JMIR Diabetes

Emerging Technologies, Medical Devices, Apps, Sensors, and Informatics to Help People with Diabetes
Volume 3 (2018), Issue 2   ISSN 2371-4379   Editors-in-Chief: Ricardo Correa, MD, EdD; Sheyu Li, MD

Contents

Original Papers

Review

Original Paper

New-Onset Diabetes Educator to Educate Children and Their Caregivers About Diabetes at the Time of Diagnosis: Usability Study

Angelina Bernier[1], MD; David Fedele[2], PhD; Yi Guo[3], PhD; Sarah Chavez[3], MPH; Megan D Smith[3], MPH; Jennifer Warnick[2], MS; Leora Lieberman[1], BS; François Modave[3], PhD

[1]Division of Endocrinology, Department of Pediatrics, University of Florida, Gainesville, FL, United States
[2]Department of Clinical & Health Psychology, University of Florida, Gainesville, FL, United States
[3]Department of Health Outcomes and Biomedical Informatics, University of Florida, Gainesville, FL, United States

Corresponding Author:
François Modave, PhD
Department of Health Outcomes and Biomedical Informatics
University of Florida
2004 Mowry Road
CTRB 3217
Gainesville, FL, 32610
United States
Phone: 1 3522945984
Email: modavefp@ufl.edu

Abstract

Background: Diabetes self-management education is essential at the time of diagnosis. We developed the New-Onset Diabetes Educator (NODE), an animation-based educational web application for type 1 diabetes mellitus patients.

Objective: Our hypothesis is that NODE is a feasible, effective and user-friendly intervention in improving diabetes self-management education delivery to child/caregiver-dyads at the time of diagnosis.

Methods: We used a pragmatic parallel randomized trial design. Dyads were recruited within 48 hours of diagnosis and randomized into a NODE-enhanced diabetes self-management education or a standard diabetes self-management education group. Dyads randomized in the NODE group received the intervention on an iPad before receiving the standard diabetes self-management education with a nurse educator. The Diabetes Knowledge Test 2 assessed disease-specific knowledge pre- and postintervention in both groups, and was compared using *t* tests. Usability of the NODE mobile health intervention was assessed in the NODE group.

Results: We recruited 16 dyads (mean child age 10.75, SD 3.44). Mean Diabetes Knowledge Test 2 scores were 14.25 (SD 4.17) and 18.13 (SD 2.17) pre- and postintervention in the NODE group, and 15.50 (SD 2.67) and 17.38 (SD 2.26) in the standard diabetes self-management education group. The effect size was medium (Δ=0.56). Usability ratings of NODE were excellent.

Conclusions: NODE is a feasible mobile health strategy for type 1 diabetes education. It has the potential to be an effective and scalable tool to enhance diabetes self-management education at time of diagnosis, and consequently, could lead to improved long-term clinical outcomes for patients living with the disease.

(JMIR Diabetes 2018;3(2):e10) doi:10.2196/diabetes.9202

KEYWORDS
mHealth; information technology; diabetes education; pediatrics

Introduction

In the United States alone, close to 19,000 new pediatric cases of type 1 diabetes mellitus are diagnosed each year [1]. Living with type 1 diabetes requires drastic lifestyle changes both for the child and the caregiver. The delivery of diabetes self-management education and support (DSMES) at the time of diagnosis to children and families through in-person diabetes education and reading materials are integral components of new-onset diabetes self-management [2], [3]. Although standard of care DSMES is effective, evidence indicates that knowledge acquisition and retention could be substantially improved by using multimedia strategies (eg, images, videos) rather than text, particularly in the context of health education and literacy [4]. Thus, image delivery methods could improve long-term clinical outcomes and costs associated with lifetime diabetes management [5]. The goal of this pilot study is to present and assess the usability and preliminary efficacy of NODE, an animated educational web-based application designed to complement the standard of care in DSMES among a representative sample of newly diagnosed children with type 1 diabetes mellitus and their parent caregivers.

Methods

The NODE program was developed to run as an iBook on the standard Apple iOS mobile operating system to complement standard DSMES. Multiple disciplines were involved in the development of NODE content and presentation including pediatric endocrinologists, certified diabetes educators, and dietitians; in addition to artists, programmers, web designers and teachers. Each element and iteration were reviewed with patients and their families in clinical and camp settings to guide the look and usability. Following the outline and content of teaching educational materials common to new-onset education, eight modules were designed to cover basic diabetes self-management topics such as: What is Diabetes, Glucose Monitoring, Insulin, Hypoglycemia or Low, Hyperglycemia or High, Nutrition, Exercise and Diabetes, and Personal Management Plan. The presentation styles within these modules incorporate illustrations, interactive animations (see Figure 1), short cartoons, demonstration videos, and simple games (see Figure 2).

The purpose of NODE is to facilitate and foster diabetes knowledge acquisition and retention, aimed at expanding and enhancing standard DSMES materials and dissemination methods. The objectives for the current study were three-fold: 1) assess the usability of NODE; 2) monitor the feasibility of implementation; and 3) assess the preliminary efficacy of NODE in improving standard DSMES at diagnosis. The pilot study was approved by the Institutional Review Board, consent and assent were obtained prior to enrollment.

Pediatric patients (ages four to 15 years) and caregiver dyads were recruited from the university hospital within 48 hours of diagnosis, and then randomized using a web-based random number generator. Half (n=8) of the participants were randomized to NODE-enhanced DSMES intervention and the others (n=8) into the Standard DSMES control group (Figure 3). The Diabetes Knowledge Test 2 (DKT2) was used to assess preliminary efficacy. The DKT2 is a 23-item validated scoring instrument, developed for both type 1 and type 2 diabetes [6]. The DKT2 includes a 14-item general sub score, and a nine-item insulin-dependent sub score, with total scores ranging from 0 to 23. NODE usability was evaluated using the System Usability Survey (SUS), a 10-item general-purpose software usability scoring instrument, with scores ranging between 0 and 100 [7], [8]. Higher scores indicate higher levels of usability (>92 = best imaginable, >85 = excellent, >72 = good, >52 = average). For all participants, demographic information of the child was collected (sex, age, ethnicity, race, preferred language) and socio-economic status of the caregiver (income, years of education) as well as the family’s baseline DKT2 score. After completion of baseline measures, the intervention group received NODE, followed by standard DSMES with a certified diabetes educator in the hospital (if admitted at diagnosis) or clinic.

Figure 1. New-Onset Diabetes Educator (NODE). This page titled “Why Test your Blood Glucose?” from the Blood Glucose Monitoring module demonstrates interactivity as patients are prompted to tap the up and down arrows. Depending on their selection, the blood glucose value in the meter screen increase or decreases while simultaneously filling or emptying the syringe in the insulin vial. Children can directly see how higher blood glucose values require higher insulin doses.

Figure 2. New-Onset Diabetes Educator (NODE) - Interactive Learning. This page titled “Can you put these steps in order?” is a game that tests a patient’s ability to drag the various steps needed for blood glucose monitoring into the correct order and check their results.

Figure 3. Intervention diagram describing the recruitment and randomization of participants in the study and the order in which the education tests and education materials were assigned for each group.

Following diabetes education which typically consists of three to four hours of one-on-one instruction within the first two days of diagnosis, participants completed the DKT2 and SUS. The control group received standard of care DSMES by a CDE, followed by administration of the DKT2. Parents completed all surveys in both the intervention and control groups immediately before any DSMES was initiated and the following day after their initial education was completed. Pre- and postintervention changes in DKT scores were assessed using T-tests as were intergroup differences. SUS scores were tallied for participants in the intervention group and descriptive statistics were generated (see Figure 3).

Results

Sixteen child-caregiver dyads were recruited and randomized between July 2016 and January 2017. The ages of pediatric patients ranged from four to 15 years, with a mean age of 10.75 (SD 3.44). Demographics and socioeconomic status variables are summarized in Table 1.

At baseline, there was no significant difference in diabetes knowledge between groups (*t*=0.71, *P*=.487). DKT2 scores for the intervention group were 14.25 (SD 4.17) pretest and 18.13 (SD 2.17) posttest, demonstrating a statistically significant increase in knowledge acquisition (*t*=–2.492, *P*=0.023). DKT2 scores for the control group were 15.50 (SD 2.67) pretest and

17.38 (SD 2.26) posttest, also demonstrating a statistically significant increase in diabetes knowledge (*t*=–2.45, *P*=.044). These results are summarized in Figure 4. Overall, the effect size, defined as the difference between the standardized mean change for the intervention group and the control group was medium (Δ=0.56). The intervention group demonstrated more improvement in education acquisition than the control group (3.88 vs 1.88); however, this additional knowledge gain was not statistically significant (*t*=–1.30, *P*=.213). The SUS total mean score was 89.2 out of a 100 possible, representing excellent usability.

Table 1. Demographics and socioeconomic status. NODE: New-Onset Diabetes Educator.

Characteristics	Control group, n (%)	NODE group, n (%)
Sex		
Female	6 (75)	4 (50)
Male	2 (25)	4 (50)
Race / Ethnicity		
White	6 (75)	7 (87.5)
African-American or Mixed	2 (25)	1 (12.5)
Hispanic / Latino	2 (25)	1 (12.5)
Education		
High School or lower	5 (62.5)	4 (50)
Associate degree or higher	3 (37.5)	4 (50)
Income		
< $25,000	3 (37.5)	0 (0)
$25,000 - $49,999	1 (12.5)	2 (25)
$50,000 - $74,999	2 (25)	3 (37.5)
$75,000 - $99,999	1 (12.5)	0 (0)
> $100,000	1 (12.5)	1 (12.5)
Not applicable / Refused to say	0 (0)	2 (25)
Preferred Language		
English	8 (100)	8 (100)
Spanish	0 (0%)	0 (0%)

Figure 4. Diabetes Knowledge Test (DKT) score change across groups, describing the pre- and postintervention DKT2 scores for the group receiving standard nurse education versus the New-Onset Diabetes Educator (NODE) group.

