Patient Experiences with an mHealth App for Complex Chronic Disease Care: Connections Despite Lack of Traditional Clinical Interactions

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Cover Page Footnote
This project was funded by the InterCommunity Health Network, a Medicaid payer in the US pacific northwest.

This research is available in Patient Experience Journal: https://pxjournal.org/journal/vol11/iss2/12
RESEARCH

Patient Experiences with an mHealth App for Complex Chronic Disease Care: Connections Despite Lack of Traditional Clinical Interactions

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ABSTRACT

Chronic diseases are costly to treat and burdensome for patients. Mobile health (mHealth) technologies might reduce costs of care and increase patient self-efficacy in chronic disease management, but the patient experience of mHealth is poorly understood. Our objective, therefore, was to evaluate patient experiences with using an mHealth app for complex chronic disease management, within a U.S. population of low-income patients. We used nurse/patient text messages from an mHealth complex chronic disease management tool, and exit interviews from patients, to assess qualitatively Medicaid patients’ experiences with a remote monitoring mHealth app. Salient themes about the patient experience included: (1) Visibility and Invisibility in the Medical System (patients felt both seen and heard when using the app), (2) Deconstructing the Clinical Encounter (patients were reassured by being able to access care from any place at any time), (3) Familiarity in the Nurse/Patient Relationship (patients felt connected to the nurses running the app), and (4) Technology as a Conduit of Caring (the technology enhanced nursing care, rather than detracting from it). M-Health apps might be a way to improve provision of care for high-utilizing patients, particularly those from historically marginalized groups.

Keywords: Patient experience, Patient-centered care, Healthcare, Equity, Quality of care, Chronic disease, Office visits, Patient-generated health data, Remote consultation, Telemedicine, Text messaging, Formal social control, Health communication, After-hours care, Health services accessibility, Telenursing, Delivery of health care, Patient care management, Nurse-patient relations

1. Background

Chronic diseases, such as diabetes or heart disease, comprise seven of the ten most common causes of...
death in the United States, and globally result in 17 million premature deaths annually. Chronic diseases incur enormous costs, for individuals, their families, and the healthcare system. United States healthcare infrastructure is not expanding quickly enough to keep pace with the growing numbers of people with chronic diseases, a problem exacerbated by the loss of hospitals, providers, and clinics in rural areas, both generally and secondarily to Covid-related burnout. Given the aging population in the U.S. and other high-resource countries, as well as the increasing numbers of people who are at risk for chronic diseases, again both in general and specifically tailored to each patient. mHealth apps might reframe the way patients and their providers manage chronic diseases, including in 77% of low-income countries. In its 2011 global report on the status of mobile health (mHealth), the World Health Organization (WHO) found that 83% of member states reported at least one current mHealth initiative, including in 77% of low-income countries. The potential benefits of mHealth apps would be particularly pronounced in remote areas, or in small urban areas that lack specialist care. mHealth apps might also benefit patients for whom lack of access to healthcare is more a matter of scheduling practicalities than a true lack of available clinics and providers.

Consensus does not yet exist differentiating the terms “mHealth,” “e-health,” “telemedicine,” and “telehealth.” For the purposes of this project we use “mHealth” to refer to apps that are either entirely independent of care providers (e.g., deliver educational materials for patients to work through on their own) or that include asynchronous involvement by a care provider (e.g., patient portal messages back and forth), along with other content.

For all its potential benefits from increased access, mHealth nonetheless is not without critique. First, despite the ubiquity with which electronic devices can be personalized, mHealth apps nonetheless tend to be one-size-fits-all, much like their printed pamphlet predecessors, rather than providing care specifically tailored to each patient. Second, by definition, mHealth relies on technology in lieu of face-to-face, synchronous interactions with healthcare providers. Thus, mHealth apps might reverse equity gains made by the patient-centered care movement: prior to the idea of patient-centeredness, it had been well documented that patients held little power in the clinical encounter. By contrast, in patient-centered care, the patient’s own knowledge of their body, as well as their preferences for types of care received, are considered as important as formal medical knowledge brought to the encounter by the clinician. mHealth apps, however, instead tend to emphasize biometric monitoring, turning the patient into quantifiable body parts, rather than a person whose knowledge and wishes must be respected.

