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ORIGINAL ARTICLE

Real-World Use and Self-Reported Health Outcomes of a Patient-Designed Do-it-Yourself Mobile Technology System for Diabetes: Lessons for Mobile Health

Joyce M. Lee, MD, MPH,[1,2] Mark W. Newman, PhD,[3] Achamyeleh Gebremariam, MS,[2] Preciosa Choi, BS, BSN,[2] Dana Lewis, BA,[4] Weston Nordgren,[5] John Costik, BS,[6] James Wedding, BS, PE,[5] Benjamin West, BA,[7] Nancy Benovich Gilby, MSE,[3] Christopher Hannemann, MS,[7] Josh Pasek, PhD,[8] Ashley Garrity, MPH,[2] and Emily Hirschfeld, BA[2]

Abstract

Background: The aim of this study is to compare demographic/disease characteristics of users versus nonusers of a do-it-yourself (DIY) mobile technology system for diabetes (Nightscout), to describe its uses and personalization, and to evaluate associated changes in health behaviors and outcomes.
Methods: A cross-sectional, household-level online survey was used. Of 1268 household respondents who were members of the CGM in the Cloud Facebook group, there were 1157 individuals with diabetes who provided information about Nightscout use.
Results: The majority of individuals with diabetes in the household sample were 6–12 years old (followed by 18 years and above, and 13–17 years), non-Hispanic whites (90.2%), with type 1 diabetes (99.4%). The majority used an insulin pump (85.6%) and CGM (97.0%) and had private health insurance (83.8%). Nightscout use was more prevalent among children compared with adolescents and adults. Children used Nightscout for nighttime, school, sporting events, and travel; adults used it for nighttime, work, travel, and sporting events. Whereas the majority of adults viewed their own data without assistance from others, among pediatric users, a median of three individuals (range: 0–8) viewed Nightscout, with a median of three devices per viewer (range: 0–7). Individuals reported that after Nightscout adoption, they checked blood glucose values with a meter less often; bolused more frequently; gave more boluses without checking first with a blood glucose meter; and experienced significant improvements in HbA1c and quality of life.
Conclusions: The Nightscout Project is a patient-driven mobile technology for health and may have beneficial effects on glycemic control and quality of life.

Keywords: Type 1 diabetes, Mobile technology, Online community, Social media.

Advances in consumer mobile technology, digital medical devices, and Cloud-based computing are creating innovative opportunities for chronic disease management, particularly in the arena of diabetes.[1] Researchers, health systems, and digital and medical device companies are developing mobile technology tools and interventions to assist with glucose monitoring and diabetes self-management, but the real-world use and impact of the vast majority of these

[1]Pediatric Endocrinology, University of Michigan, Ann Arbor, Michigan.
[2]Child Health Evaluation and Research Center, University of Michigan, Ann Arbor, Michigan.
[3]School of Information, University of Michigan, Ann Arbor, Michigan.
[4]#OpenAPS, Seattle, Washington.
[5]The Nightscout Foundation, McKinney, Texas.
[6]Center for Clinical Innovation, University of Rochester, Rochester, New York.
[7]Nightscout Community, San Francisco, California.
[8]Communication Studies and Center for Political Studies, Institute for Social Research, University of Michigan, Ann Arbor, Michigan.

systems on health outcomes are largely unknown. Recently, a group of patients and caregivers with diabetes developed their own do-it-yourself (DIY) mobile technology system for diabetes, called the Nightscout Project, which has led to rapid global adoption of mobile technology in the type 1 diabetes community.[2]

The Nightscout Project started when the father of a 4-year-old boy with type 1 diabetes hacked into his son's FDA-approved continuous glucose monitoring (CGM) system, uploading sensor glucose values to the Internet through an Android phone. This enabled him to access real-time sensor glucose data on personalized web-based, mobile, and wearable applications that he designed. Through a tweet about his achievement,[3] he connected with and shared his code with other individuals with diabetes and caregivers, who began designing DIY mobile technology systems for themselves.

Convinced of the need for this technology in the larger community, the group made the code open-source, created the Nightscout Project website[4] with instructions on how to set up the system, and opened a private Facebook group (CGM in the Cloud), which became a vehicle for dissemination of the technology across a global community as well as a forum for sharing information and troubleshooting the system. Starting with just 40 members in April 2014, the group now has 22,000 members as of January 2017.[5]

The practical application of mobile technology to a variety of chronic diseases is of great interest to the larger healthcare community, and the Nightscout Project provides a unique opportunity to learn about the adoption, use, and health outcomes of a DIY mobile technology system. We therefore conducted a cross-sectional survey of the members of the CGM in the Cloud community to compare demographic characteristics, including age, gender, race, ethnicity, education level, and country of residence; and disease characteristics of users versus nonusers of Nightscout, which was defined as the use of a device attached to the CGM system to transmit the sensor glucose readings to web-connected devices. We also sought to describe the uses and personalization of the Nightscout technology (i.e., features and interface elements used) and to evaluate changes in health behaviors and health outcomes associated with its use.

Methods

The current study leverages a purposive survey of individuals who were expected to be aware of the Nightscout diabetes monitoring system. Individuals for the study were recruited through posts to the CGM in the Cloud Facebook group. This group was chosen because it is the principal space for distribution of information about Nightscout and because individuals in the group could therefore be expected to be aware of the technology.

Between June and August of 2015, 1461 individuals completed a Qualtrics survey they could access through a link provided in a series of social media posts on Facebook and Twitter and blog posts. Participation in the survey was anonymous and voluntary and was limited to adults over 18 years of age. Individuals under age 18 were asked to have a parent complete the survey. Respondents were also asked to complete only a single survey per household. The Institutional Review Board of the University of Michigan Medical School deemed this study exempt and no financial compensation for participation was provided.

