



Understanding the needs of people aging with type 1 diabetes: a user-focused research study with prototype diabetes advance directive and setting the stage for future research

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Abstract

Purpose People living with Type 1 diabetes (T1D) are living longer than ever and facing the new “luxury” of the challenges of aging. While research is slowly expanding and addressing T1D physiology with regards to aging, there is little research addressing specific challenges and barriers to optimal care by those aging with T1D. To address this gap, this study employed human-centered design research to explore the gaps and barriers to care faced by people aging with T1D.

Methods Researchers employed human-centered design methods of needfinding and user interviews and facilitated participatory workshops. In total, 27 people with T1D (PWT1D), 5 loved ones (partners of PWT1D), and 7 healthcare providers (HCPs) were engaged.

Results Design artifacts were developed, including user personas that help visually articulate the different experiences of PWT1D and their unique needs as they age, as well as a prototype diabetes-specific advance directive that could be further refined to specifically aid those with Type 1 diabetes who are aging and requiring more interactions with the healthcare system. Initial user testing with people with T1D as well as healthcare providers demonstrated the need for such a diabetes advance directive tool or document.

Conclusion This work supports the conclusion that additional focus and scientific enquiry should be given to the needs of people aging with Type 1 diabetes, with a goal of improving the experience of all people with T1D when interacting with their care providers or with the healthcare system as a whole.

Keywords Type 1 diabetes · T1D · Aging · Advance directive · Diabetes advance directive · Care planning · Diabetes self-management · Diabetes · Patient and public involvement

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Introduction

Fifty years ago, a diagnosis of Type 1 Diabetes (T1D) often meant a shortened life span compared to people without diabetes [1]. Insulin was made from animal sources; blood sugars were determined daily by crude urine test measurements and there was no definitive knowledge of the best course of treatment or standards of care. Yet today, because of extensive scientific research and the development of better insulins, advanced technologies such as insulin pumps and continuous glucose monitoring systems, those living with T1D can be expected to live a full and long life. However, now individuals with T1D are facing other issues that often arise with aging. This situation is not dissimilar to the challenges faced by HIV patients and their healthcare professionals, where it may be seen as a “luxury” to deal with the complications of aging [2].

Even with ideal glycemic management, people with Type 1 diabetes can develop aging-related conditions, often decades ahead of people without diabetes [3, 4]. These additional complications, concomitant conditions, loss of life-long partners and friends, increased vulnerability to stressors and changes in physical abilities all contribute to a strain on their quality of life [5]. Quality of life is also impacted by financial concerns such as costs of insurance, medication, and caregivers [6].

These increased burdens are likely to increase, as the population living with diabetes increases worldwide. It is estimated that 1.6 million Americans are living with Type 1 diabetes [7], and an additional 64,000 Americans are diagnosed each year with more than 5 million Americans expected to be living with T1D by 2050 [8]. This does not include estimates of T1D as a complication of emerging diseases such as COVID-19 [9], the development of which could continue to expand the population of people living with T1D at greater rates than previously estimated. We need to begin to seek to understand T1D age-specific needs as individuals live longer than ever.

While the study of aging is not new, little research has been published specifically assessing the needs and challenges of individuals aging with Type 1 diabetes. As Bispham et al. found in a review of the aging literature in T1D, recent studies have identified an association between cognitive impairment and glycemic variability, as well as an increased risk and frequency of hypoglycemia in older adults with T1D. However, limited research exists about additional physical or mental health conditions, and the barriers to successful treatment in this population have not been addressed [10]. Recent studies have shown that there is a correlation with glucose control to mental sharpness and physical coordination decades later, with the combination of non-optimal glucose control, hypoglycemia, and high blood pressure contributing to an estimated 9.4 years of premature aging [11].

Additionally, much of this research on longevity of Type 1 diabetes and the complications related to glycemic outcomes is correlated with the landmark DCCT study, which studied people with diabetes (PWD) 1982–1993 [12], in which diabetes technology was markedly different. As such, the population of people aging with Type 1 diabetes might ultimately involve multiple sub-groups, influenced heavily by glycemic outcomes early on in diabetes experience, and further research is needed.

This paper seeks to describe recently initiated user need-finding [13] and empathy research with this population of people aging with Type 1 diabetes; the resulting development of user-centered design artifacts, for example an experience map that pinpoints all the locations of where a person with Type 1 diabetes (PWT1D) would communicate about their Type 1 diabetes, which helps articulate the different experiences of individuals with Type 1 diabetes and their unique needs as they age. This paper also describes a prototype diabetes advance directive that could be further refined to specifically aid those with Type 1 diabetes who are aging and requiring more frequent interactions with the healthcare system.

Methods

In order to understand the experiences of people living with Type 1 diabetes, we employed human-centered design methods [14] of needfinding [15] and user interviews, and facilitated participatory workshops on topics related to aging with type 1 diabetes. In total, 27 people with T1D (PWT1D), 5 loved ones (partners of PWT1D), and 7 healthcare providers (HCPs) were engaged through this research.

For recruitment, volunteers with expertise in Type 1 diabetes and aging, and staff from the University of California San Diego (UCSD) Diabetes Design Initiative (DDI), identified people with Type 1 diabetes as well as subject matter experts and clinicians in diabetes and aging to participate in the various stages of the project. This research was reviewed by UCSD’s IRB and found not to be human subjects research.

Prior to our initial user interviews ($n = 13$) with PWT1D, we sought to collect quantitative and qualitative data on lifestyles and diabetes management of the participants. The survey was a short Google Form [Google, Mountain View], with questions on their profession, age, confidence in utilizing diabetes technology, if participants have caretakers or caregivers, existing health conditions, active medications, and experiences with healthcare. In this context, a caregiver of a PWT1D may share in the responsibilities of and decisions with the PWT1D, ranging from daily assistance to occasional and as-needed help. Examples of caregivers

include anyone from a spouse or adult child to auxiliary HCP or a paid caregiver, whether occasionally or full-time. The initial survey questions were created with the intent of establishing a contextual foundation of participants' medical conditions, healthcare, and diabetes management. Out of the 13 participants who participated in the interviews, 11 also responded to the survey. Survey results were analyzed manually, with facilitation from Google Form's automated response summary function.

Interviews were conducted in a semi-structured [16], one-on-one format. We employed the Expert-Apprentice model approach to interviews, which is a form of contextual interviews [17] that involves the assumption that the target user is an expert at a subject. The goal of this method of inquiry is such that interviewees tell stories from which researchers can distill important facts and key insights. Interview topics covered technology usage, diabetes management, planning for aging, and community support. Participants were also asked about hypothetical scenarios since our research interest involved planning for the future and the topic of aging, and not all participants had necessarily faced aging or addressed the issues of their own aging directly. The goal for these topics was to allow participants to reflect on what they perceive would be future challenges in aging and Type 1 diabetes, and to identify possible gaps in the area of aging with Type 1 diabetes. The interviews were recorded through Zoom [Zoom, San Jose] cloud recordings with the permission of the participants, and coding of the interviews was performed following the completion of all interviews.

