Exploring the Challenges and Potential Alternatives to Insulin Pump Technologies

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ABSTRACT

This paper examines the current technology of diabetes management devices, primarily insulin pumps. Insulin pumps are effective tools for the precise control of glucose levels, for type 1 diabetes (T1D) patients. Many design and usability challenges still exist with insulin pump technology. In this study, we investigated current shortcomings and limitations of insulin pumps through survey (N=103) and interview (N=7) data collection methods. Our findings revealed issues with current insulin pumps including: 1) wear-ability and accessibility in public; 2) operating devices while performing demanding tasks; 3) interruptions with social activities and interactions; 4) continuity of maintenance, and 5) interface operations. Our study aspires to inform the future design of novel insulin pumps that enable people with T1D to maintain better control of their glucose levels through consistent and steady interactions with these tools during their everyday activities.

CCS CONCEPTS

• Social and professional topics → Computing / technology policy→ Medical technologies • Social and professional topics → Computing / technology policy → Personal health records

KEYWORDS

Insulin Pump, Continuous Glucose Monitor, Interface Design, Diabetes Management

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1 Introduction and Related Work

Insulin pump technology has advanced rapidly over the last decade. Major pump makers are introducing the first Food and Drug Administration (FDA) approved closed loop architecture, matching the pump with a Continuous Glucose Monitor (CGM), where the devices communicate via Bluetooth. This device network simulates the characteristics of a pancreas to regulate glucose levels more accurately. The Dexcom mobile application allows users of their proprietary CGM to track and share real-time glucose data with, designated family members and healthcare providers [2].

Pump interfaces have begun to diverge from the more traditional mechanical buttons and display. Touchscreens are being implemented in some newer designs, either integrated on the pump itself, or accompanying as a wireless controller. While touch screen interfaces are becoming more popular in insulin pump design, they still pose some limitations to users as they rely heavily on 'eyes-on' interactions. Haptic features (e.g. mechanical buttons) can play an important role in operating insulin pumps by facilitating eyes free interactions [1], but their value may be underestimated.

Additionally, people with impaired vision may have trouble using touch screens and must use other methods for managing diabetes. For example, some have elected to use V-Go which was designed for people with Type 2 diabetes. Since the device's interface consists of three buttons, and doesn't make use of a digital display, it can be operated without any visual cues. However, it has limitations: basal rates cannot be changed, and the device can only deliver one 2-unit bolus at a time. People with T1D often need much more precise dosage increments to properly manage glucose.

Other researchers have conducted studies on the design and human factors aspects of insulin pumps. For example, Tandem Diabetes researchers referred to their process as "prevention through design" and worked with end-users to test user perceptions and viability of the pump's interface, to determine what information should be present on various screens and calculate health risks that may occur during specific interactions with the pump [10]. While companies like Tandem are making strides to ensure their products are safe and easy to use, there is still a need for further research and development on the usability of insulin pumps.

Due to the nature of challenges and the lack of concrete solutions, hacking into the system software of insulin pumps became increasingly popular in the diabetes community. For example, Lewis [9] started modifying her pump and CGM, to make her alarms louder in case she experienced dangerously low glucose levels at night. This led to developing a simple algorithm that could forecast glucose levels and make dosage corrections. This work has been shared with the open-source community, which initiated #OpenAPS (Open Artificial Pancreas System) [7]. Lewis and Leibrand [6] later explored Open APS systems effectiveness and participants reported reduced average glucose levels, spent approximately 40% more time within target glucose range, and all but one improved sleep [6]. Other open source systems such as the Loop mobile app (designed for automated insulin delivery) have been developed by DIYers in the diabetes community to control older insulin pumps, via a Raspberry Pi based device (RileyLink), which translates the wireless signals of the pump, CGM, and smartphone; allowing the devices to communicate [8]. The DIY community coalesced further by introducing hashtag #WeAreNotWaiting to denote the need for more rapid technological development, increased interoperability of devices, and better data exchange. DIYers continue to use the hashtag, expressing their drive to overcome regulations and the limited proprietary technologies currently available [5].

2 Methodological Approach

We employed surveys and interviews to understand people's challenges with insulin pumps. Initial contacts were made through the Atlanta, GA chapter of the Juvenile Diabetes Foundation (JDRF), which provided context on design opportunities in developing diabetes technology as well as resources for finding study participants.

2.1 Online Survey and Interviews

A 12-question survey was dispersed to several online forums, through JDRF and personal contacts and garnered 105 responses. 66 of the respondents were female, 35 were male, and 2 did not disclose gender. Average age range of respondents was 45-54. The goals of the survey were to collect a representative sample that could show how people interact with pumps, common pain points, and most desired new features they would like to see in an insulin pump. The end of the survey featured two open-ended questions, asking participants to express their deeper opinions about current technology. Participant names were coded (R1 – R105) to protect their identities.