After excluding 193 respondents who reported that they did not use the CGM in the Cloud Facebook group, and were thus outside of the target population for the study, the remaining 1268 respondents were asked a series of questions about individuals with diabetes in their household (see Supplementary Data; Supplementary Data are available online at www.liebertpub.com/dia). The questions were developed with input from patient partners in the CGM in the Cloud community and piloted with a small number of users in two iterations before final release.

Among the 1268 eligible respondents, 1157 reported living in a household with an individual who had diabetes. Individuals whose household included a person with diabetes were asked about the demographics of the individual with diabetes as well as his/her diabetes type, diabetes management systems, insurance status, health status, and whether the Nightscout system was currently being used by an individual with diabetes in the household. The 724 individuals in Nightscout-using households were also asked about the features and interface elements of the system that various members of the household used (e.g., desktop display, mobile application, watch, and push/text notifications; see Supplementary Table S1), as well as the number and relationship of individuals who viewed the sensor glucose measurements.

Finally, respondents in Nightscout-using households were asked about their rationale for using the Nightscout system, the status of diabetes-related behaviors (frequency of blood glucose testing, frequency of bolusing—both total and without testing blood glucose levels, and frequency of downloading CGM data), as well as health indicators of the person with diabetes (HbA1c levels) before and after Nightscout use. Caregiver respondents and adults who used Nightscout (not pediatric users) were also asked about its impact on their quality of life, including how often diabetes kept them from doing normal daily activities; spending time at school/work; and spending time with friends before and after Nightscout with the following responses: never, rarely, sometimes, often, or all of the time.

Respondents were also asked whether their household had adopted CGM use because of the Nightscout system and whether they planned to continue using Nightscout or to switch to the Dexcom Share, which provided similar functionality and had just been approved by the FDA. Individuals could report mean A1c values in both standard and SI units; we converted all SI units to % points following the NGSP HbA1c standardization program conversion formula.[6]

Data analyses

To understand the composition of the CGM in the Cloud community as well as the correlates of Nightscout use, we first describe the demographic characteristics of the CGM in the Cloud users who responded to the survey. We then compared the characteristics of individuals with diabetes in households to assess the differences between users and nonusers of Nightscout. Chi-square and Fisher's exact tests were used for these comparisons.

We then report descriptive statistics for how Nightscout-using households engage with the system, and finally, we assess perceptions of diabetes care and outcomes both before and after Nightscout use among individuals who had been using a CGM for at least 6 months ($n = 629$). Comparisons of behaviors and

TABLE 1. CHARACTERISTICS OF SURVEY RESPONDENTS WHO ARE MEMBERS OF CGM IN THE CLOUD FACEBOOK GROUP, REPRESENTING ONE HOUSEHOLD

Characteristics	*Members of CGM in the Cloud (n = 1268)*
Sex	
Female	711 (74.8)
Male	237 (24.9)
Other	2 (0.2)
Unknown[b]	318
Race	
White non-Hispanic	854 (92.1)
Hispanic or Latino	26 (2.8)
Asian	10 (1.1)
Black/African American	5 (0.5)
Native Hawaiian/Pacific Islander	2 (0.2)
American Indian/Alaskan Native	0 (0.0)
Other	30 (3.2)
Unknown or do not wish to provide[b]	341
Relationship to Diabetes[a]	
The caregiver/parent/guardian of an individual with diabetes	1026 (80.9)
An individual with diabetes	242 (19.1)
A relative of an individual with diabetes	110 (8.7)
A friend of an individual with diabetes	61 (4.8)
Someone who works in the area of diabetes	54 (4.3)
A spouse/significant other of an individual with diabetes	53 (4.2)
Other	2 (0.2)
Education	
Master's, professional, doctorate degree	313 (33.8)
Associate's or bachelor's degree	465 (50.2)
High school/GED	143 (15.4)
Less than high school diploma/GED	6 (0.6)
Unknown or do not wish to provide[b]	341
Residence	
United States of America	720 (78.0)
Outside of the United States of America	203 (22.0)
Unknown[b]	345
First Hear about CGM in the Cloud Facebook Group	
Social media through Facebook	748 (59.4)
Friend	205 (16.3)
Other web/social media	81 (6.4)
Social media through blog posts	64 (5.1)
Healthcare provider	46 (3.7)
Family	45 (3.6)
Social media through Twitter	30 (2.4)
Traditional Media (article in the newspaper, or news on TV or the radio)	16 (1.3)
Other	14 (1.1)
Conference	11 (0.9)
Unknown[b]	8
First Hear about Nightscout Project	
Social media through CGM in the Cloud FB group	388 (30.8)
Social media through Facebook (other than CGM)	388 (30.8)
Friend	169 (13.4)
Other web/social media	75 (6.0)
Social media through blog posts	60 (4.8)
Healthcare provider	48 (3.8)
Family	38 (3.0)
Social media through Twitter	34 (2.7)
Traditional Media (article in the newspaper, or news on TV or the radio)	31 (2.5)
Other	21 (1.7)
Conference	6 (0.5)
Unknown[b]	10

Values are numbers (percentages).
[a]Responses were not mutually exclusive.
[b]The amount of missing data is reported, but analyses were only among complete cases.
CGM, continuous glucose monitoring.

outcomes before and after Nightscout use were assessed using a paired comparisons test. For all analyses, p-values of less than 0.05 were considered statistically significant. All analyses were performed using Stata/SE version-13.