In addition to the primary research with PWT1D ($n = 13$), we also initially interviewed an expert from the Joslin Diabetes Center to gain additional insights to the experiences of PWT1D when they interact with the healthcare system.

While interviewing people with T1D was imperative to our initial progress, we additionally conducted an online participatory workshop, hosted on Zoom, for a new group of PWT1D ($n = 4$) and their loved ones ($n = 5$). Our research goal rested on our need to find recurring patterns among our participants in order to find connections between the needs of PWT1D, their overall community, and their loved ones. We structured our workshop to have two separate breakout rooms where we separately explored the needs of our two user groups: PWT1D and their loved ones. We utilized Miro [Miro, San Francisco] as our collaborative tool during the virtual workshop, where activities were conducted with the help of facilitators. For PWT1D, participants were asked to complete a milestone activity to allow researchers to understand how life trajectory and events might influence health and diabetes care. The milestone activity asked participants to identify major life events related or unrelated to their diabetes journey and it included a display of a timeline

with empty sticky notes for participants to fill out. Participants filled out their stack of sticky notes with life events and placed them onto the timeline. For the loved ones, they were asked to participate in a Mad Libs activity, similar to a fill-in-the-blank. This activity was conducted to provide the research team with a clearer understanding of how loved ones approach providing care and support to their partners living with T1D.

From the interviews, each interview was recorded through Zoom and later transcribed by Otter.ai [Otter.ai, Mountain View]. Each team member made notes for each interview, and each key idea was grouped roughly to generate themes. We summarized these findings into an affinity map, where qualitative data was grouped together thematically to create a digestible summary of the primary data. We also developed two personas [18] based on our data synthesis.

Moving from the discovery phase of this research, we sought to further understand the specific relationship between PWT1D and their health care providers (HCPs). We conducted additional one-on-one user interviews with 6 PWT1D (5 new participants, and one prior participant from the original $n = 13$ exploratory interviews) and 3 HCPs. Recruitment of the participants was again made possible through UCSD DDI, who provided researchers with an additional list of possible participants. These interviews focused on addressing the key theme that emerged from the discovery phase of research, which was the concern of people with T1D about diabetes management and perceived control of management when interacting with the healthcare system and different types of healthcare providers, plus the concern of differing levels of experience that various HCPs have with T1D. These interviews focused on gathering insights about PWT1D experiences and their early opinions on developing a design solution that would support an identified gap between HCP and PWT1D: a diabetes advance directive. Interview topics also ranged from the relationship between PWT1D and HCP, conflicts PWT1D had experienced in past healthcare encounters, struggles of being a PWT1D and facing aging. Like the discovery phase interviews, these interviews were recorded through Zoom cloud recordings with the permission of the participants.

From these interviews, we again used identical user research methods for coding the data using transcripts (recorded through Zoom, then transcribed with Otter.ai) then inputting and organizing using affinity diagrams and clusters (e.g., actions, beliefs, histories, etc.) into a Miro board. These clusters were grouped around goals that relate back to the previously identified gaps and insights. After developing higher-level themes, potential solutions were then assessed. Using brainstorming activities (such as Crazy 5, Worst Possible Ideas, and Brainwriting), we identified that one of the

potential solutions would be a diabetes-specific health care directive, or “diabetes advance directive”.

After developing an initial diabetes-specific care directive document, which we call a diabetes advance directive, we performed one-on-one user interviews with an additional group of 6 PWT1D (5 new participants, and another prior participant from the original $n = 13$ exploratory interviews) and 3 more HCPs. With our interviews, we prepared a workflow of an illustrated hypothetical and a proposed diabetes advance directive. The workflow is a comic-based spread that visualizes how the diabetes advance directive would be used in a hospital setting, from being admitted with the diabetes advance directive in hand, to the HCP understanding the needs of the PWT1D and bringing in their endocrinologist into the conversation. Within the interview, we also tested using two different tones for the diabetes advance directive, with either formal/legal or patient-centered informal language. We made iterations to the diabetes advance directive after each interview, including changing sections of the diabetes advance directive (i.e., removing list of medications, etc.) and employing additional A/B testing [19] with ideas like bolded or unbolded and with-highlights or without-highlights. Our usability test [20] included questions on general thoughts on a diabetes advance directive, the length of the document, the tone used, etc.

Similar to the previous user interview processes, we analyzed these usability interviews by making notes after the recordings (Zoom) were transcribed with Otter.ai. However, for the usability testing interviews, the transcript was also copied into Dovetail to highlight quotes from interviewees and categorize insights that were important or recurring points. Using the ‘Insights’ option on Dovetail [Dovetail, Sydney], we reviewed our highlighted quotes to group together into an ‘Insight’ that we thought was a major theme. An example of a theme: “In general, PWT1D prefer one-page documents over lengthier and wordier documents because they believe that HCPs will not spend a lot of time reading them.” Direct quotes from the interviews were tagged to these major themes as supporting evidence.

Additionally, an affinity map [21] was developed to formulate our ideas visually, where our core themes that we developed had quotes and ideas from the user interviews. The data gathered from interviews was also used to create two personas, one each representing a person with Type 1 diabetes (see Fig. 5, Appendix) and a typical healthcare provider (see Fig. 6, Appendix) who might encounter a person with Type 1 diabetes. For this set of personas, the person with Type 1 diabetes is someone who is troubled or concerned by their interactions with a new healthcare provider, whereas the healthcare provider is concerned about the lack of available time for a healthcare encounter with a person with Type 1 diabetes, as well as realistic about their limited experience supporting people with Type 1 diabetes. To

expand on the possibilities of uses that follow the illustrated hypothetical workflow used during user interviews, we used an experience map [22] to detail the user journey and the ideal use cases. It is designed to be concise with specific locations that are touchpoints in which the diabetes advance directive can be used, showing the entire process from learning about diabetes advance directive to using the diabetes advance directive in a healthcare encounter.