Discussion

In this study, we have demonstrated the usability of NODE in a university diabetes practice setting. Though there were no statistical differences between the intervention and the control group in terms of diabetes knowledge acquisition, the intervention group exhibited significant improvements in their DKT2 scores indicating non-inferiority of treatment and a lack of negative interference with the DSMES provided by the CDE. The diabetes educators did not communicate concerns regarding the use of NODE interfering with scheduling of their time with the patient and on a few occasions reflected that their educational interaction with the patient was improved by having an initial exposure to NODE. This benefit is important as NODE is meant to be used in conjunction with standard of care DSMES when a child is diagnosed with type 1 diabetes, rather than as a standalone iPad-based education platform.

NODE was deemed highly usable by the study participants. This provides preliminary evidence that the NODE web application is a feasible intervention to enhance diabetes education for child-caregiver dyads at the time of diagnosis. Finally, NODE can easily be used at home after being discharged from hospital, and therefore has the potential to greatly increase diabetes knowledge retention, and potentially, long-term clinical outcomes for patients with type 1 diabetes. In both groups, the parents completed the survey and knowledge test but often there was a group effort or discussion in replying to the questions which involved the child. The DKT2 is not designed to assess initial diabetes knowledge and has limited capacity to test the specific material information in NODE or in any new-onset education curriculum. A pediatric-specific scale should be used in future assessments to determine if diabetes knowledge acquisition is improved. A potential weakness of the study is the small sample size, which does not allow us to stratify across race and ethnicity. However, in the context of a pilot study, this is acceptable, and still allows us to demonstrate non-inferiority, and obtain preliminary effect size for a larger study.

Given the ubiquitous nature of mobile devices across the socio-economic status spectrum [9], and substantial evidence that mobile health can improve long term clinical outcomes [10] in particular among youth [11], NODE can be used later at home and thus facilitate not only diabetes-specific knowledge acquisition, but also retention.

Having demonstrated the feasibility of implementation in the clinical setting we will build on the goal of improving efficacy in acquisition of knowledge and retention.

Authors' Contributions

FM, AB, and DF designed the study. AB, SC, MDS, and LL collected the data. FM, DF, and YG designed the data analysis. FM and YG ran the analysis. FM and AB wrote the manuscript. FM, AB, DF, and YG reviewed and edited the manuscript. FM 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 the accuracy of the analysis.

Conflicts of Interest

None declared.

References

1. Hamman RF, Bell RA, Dabelea D, D'Agostino RB, Dolan L, Imperatore G, SEARCH for Diabetes in Youth Study Group. The SEARCH for Diabetes in Youth study: rationale, findings, and future directions. Diabetes Care 2014 Dec;37(12):3336-3344 [FREE Full text] [doi: 10.2337/dc14-0574] [Medline: 25414389]
2. Beck J. 2017 National Standards for Diabetes Self-management Education and Support. 2017 National Standards for Diabetes Self-management Education and Support, Diabetes Educ 2017:14572171772296.
3. American Diabetes Association. Lifestyle Management: Standards of Medical Care in Diabetes. Diabetes Care 2018;41:S38-S50.
4. Kandula N. The relationship between health literacy and knowledge improvement after a multimedia type 2 diabetes education program. Patient Educ Couns 2009;75(3).
5. Zhuo X, Zhang P, Barker L, Albright A, Thompson TJ, Gregg E. The lifetime cost of diabetes and its implications for diabetes prevention. Diabetes Care 2014 Sep;37(9):2557-2564. [doi: 10.2337/dc13-2484] [Medline: 25147254]
6. Fitzgerald JT, Funnell MM, Anderson RM, Nwankwo R, Stansfield RB, Piatt GA. Validation of the Revised Brief Diabetes Knowledge Test (DKT2). Diabetes Educ 2016 Dec;42(2):178-187. [doi: 10.1177/0145721715624968] [Medline: 26769757]
7. Brooke J. SUS - A quick and dirty usability scale. Usability Eval Ind 1996;189(194):4-7.
8. Brooke J. SUS: A Retrospective. Journal of Usability Study 2013;8(2).
9. Pew Research Center. Mobile Fact Sheet URL: http://www.pewinternet.org/fact-sheet/mobile/ [WebCite Cache ID 6ytguHL8r]
10. Hswen YK. Beyond the Hype: Mobile TechnologiesOpportunities to Address Health Disparities. J. Mob Technol Med 2015;4(1):39-40.
11. Fedele DA, Cushing CC, Fritz A, Amaro CM, Ortega A. Mobile Health Interventions for Improving Health Outcomes in Youth: A Meta-analysis. JAMA Pediatr 2017 May 01;171(5):461-469. [doi: 10.1001/jamapediatrics.2017.0042] [Medline: 28319239]

Abbreviations

DKT2: Diabetes Knowledge Test 2
DSMES: Diabetes Self-Management Education and Support
IRB: Institutional Review Board
NODE: New-Onset Diabetes Educator
SUS: System Usability Survey

Edited by G Eysenbach; submitted 17.10.17; peer-reviewed by I de la Torre, M Hilliard; comments to author 25.01.18; revised version received 09.03.18; accepted 27.03.18; published 06.06.18.

Please cite as:
Bernier A, Fedele D, Guo Y, Chavez S, Smith MD, Warnick J, Lieberman L, Modave F
New-Onset Diabetes Educator to Educate Children and Their Caregivers About Diabetes at the Time of Diagnosis: Usability Study
JMIR Diabetes 2018;3(2):e10
URL: http://diabetes.jmir.org/2018/2/e10/
doi:10.2196/diabetes.9202
PMID:30291069

Original Paper

Experiences of Using Web-Based and Mobile Technologies to Support Self-Management of Type 2 Diabetes: Qualitative Study

Laura Kelly[1], MSc, DPhil; Crispin Jenkinson[1], DPhil; David Morley[1], PhD

[1] Health Services Research Unit, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom

Corresponding Author:
Laura Kelly, MSc, DPhil
Health Services Research Unit
Nuffield Department of Population Health
University of Oxford
Richard Doll Building, Old Road Campus
Headington
Oxford, OX3 7LF
United Kingdom
Phone: 44 1865 289425
Email: laura.kelly@dph.ox.ac.uk

Abstract

Background: The prevalence of type 2 diabetes is rising, placing increasing strain on health care services. Web-based and mobile technologies can be an important source of information and support for people with type 2 diabetes and may prove beneficial with respect to reducing complications due to mismanagement. To date, little research has been performed to gain an insight into people's perspectives of using such technologies in their daily management.

Objective: The purpose of this study was to understand the impact of using Web-based and mobile technologies to support the management of type 2 diabetes.

Methods: In-depth interviews were conducted with 15 people with type 2 diabetes to explore experiences of using Web-based and mobile technologies to manage their diabetes. Transcripts were analyzed using the framework method.

Results: Technology supported the users to maintain individualized and tailored goals when managing their health. A total of 7 themes were identified as important to participants when using technology to support self-management: (1) information, (2) understanding individual health and personal data, (3) reaching and sustaining goals, (4) minimizing disruption to daily life, (5) reassurance, (6) communicating with health care professionals, and (7) coordinated care.

Conclusions: Patients need to be supported to manage their condition to improve well-being and prevent diabetes-related complications from arising. Technologies enabled the users to get an in-depth sense of how their body reacted to both lifestyle and medication factors—something that was much more difficult with the use of traditional standardized information alone. It is intended that the results of this study will inform a new questionnaire designed to assess self-management in people using Web-based and mobile technology to manage their health.

(JMIR Diabetes 2018;3(2):e9) doi:10.2196/diabetes.9743

KEYWORDS

mobile health; qualitative research; self-care; type 2 diabetes

Introduction

The number of people diagnosed with diabetes in the United Kingdom rose from 1.4 million in 1996 to nearly 3.6 million in 2016 [1-5]. By 2025, diabetes prevalence is expected to rise further to an estimated 5 million [1]. The vast majority of those diagnosed with diabetes are categorized as having type 2 diabetes (diabetes mellitus), which is estimated to cost the UK National Health Service (NHS) approximately £8.8 billion per year in direct costs and a further £13.0 billion per year in indirect costs [6]. These costs are largely spent on treating complications, such as hypoglycemia, nerve damage, heart disease, foot ulcers, and amputations, many of which can arise through the mismanagement of the condition [6]. Health services are increasingly advocating the importance of self-management to delay complications and recommend education provision and ongoing support for people with type 2 diabetes [7-9]. However, developing the knowledge and skills needed to consistently manage and perform multiple self-care tasks can be difficult to achieve, with successful management more likely in the presence of continued support [10,11]. With greater demand placed upon diabetes health services, it is increasingly difficult to support patients in the complex task of managing their diabetes. It is, however, conceivable that use of Web-based and mobile (apps and wearables) technologies could reduce strain on health care professionals and services by supporting patients in their daily decisions regarding factors, such as diet, exercise, and medication.

Many Web-based and mobile technologies have already been developed to help users manage diabetes [12-14]. The majority of these platforms offer stand-alone functions, addressing one aspect of self-management, with their use depending entirely on the individual's desire to manage their health. For example, few mobile apps have any input from health care professionals and do not incorporate a range of basic diabetes self-care functions, such as blood glucose tracking, insulin therapy, nutrition, and physical activity [14,15]. In time, however, it is thought that technology may become more integrated with services through the transmission of data and subsequent feedback [12]. There is some evidence of this integration already in place in the United Kingdom with several systems currently being phased into existing health care pathways' collaborative care services [16,17]. Although the effectiveness and evaluation of implementing these technologies are still underway [16], people with diabetes have indicated that the use of technology may help them to set and achieve health goals, help to track progress, access helpful information, and facilitate communication with health care professionals or peers [18]. Technology-based interventions have also been effective in reinforcing diabetes self-care behavior, although some behaviors may still be best reinforced in person [19]. Improvements, for example, have been shown in relation to being active, healthy eating, problem solving, and blood glucose control [20-24]. In contrast, the effects of technology-based interventions on behaviors related to taking medicine and coping are less clear and are not always as effective when compared with "in-person" delivery [11,19]. Research has also indicated that some mobile apps on the market carry risks to the patient, for example, incorrect insulin dosage calculations following data input error [25].