In high-resource countries, some efforts have been made to evaluate mHealth interventions, but these almost always focus exclusively on either patient satisfaction or patient-user acceptability of the app itself (see for instance). Both are assessed most often via close-ended questionnaire. This focus on patient satisfaction is particularly true in the U.S., because of Affordable Care Act-driven reporting requirements.

Missing from the literature are reports of whether the actual care delivered was adequate in the medium- or long-term (i.e., did patients’ health outcomes improve or at least remain the same, compared to in-person care?). Qualitative, in-depth reports of patient experiences are also absent from the literature. The former matters for obvious reasons (we should not advocate for interventions that cause medical harm), but the latter matters as well, because patient satisfaction questionnaires are known to have a positive bias—that is, when asked, patients will mostly agree that, yes, they like their doctor and are satisfied with the care provided by that person. Furthermore, “patient satisfaction surveys only ask questions to which clinicians are interested in knowing answers, but do not allow patients to freely and openly discuss their own concerns.” Open-ended, qualitative evaluations of patient experiences with mHealth apps are necessary to ensure the mHealth trend proceeds in an equitable and just manner.

Some work to address this gap has been done in Europe, but given that U.S. culture around healthcare (and social services in general) is so different than that found in Europe, the lack of in-depth explorations of patient experiences with mHealth apps for people who live and receive care in the U.S. is a notable gap in the literature. Our objective, therefore, was to evaluate patient experiences with using an mHealth app for complex chronic disease management, using a qualitative approach unconstrained by traditional patient satisfaction questionnaires, within a U.S. population of low-income patients, defined as those on public insurance (i.e., Medicaid).
2. Methods

We used semi-structured interviews to examine patient experience of participating in a quality improvement initiative evaluating the use of an mHealth intervention for complex chronic disease management in a high-utilizing, Medicaid population. All participants in the quality improvement initiative were eligible to participate in interviews. The study was approved by the Institutional Review Board at Oregon State University. Patients and nurses both provided written informed consent.

The project took place over the course of twelve months, between April 2015 and March 2016, and was a collaboration among a mid-sized, multispecialty clinic, a local mHealth technology company, and a university, the latter employed to conduct the formal evaluation. Eligible patients were those who received primary care at the clinic, had one or more chronic disease diagnoses (diabetes, asthma, chronic obstructive pulmonary disease, and/or congestive heart failure), and had high levels of healthcare utilization in the previous 12 months (at least one hospitalization and/or several emergency department visits). Additional eligibility criteria included being at least 18 years old and enrolled in Medicaid (public insurance for low-income people; qualification criteria vary by state). Patients who had cognitive impairment requiring the aid of a caregiver were excluded. Four nurse case managers from the clinic with expertise in complex chronic disease management administered the clinical aspects of the project. The mHealth company developed and deployed the app and provided technical support to both clinicians and patients over the course of the project.

Forty-five patients were enrolled, and 37 completed the study: 6 requested to be withdrawn (two of those were because the mHealth technology was not working adequately, the other 4 were for unknown reasons), one died, and another was removed from the protocol by their physician. Length of participation ranged from six to twelve months, depending on recruitment date. The mean age of participants was 55 years (SD 12), 88% were white, non-Hispanic, and all were low-income and enrolled in Medicaid.

The intervention was delivered to patients on a cellular-enabled tablet computer, given to them at the time of enrollment, onto which the mHealth app was loaded. The nurse case managers were responsible for monitoring the health of the patients through use of a provider-facing version of the same app. Nurses were charged with around the clock, on-call periods lasting one week in length; they rotated call so that each nurse was on call for about one week out of every month throughout the project period.

The app included two primary components. First, a two-way text messaging feature that enabled patients to communicate with the on-call nurse case manager at any time of day or night. Second, patients were asked to regularly enter their diagnosis-specific health data into the app, e.g., blood glucose levels. Patients were thus able to see graphical trends in their health markers, while the on-call nurse case manager could easily monitor the entire panel of patients and promptly act on any irregularities or urgent health situations.

