dashboard views declined over time for 5 participants. In exit interviews, some attributed this decline to the lack of changes in their data, suggesting that more dynamic datapoints may encourage engagement. Providing daily or weekly readings of additional device data such as activity, nocturnal heart rate, thoracic impedance, and heart rate variability could give patients further insights into their HF status,[31] facilitating patient–provider conversations and shared decision-making.

This study supports the concept that providing additional RM data, particularly that which may be novel to many patients or involves technical language with which they may not be familiar, requires appropriate design considerations to match complexity, as well as corresponding education. Although our dashboard's datapoints, visualizations, and labels were chosen based on input from participants who also had HF and CRT devices in previous design sessions,[19,22] everyday use revealed opportunities for further tailoring and education. The active dashboard users in our study had little difficulty interpreting the data of which they likely had previous knowledge (eg, heart rate and battery life). However, even at the end of the trial, several participants lacked deep understanding of what the percent LV pacing datapoint truly indicated, and some had misinterpreted details of their data due to the complexity of the daily transmission graph. This may be exacerbated by additional complex datapoints and unfamiliar language, especially among users who are less educated and health literate. These are extremely important considerations for future design work.

Alerts and indications of normal and abnormal readings require education and personalization as well and should not have a "one size fits all" approach across patients or across datapoints. For example, we used a red/yellow/green stoplight metaphor to visually display percent LV pacing, and this may not always be interpreted effectively. For suboptimal pacing, this metaphor was generally successful in that the yellow and red zones did not cause inappropriate alarm. This was likely due to the specific instructions provided for actions to take if the participant's pacing dropped to this level. However, for individuals who have consistently low pacing, seeing the yellow or red zone may not be helpful. Conversely, P07 felt that the reassuring nature of the green zone had not accurately represented his heart health. He had recently learned that, despite consistently pacing $>92\%$, his ejection fraction had not improved, and he was quite frustrated by this news. This unintended consequence illustrates the importance of individualized patient education in the context of sharing novel health data.

Relatedly, P01's pacing dropped into the yellow and red zones due to a device issue. While she was awaiting device replacement, her doctor directed her not to worry about her pacing, regardless of the study instructions. This was an example of successful patient–provider communication. However, hypothetically, individuals could experience confusion from contrasting sets of instructions or unnecessary anxiety from continuing to receive alerts and/or see visualizations intended to generate concern. Thus, the ability to disable or modify certain features due to unique individual circumstances may be an important future design consideration for widespread RM data sharing.

Patient-centered monitoring of data has potential for improved health outcomes

Monitoring health data is a component of self-managing chronic conditions. In this study, participants monitored their percent LV pacing and took action as instructed. Literature has established that clinical monitoring of this datapoint and timely intervention for lowered pacing resulted in improved outcomes.[5,6] Our findings suggest that patients may be capable of contributing to this feedback loop if they are given access to their data.

When asked during their exit interviews, participants could identify missing transmissions on the daily pacing graph and attribute this to specific circumstances when they were away from their monitor. However, participants in our study were not prompted (via e-mail notification) to view the dashboard unless their pacing zone had changed, although we contacted them via telephone after >2 consecutive days of missed transmissions, which likely contributed to their high adherence rate overall. Our trial was small enough that it was feasible to contact participants in this way; however, on a larger scale, a feedback loop involving additional automated notifications and reminders (eg, via e-mail, text message, or portal message) could support RM adherence and prevent adverse outcomes in the first few years after implant.[32]

Patient-centered tools may increase engagement in health technology

Participants, who had adequate health literacy and were comfortable with technology, engaged with the dashboard to varying degrees, but most increased their MyChart usage during the study. This finding suggests that providing patients with a patient-centered tool may generate awareness of patient portal features, such as communicating health information between clinic and patient. This may have larger health care implications due to benefits of patient portal use.[33]

Clinical implications

The study findings provide implications for clinicians caring for patients with HF and CRT devices, as well as broader clinical implications regarding patient RM for chronic conditions.

- Sharing with patients daily RM data that confirm device function and show therapies delivered could provide reassurance and enhance outlook, supporting patient well-being and quality of life.[34]
- Adults with CRT devices monitored and took appropriate action on daily percent LV pacing data and did not self-report excess concern or unnecessary contact with their providers.
- Presentation of device data requires personalization and interpretation that matches its complexity, as well as corresponding educational information, to both facilitate understanding and avoid unintended consequences.
- This study only examined a patient-facing dashboard and not all clinicians were familiar with it, making patient–provider conversations difficult. A patient- and provider-facing dashboard, designed in partnership with both sets of stakeholders and tailored appropriately, could facilitate shared decision-making.
- Providing patients with additional tools, such as a digital RM data dashboard, could increase engagement in existing tools like patient portals.

Study limitations

The generalizability of our results is limited by small sample size and lack of diversity. All 10 participants had at least a high school education, demonstrated adequate health literacy, and rated their computer and Internet abilities as average or better. Participants, overall, were also generally engaged in their health care. These factors are of particularly high importance given the topic of study. Further research should attempt to counteract the type of volunteer bias evident in our sample in order to understand RM data sharing preferences among individuals with less education, lower engagement, and limited technology experience, who may have greater health needs.[35] Our sample lacked racial diversity, which is somewhat representative of the geographic area from which participants were recruited and was also evident in the previous design phases.[19,22] However, the experiences and opinions of our white, Midwestern American cohort are not universally shared, and further research with larger samples should include ethnic and cultural diversity that is representative of the end user population.

The first 3 participants enrolled did not start receiving data until 1 month after enrollment due to technical issues, and dashboard views did not start tracking until 1 month after these 3 participants started receiving their data.

Conclusion

Although this pilot study was small (N = 10), its results show promise with regard to the future of RM data transparency. Patients with HFrEF and CRT-Ds, aged 34–80 years, who were generally comfortable with technology and had adequate health literacy, were able to access a novel digital dashboard containing tailored RM data on their own time over 6–12 months. Overall, participants felt positively about having access to their data, and they took or could conceive of taking appropriate action from it. However, more work is needed to improve individual usefulness and understanding of RM data. This should include larger trials with more diverse patient populations, both demographically and in terms of health and technology literacy. Future work should also directly examine clinical outcomes (eg, patient health, clinical burden, economic impact) of this patient-facing RM data sharing process in order to more fully assess the impact of this emerging practice.

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