Because the survey was somewhat long (averaging 140 questions), a moderate number of respondents did not complete all of the questions. As participation in the survey was voluntary and some topics could be considered potentially sensitive, respondents were also welcome to skip any question they desired. This meant that there was a moderate amount of item nonresponse in the study. We opted to make all comparisons among individuals whose information was complete. Hence, for all analyses, we report the amount of missing data but only conduct analyses among complete cases.

Furthermore, demographic questions were not asked of 318 respondents who did not complete the survey since these questions were the final survey items. When describing the month and year of initiation of Nightscout, as a data quality check, we found that there were a number of individuals who reported a date of initiation that was implausible since less than five individuals had access to the code before February 2013 (personal communication with J. Costik, 2016), so these individuals ($n = 7$) were removed from that result.

Results

CGM in the Cloud community

Of the 1268 who were members of CGM in the Cloud community, the mean age was 41 years and 74.8% were females (Table 1). The majority were non-Hispanic whites (92.1%) and most reported being either caregivers or parents/guardians of an individual with diabetes (80.9%). Most were highly educated individuals with either a bachelor's or master's/professional/doctorate degree (84.0%). More than half of individuals were from the United States (78.0%) and 22.0% were from outside the United States. The majority of individuals reported hearing about the CGM in the Cloud community through Facebook (59.4%), followed by friends (16.3%). Few heard about the system from their healthcare providers (3.7%).

Among the 1157 respondents with diabetes in the household, 62.6% ($n=724$) reported using Nightscout, 6.8% ($n=79$) had stopped using it, and 30.6% ($n=354$) never used it. Many Nightscout nonusers provided reasons for which they discontinued or never used the technology (Supplementary Table S2). The most common explanation given for never using Nightscout was that the household member with diabetes was independent and did not need Nightscout (11.6%). Respondents who stopped using Nightscout typically did so because it was too much work (31.6%) or too technically difficult (22.8%).

To understand the correlates of Nightscout use, we compared individuals with diabetes between Nightscout-using and nonusing households (Table 2). In contrast to the largely female respondents to the study, individuals with diabetes were more evenly split with regard to sex, with slightly more males than females (48.8%). The majority of individuals using Nightscout were 6–12 years old (51.2%), followed by 0–5 years old (18.7%), 13–17 years old (15.0%), and 18 years and above (15.0%), indicating that CGM in the Cloud is most heavily used by parents and caregivers of relatively young patients. The majority of users were non-Hispanic whites (90.2%) and nearly all reported having type 1 diabetes (99.4%).

In terms of technology use, the majority of individuals used an insulin pump (85.4%) and CGM (99.9%); the latter is unsurprising given that the Nightscout system requires CGM use. Among CGM users, the vast majority also used the Dexcom G4 (94.9%). Although at the time a system for the Medtronic sensor had been developed, it was not widely used (J. Costik, 2016, personal communication).

Almost half of individuals with diabetes started CGM in the last 12 months (41.6%), and the majority reported CGM use every day of the last month. In terms of quality of life, over 80% of individuals reported excellent or very good health. The percentage of individuals with more than three episodes of severe hypoglycemia (passing out, loss of consciousness, or seizure over a 3-month period) was low and the majority of individuals reported having private health insurance (83.8%; see question wording in Supplementary Data).

There were significant differences in characteristics of individuals with diabetes who used Nightscout compared with non-Nightscout users. Figure 1a shows that among all individuals with diabetes in the respondent households, the highest proportion of Nightscout use by age group was among younger children 0–5 years (74.0%) and 6–12 years old (71.8%), compared with adolescents 13–17 years old (58.2%) and adults (41.2%). There were also significant differences by sex, type of pump, CGM use, type of CGM, and duration of CGM, and by frequency of severe low blood glucose values and type of insurance (Table 2).

A significant proportion of Nightscout users reported adopting CGM because of Nightscout: 18.5% of users ($n=134$) reported that they elected to start using a CGM, 8.7% of users ($n=63$) restarted using a CGM, and 5.9% ($n=43$) changed CGM systems.

Figure 1b shows the reasons for which individuals were using the Nightscout monitoring system. In children, it is primarily used for nighttime (79.0%) and school (78.5%), followed by sporting events, travel, and other reasons. In adults, it is used for nighttime (78.6%), work (77.7%), and travel (77.7%), followed by sporting events and other reasons.

The majority of adult Nightscout users reported not only viewing their own data (94.2%) but also identified additional viewers, including the individual's mother (31.1%) or his/her spouse (48.5%).

Among pediatric users of Nightscout, a median of 3 individuals (range: 0–8) viewed the data for any given individual, with a median of 3 devices per viewer (range: 0–7). Figure 1c shows the types of individuals who respondents said were viewing the Nightscout data. For children, the most common viewers were the mother, the father, the child himself or herself, a nurse, and a grandmother, in that order.

Figure 1d shows the types of interfaces used to view Nightscout data by individuals using the system and their caregivers for all Nightscout users. Mobile applications were most popular, followed by wearables and desktop applications.

Supplementary Table S3 shows the different interface elements and additional features of Nightscout used by the community. The majority of Nightscout users (69.2%) used both an indicator for the change in sensor glucose value in the last 5 min (feature A) and the trend arrow representing rate of change of sensor glucose value over the last 15–20 min (feature B). A majority of users set custom alarms. Alarm thresholds were customized and set at varying thresholds. Over half of users (56.5%) used the raw data provided by the system from the sensor, and close to half of users (46.8%) used the predicted glucose values from the system.