To broaden our understanding of how Web-based and mobile technologies can support self-management, further research is needed. Key biomedical outcomes, such as HbA_{1c} (glycated hemoglobin) levels, of using technologies designed to support self-management are important; however, assessing these outcomes alone neglects the complexity of how technology can assist a person to develop skills to live well with type 2 diabetes. An in-depth view on people's perspectives of using such technologies is needed to get an insight into how they can influence daily management while taking into account broader social and contextual factors. Of the relatively small proportion of diabetes-related qualitative studies in the past 30 years, only one-quarter looked at the aspects of self-management, with an even smaller number looking specifically at the experiences of using devices to aid self-management [26]. The aim of this qualitative study was to gain an insight into the experiences and views of those using Web-based or mobile technologies to support the management of type 2 diabetes.

Methods

Design and Ethics

Qualitative in-depth interviews were used to explore experiences of using Web-based and mobile technologies to support the self-management of type 2 diabetes. Ethical approval for this research was granted by the Medical Sciences Inter Divisional Research Ethics Committee of the University of Oxford (reference MS-IDREC-C1-2015-109).

Study Participants and Recruitment

Participants were aged ≥18 years with a (self-reported) clinical diagnosis of type 2 diabetes and experience of using one or more technology-based resource to support self-management. Participants were recruited through Web-based advertisements on Diabetes UK and other diabetes-related online forums. Advertisements included an electronic link that provided further information about the study and a portal to collect contact details, demographic information, and health-related technology use. The aim of this recruitment strategy was to gain a rich and comprehensive insight into experiences of using technology to support self-management among people with a range of characteristics within the study timeframe. Responders were contacted to explain the study further and arrange an in-depth interview.

As the research aim was focused, the recruitment strategy specifically targeted rich sources of data (ie, experienced users of Web-based or mobile technologies), and interviews were conducted by an experienced interviewer, it was thought that the sample size was likely to be small [27]. A specific sample size was not predetermined, however, and sampling remained continuous throughout the study until it was believed that data saturation had been achieved (ie, where no new themes are appearing) [28].

Data Collection

In-depth interviews were conducted either face-to-face or over the telephone over a 12-week period. A topic guide was informed through relevant literature relating to self-management in people with type 2 diabetes and their use of technology-based systems. Topics in the interview guide broadly included the following: knowledge and understanding, controlling and managing symptoms using technology, self-monitoring, tailored goals, dealing with complications, use of services, and feeling supported. Prompts were used to gain a deeper understanding of participant responses on important topics. Participants were also encouraged to discuss any other topics they deemed appropriate. Interviews lasted, on average, 48 min and were recorded and transcribed. Transcription of the interviews was outsourced and accuracy checked on their return by LK. Informed consent was obtained before commencing interviews, and participants were given a £20 voucher for taking part.

Data Analysis

Interview transcripts were analyzed using the framework method, allowing the authors to look at the data and conduct analysis in a systematic and comprehensive manner [29]. The framework method supports thematic qualitative analysis and consists of 5 stages: (1) familiarization with the interview data; (2) identification of a thematic framework to allow emerging issues, concepts, and themes to be listed; (3) indexing transcripts according to the thematic framework; (4) charting data through a process of extracting and synthesizing it to allow within-case and between-case comparison; and (5) mapping and interpretation of data [29,30]. All authors became familiarized with the transcripts and devised a suitable coding guide. Using a deductive approach, codes were preselected based on previous literature; however, analysis did allow for open coding where unexpected codes arose [31]. After the first few transcripts were independently coded by 2 authors to check for consistency, indexing of transcripts was performed using QSR International's NVIVO software [32]. Charting of summarized data was performed in EXCEL with illustrative quotes from participants added in comment boxes. On its completion, the charting document was circulated among the team for discussion of commonalities and differences between the data and themes finalized [31].

Results

Characteristics

A total of 10 women and 5 men took part in the semistructured interviews. The average age was 55.4 years (SD 10.68, range 41 years). A number of additional long-term conditions were reported including sciatica, psoriasis, osteoarthritis, asthma, cancers (breast, kidney, prostate), addictions (alcohol, prescribed pain killers), chronic obstructive pulmonary disease, high blood pressure, high cholesterol, removal of pancreas, ovarian cyst, Asperger syndrome, kidney disease, and stroke. At the time of being interviewed, the time since diagnosis of type 2 diabetes ranged from 3 months to 24 years. Of the 15 participants, a total of 8 participants (53%) reported being in either full- or part-time employment. Moreover, 12 participants (80%) described themselves as white British, whereas 3 participants (20%) described themselves as white "other."

Participants reported use of technology for the following purposes: recording and monitoring blood glucose (15/15, 100%), sourcing or logging nutritional information (11/15, 73%), accessing peer communication and support (8/15, 53%), sourcing or logging sport and exercise information (11/15, 73%), sourcing general information about diabetes (14/15, 93%), accessing their GP website (8/15, 53%), accessing personalized Web-based platforms (7/15, 47%), coping or reducing stress (2/15, 13%), and preparation for a consultation (4/15, 27%).

Themes

Information

Participants felt empowered to make informed decisions with the help of instant and in-depth information found on diabetes-related websites and forums. Participants reported initiating their own online research. However, some also reported being guided by health care professionals when looking for specific information. One woman described how informed, positive changes to her diet helped her to lose weight, reduce her medication, and feel better about herself:

> *Well when I had my last HbA_{1c} [reading], the last two have been high, far higher than I want them to be… So I decided myself to do something about it. I read a lot, with a little bit of support from the doctor on what to get...about low carbohydrate diet and that's where I have been using internet stuff. It's a 10-week low carbohydrate diet... I found it through the Diabetes UK website... I have been following it and doing that, using their forum, which has all sorts of people talking on it. If you have a question you can ask and the people give advice... what I have found, because I have kept the carbohydrates low since the middle of January–we've dropped two of my pills...I have actually felt sparkier, brighter and the added benefit of all of that is that I have lost 8-9 lbs.* [Participant 8, female, 64 years]

Online information also made participants aware of the potential risks and side effects of decisions they made when managing their health, particularly in relation to medication. One woman, who had experienced significant hair loss and depression after being prescribed medication in the past, used the Internet to research subsequent medications prescribed:

> *...when it [medication] was prescribed to me I went onto the net to find out more about it. It doesn't always say everything in the leaflet that you have and I am aware that with [medication] it was tested on lab rats and lab mice. And it can cause thyroid cancer, I am aware of that. What I do find, not distressing, annoying really—what I find astonishing is that when it was prescribed at no time was I ever told that. I know that because I went and I did my research to find that out because I wanted to know what it was that I was taking. I know that for every action there is a reaction, so to me I looked at it that this action meant there was a reaction somewhere... I would have [preferred to know the risks], because then it's my choice.* [Participant 5, female, 52 years]

Understanding Individual Health and Personal Data

Participants sought to understand the impact of diet and, in some cases, exercise on their blood glucose levels. All participants took regular blood glucose readings. In most cases, readings were tracked and monitored throughout the day, with 2 participants wearing a continuous blood glucose (CBG) monitor that offered readings (and alerts) in real-time. Regular monitoring enabled participants to learn about daily patterns in their blood glucose levels and gave a greater understanding of its relationship with diet and exercise. Having a greater understanding of how their body behaved contributed to an overall sense control when managing diabetes:

> *I don't measure my bloods all day every day, but I do it as a testing thing to basically learn from it. I've found from it I know which foods I can eat and which*

> *has less effect and I've discovered that exercise after a meal makes a really big difference for bringing down the blood sugar...to be honest I think...that's possibly been one of the most useful tools that I've had.* [Participant 2, female, 55 years]

Technology was particularly useful when making sense of large amounts of data, especially if an app tracked more than one aspect of health (eg, blood glucose readings plus physical activity plus diet). One man describes how graphs helped present large amounts of longitudinal data to give an overall picture of health:

> *The app on my phone has a graph and how many steps is your target for walking in a day, how much water intake and what you are eating so you can record that. So it's easy to trace that way. If you see the paper you can see the spike... It records manually your blood sugar levels and it has a little graph on the screen...then you can see over a couple of weeks how you are doing.* [Participant 4, male, 60 years]

Reaching and Sustaining Goals

Having an in-depth understanding of the relationship between factors such as diet, exercise, and medication on blood glucose levels helped participants to refine their goals when managing diabetes. Looking for patterns in personal data helped participants to consider adjustments to their lifestyle that they could maintain:

> *[Since using the Libre sensor]... I've actually managed to get my average [blood glucose level] down from 7.8 to 6.8 [mmol/L]... Because I can see more patterns of what's going on, I'm knocking it down...It gives me a little bit more control into my diet... I can see sometimes I have something to eat and it will peak quite high and I think what the hell have I eaten that's peaked so high... And I sort of think what can I do to change that?...in the mornings I was having fruit on top of my cereal... You know it was only about a tablespoon of fruit, and then it was really peaking quite a lot. I thought rather than do that, I will have the fruit later on in the day when I am dropping down a bit, which has worked for me.* [Participant 21, female, 54 years]

Technology not only enabled participants to investigate deviations in blood glucose levels from their targeted range, it could also act as a warning system to alert participants to make them more aware of when they needed to be careful about specific aspects their management for the remainder of the day:

> *The thing that I really like about [app] is that I can log everything that I eat—it gives me a daily diary. It works out my calorie level, it works out my sugar levels and I can log everything I have. So I can keep a track on my fats, I can keep track of my carbohydrates and, more importantly, I can keep track of my sugar, so I know, if it tells me the sugar—right you've got to behave this evening, or I can't have this, this evening. And I truly wouldn't be without it, it's a real informative app, you know.* [Participant 5, female, 52 years]

A total of 7 participants (7/15, 47%) discussed how apps had helped to remind and motivate them to engage in healthy self-care behaviors. Real-time logging and in-app alert systems, such as the CBG sensors and activity trackers, were particularly useful for warning participants to take action according to their predefined goals before it was too late:

> *[Apple watch] reminds me when I am not doing everything I should do... It's got my activity targets in it... if I haven't walked enough I know from the tracker that I haven't done the required number of steps ... It's also set to remind me that I need to get up from my desk and walk around every so often. So if it reminds me somewhere where it's convenient for me to get up and do anything about it, I get up and do something about it.* [Participant 18, female, 58 years]

