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Clinical Research Study

Beyond the EHR: How Digital Health Tools Foster Participatory Health and Self-Care for Patients with Diabetes



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ABSTRACT

Just as physicians managing patients with diabetes find that it is a data-driven process, for patients living with diabetes, it is even more so, as physicians see them every few months, but patients need to live with diabetes all the time. Fortunately, the advent of the web has allowed patients to connect with information, medical care, and other patients, while mobile and connected technologies such as smartphones have provided the flexibility to do this—and to manage and share their health information—from anywhere. Healthcare professionals who care for patients with diabetes should be aware of the digital health technologies that enable patients to better care for themselves, be more active participants in their healthcare, and improve the quality of their lives.

Introduction

App

Health care professionals managing patients with diabetes understand that it is a data-driven process. Indeed, electronic health records (EHRs) offer diabetes flow sheets for clinicians to track data ranging from vital signs to laboratory test results to minute-by-minute changes reported on continuous glucose monitors. Because they have more functionality than the static paper flowsheets they have supplanted, these have become indispensable tools for physicians and a component of most EHRs.

But ultimately, it is the patient living with diabetes who is in control of their outcomes. As diabetes activist Kerri Sparling has said, "[Type 1] Diabetes is forever, but the way you manage it has flexibility." Patients make lifestyle choices, choose how and whether to take their medications, and come (or don't come) to medical appointments. Most of the time, even for our most complicated patients, they take care of themselves and see physicians for a tiny fraction of their lives.^{1,2}

Fortunately, digital health technology has enabled and empowered patients living with diabetes, perhaps more than any others. These technologies have allowed patients with diabetes to be more engaged in their health and collaborate more effectively with their healthcare team.

In this paper I provide an overview of these digital technologies, how they are being used, and evidence supporting their use. I will not be exploring medication delivery systems. I will further explore how these technologies can be incorporated into care of patients with diabetes. This paper is intended to complement other related reviews.^{3,4}

Types of Tools

I have divided this section into two parts. First, I will discuss tools that require only a web browser and an Internet connection—technology that has largely existed since the mid-1990s. Then I will address tools and technologies that are mainly used via mobile technologies.

Lower Tech

The Internet has made it easier than ever to connect patients to information, to other patients, and to healthcare.

For example, once the rarified domain of physicians and scientists, the world's medical literature is now available to anyone with an Internet connection. In addition, there are tens of thousands of medical information sites targeted to patient audiences, some of which have professional medical writers and physician editorial boards. Although patients and caregivers will often find these resources on their own, they may also find less reputable information online. It is therefore important for physicians to prescribe reliable online information to their patients to get them started. This can be a useful way for patients to start to learn about their conditions while freeing up scheduled appointment time for responding to questions and having more substantive and nuanced discussions.

Abbreviations: EHR, Electronic Heath Record; CGM, Continuous Glucose Monitor; PGHD, Patient-Generated Health Data. *E-mail address:* danny@drdannysands.com

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Although the volume of reliable health information online likely dwarfs the amount of misinformation, patients will sometimes find misinformation and, hopefully, share it with their physicians (rather than acting on the suspect information without consulting their physician). When this happens, it becomes an opportunity to teach patients about the attributes of reliable vs. unreliable information. There are excellent online resources^{5,6} that can be shared with patients or be used by office staff as a guide to teach patients.

EHRs, a tool for healthcare professionals, can be equally empowering to patients as we make their record accessible through patient portals.⁷ Besides permitting patients to see their medications, problems, immunizations, test results, and appointments, most portals now permit patients to read their office notes.⁸ These notes provide insight into the physician's synthesis of the patient story and data for their clinical decision making and enable patients to be reminded of the care plan. Indeed, some organizations have optimized sections of their patient portals for patients with diabetes.⁹ Patient portals also allow patients to communicate with the healthcare team, enabling patients to both ask questions and provide information. Most portals also allow patients to share record access with their caregivers, engaging an important resource for patient care. Recent reviews found that patient portals have been shown to improve psychological outcomes, medication adherence, and use of preventive services, but there was inconsistent evidence on clinical outcomes.^{10,11} A recent systematic review of studies of patient portal use and diabetes outcomes found that there were methodologic challenges, including bias and potential confounding, but some studies did show an improvement in glycemic control associated with the use of electronic messaging.¹²