Figure 2A through E shows changes in perceived diabetes-related behaviors and outcomes that corresponded with Nightscout use among individuals who had used CGM for more than 6 months. After Nightscout adoption, individuals reported checking their blood glucose values with a meter less often ($P<0.001$), bolusing more often ($P<0.001$), and also said that they gave more boluses without checking first with a blood glucose meter ($P<0.001$). Nightscout users also reported that their HbA1c levels were about 1.0 point lower after Nightscout adoption than just before adoption (difference $P<0.001$). After Nightscout adoption, a higher frequency of caregivers or adults with diabetes reported never or rarely feeling that diabetes kept them from doing normal activities, from spending time at work, or spending time with friends.

A subset of users answered questions about the setup of the system ($n=564$). Among these individuals, the median reported setup cost was \$155.82 (mean = \$240.05) and the median monthly maintenance cost was \$10.00 (mean = \$40.47). The majority reported that the person who set up the system had no significant technology/programming expertise (64.7%). Most of the individuals did the setup themselves (78.4%), followed by family (19.7%), someone from the CGM in the Cloud community (7.3%), a friend (3.2%), and a small percentage hired a technology specialist (0.4%). A majority of individuals reported receiving help from the CGM in the Cloud community (57.5%).

Supplementary Figure S1 shows the month and year of Nightscout initiation. Relevant events labeled on the graph include the opening of the CGM in the Cloud Facebook group in April 2014 and the release of an FDA-approved CGM mobile application in March–May 2015.

A subset of individuals ($n=598$) also answered questions about whether they will continue with Nightscout or go on to use a different system. When asked if they would use the

Table 2. Characteristics of Individuals with Diabetes by Nightscout Use

Characteristic	*Total (n=1157)*	*Non Nightscout Users (n=433)*	*Nightscout Users (n=724)*	*P-value*
Sex				0.037
Male	576 (51.2)	201 (47.2)	375 (53.6)	
Female	549 (48.8)	225 (52.8)	324 (46.4)	
Unknown[c]	32	7	25	
Age				<0.001
0–5 years	173 (15.9)	45 (11.1)	128 (18.7)	
6–12 years	489 (44.9)	138 (34.2)	351 (51.2)	
13–17 years	177 (16.3)	74 (18.3)	103 (15.0)	
18 years and above	250 (23.0)	147 (36.4)	103 (15.0)	
Unknown[c]	68	29	39	
Race/Ethnicity				0.494
White non-Hispanic	985 (90.2)	371 (90.3)	614 (90.2)	
Hispanic or Latino	37 (3.4)	16 (3.9)	21 (3.1)	
Asian/Native Hawaiian/Pacific Islander	11 (1.0)	1 (0.2)	10 (1.5)	
Black/African American	7 (0.6)	3 (0.7)	4 (0.6)	
American Indian/Alaskan Native	2 (0.2)	1 (0.2)	1 (0.1)	
Other	50 (4.6)	19 (4.6)	31 (4.6)	
Unknown or do not wish to provide[c]	65	22	43	
Diabetes type				0.380
Type 1	1,146 (99.4)	430 (99.3)	716 (99.4)	
Type 2	7 (0.6)	3 (0.7)	4 (0.6)	
Unknown[c]	4	0	4	
Insulin use[a]				
Pump	990 (85.6)	372 (85.9)	618 (85.4)	0.863
Injections/Pens	210 (18.2)	75 (17.3)	135 (18.7)	0.582
Does not take insulin	3 (0.3)	2 (0.5)	1 (0.1)	0.560
Type of device among current pump users				<0.001
Insulet Omnipod	291 (29.4)	86 (23.1)	205 (33.2)	
Medtronic Minimed	265 (26.8)	120 (32.3)	145 (23.5)	
Animas One Touch Ping	215 (21.7)	72 (19.4)	143 (23.1)	
Tandem T:Slim	108 (10.9)	46 (12.4)	62 (10.0)	
Sooil Dana Diabecare	13 (1.3)	1 (0.3)	12 (1.9)	
Roche Insulin Delivery System	7 (0.7)	5 (1.3)	2 (0.3)	
Asante Snap	4 (0.4)	3 (0.8)	1 (0.2)	
Other	87 (8.8)	39 (10.5)	48 (7.8)	
Unknown[c]	167	61	106	
CGM use				<0.001
Currently use CGM	1118 (97.0)	396 (92.3)	722 (99.9)	
Used CGM, now stopped	34 (3.0)	33 (7.7)	1 (0.1)	
Never used a CGM	0 (0.0)	0 (0.0)	0 (0.0)	
Unknown[c]	5	4	1	
Type of device among current CGM users				<0.001
Dexcom G4	1011 (90.4)	326 (82.3)	685 (94.9)	
Enlite	85 (7.6)	55 (13.9)	30 (4.2)	
Paradigm	5 (0.4)	4 (1.0)	1 (0.1)	
Guardian	1 (0.1)	1 (0.3)	0 (0.0)	
Other	16 (1.4)	10 (2.5)	6 (0.8)	
Unknown	39	37	2	
Duration of CGM use among current CGM users				0.031
Less than 6 months	167 (14.9)	74 (18.7)	93 (12.9)	
6 months to less than 1 year	299 (26.7)	98 (24.7)	201 (27.8)	
1 year to less than 2 years	283 (25.3)	84 (21.2)	199 (27.6)	
2 years to less than 3 years	155 (13.9)	56 (14.1)	99 (13.7)	
3 years to less than 4 years	72 (6.4)	24 (6.1)	48 (6.6)	
4 years to less than 5 years	46 (4.1)	19 (4.8)	27 (3.7)	
5 or more years	96 (8.6)	41 (10.4)	55 (7.6)	
Unknown[c]	39	37	2	