In addition to progress reports and practical reminders to reach targets, technology emotionally supported participants by allowing them to record feelings or feel encouraged to continue practicing good behaviors through feedback. Participants described how seeing progress and receiving positive signals motivated them to continue managing their health. A small number of participants had experience of using mobile apps that used gamification techniques to encourage motivation. Although one man felt this style of encouragement was not pitched to his level, one woman described how these techniques kept her engaged and motivated:

> *[The app] is quite user friendly, it's got this kind of image...you put your [blood glucose level] figure in to control your blood sugar monster...it's quite fun as well, so I think it's motivational... When you put your blood sugar in, the more that you do, the more you kind of use those stickers to get your blood sugar and this little kind of monster gets chained up, he is literally put in chains. So the motivation is to chain up the monster.* [Participant 14, female, 44 years]

Minimizing Disruption to Daily Life

Technology was used as a tool to maximize convenience when managing diabetes and to minimize the chances of disruption to everyday life. CBG sensors reduced the time taken to manually check blood glucose levels and conveniently gave alerts, warning the wearer when they were approaching specific thresholds. This resulted in minimum disruption to daily plans. For example, wearers could schedule appointments or get to and from work knowing their blood glucose levels would be within the "safe limits" for driving:

> *I like the alarm [on the CBG monitor], I often have it off at work, not because I am at work, just because my blood sugar is usually higher at work. And I can look at it if I want to see it. But then in the evening, which is, when I have more hypos, or I am out doing whatever I am doing, I have the alarms on then. It says things like you are low and then you have to wait 45 minutes before you can drive... So that never really*

> *happens with the alarms because if I have to drive from work, I set the alarm at 5 [mmol/L] and then I never get that low blood sugar, so I am going to have to wait to drive. You know it doesn't get in the way... Whereas before, often I would go low in the evening, because I often do walking the dog and then if I had one [hypo] in the evening I had to wait an hour and I would be an hour late.* [Participant 15, female, 29 years]

Apps were used as a management aid when participants were not in their usual routine. Participants discussed using a range of apps that helped them research the nutritional content of food on a menu when dining out. This resource reduced the anxiety associated with not knowing what to eat in a restaurant. Other useful feature of apps when eating out was the opportunity to log food on the go so that diet could be accurately recorded with minimal effort:

> *So I went out to lunch with a friend yesterday lunchtime and I sat there with my phone, worked out how much carbs I had got in my meal and just sat there at the table and just tapped it in. I tapped in how much insulin I was taking, instead of thinking "Right I must remember to do that when I get home." And then by the time you get home, things happen and you have forgotten it. And that has been brilliant. Also because it is so easy to do, because it is there, you do it... My husband said it has helped with my discipline, it really has.* [Participant 12, female, 70 years]

Although technology was viewed as a largely helpful and convenient resource, some frustrations were reported regarding ease of use. Inconveniences included difficulties in entering data (eg, apps requiring the use of imperial units instead of metric units) or the requirement of purchasing new equipment to wirelessly input data to an app:

> *There is nothing wrong with the app itself, but it was designed to be used with an iHealth BP monitor. I have a glucose monitor and I thought I am not spending another couple of hundred quid, the monitors I have got are what my doctor wanted me to have and to use them...[to input readings], manually it was too much like hard work. I just wanted to open it up, put the figures in and shut it down. So that didn't get very far.* [Participant 13, male, 70 years]

Reassurance

Participants reported feeling reassured when they knew they were managing their diabetes well. In 6 cases, where blood glucose levels were consistently stable, participants described only taking blood glucose readings periodically, acting as a "checking" system, whereas another participant described checking her blood glucose levels periodically to reassure herself that symptoms she was experiencing were not related to her diabetes:

> *Sometimes the feeling of being anxious is the same as being hyper. So I wanted to be sure am I nervous or am I low.* [Participant 15, female, 29 years]

Information found online also offered reassurance to participants. Forums, in particular, were useful for instances where participants did not fit the text book patient and were looking for nonstandard advice from peers:

> *Health services are wonderful at the norm; they are not that good when you don't follow what the textbook says should be happening. And that's where the forums can come in, because actually it's quite reassuring there is an awful lot of non-standard people out there.* [Participant 18, female, 58 years]

Communicating with Health Care Professionals

Technology used in daily management routines, usually apps, aided participants when describing their general health trends and communicating with health care professionals during consultations. A total of 7 participants (7/15, 47%) cited times where their electronic recordings helped them during consultations by providing real-time "evidence" on daily patterns. Providing a detailed picture of their daily well-being conveyed whether their current management practices were working effectively for them and enabled them to have some control of how to proceed with their care. Moreover, 3 participants (3/15, 20%) reported a change in treatment due to the use of technology within their consultation. One man gives an account of how technology helps him to be a partner in his health care decisions:

> *When I am talking to the doctor I don't want to be sort of trying to remember what happened six weeks ago... We've both got a very good link here, a nice graph that she can look at as a doctor and say—"What happened there?"—"Yes, this one is working out quite well"... I can also share it with her; I can export it to her... I can just say whether I want one day, month, or year or I can do a custom layout and I can send it as a PDF, CSV or HTML... Sometimes my doctor says, "Any chance of sending a chart a few days before you come in?," so they can look at it and I say—"Yes fine, off you go"... my view is if you have got 10 minutes, let's make it really count. So I don't like going in and spending five minutes explaining what my readings have been.* [Participant 13, male, 70 years]

Although this approach generally helped to make efficient use of consultation time, one respondent noted the presentation of data could be misleading in consultations as her app used thresholds to color code blood glucose reading ranges. In a busy consultation, this could be misinterpreted:

> *...it's very visual and you can go through it and you can compare one week's total to another week...my GP will look at the app...It comes up in different colours, so they generally look at the colours literally, because green is within the bounds that are acceptable and the reds are either side, whether they are too low or too high. I've had my GP say to me,*

> *"Oh you're too low here" and I have pointed out it's 3.9 and I'm normally 4.2, so I am not worried about 3.9... The monitor [readings are] about 20% either way [of true reading] I think, it's not perfect.* [Participant 14, female, 44 years]

Coordinated Care

Electronic tools were rarely provided by or integrated with health care services. One participant, however, discussed using an electronic record that detailed medical history and upcoming appointments. This enabled him to coordinate aspects of his care. The effect was a more streamlined approach to managing his health, more certainty on what to expect when meeting health care professionals and sense of partnership in decisions:

> *I am a happy bunny. It's [electronic patient record] very good; it's got my medical history on here, linked to the NHS records direct...[It's] Brilliant because I find in the self-management side of things, my major problem isn't the doctor I face, it isn't the specialists at the hospital ...my main problem is stuff getting lost between them on the admin side... So if I am seeing a doctor tomorrow and she says "I want you to do bla bla bla," I will get an appointment for you within three weeks, I can check my records and make sure it has been done and if it hasn't been done, it helps me ring up and chase it... I am a strong believer in knowledge is power basically... I enjoy being an equal partner.* [Participant 13, male, 70 years]

Discussion

Principal Findings

Health care services are under increasing pressure to cope with the rising number of people diagnosed with type 2 diabetes. Patients need to be supported to manage their condition to improve well-being and prevent further diabetes-related complications arising. Web-based and mobile technologies may offer one solution to supporting those with type 2 diabetes with this management, but there is currently limited qualitative research into their effect on self-management [26]. This study explored the views and experiences of men and women using technology to support self-management.

This research demonstrates how technology supported users to maintain individualized and tailored plans when managing their health. It was clear that participants wanted to feel informed when managing their health, feel reassured that they were managing their health effectively, and, where possible, wanted self-care tasks to be minimally intrusive to their daily life. Technologies enabled users to get an in-depth sense of how their body reacted to both lifestyle and medication factors, something that was much more difficult with the use of traditional "standardized" information alone. Understanding how their body reacted to lifestyle and medication factors was welcomed among the sample and this understanding was enhanced through resources which helped to organize and make sense of vast amounts of longitudinal data (eg, through output in the form of graphs and charts). Wearable devices, such as the CBG monitors, were particularly helpful in that they offered real-time solutions and alerts. The use of available technologies appeared to motivate participants to achieve and sustain healthy goals when managing their diabetes. It is important to note, however, that participants responded to aspects of technology designed to motivate and incentivize engagement in different ways. The success of engagement features, which Nelson et al [33] refer to as functions for "engagement promotion," was dependent on the preferences of the user. For example, although one woman enjoyed gamification techniques (unlocking achievements), one man considered them as childish elements of an otherwise useful resource. Participants also voiced frustrations with the need to buy new, compatible devices (such as wireless devices with Bluetooth functionality) and difficulties in entering data (eg, the requirement of inserting imperial units).

Participants were very focused in their wants and needs from technology and indicated that they "shopped around" to find mobile apps or other tools, such as CBG sensors, that targeted their requirements. If a particular app, for example, did not provide the right information or was not easy to use, they proceeded to try alternatives reasonably quickly. Furthermore, although data were not collected on how long participants had been using specific technologies, some participants did reflect on periods of high and low technology usage. For those with varying usage intensity, periods of high intensity tended to reflect an "event" (eg, the introduction of a new diet) and low usage reflected periods when they felt their blood glucose levels were under control. Understanding more about the reasons behind swift dropout when using a new mobile app and reasons for varying intensity of usage are interesting as digital health interventions are frequently faced with challenges of high attrition rates [34,35]. Attrition and periods of low usage are problematic from a research perspective when trying to prove the effectiveness of a Web-based or mobile technology; however, this study indicates that this challenge is reflective of how people use technology in real life. That is, they often use multiple apps to cater for a complex condition when self-managing, they are selective when looking for self-management tools and swiftly discard those that do not complement their lifestyle, and the intensity of their use will vary over time.

This study builds on existing research by providing an in-depth overview on how people can use multiple Web-based and mobile technologies to support diabetes management in their daily lives. Many previous studies have evaluated how a specific intervention was used [36-38]; however, this study encouraged participants to share experiences of using a combination of resources, more comparable to practices in daily life. Although the use of multiple apps may, in part, be due to the limited functions provided by one mobile app alone [12,39], this research indicated users appreciate multiple functions to have a holistic view of the relationships between various lifestyle factors on their health. Supporting previous research [40], these interviews showed that health technologies can give people with diabetes a heightened awareness of lifestyle factors on their blood glucose levels and encourage problem-solving through making changes to their diet and/or activity levels after identifying reasons for highs and lows. As this study explored current and past experiences of technologies, it also provided examples of how participants sustained changes in behavior. Related research in the context of other long-term conditions [41] can also be drawn upon to support these findings, which demonstrate the importance of having the flexibility to tailor, personalize, and prioritize self-management approaches using health technologies.