Interviews were conducted after completion of the survey to collect more in-depth data around participants issues with insulin pumps. Seven participants were recruited through a JDRF Facebook group and through contacts at JDRF corporate offices in Atlanta. The interview format started with introductory questions focused on pump model, wearing location, and inquiring about other 3rd party apps or products each person might use. The main section consisted of situational questions that related to using insulin pumps for routine activities, like taking a meal bolus. Final questions focused on using pumps in situations where it might be difficult to do so. Participants included 5 females and 2 males. The average age range of all participants was 34-44. All interviewees use CGM's. Two of the female participants also use the tidepool open source system. One tidepool user also suffers vision loss due to diabetic retinopathy. Participant names were coded (P1 – P7) to protect their identities. Answers from the survey and interviews were organized into an affinity diagram for emerging themes and underlying codes.

3 Results from Survey and Interviews

The analysis of data through affinity diagram revealed several major themes including: 1) Wear-ability and accessibility issues in public; 2) Operating insulin pumps while performing demanding tasks; 3) Inconveniences during social activities and interactions; 4) Continuity of maintenance, and 5) Interface operations.

3.1 Wear-ability and Accessibility Issues in Public

Several participants shared unique experiences, relating to wearing pumps. Figure 1 gives visual context for all the wearing locations mentioned by each participant. The number of devices carried also varied, from two to six devices at a time. Participants expressed difficulty when attending formal events. P2 described her experience on her wedding day as: "My wedding day was difficult. Trying to figure out, 'where can I even stick stuff?' I don't want it in pictures. Where can I put my devices so that they'll be hidden and still work?" Several women stated the challenges of accessing the device in public. As P4 stated, "I've had diabetes long enough that I'm like, 'I need to do what I need to do.' And if that means reaching into my shirt in public, then no big deal. I would love it if I didn't have to do that." R87 raised a similar concern and mentioned: "At a wedding, wearing a dress, had an insulin pump clipped to the bra but the neckline did not allow me to reach in and pull out."

Overall, eleven female survey contributors commented on pumps being hard to access while wearing a dress. Several other female respondents expressed difficulty when they have to wear devices underneath clothing, and women's clothing often doesn't have adequate pockets. "It can be difficult if I don't have pockets. If I'm wearing a skirt and am out to dinner and have to bolus, I have to put my hand down (or up) my skirt to get my pump out." (R49). One female participant even commented she had to "quit wearing dresses and skirts since it is difficult to get to my pump without having to find a bathroom; I have even gone off the pump for 24 hours so I could function easily at my son's wedding." (R88).

3.2 Operating Insulin Pumps while Performing Demanding Tasks

Managing diabetes often involves re-focusing one's attention from normal daily activities to deal with insulin pumps. Participants shared their concerns about getting an alert from a pump or CGM while driving or performing activities that demand focused attention. For example, R52 stated: "I sometimes have difficulty changing my device because of time. I am a teacher so I can't just stop what I'm doing for diabetes. Just life with diabetes."

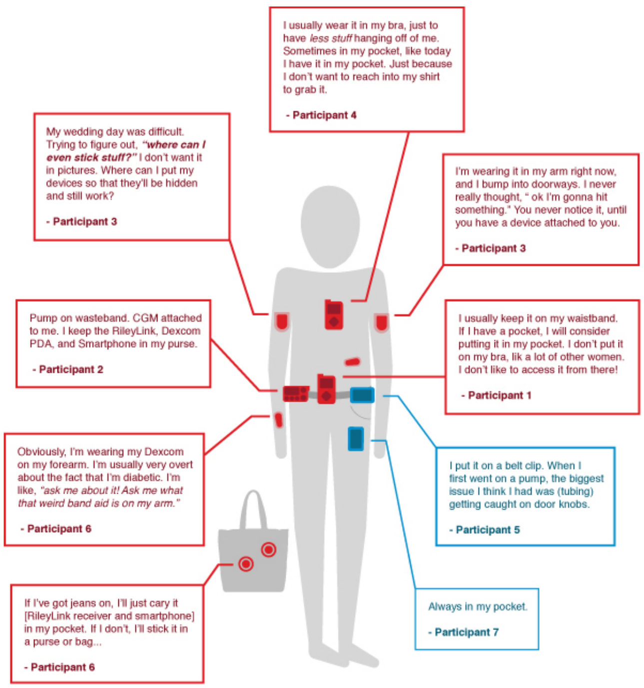

Figure 1: Illustrated depiction of the various locations where interviewees wear pumps and related devices.