(*continued*)

TABLE 2. (CONTINUED)

Characteristic	*Total (n = 1157)*	*Non Nightscout Users (n = 433)*	*Nightscout Users (n = 724)*	*P-value*
Median days of CGM use in last month	31 days	31 days	31 days	
Current health status				0.046
Excellent	469 (40.5)	159 (36.7)	310 (42.8)	
Very Good	473 (40.9)	176 (40.7)	297 (41.0)	
Good	173 (15.0)	79 (18.2)	94 (13.0)	
Fair	38 (3.3)	18 (4.2)	20 (2.8)	
Poor	4 (0.4)	1 (0.2)	3 (0.4)	
Number of episodes of severe low blood sugar over the last 3 months				0.004
0–2 episodes	1113 (96.4)	412 (95.6)	701 (96.8)	
3–4 episodes	10 (0.9)	7 (1.6)	3 (0.4)	
5–6 episodes	5 (0.4)	3 (0.7)	2 (0.3)	
7–8 episodes	2 (0.2)	0 (0.0)	2 (0.3)	
9 episodes	8 (0.7)	6 (1.4)	2 (0.3)	
10 or greater	17 (1.5)	3 (0.7)	14 (1.9)	
Unknown[c]	2	2	0	
Insurance plan in the past 12 months				0.012
Private health insurance	804 (83.8)	336 (84.6)	468 (83.1)	
Public health insurance[b]	132 (13.8)	50 (12.6)	82 (14.6)	
No health insurance	23 (2.4)	11 (2.8)	12 (2.1)	
Single service plan	1 (0.1)	0 (0.0)	1 (0.2)	
Unknown or do not wish to provide[c]	197	36	161	
Country				
United States of America	764 (78.8)	314 (78.7)	450 (78.9)	
Canada	44 (4.5)	13 (3.3)	31 (5.4)	
United Kingdom	41 (4.2)	15 (3.8)	26 (4.6)	
Australia	35 (3.6)	15 (3.8)	20 (3.5)	
Sweden	15 (1.5)	5 (1.3)	10 (1.8)	
New Zealand	9 (0.9)	6 (1.5)	3 (0.5)	
Italy	8 (0.8)	5 (1.3)	3 (0.5)	
Finland	7 (0.7)	3 (0.8)	4 (0.7)	
Romania	7 (0.7)	5 (1.3)	2 (0.4)	
Germany	5 (0.5)	1 (0.3)	4 (0.7)	
Austria	3 (0.3)	3 (0.8)	0 (0.0)	
Croatia	3 (0.3)	2 (0.5)	1 (0.2)	
Denmark	3 (0.3)	2 (0.5)	1 (0.2)	
Ireland	3 (0.3)	1 (0.3)	2 (0.4)	
The Netherlands	3 (0.3)	2 (0.5)	1 (0.2)	
Norway	3 (0.3)	1 (0.3)	2 (0.4)	
Spain	3 (0.3)	2 (0.5)	1 (0.2)	
Israel	2 (0.2)	0 (0.0)	2 (0.4)	
Argentina	1 (0.1)	1 (0.3)	0 (0.0)	
Belarus	1 (0.1)	0 (0.0)	1 (0.2)	
Belgium	1 (0.1)	1 (0.3)	0 (0.0)	
Brazil	1 (0.1)	0 (0.0)	1 (0.2)	
Bulgaria	1 (0.1)	0 (0.0)	1 (0.2)	
China	1 (0.1)	0 (0.0)	1 (0.2)	
Czech Republic	1 (0.1)	0 (0.0)	1 (0.2)	
France	1 (0.1)	1 (0.3)	0 (0.0)	
Japan	1 (0.1)	0 (0.0)	1 (0.2)	
Mexico	1 (0.1)	1 (0.3)	0 (0.0)	
Poland	1 (0.1)	0 (0.0)	1 (0.2)	
Unknown[c]	188	34	154	

Values are numbers (percentages) unless stated otherwise. N represents the number of respondents to each question.

[a]Responses were not mutually exclusive; includes only respondents who provided diabetes type.

[b]Medicare, MediGap, Medicaid, State Children's Health Insurance Program, Military healthcare, Indian Health Service plan, Other state-sponsored health plan, Other government-sponsored health coverage plan.

[c]The amount of missing data is reported, but analyses were only among complete cases.