Limitations

Some limitations of this study must be acknowledged. These are largely related to the transferability of the findings. Despite efforts to include a range of backgrounds within the sample, those from a nonwhite background were not represented and only 3 classified themselves in a non-British category. Older people, however, were represented in the sample, which was particularly welcomed given that they can have problems engaging with technology [33,42]. This sample also represented a self-selecting group of people with type 2 diabetes who were comfortable using technology. As such, these findings are limited in their transferability to people with type 2 diabetes who do not use technology and have low motivation to use technology in the management of their health. However, the authors purposely chose to recruit rich sources of data in the time available to them. Exploring possible reasons why people do not use technology in the management of their health was not in the scope of this study.

In contrast to the research reported by Ancker [43], participants in this sample were largely enthusiastic when tracking and monitoring their own health. This may have been due to self-selection; however, it may have also been related to participants being able to move on from apps that were inconvenient in favor of technology more suited to their preferences. Furthermore, although participants in this sample reported multiple long-term conditions, Ancker’s focus was on people with multiple conditions, which may have resulted in feelings of being overwhelmed. Although participants discussed negative aspects of using technology in functional terms, for example, frustration with data entry, there was limited information on possible negative health effects of using these technologies. This may, in part, be due to participants swiftly moving on from technologies that did not meet their requirements. Negative aspects of using technology to support self-management may be something that would benefit from further research in the future.

Conclusions

Patients need to be supported to manage their condition to improve well-being and to prevent diabetes-related health complications arising. Technologies enabled users to get an in-depth sense of how their body reacted to both lifestyle and medication factors, something that was much more difficult with the use of traditional “standardized” information alone. Health care professionals who are responsible for educating and supporting those with type 2 diabetes may find Web-based and mobile technologies to be invaluable tools for engaging with their patients and tailoring information during a consultation.

These findings demonstrate how those engaged in technology use multiple apps to optimize self-management. Developers in Web-based and mobile technologies should aim to help the user manage a range of self-care tasks from one app to offer a more holistic experience. This study also highlights the difficulties for developing and assessing digital behavioral interventions due to users’ adoption of multiple technologies and swift dropout. Researchers and Web developers should place more emphasis on rates of retention in the use of technology-based interventions as opposed to rates of initial adoption of the intervention.

Acknowledgments

The authors would like to thank Diabetes UK and Diabetes Support Forum UK who helped with recruitment by circulating the study recruitment link. The authors would also like to thank the participants who volunteered their time to take part in the study. This study was funded internally within the Health Service Research Unit, Nuffield Department of Population Health, University of Oxford. LK receives funding from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care Oxford at Oxford Health NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

Authors' Contributions

LK contributed to the study design, performed the interviews, and played a lead role in the analysis. CJ and DM contributed to the study design and analysis. All authors contributed to and approved the final manuscript.

Conflicts of Interest

None declared.

References

1. Diabetes UK. Diabetes in the UK 2012: Key statistics on diabetes URL: https://www.diabetes.org.uk/Professionals/Position-statements-reports/Statistics/Diabetes-in-the-UK-2012 [accessed 2017-12-14] [WebCite Cache ID 6vhnzlo3p]
2. HS Digital Health and Social Care Information Centre. Table 15: Recorded disease prevalence, achievements and exceptions, high dependency and other long term conditions group, diabetes mellitus, 2016-17, region level URL: http://digital.nhs.uk/catalogue/PUB30124 [accessed 2017-12-14] [WebCite Cache ID 6vhhVhQzA]

3. Scotland Information Services Division. Isdscotland. Scotland 2015/16 QOF Prevalence Data, NHS Board and Scotland level data, Prevalence reported from QOF registers (practices with any contract type) URL: http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/2015-16/Register-and-prevalence-data.asp [accessed 2017-12-14] [WebCite Cache ID 6vhhBp3fK]
4. Northern Ireland Department of Health. 2016/17 raw disease prevalence trend data for Northern Ireland, Table Prevalence Registers URL: https://www.health-ni.gov.uk/publications/201617-raw-disease-prevalence-trend-data-northern-ireland [accessed 2017-12-14] [WebCite Cache ID 6vhgaliHQ]
5. Welsh Government Statistics and Research. Welsh Government. Information from the General Medical Services Quality and Outcomes Framework Statistics for Wales, 2015-16 URL: http://gov.wales/statistics-and-research/general-medical-services-contract/?tab=previous&lang=en [WebCite Cache ID 6vhfnG1z7]
6. Hex N, Bartlett C, Wright D, Taylor M, Varley D. Estimating the current and future costs of type 1 and type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. Diabet Med 2012 Jul;29(7):855-862. [doi: 10.1111/j.1464-5491.2012.03698.x] [Medline: 22537247]
7. Haas L, Maryniuk M, Beck J, Cox CE, Duker P, Edwards L, 2012 Standards Revision Task Force. National standards for diabetes self-management education and support. Diabetes Care 2012 Nov;35(11):2393-2401 [FREE Full text] [doi: 10.2337/dc12-1707] [Medline: 22995096]
8. Powers MA, Bardsley J, Cypress M, Duker P, Funnell MM, Fischl AH, et al. Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. Diabetes Educ 2015 Aug;41(4):417-430. [doi: 10.1177/0145721715588904] [Medline: 26047627]
9. National Institute for Health and Care Excellence. NICE. 2015. NICE guideline: Type 2 diabetes in adults: management (NG28) URL: https://www.nice.org.uk/guidance/ng28 [accessed 2018-03-06] [WebCite Cache ID 6xiP3TgFy]
10. Heinrich E, Schaper NC, de Vries NK. Self-management interventions for type 2 diabetes: a systematic review. Eur Diabetes Nurs 2010;7(2):71-76. [doi: 10.1002/edn.160]
11. Pillay J, Armstrong MJ, Butalia S, Donovan LE, Sigal RJ, Vandermeer B, et al. Behavioral programs for type 2 diabetes mellitus: a systematic review and network meta-analysis. Ann Intern Med 2015 Dec 1;163(11):848-860. [doi: 10.7326/M15-1400] [Medline: 26414227]
12. Arnhold M, Quade M, Kirch W. Mobile applications for diabetics: a systematic review and expert-based usability evaluation considering the special requirements of diabetes patients age 50 years or older. J Med Internet Res 2014;16(4):e104 [FREE Full text] [doi: 10.2196/jmir.2968] [Medline: 24718852]
13. Martínez-Pérez B, de la Torre-Díez I, López-Coronado M. Mobile health applications for the most prevalent conditions by the World Health Organization: review and analysis. J Med Internet Res 2013;15(6):e120 [FREE Full text] [doi: 10.2196/jmir.2600] [Medline: 23770578]
14. Brzan PP, Rotman E, Pajnkihar M, Klanjsek P. Mobile applications for control and self management of diabetes: a systematic review. J Med Syst 2016 Sep;40(9):210. [doi: 10.1007/s10916-016-0564-8] [Medline: 27520615]
15. Dennison L, Morrison L, Conway G, Yardley L. Opportunities and challenges for smartphone applications in supporting health behavior change: qualitative study. J Med Internet Res 2013;15(4):e86 [FREE Full text] [doi: 10.2196/jmir.2583] [Medline: 23598614]
16. Ross J, Stevenson F, Dack C, Pal K, May C, Michie S, et al. Evaluating the implementation of HeLP-Diabetes within NHS services: study protocol. BMC Health Serv Res 2014 Feb 04;14:51 [FREE Full text] [doi: 10.1186/1472-6963-14-51] [Medline: 24495515]
17. Mapmyhealth. 2016. Making Patient Self-Management a Reality URL: http://www.mapmyhealth.co.uk/ [accessed 2018-03-06] [WebCite Cache ID 6xiWBVfdm]
18. King DK, Toobert DJ, Portz JD, Strycker LA, Doty A, Martin C, et al. What patients want: relevant health information technology for diabetes self-management. Health Technol 2012 Mar 5;2(3):147-157. [doi: 10.1007/s12553-012-0022-7]
19. Chen L, Chuang LM, Chang CH, Wang CS, Wang IC, Chung Y, et al. Evaluating self-management behaviors of diabetic patients in a telehealthcare program: longitudinal study over 18 months. J Med Internet Res 2013;15(12):e266 [FREE Full text] [doi: 10.2196/jmir.2699] [Medline: 24323283]
20. Pal K, Eastwood SV, Michie S, Farmer AJ, Barnard ML, Peacock R, et al. Computer-based diabetes self-management interventions for adults with type 2 diabetes mellitus. Cochrane Database Syst Rev 2013;3:CD008776. [doi: 10.1002/14651858.CD008776.pub2] [Medline: 23543567]
21. Schmitt A, Gahr A, Hermanns N, Kulzer B, Huber J, Haak T. The Diabetes Self-Management Questionnaire (DSMQ): development and evaluation of an instrument to assess diabetes self-care activities associated with glycaemic control. Health Qual Life Outcomes 2013;11:138 [FREE Full text] [doi: 10.1186/1477-7525-11-138] [Medline: 23937988]
22. Murray E, Sweeting M, Dack C, Pal K, Modrow K, Hudda M, et al. Web-based self-management support for people with type 2 diabetes (HeLP-Diabetes): randomised controlled trial in English primary care. Br Med J Open 2017 Sep 27;7(9):e016009 [FREE Full text] [doi: 10.1136/bmjopen-2017-016009] [Medline: 28954789]