Weekly team project meetings included the project’s PI (MM), the evaluation team (JL, MB), the four nurse case managers, and representatives from the technology company; we discussed overall progress of the project, as well as specifics of patient care and app functioning as necessary. From these meetings, and field notes taken at same, we were able to learn important details of how the app functioned for both nurses and patients, and how nurses and patients interacted through use of the app in the provision of care. Patients were not present at the meetings, but we learned something of their experiences through the nurses’ weekly reports. These details informed the exit interview question guide: at the close of the project, all 37 patients were invited to participate in open-ended, semi-structured exit interviews; twenty-seven such interviews were completed (JL and MB did the interviews).

Detailed quantitative evaluation results from this project have been reported elsewhere, and included pre- and post-intervention questionnaire data, blood glucose data for patients with diabetes, and examination of cost data from Medicaid billed charges and paid claims. Briefly, the blood glucose data revealed no clinically-meaningful change across the sample during the project. While some individual patients did achieve reductions in, or stabilization of, blood sugar levels, others experienced either no change or increases in average blood sugar during the project. Conversely, pre/post patient-reported outcomes indicated statistically significant improvements in self-rated health, the degree to which pain interfered with daily living and mobility, and overall quality of life. This paradoxical finding, that patients’ subjective experiences of their health improved, even
though clinical measures of “health” remained unchanged, invited further investigation. The current manuscript thus explores patient experiences qualitatively, using the 12 months’ worth of nurse/patient text messages and transcripts from patient exit interviews.

Interviews were recorded and transcribed (JL), then two investigators independently coded (JL, MC) and analyzed the transcripts using NVivo 10 (QSR International Pty Ltd., 2012). Initial coding of the transcripts utilized an open, consensus coding structure, guided by the theoretical framework outlined by Elizabeth Carpenter-Song in her research on chronic disease and mental health. First, we independently created initial coding schemas. Once we achieved consensus on the codes, we continued analyzing the interview transcripts, in an iterative process whereby initial codes, indicators, and concepts were discussed in detail and continually compared and refined against the interview data. As key themes began to emerge, these concepts were elaborated on and transformed into more robust theoretical categories informed by the larger body of social science literature on mHealth, thus generating an analysis at once grounded in the patient experience and simultaneously engaging broader theoretical categories.

The text messages sent between nurses and patients via the mHealth app allowed us to evaluate patient/provider interactions more directly. Once exported, the corpus of text messages over the course of the year-long project spanned nearly 1,000 pages. We used this text message data to further refine and illustrate the themes that emerged from exit interviews.

3. Results

We identified four salient themes that help to explain how mHealth affects patients’ experiences of chronic disease management: (1) Visibility and Invisibility in the Medical System, (2) Deconstructing the Clinical Encounter, (3) Familiarity in the Nurse/Patient Relationship, and (4) Technology as a Conduit of Caring. Collectively, participant narratives suggest that mHealth, as utilized in this study, improved patient perceptions of wellbeing by reducing temporal and geographic barriers to care, flattening power hierarchies between patient and provider, and by fostering a sense of connectedness and familiarity that made participants feel seen and cared for. Below we discuss these emergent themes, supported by excerpts from interview narratives and patient-nurse text messages.

3.1. Visibility and invisibility in the medical system: “That wall over there that messes everything up”

For many participants, the medical care they received before enrolling in this project lacked depth, consistency, and quality, as has been documented by previous scholars in other populations. Patients described instances when previous experiences with care providers left them feeling disconnected and uncared for. For example, during a discussion of current and past health issues, Eric noted that he once had difficulty in getting relief from knee pain that continued after having knee replacement surgery:

[W]hen they did surgery on this knee, [they] took out the kneecap and left the artificial one in. And every time I ask the doctor to look at it, he’s says “Oh, your kneecap’s ok, but we can’t do anything about it.”

The doctor’s dismissive response to Eric’s ongoing experience of knee pain exemplifies how people are often made to feel invisible within a medical system that can prioritize the specialized knowledge of care providers over the lived experiences of patients. Other patients in the study described similar past experiences when interactions within the healthcare system left them feeling confused, ignored, or invisible. Some used terms like “wall/walled off,” “obstacle,” “blockade” and “hurdle” to describe systemic barriers to care and connectedness that left them feeling unseen and unheard as in the quote used to name this theme: “That wall over there that messes everything up.” These experiences with impediments that frustrate attempts to access care were juxtaposed against the highly responsive care received as a participant in this mHealth project.