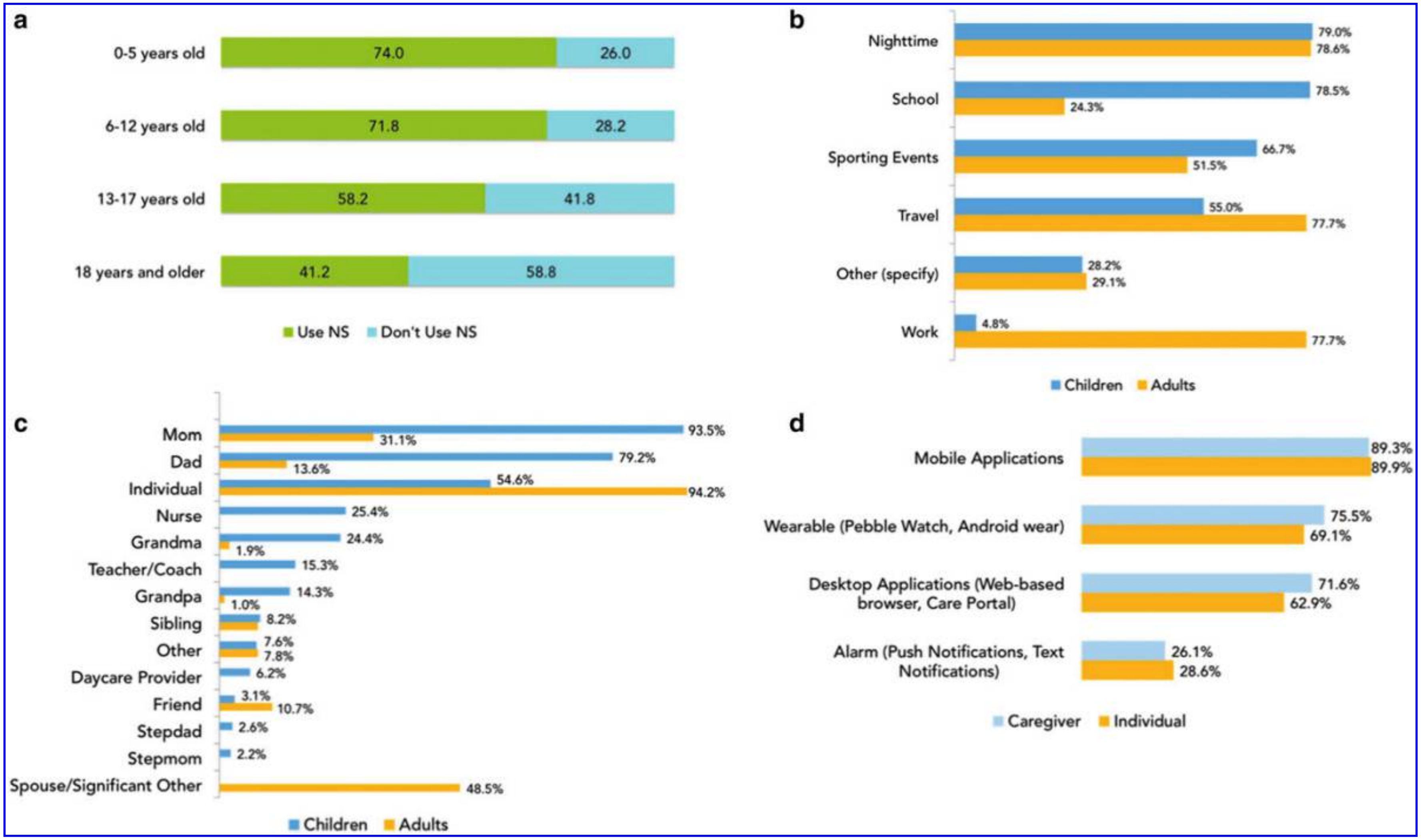

FIG. 1. **(a)** The proportion of individuals who use Nightscout versus those who do not use Nightscout among all individuals with diabetes in the respondent households ($n=1089$). **(b)** Domains for Nightscout use stratified by children ($n=582$) and adults ($n=103$). **(c)** Individuals viewing Nightscout data, stratified by children ($n=582$) and adults ($n=103$). **(d)** Features used to view Nightscout data by individuals ($n=437$) wearing Nightscout and caregivers ($n=656$).