23. Whitehead LC, Crowe MT, Carter JD, Maskill VR, Carlyle D, Bugge C, et al. A nurse-led interdisciplinary approach to promote self-management of type 2 diabetes: a process evaluation of post-intervention experiences. J Eval Clin Pract 2017 Apr;23(2):264-271. [doi: 10.1111/jep.12594] [Medline: 27417302]
24. Hunt CW. Technology and diabetes self-management: an integrative review. World J Diabetes 2015 Mar 15;6(2):225-233 [FREE Full text] [doi: 10.4239/wjd.v6.i2.225] [Medline: 25789104]
25. Huckvale K, Adomaviciute S, Prieto JT, Leow MK, Car J. Smartphone apps for calculating insulin dose: a systematic assessment. BMC Med 2015;13:106 [FREE Full text] [doi: 10.1186/s12916-015-0314-7] [Medline: 25943590]
26. Hennink MM, Kaiser BN, Sekar S, Griswold EP, Ali MK. How are qualitative methods used in diabetes research? A 30-year systematic review. Glob Public Health 2017 Feb;12(2):200-219. [doi: 10.1080/17441692.2015.1120337] [Medline: 26758478]
27. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res 2015 Nov 27. [doi: 10.1177/1049732315617444] [Medline: 26613970]
28. Ziebland S, Wright L. Qualitative research methods. In: Jenkinson C, editor. Assessment and Evaluation of Health Care and Medical Care. Maidenhead: Open University Press; 1997.
29. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. Analysing Qualitative Data. London: Routledge; 1994.
30. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. Br Med J 2000 Jan 8;320(7227):114-116 [FREE Full text] [Medline: 10625273]
31. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013 Sep 18;13:117 [FREE Full text] [doi: 10.1186/1471-2288-13-117] [Medline: 24047204]
32. QSR International. NVivo qualitative data analysis software. Version 9 ed.: QSR International Pty Ltd; 2010. URL: https://www.qsrinternational.com/nvivo/home [accessed 2018-05-06] [WebCite Cache ID 6zDIIhOXI]
33. Nelson LA, Coston TD, Cherrington AL, Osborn CY. Patterns of user engagement with mobile- and web-delivered self-care interventions for adults with T2DM: a review of the literature. Curr Diab Rep 2016 Dec;16(7):66 [FREE Full text] [doi: 10.1007/s11892-016-0755-1] [Medline: 27255269]
34. Garabedian LF, Ross-Degnan D, Wharam JF. Mobile phone and smartphone technologies for diabetes care and self-management. Curr Diab Rep 2015 Dec;15(12):109. [doi: 10.1007/s11892-015-0680-8] [Medline: 26458380]
35. Powell J, Hamborg T, Stallard N, Burls A, McSorley J, Bennett K, et al. Effectiveness of a web-based cognitive-behavioral tool to improve mental well-being in the general population: randomized controlled trial. J Med Internet Res 2013;15(1):e2 [FREE Full text] [doi: 10.2196/jmir.2240] [Medline: 23302475]
36. Yu CH, Parsons JA, Mamdani M, Lebovic G, Hall S, Newton D, et al. A web-based intervention to support self-management of patients with type 2 diabetes mellitus: effect on self-efficacy, self-care and diabetes distress. BMC Med Inform Decis Mak 2014 Dec 14;14:117 [FREE Full text] [doi: 10.1186/s12911-014-0117-3] [Medline: 25495847]
37. Urowitz S, Wiljer D, Dupak K, Kuehner Z, Leonard K, Lovrics E, et al. Improving diabetes management with a patient portal: a qualitative study of diabetes self-management portal. J Med Internet Res 2012;14(6):e158 [FREE Full text] [doi: 10.2196/jmir.2265] [Medline: 23195925]
38. Hofmann M, Dack C, Barker C, Murray E. The impact of an Internet-based self-management intervention (HeLP-Diabetes) on the psychological well-being of adults with type 2 diabetes: a mxed-method cohort study. J Diabetes Res 2016;2016:1476384 [FREE Full text] [doi: 10.1155/2016/1476384] [Medline: 26682226]
39. Hoppe CD, Cade JE, Carter M. An evaluation of diabetes targeted apps for Android smartphone in relation to behaviour change techniques. J Hum Nutr Diet 2017 Jun;30(3):326-338. [doi: 10.1111/jhn.12424] [Medline: 27747955]
40. Fritschi C, Quinn L, Penckofer S, Surdyk PM. Continuous glucose monitoring: the experience of women with type 2 diabetes. Diabetes Educ 2010;36(2):250-257 [FREE Full text] [doi: 10.1177/0145721709355835] [Medline: 20016057]
41. Glynn L, Casey M, Walsh J, Hayes PS, Harte RP, Heaney D. Patients' views and experiences of technology based self-management tools for the treatment of hypertension in the community: a qualitative study. BMC Fam Pract 2015 Sep 09;16:119 [FREE Full text] [doi: 10.1186/s12875-015-0333-7] [Medline: 26354752]
42. Tieu L, Sarkar U, Schillinger D, Ralston JD, Ratanawongsa N, Pasick R, et al. Barriers and facilitators to online portal use among patients and caregivers in a safety net health care system: a qualitative study. J Med Internet Res 2015;17(12):e275 [FREE Full text] [doi: 10.2196/jmir.4847] [Medline: 26681155]
43. Ancker JS, Witteman HO, Hafeez B, Provencher T, Van de Graaf M, Wei E. “You Get Reminded You're a Sick Person”: personal data tracking and patients with multiple chronic conditions. J Med Internet Res 2015;17(8):e202 [FREE Full text] [doi: 10.2196/jmir.4209] [Medline: 26290186]

Abbreviations

CBG: continuous blood glucose
HbA$_{1c}$: glycated hemoglobin
NHS: National Health Service

Edited by G Eysenbach; submitted 29.12.17; peer-reviewed by J Ross, S Lie, U Öberg; comments to author 01.02.18; revised version received 06.03.18; accepted 07.03.18; published 11.05.18.

Please cite as:
Kelly L, Jenkinson C, Morley D
Experiences of Using Web-Based and Mobile Technologies to Support Self-Management of Type 2 Diabetes: Qualitative Study
JMIR Diabetes 2018;3(2):e9
URL: http://diabetes.jmir.org/2018/2/e9/
doi:10.2196/diabetes.9743
PMID:30291098

Review

Models Used in Clinical Decision Support Systems Supporting Healthcare Professionals Treating Chronic Wounds: Systematic Literature Review

Clara Schaarup[1], BSc, MSc; Louise Bilenberg Pape-Haugaard[1], MSc, PhD; Ole Kristian Hejlesen[1], MSc, PhD

[1] Department of Health Science and Technology, Aalborg University, Aalborg East, Denmark

Corresponding Author:
Clara Schaarup, BSc, MSc
Department of Health Science and Technology, Aalborg University
Fredrik bajers vej 7C
Aalborg East, 9220
Denmark
Phone: 45 99409940
Fax: 45 98154008
Email: csch@hst.aau.dk

Abstract

Background: Chronic wounds such as diabetic foot ulcers, venous leg ulcers, and pressure ulcers are a massive burden to health care facilities. Many randomized controlled trials on different wound care elements have been conducted and published in the Cochrane Library, all of which have only a low evidential basis. Thus, health care professionals are forced to rely on their own experience when making decisions regarding wound care. To progress from experience-based practice to evidence-based wound care practice, clinical decision support systems (CDSS) that help health care providers with decision-making in a clinical workflow have been developed. These systems have proven useful in many areas of the health care sector, partly because they have increased the quality of care, and partially because they have generated a solid basis for evidence-based practice. However, no systematic reviews focus on CDSS within the field of wound care to chronic wounds.

Objective: The aims of this systematic literature review are (1) to identify models used in CDSS that support health care professionals treating chronic wounds, and (2) to classify each clinical decision support model according to selected variables and to create an overview.

Methods: A systematic review was conducted using 6 databases. This systematic literature review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement for systematic reviews. The search strategy consisted of three facets, respectively: Facet 1 (Algorithm), Facet 2 (Wound care) and Facet 3 (Clinical decision support system). Studies based on acute wounds or trauma were excluded. Similarly, studies that presented guidelines, protocols and instructions were excluded, since they do not require progression along an active chain of reasoning from the clinicians, just their focus. Finally, studies were excluded if they had not undergone a peer review process. The following aspects were extracted from each article: authors, year, country, the sample size of data and variables describing the type of clinical decision support models. The decision support models were classified in 2 ways: quantitative decision support models, and qualitative decision support models.

Results: The final number of studies included in the systematic literature review was 10. These clinical decision support models included 4/10 (40%) quantitative decision support models and 6/10 (60%) qualitative decision support models. The earliest article was published in 2007, and the most recent was from 2015.

Conclusions: The clinical decision support models were targeted at a variety of different types of chronic wounds. The degree of accessibility of the inference engines varied. Quantitative models served as the engine and were invisible to the health care professionals, while qualitative models required interaction with the user.

(JMIR Diabetes 2018;3(2):e11) doi:10.2196/diabetes.8316

KEYWORDS

clinical decision support systems; statistical model; neural networks; logistic models; linear models; foot ulcer; diabetes; health personnel; systematic review; chronic wounds

Introduction

Background

Chronic wounds such as diabetic foot ulcers, venous leg ulcers, and pressure ulcers are a massive burden on the health care facility [1-4]. The costs of treating chronic wounds are considerable, among other things because of the length and complexity of ulceration [2,5,6]. In Denmark, wound care of chronic wounds is organized by specialized hospital units, general practitioners, nursing clinics in municipalities and community nurses visiting people with chronic wounds in their homes [7].