Although physicians do their best to educate patients, a critical source of knowledge is from peers and peer groups. As media scholar Pierre Lévy wrote, "Nobody knows everything, everybody knows something; all knowledge resides in networks."¹³ Our patients with diabetes can learn from networks of peers. Although individuals online do provide information that is misleading or incorrect, mature networks of patients tend to be self-correcting¹⁴⁻¹⁶ due to a phenomenon that has been called "the wisdom of the crowd." These online social networks, which provide both medical and psychosocial peer support, can take place in dedicated patient communities or in other channels, such as Facebook Groups, Instagram, TikTok, and others.

The COVID-19 pandemic has accelerated the use of telehealth, to provide safer options to in-office care.^{17,18} As physicians and patients have used it, they have learned that telehealth also increases convenience, which makes it easier for patients to keep their appointments and lowers barriers to more frequent touch points, which has been linked to improved diabetes control.¹⁹ But a telemedicine-only approach limits the physical examination, posing challenges when detecting and managing diabetic foot disease.²⁰

Higher Tech

Technology has advanced in other ways, as well, allowing devices to do what once was impossible and connecting, via the Internet, to other devices, healthcare providers, and cloud-based decision support.

While many tools are available through websites, increasingly, patients are accessing these tools through smartphone apps, which have the advantage of always being available, wherever users may be. While websites have the advantage of being accessible either on a laptop computer or a smartphone, some apps do not have websites and can only be accessed through a smartphone. According to a 2021 industry report,²¹ there are currently over 350,000 health apps, with an average of 250 new apps released per day. While many are wellness apps, 47% are related to managing clinical conditions or care. Of the disease-specific apps, 15% are diabetes apps. Most health apps have relatively few downloads, and a small number comprise almost half of the downloads. The Association of Diabetes Care & Education Specialists maintains a helpful database of diabetes apps indexed by platform and functionality and provides a detailed feature list of each.²²

Some apps are free or are available in free versions, but many apps that offer more functionality or that don't display ads require a one-time or ongoing subscription fee.

Many patients with diabetes have trouble managing their oftencomplex medication regimens, resulting in nonadherence, which results in adverse events and poor outcomes. Fortunately, technology can be helpful here. Patients can set alarms on their smartphones to remind them about medications, but dedicated apps allow patients to manage their medication lists. One popular free app, Medisafe, allows patients to download their medication lists, reminds them when it's time to take a medication, tracks adherence, lets patients enlist the help of friends and family in remembering to take their medications, and provides education about medical conditions.²³ While there is evidence that these apps can increase adherence and awareness of medications, convincing evidence showing impact on clinical outcomes is lacking.

Tracking data about dietary consumption is also important for many patients with diabetes. Although this can't be done automatically, a number of apps make it quite easy, with extensive online databases of the nutritional content of various foods and beverages, including dishes from national chains. One example is MyFitnessPal,²⁴ which boasts 200 million users.²⁵

Many apps make it easy to track activity and calorie expenditure. Some of these require users to enter their activities, but most utilize the built-in accelerometer and/or GPS of smartphones to track activity or integrate activity data from smartwatches or dedicated activity trackers ("wearables") that are often worn on the wrist and use photoplethysmography to measure heart rate. Some apps specialize in specific activities, such as running or cycling, while others track a variety of activities. Many apps will also integrate data from a variety of sources, presenting users with a unified view of their activities, caloric expenditure, steps taken, and even standing time (some of this is imputed from motions of arms during specific activities, often combined with GPS data for activities like cycling). But there are challenges. For example, some devices detect movement from arm swinging but not body movement or heart rate. Even devices that have the latest technology fall short on measuring things like weight training, Pilates, or the increasingly popular high-intensity interval training.