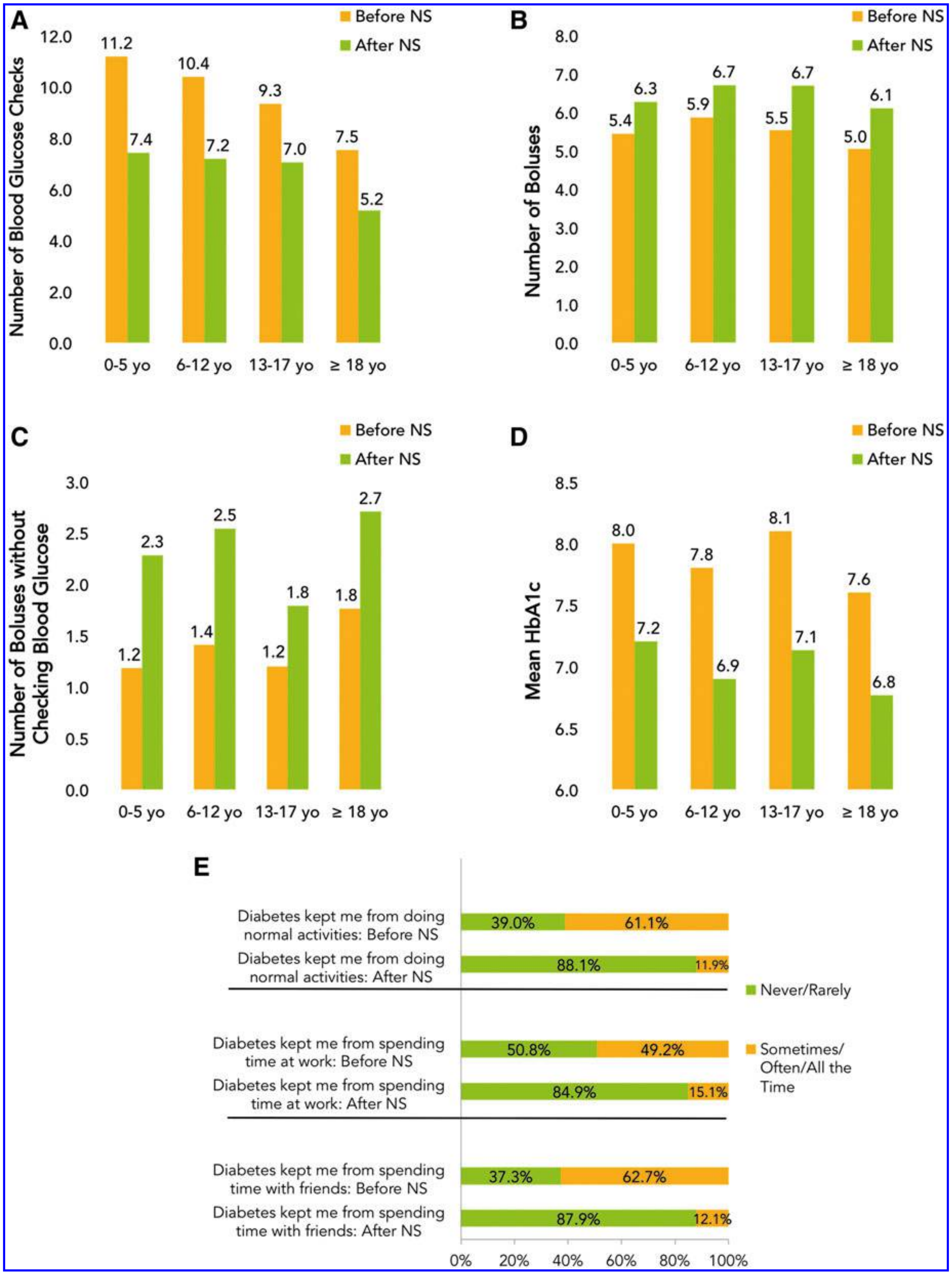

FIG. 2. **(A)** Mean number of blood glucose checks per day using a glucose meter before and after Nightscout use, by age category ($n = 502$). **(B)** Mean number of short-acting insulin boluses given per day before and after Nightscout use, by age category ($n = 504$). **(C)** Mean number of boluses per day given without a blood glucose check using a meter before and after Nightscout use, by age category ($n = 494$). **(D)** Mean self-reported HbA1c before and after Nightscout use, by age category ($n = 356$). **(E)** Quality of life before and after Nightscout use.

newly FDA-approved commercial sharing system for the CGM, many opted to use both systems (34.0%). In total, 53.0% reported that they would continue with Nightscout and 52% reported that they would use Dexcom Share.

Discussion

To our knowledge, this is the first formal research study that focused on the CGM in the Cloud community and the Nightscout Project, which provides valuable information about the personalization and real-world use of a patient-designed DIY sensor glucose mobile monitoring system, and its effects on disease management and self-reported health outcomes. We did find statistically significant decreases in self-reported HbA1c and improvements in perceived quality of life across all age groups after the adoption of Nightscout compared with before adoption.

There are a variety of possible reasons for which Nightscout users reported improvements in their self-reported diabetes outcomes. Because Nightscout enables 24-h access to sensor glucose data for multiple family members, the system provides more opportunities to address rising or elevated sensor glucose measurements. This explanation is bolstered by the fact that Nightscout users reported giving a higher frequency of short-acting insulin boluses after adoption compared with beforehand. Nightscout use thus appears to facilitate more intensive control and thus reductions in HbA1c.

In the pediatric population, one might speculate that greater access to CGM data across a network of caregivers could allow for more coordinated and proactive care. In the adult population, although individuals are less likely to have a caregiver involved, additional access to multiple views of data (e.g., sensor glucose measurement that is easily glanceable on a watch instead of having to pull out a receiver to see sensor glucose measurements) could provide more opportunities for action.

In addition, our finding that individuals were checking blood glucose less frequently with the Nightscout technology suggests that individuals were relying on CGM alone for insulin dosing decisions, which is notable given the recent FDA panel recommendation to support CGM for insulin dosing.[7]

A 2012 Cochrane review of RCTs of CGM for T1D reported a change in HbA1c ranging from 0.2% to 0.7% for patients starting with CGM alone versus starting CGM with an insulin pump.[8] However, this review was based on studies that used older CGM technology, which could have been retrospective as well as real time, and did not have a mobile technology component. Despite the fact that our study design and population were different, the self-reported improvements do seem to be within a plausible range of improvement.

In terms of improvements in the quality of life for caregivers or adults with T1D, the differences pre- and post-adoption were significant. The majority of pediatric and adult users of Nightscout used the technology for nighttime because of the well-established risks of nocturnal hypoglycemia.[9] Qualitatively, there were a number of outcomes that parents reported in the survey, including the ability of the parent/caregiver to remotely monitor a child with T1D, freedom to view data from wearable devices, and the value of accessing raw data from the sensor when traditional CGM metrics were unavailable.

There was a standard set of features in the Nightscout package that individuals could use to view the data. Wearables in particular were quite popular, interestingly not only for the caregivers but also for individuals wearing the Nightscout rig, who already had direct access to the data through the CGM receiver. We suspect that this may be due to convenience—the ability to glance at a wearable such as a wristwatch is easier than pulling out the laptop or the mobile phone—as well as social norms.[10] Anecdotally, individuals reported that glancing at a watch made it more socially acceptable to check sensor glucose data frequently.

Finally, there was personalization of interface features used by the population. As expected, individuals reported using features that are normally part of the typical CGM receiver, such as sensor glucose measurement, trend line, and alarms. Interestingly, at least half of users did report using unapproved features, including raw data from the sensor, which are typically not seen by the user on the CGM receiver, as well as predicted sensor glucose levels. Presumably, users found the raw data useful as they provide a measure of approximate sensor glucose values when estimates from the CGM are too imprecise to provide an official reading.