Results

Based on our survey sent out prior to the initial interviews to assess people’s experiences interacting with the healthcare system, we found that for the 11 participants (average age of 62; see Table 1), the average rating for level of comfort when using technology was a 7 out of 10. When asked about whether they have a caretaker, which we left it up for the participants to interpret the term “caretaker”, 8 out of 11 said they don’t have caretakers. We also asked them how they would describe their experience with the healthcare system, and one of the common terms described was “frustration”, but there were also words such as competent and satisfactory. This indicates a high level of diversity in terms of experiences people with Type 1 diabetes have when interacting with the healthcare system. From the survey, we also found that many of our participants have other medical conditions such as arthritis, hypothyroidism, and retinopathy. It is worthwhile to consider that people are self-reporting these

Table 1 Results from an initial survey assessing demographics of 11 of 13 individuals participating in interviews regarding experiences with type 1 diabetes, aging, and interactions with the healthcare system

Demographic Categories	Count	Percentage
Gender		
Female	7	63.6
Male	4	36.4
Age		
18–24	0	0
25–34	1	9.1
35–44	0	0
45–55	1	9.1
55–64	2	18.2
65+	7	63.6
not specified	0	0
Ethnicity		
Euro-American/Caucasian	10	90.9
African American	0	0
Hispanic/Latino(a)	0	0
Asian American	1	9.1
Other	0	0

statistics, although studies have shown that self-reporting is relatively accurate [23].

A common pattern we discovered through our interviews revealed perceived HCP indifference to new technologies and tools presented by their patients. Care providers may be unaware, unskilled, and even intimidated when exposed spontaneously in patient encounters to new diabetes technologies, given their limitations in resources and respective attitudes towards meeting their patient's specific needs. A patient who visits their provider with intentions of introducing a fascinating tool that they've successfully relied on over time to manage their diabetes may find themselves at a crossroads with a HCP who may not be as receptive to the tools, especially if the HCP has not been previously trained on that particular technology.

Based on the 13 initial semi-structured interviews, we synthesized our findings into two personas. Personas are fictional characters, which are created based upon previous research findings in order to represent the different user types that might use a service, product, site, or brand in a similar way. The first persona can be identified as someone who is tech savvy and proactive in their diabetes management. In the fictional character/persona of Sam (see Fig. 1), they are someone with the goal and interest of being in control of management, especially in the context of being under care of a health care provider during doctor visits. He is also interested in being knowledgeable of new diabetes technology and research, such as open source automated insulin delivery. Being physically able to maintain healthy exercise and management routines as well as enjoy outdoor hobbies and activities and staying with their primary care doctor, endocrinologist, and other care providers long term are important to them. Some pain points and concerns they might have included the inability to access some advanced tech as a result of FDA regulation or other barriers, losing control over their diabetes care management (as when hospitalized or cognitive issues from aging), the increasing amount of complications due to aging, and posing as a source of burden for their family.

The second persona and journey represent someone who is less comfortable with technology and cares a lot about simplicity. These characteristics can be personified through the persona of Avery (see Fig. 2), and her goals and interests might be to prioritize prevention of health complications, staying consistent with her way of managing diabetes, minimizing the effects of her conditions, and enjoying time with family. Her concerns and pain points would be more associated with losing control over the daily management process due to unexpected health conditions that may arise in the future such as cognitive impairment. She might be concerned with losing her support system, and not having enough knowledge about the latest technology and research, as well as dealing with the healthcare red tape and the

time-consuming steps that may prohibit immediate access to types of care and treatment.

Avery represents a demographic that does not rely on advanced technologies to manage their health and is nonetheless proactive in managing their diabetes. Her priorities are less focused on exploring the potential of new technologies and research, and more about practical needs, focused on prevention and minimizing long term negative effects of diabetes and aging to prevent major health complications in the future. Even with the absence of new technologies, people like Avery have adopted their own daily management and care, which has served them well over the years. Because of this self-adopted structure, aging poses instability that may affect Avery's sense of security and comfort in her process of maintaining her diabetes management practices as they age.

In contrast to the persona of Avery, Sam, a person aging with Type 1 diabetes, represents PWT1D who rely heavily on advanced technologies to maintain control and manage their diabetes. He is, in particular, a self-proclaimed tech-enthusiast fascinated by the newest diabetes technologies and emerging research. People like Sam have devoted time and resources over time to learning new technologies and integrating them into their daily lives. Because of this extensive commitment, people like Sam fear that chronic and acute health complications that come with aging may disrupt the sense of control and independence they have developed over the years. People like Sam, who have associated control with technology, may require external care management that is adaptable and inclusive to these advanced tools. In the presence of complications, people like Sam may attempt to seek assistance to operate their tools, which may require more resources to find compatible caretakers and or caregivers. (In Fig. 3, see a comparison between the personas of Sam and Avery, and how the source of their chosen support differs.)

From the interviews and usability test that we conducted following the initial exploratory research, the design work also resulted in a document titled the Type 1 Diabetes Advance Directive, a one-page document detailing the diabetes management, wishes, and preferences for shared decision-making for PWT1D (see Fig. 4). The document aims to improve the quality of care for PWT1D in a healthcare setting by providing patients with an ability to initiate and engage in shared decision making with autonomy, ultimately initiating a conversation with healthcare providers in healthcare settings to improve the quality of care received by the person with Type 1 diabetes.

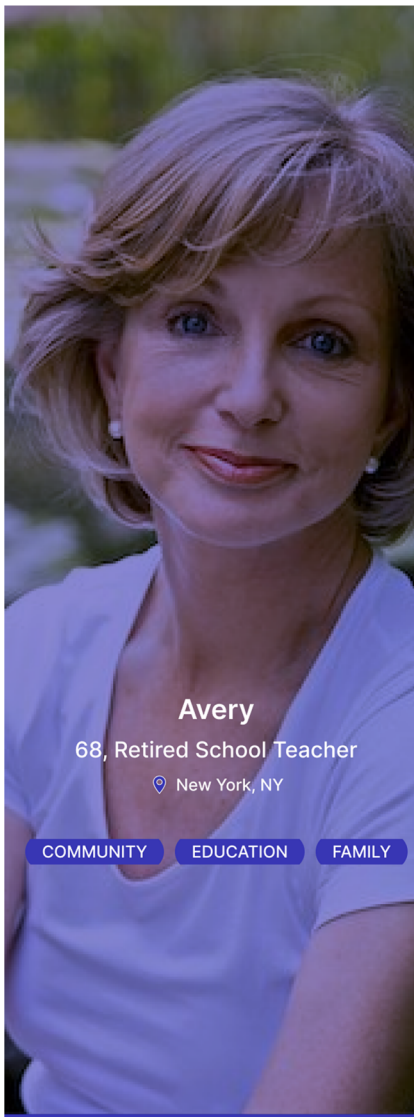
From our user-testing interviews, we sought feedback from three HCPs from highly accredited medical institutions about a diabetes-specific advance directive document. Physician A, [Endocrinologist, Stanford Health Care], claimed that due to their already-existing hospital-wide database