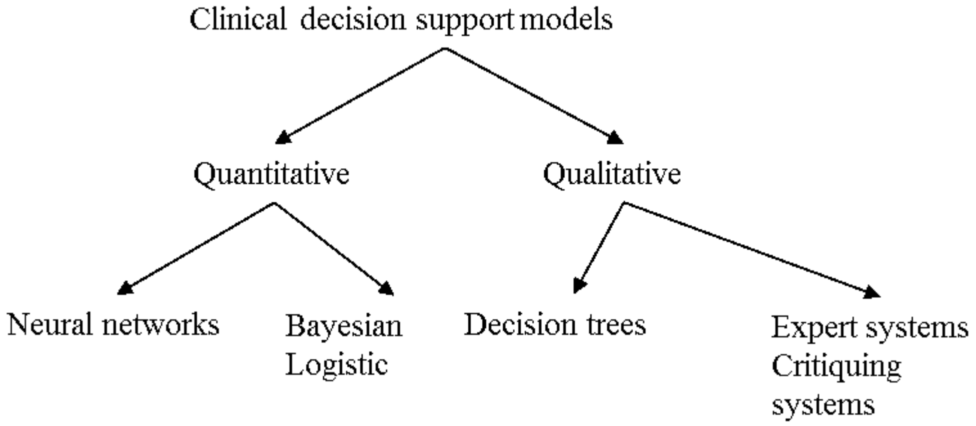
Conventional care of chronic wounds includes [1,2,4,8-11]: debridement, off-loading, antibiotic treatment in case of infection and add-on therapies such as negative-pressure wound therapy. Many randomized controlled trials on these elements have been conducted and published in the Cochrane Library [12-20]. The conclusion of almost all of the randomized controlled trials is that health care professionals are forced to rely on their own experience when making decisions regarding the treatments. A recent study [21] from 2017 has likewise examined community nurses’ professional basis for treating diabetic foot ulcers and found that they have to rely on experience and to ask colleagues for advice when undertaking wound care.

In an attempt to increase the evidential basis and help nurses proceed from experience-based practice to evidence-based practice, several alternatives have been considered. One of these involves the development and application of health information technology systems [22,23]. An example of a health information technology system is clinical decision support systems (CDSS), which are characterized by their ability to analyze data to enhance health care providers’ ability to make decisions in a clinical workflow [24,25]. According to van Bemmel and Musen [26] the models used in CDSS are either quantitative decision support models or qualitative decision support models, depending on the techniques that are applied in the clinical decision support model. The techniques applied in quantitative decision support models are typically based on well-defined statistical processes and make use of training sets of patient data. Thus, it becomes objective and reproducible [26]. The techniques applied in qualitative decision support models frequently use features that have been proposed by experts and are based on clinical studies [26,27].

As it can be seen in Figure 1, examples of the different approaches from left to right range from data-intensive approaches to knowledge-intensive approaches. According to Shortliffe et al [27] it is possible to distinguish between four types of knowledge: (1) knowledge derived from data analysis, (2) judgemental or subjective knowledge, (3) scientific or theoretical knowledge, and (4) high-level strategic knowledge or “self-knowledge”. These authors elaborate on their understanding of “judgmental” knowledge as follows: “*experience and opinions of experts regarding an issue about which the formal data may be fragmentary or non-existent* ” [27]. In this systematic literature review, expert systems will be considered in the light of Shortliffe et al [27] and their understanding of judgemental knowledge.

Over the decades, CDSS have proven to be useful in many areas within the health care sector [23-25,28-33], partly because CDSS have increased the quality of care provided, and partly because they generate a solid basis for evidence-based practice. In the Bright et al [23] systematic review from 2012, the goal was to evaluate the effect of CDSS on clinical outcomes, health care processes, workload and efficiency, patient satisfaction, cost and provider’s use and implementation. In total, Bright et al [23] systematically reviewed 148 randomized, controlled trials. They concluded that CDSS could improve health care process measures; however, the evidence regarding all the other areas they investigated was sparse. In the Blum et al [30] systematic review from 2014, the literature was systematically reviewed for content and application of computer-based CDSS, and their effects on patient-reported outcome were considered. Fifteen studies were included in this review. Blum et al [30] reported no negative effects related to patient-reported outcomes. At the same time, they described marginally positive effects of CDSS on specific patient-reported outcomes [30]. Both systematic reviews had a particular focus on clinical outcomes. None of the systematic reviews focused on CDSS within the field of diabetic foot ulcer care. In fact, it was not possible to identify any overview of existing CDSS within the area of diabetic foot ulcer wound care.

Figure 1. Clinical decision support models can be grouped according to different classifications. Included here are examples of the different approaches related to each classification.



The aims of this systematic literature review are (1) to identify models used in CDSS from the past decade that support health care professionals treating chronic wounds, (2) to classify each clinical decision support model, and (3) to create an overview.

Methods

Protocol Registration

The present systematic literature review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for systematic reviews [34]. The protocol for this systematic literature review was registered on the online prospective review database (PROSPERO) with the registration no.: CRD42017068495 [35]. We used the PRISMA checklist, which is an author guidance for reporting systematic reviews to report the 10 studies. We could have used the Consolidated Standards of Reporting Trials CONSORT checklist, however, that specific author guidance is more applicable for reporting randomized trials.

Information Sources

Publications from MEDLINE/PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), The Cochrane Library, Excerpta Medica dataBASE (EMBASE), Scopus and Web of Science were searched in March 2017 to identify articles that described and discussed clinical decision support models supporting health care professionals treating chronic wounds.

Search Strategy

The selected databases used different terminology in indexing articles, meaning that there is a risk that not all relevant articles are identified during a search. In an attempt to include all relevant articles, we used thesauruses, a systematic record in databases of subject headings used to index articles. To organize the search systematically, we grouped the search terms around three facets: ‘algorithm’, ‘wound care’, and ‘clinical decision support systems’. Further elaboration of the search terms used for eligible articles in the three facets can be seen in Table 1. The search strategy consisted of three facets, respectively: Facet 1 (Algorithm), Facet 2 (Wound care) and Facet 3 (Clinical decision support system). The terms within each facet were a mix of Medical Subject Headings (MeSH) terms and synonyms. Between each facet, the Boolean operator AND was applied, and between each MeSH term and synonyms the Boolean operator OR was applied. Only a few limitations were marked in the search criteria. Limitations included studies written in languages other than English, literature published before 2006 and studies conducted on animals and children. In the databases, children were defined as subjects younger than 19 years old. We were not interested in wound care algorithms related to animals since wound healing in animals may differ from wound healing processes in human beings.

Inclusion and Exclusion Criteria

The focus of this study was on models used in CDSS within the area of wound care related to chronic wounds. We, the author and the co-authors, were interested in studies that presented algorithms, models, and that were relevant for wound care as well as studies that presented wound care decision support systems or clinical decision support models. Since wound care differs depending on whether the wound is acute or chronic, we excluded studies based on acute wounds or trauma.

We excluded studies that presented guidelines, protocols, and instructions focusing on wound care since they do not require progression along an active chain of reasoning from the clinicians, just their focus. Furthermore, clinical decision support models serve as learning tools, which was of interest to us. Finally, studies were excluded if they had not undergone a peer review process.

Study Selection and Data Extraction

The reference management software program Legacy Refworks (version 2.0, 2010) was used to handle the articles. In order to remove duplicates in the identified references, the functions ‘Exact Duplicates’ and ‘Close Duplicates’ were applied.

Titles and abstracts of the identified citations were read to screen the articles using the inclusion and exclusion criteria described in the previous section. The articles that remained were then read in full to extract relevant information. Afterward, cross-referencing techniques were applied on the reference lists of the included articles to identify literature that had not been discovered through the systematic literature search. The extracted information included authors, year, country, a sample size of the data, and variables describing the type of clinical decision support model [26].

Table 1. The three facets below, shows the search strategy applied in the systematic literature review. Each facet consists of MeSH terms and synonyms. Between each MeSH term and synonym, the Boolean operator OR is used and between each facet the Boolean operator AND is applied.

Facet 1 (Algorithm)		Facet 2 (Wound care)		Facet 3 (Clinical decision support system)
Regression analysis OR Statistical models OR Linear models OR Loglinear model OR Multivariate logistic regression OR Logistic models OR Regression analysis OR Logistic regression OR Artificial neural network OR Theoretical model OR Computer simulation OR Prediction OR Bayes theorem OR Prognosis OR Forecasting OR Artificial intelligence OR Artificial intelligence OR Algorithm-based OR Model-based OR Model OR Algorithms OR Prescriptive OR Pattern recognition OR Data mapping OR Text mining OR Data mining	AND	Therapy OR Wound treatment OR Wound management OR Wound assessment OR Pressure ulcer care OR Wound care OR Skin care OR Skin care OR Foot care OR Larval therapy OR Autolytic debridement OR Chemical debridement OR Mechanical debridement OR Surgical debridement OR Debridement	AND	Clinical decision support systems

To reduce bias during the selection and reviewing process, the author, together with one of the co-authors, systematically went through each article, discussed the scope of each article and decided whether an article was relevant in proportion to our systematic literature review. The interrater reliability was not calculated in this study. However, it could have been prudent.

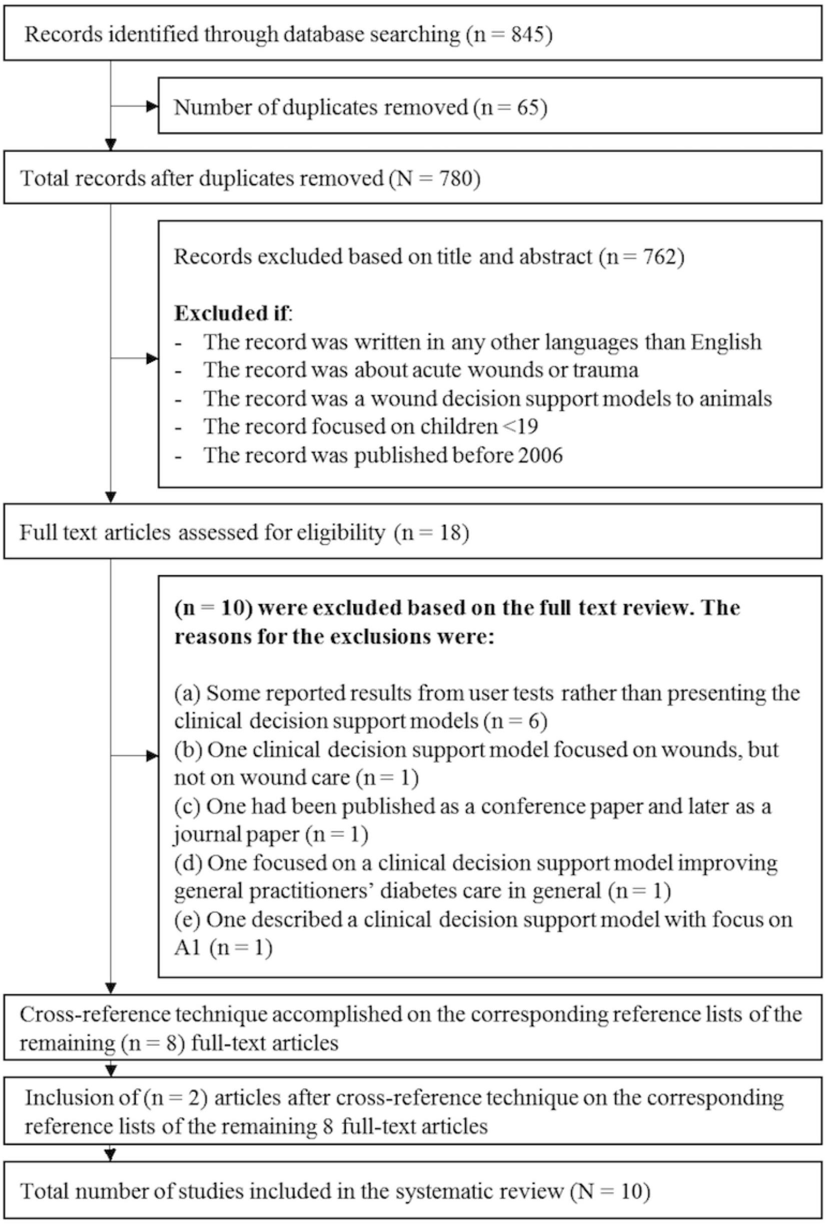
The included models used in the CDSS from the studies were subsequently described and classified according to selected variables, as defined by van Bemmel and Musen [26] and supplemented with components from Shortliffe et al [27]. The models were classified in two ways: (1) quantitative decision support models, and (2) qualitative decision support models (Figure 1).