Not surprisingly, the majority of the study population of Nightscout users were pediatric, a population for whom remote monitoring is a particularly valuable tool as parents must comanage care of the diabetes with their child. Although a majority of primary caregivers (mothers and fathers) used the technology, there was a wide variety of secondary caregivers as well, revealing the breadth of caregivers involved in the care of diabetes. The fact that the adoption was highest among the youngest age groups and then decreased during adolescence likely reflects the greater independence with self-care that adolescents undertake as they transition into adulthood.

Most Nightscout users surveyed were also white, well-educated, and had private insurance. Nightscout requires having access to a CGM, and only 11% of individuals with T1D use a CGM.[11] Among individuals with T1D, CGM users tend to have a higher educational level, higher household income, and are more likely to have private health insurance[11]; therefore, increased uptake of this technology could worsen health disparities in diabetes care unless CGM technology and mobile technology become more widely disseminated within the T1D population.

Because it is a DIY product, Nightscout setup is not a simple consumer experience. It requires buying the right components, implementing computer code, setting up a database, and dealing with technical issues. This was a barrier for at least 1/3 of the respondents who joined the CGM in the Cloud community, but elected not to use Nightscout. This may also explain why the number of individuals adopting Nightscout dropped after May 2015 following the release of the FDA-approved Dexcom Share.

Despite this apparent hurdle, a majority of Nightscout users reported that they did not have significant technical programming expertise. Presumably, these individuals may have been aided by videos and information provided on the website; they also appear to have benefitted from technical support provided by members of the Facebook group. Interestingly, a majority of individuals reported that they would continue with Nightscout and/or use a hybrid system of Nightscout and the commercial solution, which suggests an ongoing desire for patient-designed innovation, despite commercial product availability.

We must acknowledge that social media has played an important role in the creation and dissemination of Nightscout as the majority of respondents learned about the system through Facebook. It is clear that social media is a critical tool for dissemination of knowledge, tools, and technologies across the globe, independent of formal healthcare delivery systems.

To our knowledge, this is one of the few studies to describe real-world uses of mobile technology for chronic disease management. Because users in the community were building their own DIY solutions for health, they had the opportunity to personalize their systems to a greater degree than if they were using commercial standardized systems, leading to creation of a variety of patient-designed innovative solutions and systems. Prototypes of these systems may ideally guide the design and development of commercial digital services and products that are more user-centered.

Strengths of our study include the relatively large sample of users from the CGM in the Cloud community, the description of personalization of the technology across users, and the measurement of how users perceived their health outcomes had changed while using the technology. Notably, the examination of any real-world use of a select technology is coupled with a number of challenges. The individuals in the CGM in the Cloud community likely represent a proactive set of T1D households, who were interested in learning about Nightscout in the first place.

Furthermore, Nightscout adoption was also driven by a self-selection mechanism among a subset of households. These individuals were early adopters of the technology and were likely to be more proactive diabetes managers than we would expect to find if the technology were more widely distributed and easy to implement. In addition, only a subset of the Nightscout users in our survey self-reported outcomes. We therefore cannot be sure that the self-reported health improvements did not stem from other attributes of the individuals. Hence, we cannot conclude that more widespread availability of the technology would result in similar improvements in diabetes indicators at a societal level.

Nonetheless, the improvements respondents report in diabetes management are sizable, and there is little reason to expect these changes outside of some sort of intervention. Furthermore, by limiting our pre- and postuse analyses to individuals who had been using a CGM for at least 6 months before starting Nightscout, we can rule out the most likely confounder.

The reliance on self-report measures from a set of individuals who opted to take the current survey also poses some limitations. As with all self-report measures, individuals may be predisposed to answer in ways that are self-validating, especially when answering retrospective questions.[13] This means that individuals may overestimate the improvements they experienced while using Nightscout. We think this is unlikely, however, for two reasons. First, HbA1c is a highly salient metric for diabetes patients,[14] especially those who are more motivated, increasing the likelihood of an accurate recall. Second, if individuals were responding in an entirely self-affirming manner, we would expect to see Nightscout use correspond with an increase in reported blood glucose testing, which we did not observe. The opt-in process ensures that the sample of individuals acquired cannot be safely generalized to even the 12,000 members of the CGM in the Cloud Facebook group. Instead, we believe the results of the study are instructive, in that they illustrate some of the core reasons that individuals adopt these DIY technologies and the benefits they seem to derive from them.

For patients, providers, healthcare delivery systems, and private industry preparing for a mobile and digital transformation inside healthcare, the Nightscout Project provides an instructive, patient-driven real-world example of the deployment of mobile technology for health. Furthermore, the story of Nightscout and its potential impact on outcomes suggest that participatory DIY technologies created by patients and caregivers represent a powerful opportunity for creating innovations in healthcare.

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Authors' Contributions

J.M.L., D.L., W.N., J.C., J.W., B.W., J.P., and E.H. contributed to the conception and design of the work. J.M.L., P.C., E.H., J.P., and A.G. contributed to acquisition and analysis of the data. J.M.L., M.W.N., N.B.G., C.H., J.P., A.G., A. Garrity, and E.H. contributed to the interpretation of data for the work. All authors provided drafting of the work or revising it critically for important intellectual content and final approval of the version to be published. J.M.L. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and accuracy of the data analysis.

Author Disclosure Statement

J.M.L. does consultancy for Verily and Samuelsson Associates and is paid for her position as Social Media Editor of JAMA Pediatrics and has no other relationships or activities that could appear to have influenced the submitted work. No other potential conflicts of interest relevant to this article were reported.

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Address correspondence to:
Joyce M. Lee, MD, MPH
Pediatric Endocrinology
University of Michigan
300 NIB, Room 6E14
Campus Box 5456
Ann Arbor, MI 48109-5456

E-mail: joyclee@med.umich.edu