When asked about his general impressions of the project, Thomas expressed his enthusiasm by saying:

I like being able to have someone to communicate with on a direct basis, in the sense that I could type out a message and it went to the person I needed to communicate with, instead of going through that wall they create over there which messes everything up, and I really hate. So that then I could get a direct communication back without things getting fuzzed over.

In Thomas’s prior experiences, the barriers he faced in accessing care led him to feel that he was “walled off” from his care providers and unable to communicate effectively about his healthcare needs. Conversely, being able to communicate directly with nurse case managers using the app in this project facilitated a sense of connection, support, and of “being seen”:
The nurses were very helpful, and knowledgeable... and they were asking me if I wanted the nutritionist or the endocrinologist, et cetera. They were good about trying to connect me with who I needed to be connected with. And also to help me get that actually done. Instead of just saying “Well, you should do this,” they set it up.

The nurse case managers in this example not only provided validation to Thomas’ experiences but helped him navigate the convoluted specialist referral process.

Power dynamics impact the patient experience of medical care. Participants in this study were exclusively low-income and on Medicaid, and as such, were acutely aware they begin any clinical encounter in a position of even lower power than the “average” middle or higher income patient with private insurance. It is thus unsurprising that they historically felt unseen and unheard by the medical system. Indeed, patients in this study described, for example, doctors who dismissed their lived experience as inconsequential, a lack of communication between providers who were, in theory, collaborating to provide critical medical care, and the system itself imposing obstacles to accessing care. In contrast, with the mHealth app, patients reported feeling truly seen and heard by the nurses in a way that felt authentic and imbued with “genuine connection” and emotive caring.

3.2. Deconstructing the clinical encounter: “They were there day and night . . . available any time, any place”

A centrally important feature of this project was that it upset expectations of a “clinical encounter.” The use of mobile technology, in combination with around-the-clock ability to communicate with nurse case managers, obfuscated the boundaries and limitations of a typical, 10–20 minute, in-person, appointment-based clinical encounter. Use of the app brought the clinic into the everyday lives and experiences of patients, dramatically increasing their ability to access care at any time, in any location, and without the constraints of the traditional clinical setting. This access featured prominently in patient narratives. In addition, the app enabled patients and nurses to elongate a given clinical encounter over an indefinite period of time; a single “encounter” might therefore take place over the course of an entire day, as the following text exchange illustrates:

Carol, 10/30/2015 07:49 PM: When I took my bp [blood pressure], it was 183 over 70. since it was high, I panicked and took it again and it was 170 over 87. I was talking on the phone and doing other things just before I took it at 7.30 pm a bit later than I wanted.

Nurse, 10/31/2015 02:13 AM: hi carol im sorry. i wasnt feeling well and fell asleep. just let me know if bp is staying up in the morning or if you have any other symptoms like headache, shortness of breath or chest pain.

Nurse, 10/31/2015 02:16 AM: this was probably just a single situational high blood pressure based on what you were doing prior to checking. and it did come down slightly on recheck.

Carol, 10/31/2015 04:21 PM: Thank you for reassuring me about my bp. [Name omitted] just took my bp and it was 132 over 72. i cant understand why I get higher readings on my machine. Taking my own bp always makes me nervous because Im afraid it will be too high . . . [the assisted living facility] always uses a wrist bp device and it usually reads lower.

As the above exchange illustrates, communication about a single, non-urgent component of clinical care could be distributed over time, unfolding organically over nearly 24 hours. The informal structure and content of exchanges between nurses and patients reinforced the notion that care was accessible at any time. Furthermore, this episode would likely never have happened during a “regular” clinical encounter; without access to this app, Carol likely would not have contacted a care provider about a single, high blood pressure reading, even if it was worrisome. The app facilitated ongoing, day-to-day care, rather than the usual sporadic office visits.

For Diane, increased access meant that she could maintain communication with her care providers in situations that would typically have interrupted access to her primary care provider:

I used it [the app] when I went on vacation, ’cause I wanted to see what it was like when I was out of town . . . if something came up, I still had the personal touch of somebody knowing what was going on. And I would communicate with them, saying I was going on vacation.