Many activity tracking apps provide positive reinforcement and encouragement for frequent use or for achieving other goals, often enhanced by gamification, allowing users to compete with friends and family. Many devices will prompt the wearer to stand or be more active when it detects sedentary behavior. While the accuracy of activity tracking using wearable devices is highly variable and may not be precise enough for patients with type 1 diabetes to algorithmically titrate their insulin,²⁶⁻²⁹ it is directionally correct and can provide useful feedback and encouragement to patients.^{30,31}

Just as diabetes management by clinicians is data driven, so too is diabetes self-management by patients. Tracking vital signs, such as weight and blood pressure, is important. And many patients with diabetes also need to track their blood glucose and its response to diet and activity changes. Historically we have asked patients to record their data on paper, but today tracking can be done using a plethora of dedicated downloadable smartphone apps, some of which integrate with Bluetooth-enabled devices so that patients do not need to manually enter their data. Most of these apps offer interpretation of data trends, education, and multimedia coaching (sometimes with a connection to live coaches), which of course cannot be done with handwritten diabetes logs. One such free app, called mySugr, integrates with Accu-Chek glucometers. It tries to make tracking glucose more fun, advertising that it will "Make diabetes suck less."32 A systematic review of digital health tools for diabetes self-management found that smartphone-based interventions lowered hemoglobin A1c by 0.5%.³³ A 2016 metaanalysis found a statistically insignificant reduction of hemoglobin A1c of 0.36% for type 1 diabetes but a mean reduction of 0.41% in type 2 diabetes (af-

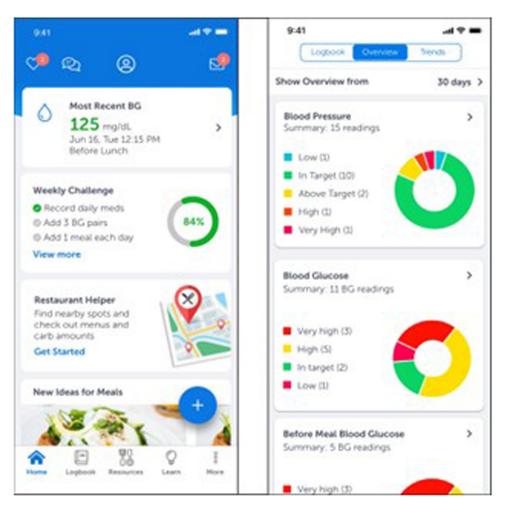


Figure 1. Screenshots from Welldoc patient app. (Courtesy of Welldoc.)

ter exclusion of lower-quality studies).³⁴ A 2018 metaanalysis using different methods found a statistically significant reduction of 0.39%, with the strongest effect in patients with baseline hemoglobin A1c > 7.5%.³⁵ Another 2018 metaanalysis found a 0.49% reduction in A1c in patients with type 1 and a 0.57% reduction in patients with type 2 diabetes. The authors commented on the importance of healthcare professional involvement.³⁶ Overall, it seems the impact of these apps is as good as some of our medications.

There are other systems that, such as the FreeStyle Libre 2 app,³⁷ FreeStyle Libre 3 app,³⁸ and Dexcom Clarity³⁹ that integrate with other specific devices and permit patients to track blood glucose measurements and other information and share them with their healthcare professionals. There is some evidence that these may improve diabetes care.⁴⁰⁻⁴²

Finally, there are digital health tools that incorporate some combination of personalized education and care plans, data management, data sharing with diabetes professionals, coaching through online chat and/or video, and peer support. Usually, these platforms are sponsored by employers, health plans, or other risk-bearing entities. Often the programs provide customized hardware, such as glucose meters, and may provide unlimited access to diabetes supplies, such as test strips, and may even incorporate continuous glucose monitors. In addition to diabetes, some of these products offer programs for other chronic conditions. Examples of these platforms are Livongo,⁴³ Welldoc BlueStar (see Figure 1),⁴⁴ and Omada.⁴⁵ There is some clinical trials data demonstrating benefits of these programs, including reductions in hemoglobin A1c as good as some medications.⁴⁶⁻⁵⁰ A recent review of "connected diabetes care" programs affirmed their potential to improve diabetes care.⁵¹ A summary of selected digital technologies and their features are shown in Figure 2.

Discussion

Challenges

Patient Factors

Not surprisingly, the potential benefits of these technologies are limited to patients who use them.^{52,53} And there are many reasons that patients may not use them,^{54,55} which suggests that increased use of these digital health tools may increase health disparities for patients with diabetes. Systematic reviews identify patient factors, provider factors, technology, and organizational factors correlated with adoption but found that studies were heterogeneous in methodology and results. We were unable to find studies of digital health adoption specific to patients with diabetes.