Fig. 1 A persona of a person with Type 1 diabetes who is tech savvy and proactive in their diabetes management

system, supplemental self-documented reports from patients would not be necessary or useful. This physician bases their claim on their interaction with an institutionally backed technology that they trust as secure and effective in archiving patient documents and records. While this presents an impressive outlook, we must be cognizant of the context that this physician operates within, which is a highly endowed and reputable university. Not all PWT1D have proximal nor financial access to enter such facilities and benefit from its

impressive resources. Based on this, how might the quality and outcome of care unfold for patients who are admitted or only have access to hospital settings that do not have well-established and centralized database systems? Patients who want to take the initiative to present their own records may be faced with feelings of distrust and invalidation from the very institution that their wellbeing rests upon. Contrary to Physician A, our second physician, Physician B [Endocrinologist, University of California—San Diego], affirmed the



Bio

Avery is a retired school teacher who left her career due to discrimination and complications. She had surgeries for her complications. She partly relies on her spouse when managing diabetes and two coexisting conditions—hypothyroidism and arthritis—that have added onto their symptoms and quality of life.

Goals & Interests

- AVOID FURTHER HEALTH COMPLICATIONS**
Minimize the chances of developing further health complications by maintaining a healthy lifestyle and regularly seeing their care team
- MAINTAIN CONTROL OF DIABETES**
Maintain their ideal Time in Range by staying consistent with current management process with their current tech and tools
- MINIMIZE EFFECTS OF CURRENT CONDITIONS**
Minimize long term effects of arthritis pain and thyroid issues to avoid surgery and or being admitted to the hospital
- ENJOY RETIREMENT**
Enjoy travelling and quality time with family, especially grandchildren, all while remaining safe and healthy

Pain Points & Concerns

- CO-EXISTING CONDITIONS & COMPLICATIONS**
Losing control over daily management process due to unexpected health conditions that may arise in the future such as cognitive impairment and neuropathy
- LOSING CURRENT SUPPORT SYSTEM**
Losing loved ones and support system who are also experiencing aging in their own way and or may also have diabetes
- LACK OF ACCESS TO LATEST TECH & RESEARCH**
Lack access to knowledge of latest research and technologies and better health care options or systems of care
- HEALTHCARE REDTAPE**
Dealing with the red tape of Medicare and other insurance limitations and time consuming steps that may prohibit immediate access to types of care and treatment

Satisfactions

In-patient care	30%
Primary Care	70%
Endocrinologist	90%
Insurance	20%
Technology	90%

Diabetes Technology

Dexcom

Avery uses dexcom as her continuous glucose monitor.



Avery uses the Omnipod insulin pump to get insulin. The pump is changed every 3 days.

Support System

Spouse	● ● ● ● ●
Diabetes group	● ● ● ● ●
Other Friends	● ● ● ● ●
Other Family	● ● ● ● ●

I really didn't think I was going to have to think about getting older with diabetes, because the projections for living were not that good, didn't think I was gonna live to be, in my 60s, for sure. I do regret like all those years of rebellion that have contributed to complications.

Fig. 2 A persona of a person with Type 1 diabetes who cares about simplicity with regards to diabetes management

value of such a document or tool. Despite their institution’s sufficient resources, Physician B states that such a document would not present any redundancy to the care team. In fact, the more documents the care team has, the better they will be able to validate their decisions and course of treatment for the patient. Physician B also believes that such a document or tool would provide a sense of comfort for the patient, which, in turn, can help positively influence their interaction and receptiveness towards their assigned care team,

improving their overall quality of care relative to their own expectations.

Discussion

In order to understand the diverse backgrounds and experiences of our group of participants living with Type 1 diabetes, our team conducted community-based participatory



Fig. 3 A comparison between the two personas of individuals with Type 1 diabetes

design research [24] methods to create an inclusive space for exploratory research to address the topic of aging with T1D with 27 PWT1D, 5 loved ones, and 7 HCPs. While the majority of existing Type 1 diabetes literature focuses on the physiology of T1D and aging [3, 10, 25, 26], our team addresses how physiological and biological factors also affect the psychological and social factors that play as critical determinants that shape the quality of life of people aging with Type 1 diabetes.

Through this research, we have learned that people who are aging with T1D rely on support from others for advocacy and validation, especially when interacting with the healthcare system and professional healthcare providers.

For example, diabetes technology such as continuous glucose monitors, connected insulin pens, and insulin pumps can now provide real-time diabetes datasets [27] that can be shared with and interpreted by the patient's care provider to help inform healthcare. While these technological resources have exponentially increased in its production and accessibility in recent years, it is critical to avoid the assumption that every patient with T1D has consistent access to these resources [28]. Moreover, it is important to recognize that each PWT1D has a unique level of interest and capacity to manage their disease. Additionally, not all healthcare providers are trained to use the data from these devices, such as when a patient presents to primary care, urgent care, or emergency department for non-diabetes focused care needs

[29]. There can be a mismatch in expectations of care [30] on both sides, depending on whether patients have access to these technologies or not [31], and whether healthcare providers are aware of the extent of these technologies' role in their patients' diabetes management. Further exploration should consider not only the hardware technologies themselves but also tangible recorded datasets and information that provide a comprehensive view of diabetes management and may also serve to leverage the patient's credibility from the perspective of a care provider who is hesitant to interact with, or rely on data from, their patients' diabetes tools.

Assuming that new technologies are the cure-all for this problem will prevent us from really understanding the root problem(s) of distrust and communication gaps between patients and healthcare providers. When proposing new solutions that are technically/technologically driven, it isn't enough to create a functional tool if the overarching need is to improve physician–patient interaction [32]. New health management technologies also must have the potential to be structured with patient-centered design thinking and patient–physician interaction [33] as its forefront objectives and take into account the power dynamics of various types of healthcare interactions and settings.

Aside from technology, human assistance and labor also come into play as external resources, especially when material resources are limited. Not only do online diabetes community pages exist to serve as hubs for storytelling

Fig. 4 An example prototype Diabetes Advance Directive, a one-page document detailing the diabetes management, wishes, and preferences for shared decision-making for people living with diabetes

Alexise Berousberg
D.O.B 4/6/1974

Type I Diabetes Care Directive

Endorsed by Dr. Emily Ahn

To whom it may concern:

I have **Type 1 Diabetes Mellitus (INSULIN DEPENDENT)**. I require a constant delivery of insulin to live and manage my disease. This document outlines key health information and my important wishes.