Within the constraints of cellular access, patients in this study could enter biometric data and contact nurses regardless of their physical location. In Diane’s case, a care provider known to her was accessible when she went on vacation. Many patients similarly
expressed appreciation for the portable nature of the app.

Traditionally, the clinic space and clinical encounters reify power dynamics. During face-to-face, traditional clinical encounters, patients are aware of the body language, clothing, and other non-verbal cues from their care providers (e.g., patients wait for physicians, never the other way around)—and each of these reinforces the notion that clinicians have more power than their patients. However, when the clinical encounter occurs asynchronously, outside the clinic, without physical or even video contact between patient and provider, these non-verbal cues are no longer present, and the system is disrupted. Patients were able to engage with the nurses through the app in a manner that was different than their normal way of being during a clinical encounter, and numerous patients highlighted this aspect of their project experience specifically during exit interviews. In our study, the “clinical encounter” was stripped of the most readily recognizable aspects of traditional biomedicine: nurses waited for patient responses as often as patients waited for nurses, there was always enough time for all questions to be answered, and no one cared what anyone was wearing. While similar mHealth apps would likely always disrupt traditional clinical encounter power dynamics in these ways, it may have been more apparent in our population, most of whom brought to the project a lifetime of living at a low SES and having little social capital to leverage in healthcare settings.

3.3. Familiarity in the nurse/patient relationship: “You couldn’t ask for a better bunch of girls”

Many patients expressed a high degree of investment in the relationships they built with the nurse case managers over the course of the project. The extent to which patients valued this relationship was reflected in the language they used, and text message transcripts support patients’ perceptions that nurses deliberately cultivated an informal, familiar relationship. In addition to encouraging patients to engage in regular, non-clinical interactions via the app, nurses used text messages to convey a sense of familiarity through informal grammatical constructions and use of language.

Nurse: Have you noticed your BS [blood sugars] for the last week have been steady at low 200’s??? Ya HOOOOO!!!! And I am still waiting for my “one good thing you did for yourself today” note you need to send me. This is certainly something! good job.

The explicitly friendly tone of the above message is echoed throughout the text message transcripts. Yet even when messages were more explicitly clinical in nature, they often incorporated elements of informality, such as the use of emoticons, that acted to reinforce familiarity between nurses and patients.

Throughout the exit interviews, a notable pattern emerged of patients referring to nurse case managers using familiar terms, rather than professional markers. Nurses were often referred to as “girls,” “ladies,” or “sisters,” denoting a more intimately familiar association than would be expected in a primarily clinical relationship. Again, nurses in this project seemed to deliberately cultivate this familiarity, but patient use of familiar terms could also indicate patients seeking to disrupt traditional power dynamics, whether consciously or not. Regardless, the patient exit interview narratives revealed a patient/provider relationship imbued with mutually shared emotional caring. Summing up his feelings about the end of the project, Edward said “I was just telling the girls in there, I’m a bit teary eyed this is all coming to a close. I’m going to kind of miss them. I’m losing a bunch of sisters, is what I’m losing.”

Communication between nurses and patients acted to narrow the social distance, leveling the power differential between the two parties. Because the written communications that were the primary mode available for forging the patient-nurse relationship were characterized by familiarity and reciprocal, affective caring, and provided an avenue through which patient experience was acknowledged and validated, the distance in social space between nurses and patients was effectively narrowed, and power differences receded from the foreground of interactions. Differences in power did not cease to exist, but the way power operated within the bounds of the relationship shifted toward a more egalitarian arrangement, allowing patients to experience a degree of satisfaction in the patient-provider relationship that they reported as special and atypical relative to previous experiences within the medical system.

3.4. Technology as a conduit of caring: “It brings you into the fold”

The technology itself featured prominently in patient narratives. Patients carried out almost all of the study activities using app-enabled tablets, and communication with nurses was almost entirely through text message within the app. Technology thus served an essential function as a conduit through which clinical and emotive care were accessed by patients. The link
between technology and the nurse/patient relationship was evident when patients were asked to reflect on their experiences using the tablet and the app:

Being involved with the tablet kind of brings you into the words, you read the messages every day... I like that idea of being involved, it brings you into the fold on it, you know, and just feed back in. You can talk back in.