Literacy encompasses several factors that may be barriers to patient adoption of these technologies. For example, patients with limited ability to read will not be able to navigate the use of an app. Since few of these systems accommodate non-English speakers, this further limits populations that could benefit from these technologies. Furthermore, patients may be literate and comfortable with the language but uncomfortable using technology (limited "tech literacy"). Poorly designed user interfaces may also discourage patient adoption, even those comfortable with technology.

Patients with vision or hearing deficits may not be able to use apps or systems that depend on visual representations or voice coaching.^{56,57} And although Pew Research Center reports that 77% of US adults have

Technology	Examples	EHR Integration	Communication with Care Team	Patient- Generated Data Integration	Care Coaches
Information websites	ADA, NIDDK, MedlinePlus, DiaTribe, DiabetesMine	×	X	X	×
Patient portals	<u>MyChart,</u> <u>HealtheLife</u> , <u>My HealtheVet</u>	Yes	Yes	Possible	No
Online patient support networks	<u>Bezzy T2D,</u> <u>TuDiabetes</u> , <u>The Diabetes</u> <u>Link</u>	X	X	X	X
Telehealth	AmWell, TelaDoc, Doximity, EpicCare	Sometimes	\checkmark	Not true integration	×
Medication tracking and personal health records	<u>Apple Health,</u> <u>CareZone,</u> <u>EveryDose,</u> <u>Medisafe</u>	Download only	X	\checkmark	X
Nutritional data tracking	<u>Cronometer</u> , <u>FoodNoms</u> , <u>MyFitnessPal</u>	X	X	\checkmark	X
Diabetes data management	Dexcom Clarity, Freestyle Libre 2 app and Libre 3 app, Glooko, mySugr, SugarMate	Sometimes	Sometimes		X
Fully integrated diabetes management systems	<u>Livongo</u> , <u>BlueStar</u> , <u>Omada</u>			\checkmark	V

Figure 2. Features of representative digital health technologies for diabetes.

Table 1

Patient Factors Leading to Poor Adoption of Digital Health Technologies and Potential Mitigation Strategies.

Patient factor	Mitigation Strategy		
Low literacy	Education, interface design		
Limited English proficiency	Multilingual applications		
Low technical literacy	Education and support		
Disabilities	Interface design		
Inadequate Internet access	Subsidized access		
Inability to afford hardware	Financial supports or device loans		
Lack of support	Proactive and easily available technology support		
Lack of self-efficacy or understanding	Education and support		
importance of self-care			

access to broadband at home, this number drops to 64% for those 65 and older—although 15% of US adults do not have broadband and report exclusively using their smartphones to access the Internet.⁵⁸ Finally financial constraints can impact adoption of these technologies, as smartphones, Internet access, and even apps are beyond the reach of many.

There are other factors that may affect use, such as patient low selfefficacy, not understanding the importance of self-management, lack of encouragement or feedback by their healthcare team, interference with the patient-physician relationship, poor technology support, and concerns about privacy and security of their information. This last issue is especially important since a recent study found that 88% of health apps in the Google Play Store could potentially collect user data.⁵⁹ And this health data stored by health apps is potentially vulnerable to hackers⁶⁰ and we have seen a rise in data breaches.⁶¹ A 2020 Accenture survey of consumers found that while 83% of respondents trusted their physicians to keep their information secure, only 45% trusted tech companies.⁶²

Some of the patient factors that are barriers to use of digital health technologies and potential mitigation strategies are listed in Table 1.

Clinician and Practice Factors

Although patients are the primary users of the technologies outlined in this review, the utility of many of these technologies is enhanced when the healthcare professionals and the patient can collaborate in managing the patient's health. But physician participation and encouragement can be an important factor in encouraging patient adoption of digital health technologies, while skepticism can discourage its use.⁶³

Historically, patients have shared data on written logs, but increasingly patients use electronic devices to record their data from glucometers, blood pressure monitors, scales, and other devices that record a history of measurements and sometimes upload them to the cloud. Health apps can also store data in the cloud. Data that patients collect between patient visits is called patient-generated health data (PGHD)⁶⁴ and includes not only biometrics but also symptom scores, patient-reported outcome measures, and activity metrics. It makes sense that this data might be shared electronically with their healthcare teams.