My Type 1 Diabetes is well-managed (HbA1c = 5.8%, 8/23/2021). Keeping my blood sugar level between 80-150mg/dl is essential to avoid future complications. **When I am sound of mind, I am the best person to manage my diabetes. I want to retain control of my management using the CGM and pump. In other cases, I wish my endocrinologist Dr. Emily Ahn be consulted.**

Diabetes Management

- Blood Glucose monitoring: Dexcom G6 CGM that measures my blood sugar every 5 minutes.
- Insulin administration/pump: Omnipod
- Software: Nightscout that gives access to real time blood sugar.


Insulin Dosing


- Insulin type: Lispro
- Basal Insulin rate: 0.8 - 1.0 U/h
- Insulin to carbohydrate ratio: 1 units to 15 g
- Insulin sensitivity factor:
1 unit of insulin decrease bg by 35 mg/dL


Contacts

Please contact my Endocrinologist Dr. Ahn or Diabetes Advocate Mr. Do if the following decisions are to be made:

- Remove my Dexcom/Ominipod device.
- Change settings of my devices.
- Put steroid or glucose in IV.


Dr. Emily Ahn
Endocrinologist, Stanford Health
837-682-5777


Sam Do
Diabetes Advocate, T1D PWD
363-263-5517


Alexise Berousberg
Last updated: 8/23/2021

and network building [34], but they also serve as a digital space to access tangible resources. A participant once recalled their inability to access refills for insulin supply, in which they were able to find through a proximal source: a community member they met online who had an excess supply of insulin. In this scenario, our participant depended on their virtual community to fulfill an urgent need that was stifled by bureaucratic delays [35]. Apart from urgent needs, social networks also have the power to build long-term

relationships [36] where people can find support groups, potential advocates, and life-long friendships, greatly enhancing the quality of social life for people aging with T1D. With this noted, there are limitations to this resource [37] in that one must first build genuine relationships with strangers in order to build that trust in exchange for important yet limited resources. This process takes time, effort, and energy especially within a digital space, which is an environment that one must first adapt to and learn how to navigate, and may not be accessible to all.

With regards to specific concerns around aging with T1D, a perceived loss of control was marked as the prominent concern for our T1D participants when envisioning the course of their future. With the increased availability of diabetes technology, self-management (which is often described or alluded to as “control” by the healthcare establishment) is key for PWT1D [38]. Diabetes tools and general management practices have increasingly allowed for PWT1D to achieve better clinical outcomes with diabetes. From being able to self-administer insulin dosages through their preferred tools, and to capture blood glucose data through the tools of their choosing, people with Type 1 diabetes are concerned with losing this ability to control and have autonomy over their choices in their daily care and management. Aging poses further unpredictable physical, cognitive, and psychological challenges to people’s sense of control, disrupting what they have built over time through daily habits and practices.

One of our youngest participants, a 30-year-old woman, described her relationship with Type 1 diabetes as an interaction with the “dual brain.” A second “dual brain” helps her manage her diabetes, and she worries that over time that she may lose the sense of control that this second brain has provided her. With loss of control, people may turn to external assistance and labor from friends or loved ones that may be trained to replicate this dual brain. However, the mere idea of handing their “dual brain” to an external source, such as a caretaker or even a physician, presents worry that these external sources, despite their textbook knowledge and empathy, will not have the time or capacity [39] to properly replicate the personalized system that they’ve trained to perform for years, especially in real-time. Additionally, when faced with an acute illness or situation such as an ER visit or hospitalization, planned or unplanned, there are additional scenarios where healthcare providers or the system set up by the healthcare system may seek to take control and management of diabetes from the patient, even if they are still equipped and fully able to self-manage daily diabetes tasks. This is a key source of friction between PWT1D and the healthcare system on an ongoing basis.

Our sample pool of participants ($n = 27$ PWT1D across all steps of this research) all had varying perspectives and backgrounds in their experiences and perceptions with Type 1 diabetes and aging. Despite these differences, they were all anchored by their shared concern of losing control over their daily management routines and routes of care as they age over time. Based on our participants’ main commonalities and differences, we were able to synthesize our participant sample into two general yet distinct personas. The

design research method of creating personas provides this study with fictional representations of our sample pool of participants, all who come from different walks of life yet share distinct characteristics and needs. Our two personas are distinguished primarily by their comfortability with and access to advanced technologies, as well as their capacities to plan for aging.

In comparison to Avery, Sam presents a vastly different set of challenges. Understanding a section of our demographic that has more experience with new technologies provides us with a valuable perspective on the true effectiveness of technological tools in shaping quality of life in several aspects, not just in the physiological sense. Many of our self-proclaimed tech-savvy participants rely heavily on do-it-yourself (DIY) versions of highly personalized open source automated insulin delivery systems [40]. These systems leverage existing insulin pumps and continuous glucose monitors (CGM) alongside an open source algorithm to adjust insulin delivery [41]. With the rise of DIY diabetes tools such as automated insulin delivery systems, we see more clearly the limitations of current commercialized tools [42] and the initiative many PWD have had to take [43] in order to meet their own specific needs. Through these DIY tools, we see a greater level of initiative and engagement by PWD than many healthcare providers typically expect. Part of the PWT1D community who have recognized that they are progressing into aging have created new social media groups to provide support for those who need it and know to seek it out.

However, despite their advances, this niche community has found challenges in communicating the power of their diabetes tools (DIY automated insulin delivery systems or even traditional standalone insulin pumps and CGMs) to healthcare providers and educators—in part due to the traditional structures of the healthcare system. Historically, new tools are developed by companies and rolled out with training to healthcare providers. More recently, advances in technology have made it possible for PWT1D to directly choose and adopt technologies before HCPs have gained their own experiences with them. Many HCPs, especially those who are not as knowledgeable and up to date in Type 1 diabetes, would have a learning curve [44] in order to establish validation in their patient’s self-reported needs relative to the technologies they heavily trust and depend on. This may prevent patients from feeling open and transparent about negotiating their comprehensive needs and expectations in their care, which may also cause tension in the overall HCP-PWT1D interaction.

Through a more general lens, HCP-PWT1D interaction may also be complicated outside the emphasis of

special technologies. A common pattern we discovered addressed the invalidation that many of our participants experienced when presenting non-pre-existing injuries or concerns that become immediately justified as primary and sole result(s) of diabetes. This overgeneralization of new symptoms and signs may rule out other underlying conditions and may leave the patient feeling unaddressed, ignored, and even blamed, despite how well they manage their diabetes on a daily basis. This invalidation may cause PWT1D to deeply reflect on their trust on the overall healthcare system, leading them to question the competence of institutions, their care providers, and established protocols that are often prioritized over directly addressing individual patient needs.