-Charles

I like talking to them on the tablet, and I thought that they could get me help if I needed it. And they were just always very pleasant and uplifting. They raised my spirits a lot of times.

-Theresa

The technology also facilitated the development of close ties between nurses and patients by providing a venue in which patients felt safe discussing difficult, embarrassing, or emotion-laden topics. For Edward, the tablet provided the opportunity to discuss issues with his care provider that would have felt too difficult to broach in a face-to-face consultation: “It gives you the chance, at least you can say something if you want to. And without ‘Ah gee, I have to up and say all this stuff to them in front of them.’ To me it was easier.” These discussions were sometimes of a particularly personal nature, as described here by Elaine:

They were also there for me whenever I had other issues arise at the house, like fighting with my significant other... I used [the tablet] as a tool to ask questions, or also I would talk to the ladies about my emotional state of mind, and they would give me tips on different things to do.

Nurses and technology were linked in patient narratives in a manner that makes clear how these two key aspects of the project were dependent on one another as joint catalysts that enabled patients to receive care they perceived as vital to their wellbeing. Technology as a conduit for caring both facilitated connection (via ease of access) and offered some distance, reducing the embarrassment that can accompany one-sided sharing of sensitive information. Together these functioned to further flatten the power hierarchy between patient and provider by decreasing the vulnerability patients felt when needing to disclose more personal information, yet keeping lines of communication open.

While the majority of participants in this project appreciated the value of the technology as a conduit of caring, the technology did not always work, and this was a source of frustration for many participants, especially early on in the project. Indeed, two people dropped out within the first two weeks because of technical difficulties that felt insurmountable. By month three or so, the technology kinks were worked out, and all remaining patient complaints about the technology were about not having permissions to install additional apps on the tablet.

4. Discussion

In our qualitative analysis of patient experiences using an asynchronous mHealth app to interact with a team of nurses, we found overwhelmingly positive support for the project. Patients liked that they could “bring the clinic with them,” and interact anytime, anywhere. They thought the app broke down usual barriers to accessing care or information. Rather than the theoretically-expected de-personalization from a tracking app with no live interaction,\textsuperscript{15,17,18,20,21} the low-income patients in our study reported feeling cared for and seen/heard by the project nurses. While there were some complaints about the technology not always working properly, these were mostly resolved by the technology support team early in the project, and the overall message from patient participants was highly positive.

We found a disconnect between existing interpretations of the impact of mHealth (telehealth, etc.), on the patient-provider relationship wherein researchers have argued that technology is “cold,” impersonal, “low touch,” and too focused on quantitative, measurable biometrics rather than patient emotions and experiences.\textsuperscript{15,17,18,20,21} However, in this sample of low-income patients with chronic health conditions, participants reported feeling better cared for when using the app.

We can imagine three possible explanations for this apparent paradox: (i) existing academic criticisms of technology in medicine are theoretical, and do not hold up when tested in real-world situations that center patient voices; (ii) because of their marginalized status as low-income individuals with complex, chronic healthcare needs, patients in our study were receiving such substandard care prior to their participation that almost any intervention would have been perceived as helpful; (iii) our app was run by nurses, who both stereotypically are seen as more caring and nurturing than other types of providers\textsuperscript{42} but also are trained to practice in a more patient-centered way that values connecting with patients as
individuals. In practice, it is likely a combination of these. Patients certainly did have documented challenges accessing healthcare previously. Patients in our study also referred to the nurses with extremely familiar, even demeaning or condescending, terms such as “girls.” Perhaps they would not have felt the same connection nor taken the same liberties with a different practitioner type or with a differently gendered provider. Nonetheless, it is clear that for this study sample using this particular mHealth app, intimacy, connection, support, and trust were enhanced alongside perceptions of self-rated health. Can reliance on technology negatively influence provider-patient relationships and decrease the quality of care as has been suggested by critics of mHealth? Certainly. Does it always or necessarily? Apparently not. Patient experiences in this study significantly complicate and nuance this question.