If this data is readily available, it can be reviewed in the office by members of the health team during visits. But if this requires that the clinician log in to a system separate from the EHR, it becomes a barrier to using electronic data; physicians may find it quicker to visually scan a paper record or data on the patient's glucometer or application.

But if patients are collecting data, and physicians are ostensibly responsible for managing their entire patient panels, then physicians should also care about data *between* scheduled visits. Whether through telephone calls or through e-mail,⁶⁵ physicians have been asking patients to share their health data between visits for decades. But digital tools should enable structured data to be shared automatically with the patient's diabetes care team, in real time.

Healthcare payment models likely have an impact on physician willingness to engage in care outside scheduled patient visits. In a fee-forservice environment without financial incentives for population health, physicians may not be able to devote time and resources to managing patients between visits, but capitation and quality contracts can provide these incentives.⁶⁶ With the increasing prevalence of quality-based contracts over time,^{67,68} this will gradually become less of a concern, although there is evidence that the growth of Accountable Care Organizations has leveled off recently.⁶⁹

Espinoza et al. argue that we need data standards and implementation policies to support integration of Continuous Glucose Monitor (CGM) data into the EHR and they outline a path forward.⁷⁰ CGM data is not unique—few practices have policies permitting the incorporation of any PGHD into their health records. Interoperability standards to permit data uploads have been published and continue to evolve.⁷¹ Despite this, few health systems or practices have implemented tools that enable patients to upload data directly to the EHR. Besides requiring new technology implementation, there remain other policy concerns that must be addressed.

For example, data must include information about the data source (e.g., patient or clinician), the device used to collect the data, and when and where it was collected. Policies and protocols must exist to manage the review of solicited (e.g., "please send me your glucose measurements next week") vs. unsolicited data that may be transmitted by the patient's action or automatically. Physicians may have legitimate concerns about unsolicited data that is saved in the EHR between visits, especially if it is clinically worrisome. Is the physician liable if such data is not reviewed in a timely manner and the patient suffers harm? One solution would be to deploy programs that continuously summarize and analyze incoming data streams and alert care teams to concerning values and trends. Addressing these issues would go a long way toward increasing physician acceptance of incorporating PGHD in the EHR.

Some of the programs discussed above use a dedicated diabetes management team outside the physician's office, funded by the employer or health plan, which circumvents this problem. However, these systems disintermediate the physician, which may be problematic to the physician who may no longer feel in control of managing their patients' care. Even worse, the outside care team may not adequately communicate with the physician, or this communication may add time to the workday. In addition, the patients' data from the program may not be available in the context of the EHR. Any of these factors may lead physicians to discourage patient participation in digital health programs.

Another factor that may impact physician adoption is how data gets shared with physicians and their teams. Physicians spend their days in their EHRs, so anything that requires them to utilize an outside system that then necessitates an additional login is a huge disincentive. In addition, when data is collected (or drugs are prescribed) outside the EHR, then the data in the EHR becomes incorrect or incomplete. A recent literature review of barriers and facilitators of adoption of digital health technologies among cardiologists emphasized this point:

"Without proper integration and interoperability, DHT uptake will likely be limited to clinicians who are highly motivated to adopt technologies despite the inefficiencies in workflow that come from information siloes."⁷²

Conclusions

While healthcare professionals may see a given patient with chronic conditions, such as diabetes, a handful of times each year, patients who live with chronic conditions, such as diabetes, must manage their conditions throughout their lives, something that Brennan calls the "carebetween-the-care."⁷³ Healthcare professionals rely on EHRs to enable them to manage patient information. But the Internet, ideally using connected mobile devices with apps, creates an infrastructure that will allow patients to connect to information, healthcare, and each other and may improve outcomes, self-efficacy, and engagement in health.

While patient self-care is essential, physicians increasingly assume responsibility for managing the quality and cost of their patients' care. To do so, they will depend on patient-generated data outside the boundaries of traditional visits. Therefore, physicians will need to collaborate with patients to cocreate their health outcomes. Connected digital health technologies will be the platform that enables this collaboration.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships that may be considered potential competing interests: Shareholder, American Well.

Disclosures

Employee and shareholder, WKD. SMRT Shareholder, American Well.

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