PWT1D interact with the healthcare system in a number of ways, not just in planned encounters but also for acute and emergent healthcare needs. In understanding these two additional perspectives, we may discover potential opportunities to improve the patient experience through their interactions with nurses and other care providers, such as physician assistants, anesthesiologists, medical assistants, and social workers, and the various care settings they work within. This variability of care presents inconsistencies and misalignments between various health care teams and protocols and patient expectations, especially for those living with diabetes, which in turn may deepen distrust and uncertainty for people who may not receive consistent levels of care.

Limitations

While our study provides valuable insights into PWT1D attitudes about aging, there are some limitations to our findings. Our study utilized two convenience samples of people with diabetes who happened to be connected to or known to volunteer experts in Type 1 diabetes and/or staff from UCSD DDI. Neither sample used in the interviews or user testing are representative of the general T1D population. The lack of diversity might introduce bias to our data. However, this was not meant to be conclusive research, but used to narrow down the potential issues in Type 1 diabetes and aging and provide a starting point for potential design-related solutions that could and should be explored further, including with more representative groups of people with diabetes.

Due to our lack of access to non-physician care providers, our study does not include the perspectives of nurses and other non-physician care providers, who are still,

nonetheless, highly involved in executing the patient's course of treatment. Interviews with nurses of all licenses would be especially invaluable to future studies in that they have much more frequent and closer proximity to their patients and more direct forms of daily care and management, especially in terms of administering life-altering medication and fluids and performing basic life support procedures that are heavily tied to acknowledging the patient's specialized orders.

Discovering which factors expand inaccessibility of diabetes technologies may bring clearer insight as to how different levels of inaccessibility affect the quality of the relationship and trust-building process that form between care providers and people aging with T1D.

Conclusion

People with Type 1 diabetes are now living longer and facing the new “luxury” of the challenges of aging. While research is slowly expanding and addressing T1D physiology with regards to aging, there is little research addressing specific challenges and barriers to optimal care by those aging with T1D. To address this gap, this study employed human-centered design methods of needfinding and user interviews to explore the gaps and barriers to care faced by people aging with T1D, including the development of design artifacts such as personas and experience maps to help articulate the different experiences of individuals with Type 1 diabetes and their unique needs as they age. The study also resulted in the development of one potential new tool, a diabetes advance directive[45], that could be further refined to specifically aid those with Type 1 diabetes who are aging and requiring more frequent interactions with the healthcare system. Initial user testing with people with T1D as well as healthcare providers demonstrated the need of such a diabetes advance directive tool or document. Future research should test this concept further with a variety of healthcare providers in a variety of care environments and care scenarios, in addition to testing with a more representative sample of people aging with Type 1 diabetes. This work supports the conclusion that additional focus and scientific enquiry should be given to the needs of people aging with Type 1 diabetes, with a goal of improving the experience of all people with T1D when interacting with their care providers or with the healthcare system as a whole.

Appendix

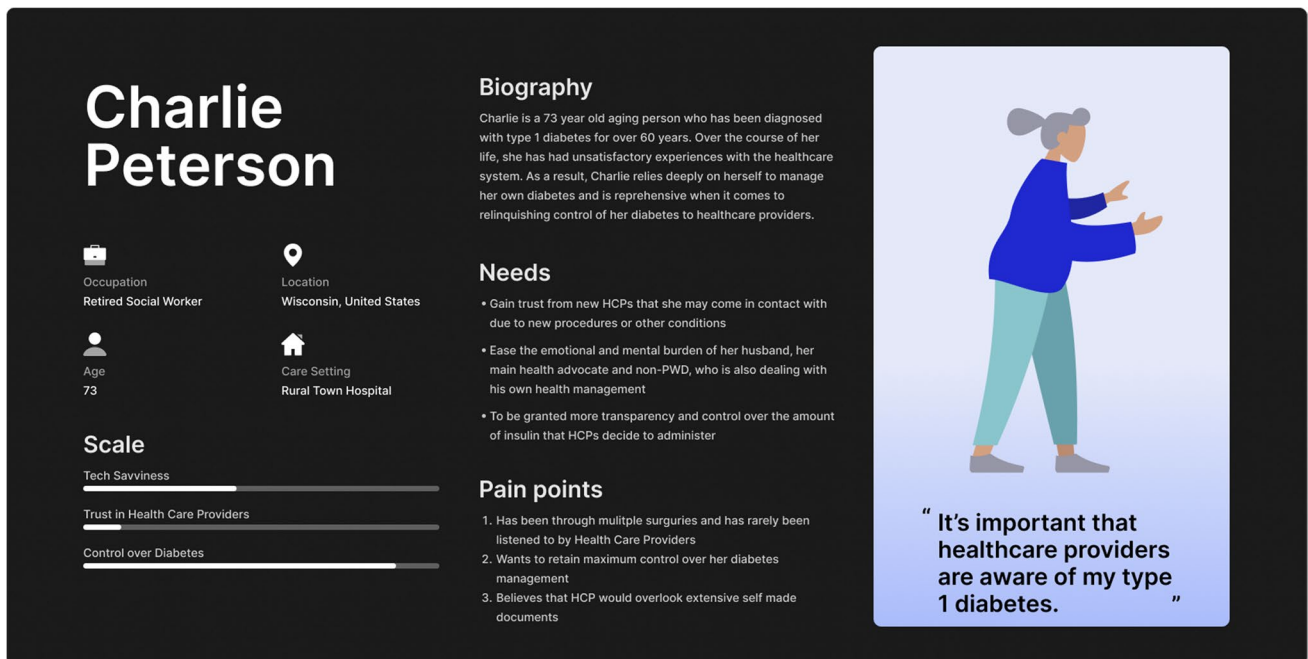


Fig. 5 A persona of a person with Type 1 diabetes who is troubled or concerned by their interactions with a new healthcare provider