Thirteen respondents mentioned feedback as an issue that interrupts daily activities, such as driving. R36 stated: "I often get alarms when driving. This by far is the most inconvenient time as I want to respond and, if necessary, administer a bolus. This is often very awkward." It is, however, important to note how integral these alerts are as safety factors. R90 stated: "I knew the pump would alarm again... until the glucose ingested increased BG [blood glucose] levels. Wish I could acknowledge, treat, and ignore. (saying this, I will admit the alarm setup has saved my bacon late at night a few times)". Different strategies were employed to deal with this issue. On the subject of getting pump alerts while driving, P4 stated: "I know the functions and I'm a safe driver in general. But I would just pull it out and try to take care of it at the next stoplight." P1 mentioned pump interaction without taking her eyes off the road: "I've memorized functions. I bolus while driving...Like if it says I'm high, and it's alerting me, I will lie about eating carbs just to get the bolus." P7 stated using a passenger's help, while driving: "A lot of the time, if I'm on a road trip, my girlfriend might be sitting in the passenger seat. And I'll hand her the pump and be like, 'can you give me 5 units?'" P5 also stated: "If I have someone else in the vehicle, like my brother for example. If he's in the passenger seat, I'll just say, 'hey, here's my pump.'"

3.3 Inconveniences During Social Activities and Interactions

Participants discussed situations where pumps impeded a social activity. P5 mentioned one academic situation, in particular. "I had a professor who had a really stringent rule as far as phones. 'If I hear your phone, you gotta' buy donuts for the whole class…' One day, I ran out of insulin in class. Of course, it started beeping like a madman. Long story short, it made noise and the professor said, 'We've got our first phone. I guess you're buying donuts for the whole class!'". Several participants mentioned experiences where their pumps became a public distraction.

Connectivity was also discussed within the arena of social activities. P6 mentioned a different scenario, relating to Bluetooth connectivity. "Big events like concerts or sporting events can be hard…I've been in a couple situations, even recently, where there are so many other devices in the same dense little area that my Bluetooth just craps out…I went to a concert with my husband a couple weeks ago, and my Dexcom kept losing signal."

Alerts were also mentioned as a common pain point. Several respondents described situations of experiencing unwanted beeping and alerts in public situations. P7 expressed a desire for customizable alert settings for different pump functions. "It would be good to have different customizable things for different features…Every time I'm low or high, I don't want it beeping as loud as I want it beeping if I have an occlusion." [P7]. Also, R37 stated: "It beeped during a meditation class and I was asked to leave it in the car next time." Overall, 22 survey respondents mentioned dissatisfaction with alerts and interruptions with social activities. One participant even stated that she had to ignore the alarm to complete her tasks: "When I run out of insulin at work and I have an hour left, I want to stay… with slowly elevating blood sugar so that I can finish. I have a time sensitive job and I have to triage... I can't do that when it beeps every 5 minutes… I can't afford to waste insulin, so I push my limits."

3.4 Continuity of Maintenance

Several participants brought up issues related to continuous maintenance and retention of their devices, in order to function well while they are involved in other critical activities. As R66 stated: "It always runs out [of insulin] at the worst time in a meeting because I try to use all my insulin and extend the pump supplies." R80 described her experience with her device as: "I was in a staff meeting when I got a high alert--it was kind of awkward trying to pull my pump out of my pocket to give a correction." A similar issue occurred with a device's battery as described by R29: "battery needed changing during a work meeting and it alarmed every 5 minutes. I couldn't turn it off because it was under my clothes so I had to excuse myself." Many participants shared their concerns about device malfunctions and complex operations. As R22 described: "I can't figure out how to turn it off.... It randomly will vibrate and say 'please check your pump. You entered a high value 4:30 hours ago' or something like that." These issues are critical as they may cause loss of valuable insulin, as R17 stated: "I accidentally hit load a new cartridge on my pump when I was on that screen after changing my site. It made me go through the whole process of filling my tubing a second time and wasted ten units of insulin with no way for me to override it."

3.5 Insulin Pump Interface Operations

Many participants expressed issues with the user interface. 16 survey respondents' open-ended comments mentioned interface navigation as an issue and taking excessive steps was the most prominent theme among comments relating to interfaces as R98 stated: "[Need to] go through so many steps to do a simple bolus!" One interview participant mentioned the bolus history screen: "One of my biggest complaints on this pump is the recall history. Bolus/Basal history is a very poorly organized section of the interface. Hard to tell boluses apart. No logical spreadsheet breakdowns." (P7). Some survey respondents also suggested making updates to interface content: "Read more information on the homepage of screen." (R91). Five respondents also mentioned screen content visibility as an issue. R58 commented: "Bigger print for the screen". R86 also stated: "The ability to make the PDM screen a bit larger", when referring to her wireless controller. While insulin pumps offer a quick bolus feature to allow users to program a bolus without going through sub-menus, P7 found the feature difficult to operate: "I'm not really a fan of it. I think the button is really hard to press. You have to hold it down. And then you can initiate. Yeah, it's hard to do, and it's easier to just go straight to the normal bolus."