Taken together with the quantitative results of the project, this qualitative analysis confirms that mHealth apps can have positive impacts on wellbeing, at the same time revealing that those impacts may not be as straightforward as simple improvements in traditional clinical markers of “health.” If, as in this study, mHealth applications serve to disrupt the pre-existing expectations, unequal power structures, and norms of the biomedical system, they have the potential to serve as tools for patient empowerment, which may ultimately lead to an increased sense of wellbeing. Conversely, if mHealth applications are designed without consideration of these factors, they may instead further alienate patients who might already be struggling with barriers to high-quality care for chronic health conditions. This may be the case for the two patients in our study who dropped out because the technology did not work for them.

Our project also raised important questions about what happens to patients when mHealth projects are discontinued. The landscape of mHealth research is littered with pilot projects (the so-called “plague of pilots,” or “pilotitis”), almost none of which are scaled up after the pilot phase. Given the slow pace of academic work (get funding, get IRB approval, enroll patients, analyze data, publish work) versus the lightning fast pace of technology improvements and updates, likely some of the issue with lack of project continuation is whatever app version was used is long outdated by the time the evaluation has been completed—indeed, sometimes the company no longer exists. This issue may be intractable. However, if mHealth does in fact show potential for improving the health and lives of its users, we face an ethical quandary that must be addressed, and quickly.

In this study, participants expressed eagerness for the program to continue, and anxieties about it ending. One reported that in the short duration between the conclusion of the project and her exit interview, she had experienced a worsening of her health that she attributed to discontinuation of the study. The proliferation of discontinued pilot projects has created a clear and urgent need for researchers to investigate the effects of repeatedly ending such programs abruptly, without adequately addressing patient needs after the program’s conclusion. This problem is exacerbated by the fact that patients in many studies are elderly, living in poverty, or face either geographical or social isolation in relation to their diagnoses. Government and private funders so anxious to reap the economic benefits of mHealth innovations would do well to remember the people behind the data. Collectively, we must find ways to rigorously evaluate mHealth technology interventions and scale up the promising ones, while reducing harms to pilot project participants.

5. Limitations

Our project is not without limitations. First and foremost, this is a very select patient population: Medicaid enrollees from one region of the country, mostly young enough to be completely comfortable with technology. We also excluded those who needed a full-time caregiver, and had none with visual or other impairments. While screen reader technology may have interfaced seamlessly with the mHealth app, we did not test this. We also enrolled only English speakers. There is a large Spanish-speaking population in our area, and their experience may well have been different. Would these results translate to other populations? Possibly, but this is not guaranteed.

Second, there were six people who dropped out of the study, at least two of which were early losses to follow-up specifically because the technology did not work seamlessly. We deliberately gave out cellular-enabled tablets with the mHealth app loaded, so lack of technology/internet access would not be an issue, but everyone in our sample already had multiple devices, so there was perhaps little benefit gained from providing the tablets. Third, and related, we did not conduct exit interviews with everyone due to project staffing shortages and some participants declining the interview. Regardless, we do have text message transcripts from all participants, and we observed no
differences in the kinds of issues raised nor the tone of messages, when comparing those who did and did not complete an exit interview.

6. Conclusion

mHealth is widely considered an integral component of health and healthcare improvement efforts in the twenty-first century.\textsuperscript{14} We collectively, therefore, have an obligation to understand the impacts mHealth can have on health systems, as well as on the individuals within them.\textsuperscript{11} Although some have argued that the shift of health monitoring and care delivery activities out of the clinic and into the home will require individuals to engage in increased self-discipline alongside mounting pressures to conform to standards and protocols set by biomedical systems without patient input,\textsuperscript{20,21,24,30,34–36} findings from this study suggest that mHealth technologies might also serve to disrupt those expectations. mHealth technologies can be experienced as conduits of improved, supportive, connected, authentic, and holistic care.

Acknowledgments

The authors gratefully acknowledge the nurse case managers who provided remote care for patients in this project: Erin Bartek, Laurie Kerp, Kathy Nepper, and Lindsay Rickli. We also thank Rosa Wolff and Bobby Bangs, who provided tech support to the patients.

Funding

This project was funded by the InterCommunity Health Network, an Oregon Coordinated Care Organization (Medicaid Payer).

Themes

This submission aligns with the PXJ themes of interactions, integrated nature, and person-centeredness.

Conflict of interest

The authors declare no conflict of interest.

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