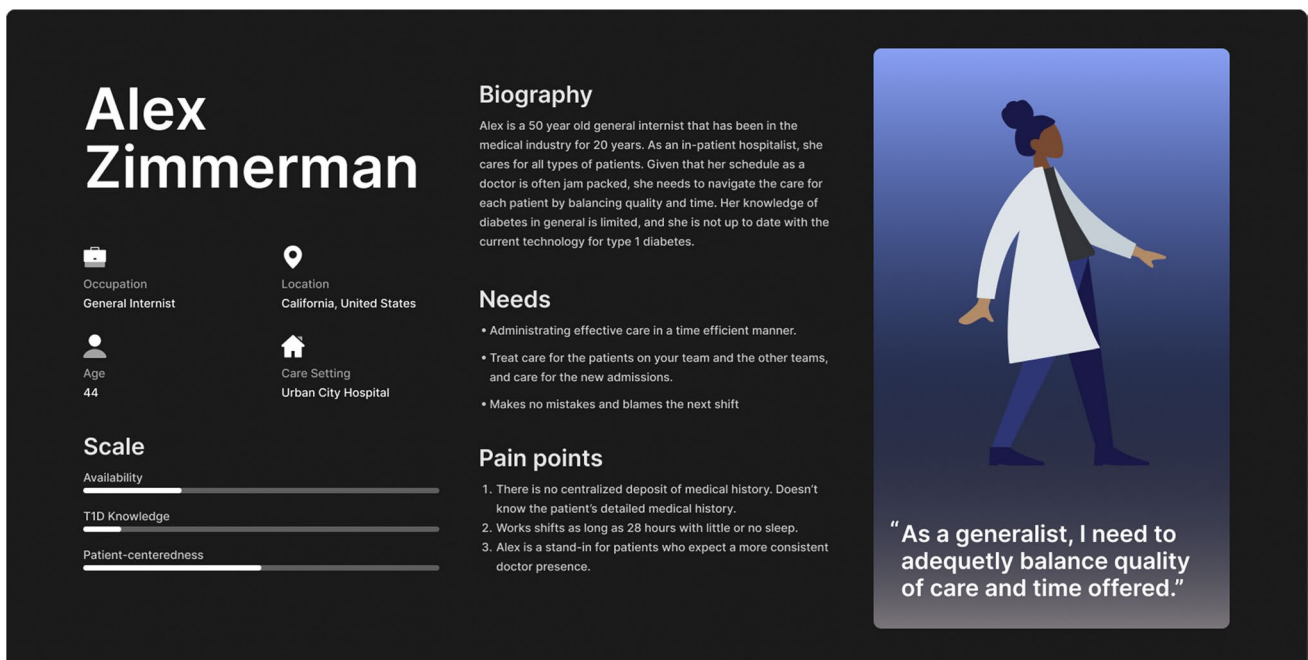


Fig. 6 A persona of a healthcare provider concerned about the lack of available time for a healthcare encounter with a person with Type 1 diabetes, as well as realistic about their limited experience supporting people with Type 1 diabetes

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Authors' contributions DL created the initial outline of the manuscript. DL, JM, JE, JeL, JoL, and DT co-wrote the initial draft. DL, JM, JE, JeL, JoL, DT, HR, and EAS all contributed to revisions and reviewed and approved the final version of the manuscript.

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Declarations

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Consent to participate Not applicable.

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References

1. Miller RG, et al. Improvements in the life expectancy of type 1 diabetes: the Pittsburgh epidemiology of diabetes complications study cohort. *Diabetes*. 2012;61(11):2987–92. <https://doi.org/10.2337/db11-1625>.
2. Advances in HIV treatment uncover a new issue: Aging. Healio. (n.d.). https://www.healio.com/news/infectious-disease/20140218/10_3928_1081_597x_20140101_00_1333149. Accessed 15 Nov 2021.
3. Ryan C. Diabetes, aging, and cognitive decline. *Neurobiol Aging*. 2005;26(1):21–5. <https://doi.org/10.1016/j.neurobiolaging.2005.09.006>.
4. Rosenthal MJ, Fajardo M, Gilmore S, Morley JE, Naliboff BD. Hospitalization and mortality of diabetes in older adults: A 3-year prospective study. *Diabetes Care*. 1998;21(2):231–5. <https://doi.org/10.2337/diacare.21.2.231>.
5. Caspersen CJ, Thomas GD, Boseman LA, Beckles GLA, Albright AL. Aging, diabetes, and the public health system in the United States. *Am J Publ Health*. 2012;102(8):1482–97. <https://doi.org/10.2105/AJPH.2011.300616>.
6. Sussman, et al. Estimated lifetime economic burden of type 1 diabetes. *Diabetes Technol Ther*. 2020;22(2):121–30. <https://doi.org/10.1089/dia.2019.0398>.
7. Centers for Disease Control and Prevention. National Diabetes Statistics Report, 2020. Atlanta, GA: Centers for Disease Control and Prevention, U.S. Dept of Health and Human Services; 2020.
8. Type 1 diabetes statistics. Beyond Type 1. 2021. <https://beyondtype1.org/type-1-diabetes-statistics/> Accessed 15 Nov 2021.
9. Marchand L, Pecquet M, Luyton C. Type 1 diabetes onset triggered by COVID-19. *Acta Diabetol*. 2020;57:1265–6. <https://doi.org/10.1007/s00592-020-01570-0>.
10. Bispham JA, Hughes AS, Driscoll KA, et al. Novel challenges in aging with type 1 diabetes. *Curr Diab Rep*. 2020;20:15. <https://doi.org/10.1007/s11892-020-01298-9>.
11. Jacobson AM, et al. Cognitive performance declines in older adults with type 1 diabetes: results from 32 years of follow-up in the DCCT and Edic study. *Lancet Diab Endocrinol*. 2021;9(7):436–45. [https://doi.org/10.1016/s2213-8587\(21\)00086-3](https://doi.org/10.1016/s2213-8587(21)00086-3).
12. Nathan, D. M., & DCCT/EDIC Research Group. The diabetes control and complications trial/epidemiology of diabetes interventions and complications study at 30 years: overview. *Diabetes Care*. 2014;37(1):9–16. <https://doi.org/10.2337/dc13-2112>.
13. Patnaik D, Becker R. Needfinding: The why and how of uncovering people's needs. *Design Management Journal (Former Series 1999)*. 2010;10(2):37–43. <https://doi.org/10.1111/j.1948-7169.1999.tb00250.x>.
14. Flood M, Ennis M, Ludlow A, Sweeney FF, Holton A, Morgan S, Clarke C, Carroll P, Mellon L, Boland F, Mohamed S, de Brún A, Hanratty M, Moriarty F. Research methods from human-centered design: Potential applications in pharmacy and health services research. *Res Social Adm Pharm*. 2021;17(12):2036–43. <https://doi.org/10.1016/j.sapharm.2021.06.015>.
15. Brenner W, Uebernickel F, Abrell T. Design thinking as mindset, process, and toolbox. In: Brenner W, Uebernickel F. (eds) *Design thinking for innovation*. Springer, Cham; 2016. https://doi.org/10.1007/978-3-319-26100-3_1.
16. Galletta A. *Mastering the semi-structured interview and beyond: from research design to analysis and publication*. New York, USA: New York University Press; 2013. <https://doi.org/10.18574/9780814732953>.
17. Salazar K. Contextual inquiry: inspire design by observing and interviewing users in their context. Nielsen Norman Group. 2020;6.
18. Adlin T, Pruitt J. *The essential persona lifecycle: Your guide to building and using personas*. Morgan Kaufmann; 2010.
19. King R, Churchill EF, Tan C. *Designing with data: improving the user experience with A/B testing*. O'Reilly Media, Inc.; 2017.
20. Bastien JC. Usability testing: a review of some methodological and technical aspects of the method. *Int J Med Informatics*. 2010;79(4):e18-23. <https://doi.org/10.1016/j.ijmedinf.2008.12.004>.
21. Lepley CJ. Problem-solving tools for analyzing system problems: The affinity map and the relationship diagram. *JONA: J Nurs Admin*. 1998;28(12):44–50.
22. Camere S, Schifferstein HN, Bordegoni M. Materializing experiential visions into sensory properties: The use of the experience map. In *Celebration & Contemplation, 10th International Conference on Design &, Amsterdam, Netherlands 2016 Sep* (pp. 27–30).
23. Goldman N. Evaluating the quality of self-reports of hypertension and diabetes. *J Clin Epidemiol*. 2003;56(2):148–54. [https://doi.org/10.1016/s0895-4356\(02\)00580-2](https://doi.org/10.1016/s0895-4356(02)00580-2).
24. Racadio R, Rose EJ, Kolko BE. Research at the margin: participatory design and community based participatory research. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2 2014* (pp. 49–52). <https://doi.org/10.1145/2662155.2662188>.
25. Frier B, Yang P, Taylor AW. Diabetes, aging and physical activity. *Eur Rev Aging Phys Act*. 2006;3(2):63.
26. Ahima R. Connecting obesity, aging and diabetes. *Nat Med*. 2009;15:996–7. <https://doi.org/10.1038/nm0909-996>.