Haptic feedback was mentioned to be a potential interaction method for people with vision impairment, as well as a universal feature for those who feel the need to operate pumps without having to look at a screen. 29 respondents admitted to using their pumps without looking at the screens, on occasion. Also, 58 respondents shared their desire to operate pumps without having to look at the screen.

4 Discussion and Further Work

Initial findings in this study have revealed some insight into the hardships people with T1D face. Wear-ability, accessibility, continuity of maintenance, and operating pumps during social activities emerged as major challenges with current insulin pumps. Women, in particular, face many challenges with wear-ability aspects, from choosing clothing, to finding viable wearing locations which would allow for safe and consistent device usage. Therefore, it appears that it would be beneficial to examine existing wear-ability frameworks in designing the future insulin pumps. Also, implementing a more humanistic form language could allow these devices to conform to the human body in a more comfortable and stable fit, while adding to the pump's structural integrity [3].

Interface operation was the main discussion topic in interviews and survey comments. Pump interfaces vary widely, and many user flows incorporate a series of confirmation screens designed to prevent things like accidental boluses. It's important to determine where confirmation screens are necessary but may still be possible to design streamlined user flows. In regard to the bolus history section, some pump bolus history screens don't feature clear breaks between each bolus given. In P7's example, all previous boluses appear to merge together. This may be considered a false cognitive affordance [4] rather than an organized spreadsheet, making the content more difficult to interpret.

Based on the discussion around V-Go pumps, some retinopathy patients must resort to alternative means for using traditional pumps. Overall, a user centered approach, similar to the "prevention through design" study [10], may be beneficial for future iterations on designing user flows. On a more universal level, the survey and interviews revealed a number of people who may have to use pumps in situations where they can't look at a device screen. A possible design solution for these use cases is a haptic interface, which facilitates 'eyes free' interaction. Such a device can potentially resolve several issues brought up by participants including getting access to insulin pumps for quick operations in public places. The next phase of this project is to conduct participatory design workshops, prototype insulin pump designs based on input from people with T1D, followed by a model interface design. Finally, we plan on conducting user tests to evaluate the model interface's efficacy for people with T1D.

REFERENCES

[1] B. Buxton. (2007). Multi-touch systems that I have known and loved. Microsoft Research, 56, 1-11.

[2] J. Espinoza, P. Shah, J. Raymond. (2020). Integrating continuous glucose monitor data directly into the electronic health record: proof of concept. *Diabetes Technology and Therapeutics*, (ja). 570-576. doi: 10.1089/dia.2019.0377

[3] F. Gemperle, C. Kasabach, J. Stivoric, M. Bauer, R. Martin. (1998). "Design for wearability," Digest of Papers. Second International Symposium on Wearable Computers (Cat. No.98EX215), Pittsburgh, PA, USA, pp. 116-122, doi: 10.1109/ISWC.1998.729537

[4] T.-M. Hng, D. Burren. (2018). Appearance of Do-It-Yourself closed-loop systems to manage type 1 diabetes. Intern Med J, 48: 1400-1404. doi: 10.1111/imj.14105

[5] Rex Hartson. (2003). Cognitive, physical, sensory, and functional affordances in interaction design, Behaviour & Information Technology, 22:5, 315-338, doi: 10.1080/01449290310001592587

[6] D. Lewis, S. Leibrand. (2016) Real-World Use of Open Source Artificial Pancreas Systems. Journal of Diabetes Science and Technology. Vol 10 6, 1411. doi: 10.1177/1932296816665635

[7] DIYPS.org. Dana Lewis. Retrieved March 7, 2020 from https://diyps.org/about/dana-lewis/

[8] LoopDocs. RileyLink FAQs. Retrieved February 2020 from https://loopkit.github.io/loopdocs/faqs/rileylink-faqs/

[9] Sean Michael Ragan. 2018. Medicine Ignored This Insulin Problem. Hackers Solved It. Retrieved from https://medium.com/neodotlife/dana-lewis-open-aps-hack-artificial-pancreas-af6ef23a997f

[10] N.E. Schaeffer. (2012) The Role of Human Factors in the Design and Development of an Insulin Pump. *Journal of Diabetes Science and Technology.* 2012;6(2):260-264. doi:10.1177/193229681200600208