27. Scheiner G. CGM retrospective data analysis. *Diabetes Technol Ther.* Feb 2016.S2–14-S2–22. <https://doi.org/10.1089/dia.2015.0281>
28. Divan V, Greenfield M, Morley CP, Weinstock RS. Perceived burdens and benefits associated with continuous glucose monitor use in type 1 diabetes across the lifespan. *J Diabetes Sci Technol.* 2022;16(1):88–96. <https://doi.org/10.1177/1932296820978769>.
29. Beck RW, Bergenstal RM, Laffel LM, Pickup JC. Advances in technology for management of type 1 diabetes. *The Lancet.* 2019;394(10205):1265–73. [https://doi.org/10.1016/S0140-6736\(19\)31142-0](https://doi.org/10.1016/S0140-6736(19)31142-0).
30. Lee PY, Khoo EM, Low WY, Lee YK, Abdullah KL, Azmi SA, Ng CJ. Mismatch between health-care professionals' and patients' views on a diabetes patient decision aid: a qualitative study. *Health Expect.* 2016;19(2):427–36. <https://doi.org/10.1111/hex.12366>.
31. Walker AF, Hood KK, Gurka MJ, Filipp SL, Anez-Zabala C, Cuttriss N, Haller MJ, Roque X, Naranjo D, Aulisio G, Addala A. Barriers to technology use and endocrinology care for underserved communities with type 1 diabetes. *Diabetes Care.* 2021;44(7):1480–90. <https://doi.org/10.2337/dc20-2753>.
32. Heisler M, Bouknight RR, Hayward RA, Smith DM, Kerr EA. The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. *J Gen Intern Med.* 2002;17(4):243–52. <https://doi.org/10.1046/j.1525-1497.2002.10905.x>.
33. Beverly EA, Worley M, Prokopakis K, Ivanov N. Patient-physician communication and diabetes self-care. *Journal of Clinical Outcomes Management.* (November 2016) 23:11. Available online at: <https://www.mdedge.com/jcomjournal/article/146123/diabetes/patient-physician-communication-and-diabetes-self-care>. Accessed 25 Jan 2022.
34. Bedford-Petersen C, Weston SJ. Mapping individual differences on the internet: case study of the type 1 diabetes community. *JMIR Diabetes.* 2021;6(4): e30756. <https://doi.org/10.2196/30756>.
35. Litchman ML, Oser TK, Wawrzynski SE, Walker HR, Oser S. The underground exchange of diabetes medications and supplies: donating, trading, and borrowing, oh my! *J Diabetes Sci Technol.* 2020;14(6):1000–9. <https://doi.org/10.1177/1932296819888215>.
36. Warshaw H, Hodgson L, Heyman M, et al. The role and value of ongoing and peer support in diabetes care and education. *Diabetes Educ.* 2019;45(6):569–79. <https://doi.org/10.1177/0145721719882007>.
37. Newman, MW, Lauterbach, D, Munson, SA, Resnick, P, Morris, ME. It's not that I don't have problems, I'm just not putting them on Facebook: challenges and opportunities in using online social networks for health. In: *Proceedings of the ACM Conference on Computer-Supported Cooperative Work.* New York, NY: Association for Computing Machinery; 2011:341–350.
38. Lee JM, Rusnak A, Garrity A, et al. Feasibility of electronic health record assessment of 6 pediatric type 1 diabetes self-management habits and their association with glycemic outcomes. *JAMA Netw Open.* 2021;4(10): e2131278. <https://doi.org/10.1001/jamanetworkopen.2021.31278>.
39. Nguyen Q, Iyyavoo AA, Parkin CG. Use of retrospective continuous glucose monitoring data is underrated and underused. *J Diabetes Sci Technol.* 2022;19:19322968211070836. <https://doi.org/10.1177/19322968211070837>.
40. Lewis D. History and perspective on DIY closed looping. *J Diabetes Sci Technol.* 2019;13(4):790–3. <https://doi.org/10.1177/1932296818808307>.
41. Lewis D. Do-It-yourself artificial pancreas system and the openAPS movement. *Technol Diabetes Endocrinol Metab Clin N Am.* 2020;49(1):203–13. <https://doi.org/10.1016/j.ecl.2019.10.005>.
42. Lewis D. How It started, how it is going: the future of artificial pancreas systems (automated insulin delivery systems). *J Diabetes Sci Technol.* 2021;15(6):1258–61. <https://doi.org/10.1177/19322968211027558>.
43. Lewis D, Leibrand S. Real-world use of open source artificial pancreas systems. *J Diabetes Sci Technol.* 10(6):1411–1411. <https://doi.org/10.1177/1932296816665635>
44. Murray JA, Clayton MF, Litchman ML. Health care provider knowledge and perceptions of FDA-approved and do-it-yourself automated insulin delivery. *J Diabetes Sci Technol.* 2020;14(6):1017–21. <https://doi.org/10.1177/1932296819895567>.
45. Lewis D. The need for diabetes advance directives to support the care of people with diabetes. *J Diabetes Sci Technol.* 2022. <https://doi.org/10.1177/19322968221076558>.

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