Results

Study Selection

Figure 2 depicts the flowchart of the selection process of articles included in the systematic literature review. Systematic searches led to the identification of 845 articles. Before starting the preliminary screening process of titles and abstracts, we removed 65 duplicates, ending up with 780 records to screen. The screening process followed the inclusion and exclusion criteria, as explained in the method section, leaving 18 articles for full-text review. There were 10 articles excluded based on the full-text review process. The corresponding reference lists of the remaining 8 full-text articles were reviewed in the same way as the full-text articles had been. This extra step resulted in the identification of 2 additional articles. Hence, the final number of studies included in the systematic review was 10. The earliest relevant article was published in 2007, and the most recent was from 2015.

Figure 2. The flowchart visualises the selection process of the articles included in the systematic literature review.



Records identified through database searching (n = 845)

Number of duplicates removed (n = 65)

Total records after duplicates removed (N = 780)

Records excluded based on title and abstract (n = 762)

Excluded if:
- The record was written in any other languages than English
- The record was about acute wounds or trauma
- The record was a wound decision support models to animals
- The record focused on children <19
- The record was published before 2006

Full text articles assessed for eligibility (n = 18)

(n = 10) were excluded based on the full text review. The reasons for the exclusions were:

(a) Some reported results from user tests rather than presenting the clinical decision support models (n = 6)
(b) One clinical decision support model focused on wounds, but not on wound care (n = 1)
(c) One had been published as a conference paper and later as a journal paper (n = 1)
(d) One focused on a clinical decision support model improving general practitioners' diabetes care in general (n = 1)
(e) One described a clinical decision support model with focus on A1 (n = 1)

Cross-reference technique accomplished on the corresponding reference lists of the remaining (n = 8) full-text articles

Inclusion of (n = 2) articles after cross-reference technique on the corresponding reference lists of the remaining 8 full-text articles

Total number of studies included in the systematic review (N = 10)

Quantitative Decision Support Models

A total of 4 of the 10 (40%) articles from the systematic literature review presented a quantitative decision support model [36-39]. The oldest of the 4 studies was published in 2010, and the newest was from 2015. Of these, 2 studies were published in Spain, and the remaining 2 were published in India and the United States (Table 2). All 4 studies present quantitative decision support models as proof of concepts.

The applied techniques in these 4 quantitative decision support models covered the following: Neural Networks, Support Vector Machines, Random Forest Decision Tree, Bayesian Belief Networks and Logistic Regression (Table 3). The data sets applied in the clinical decision support models encompassed the sizes (n=113, n=73, n=74, n=113) and 3 of the 4 (75%) data sets involved images of wounds [36,38,39]. Only in 1 of the 4 (25%) quantitative decision support models did the data set comprise demographic and clinical information such as gender, age, body mass index, tobacco use, instead of wound images [37].

The professionals who had access to 3 of the 4 (75%) quantitative decision support models were health care professionals who detect, estimate, diagnose, and register crucial tissue measurements for pressure ulcer diagnosis. They are also health care professionals who undertake wound care for chronic wounds (Table 4), [36,38,39]. The last quantitative decision support model by Forsberg et al [37] was applicable only for surgeons working in a hospital setting who needed to improve their medical decision-making.

The accessibility of the inference engines of the 4 quantitative decision support models was low. The 4 quantitative decision support models should help health care professionals in decision-making situations, but health care professionals could not follow the statistical processes performed on the data material by personal inspection. They could only see the outcome of the statistical processes (Table 4).

The focus in each of the 4 quantitative decision support models varied. The quantitative decision support model by Veredas et al [36] from 2015 presented a clustering-based image segmentation approach along with statistical methods to accomplish automatic tissue recognition for pressure ulcer diagnosis. The decision support model helped health care professionals in making decisions, but was only the engine and therefore was not available or visible to the health care professionals. The quantitative decision support model by Forsberg et al [37] from 2015 combined biomarker data with clinical observations and generated predictive algorithms that helped surgeons identify when to close or otherwise cover wounds in high-risk military and civilian populations. Similar to the previous decision support model by Veredas et al [36] from 2015, the model by Forsberg et al [37] was also part of the engine and hence not visible to health care professionals.

Table 2. An overview of who the publication authors were, the year the publication was published and where the publication was published.

Reference No.	Publication Authors	Year Published	Country Where Published
[36]	Veredas FJ, Luque-Baena RM, Martín-Santos FJ, Morilla-Herrera JC, Morente L	2015	Spain
[37]	Forsberg JA, Potter BK, Wagner MB, Vickers A, Dente CJ, Kirk AD, Elster EA	2015	US
[38]	Mukhejerjee R, Manohar DD, Das DK, Achar A, Mitra A, Chakraborty C	2014	India
[39]	Veredas F, Mesa H, Morente L	2010	Spain

Table 3. The table provides an overview of which type and size of data the models were based on, and the applied techniques in the clinical decision support systems.

Reference No.	Data Presented in the Article	Applied techniques in the clinical decision support systems
[36]	Data consisted of (n=113) images of pressure ulcers on sacrum and hips.	• K-means clustering algorithm for image segmentation. • Three machine learning approaches (1) Neural Networks, (2) Support Vector Machines, and (3) Random Forest Decision Trees
[37]	Data consisted of (n=73) participants (a mix of soldiers and civilians) with at least one extremity wound >75cm^2.	• Parametric statistical and machine learning methodologies (1) Bayesian Belief Networks, (2) Random Forest Analysis, and (3) Logistic regression using Least Absolute Shrinkage and Selection Operator. • Statistical differences between the continuous variables and wound outcomes were evaluated using the Mann-Whitney U test and the post hoc Tukey-Kramer assessment.
[38]	Data consisted of (n=74) images of chronic wounds from the Medetec medical image database.	• Fuzzy divergence-based thresholds used for wound contour segmentation. • For wound tissue classification (1) Bayesian classification, and (2) Support vector machine.
[39]	Data consisted of (n=113) images of sacrum and hip pressure ulcers.	• Image processing techniques: filtering, kernel smoothing by the mean shift procedure and region growing. • Statistical analysis: (1) A hybrid approach based on Neural networks, and (2) Bayesian classifiers.

Table 4. An overview of the quantitative decision support models' accessibility of the inference engines, what type of wounds it focuses on and the type of professionals who have access.

Reference No.	Accessibility of the inference engines of the system	Type of Wounds	Professionals, who have access to the system
[36]	The clinical decision support model aims to help clinicians in decision-making situations. Health care professionals cannot access the inference engine and cannot follow the statistical processes performed on the data by personal inspection. They can only see the outcomes of the statistical processes.	Pressure ulcers	Health care professionals who detect, estimate, diagnose and register important tissue measurements for pressure ulcer diagnosis
[37]	The clinical decision support model aims to improve decision-making when surgeons need to know if they must close or cover a wound. Surgeons cannot access the inference engine and cannot follow the ongoing statistical processes in the decision support model. They can only see the outcomes of the statistical processes.	Chronic wounds	Surgeons in hospital settings
[38]	The decision support model helps health care professionals identify necrotic tissue within chronic wounds. Clinicians cannot access the inference engine. They can only see the outcomes of the statistical processes.	Chronic wounds	Health care professionals who undertake wound care for chronic wounds
[39]	The decision support model helps health care professionals care for pressure ulcers. The health care professionals cannot access the inference engine and cannot follow statistical processes. They can only see the outcomes of the statistical processes.	Pressure ulcers	Health care professionals who detect, estimate, diagnose and register important tissue measurements for pressure ulcer diagnosis

The quantitative decision support model by Mukherjee et al [38] from 2014 was a clinical decision support model that could identify necrotic tissue in chronic wounds. Like the 2 previous decision support models, Mukherjee's model helped health care professionals, but the statistical processes were again not visible to health care professionals, as only the outcomes of the statistical processes were shown. The last quantitative decision support model by Veredas et al [39] from 2010 was also an engine that could recognize tissue in pressure ulcer images, and it was therefore also invisible to health care professionals.

Pressure ulcers were the focus of 2 of the studies [36,39]; the remaining 2/4 (50%) focused on chronic wounds [37,38].

Qualitative Decision Support Models

There were 6 articles (6/10, 60%)from the systematic literature review that presented a qualitative decision support model [40-45]. The oldest article was published in 2007, and the newest was published in 2015. Five of the six studies (83%) were published in the United States while the remaining study (1/6, 17%) was published in Great Britain (Table 5). Five of the six studies (83%) present qualitative decision support models as proof of concepts. Only the study by Smith and Gibson [42] from 2013 present a qualitative decision support model which the health care professionals used.

The applied techniques in the 6 qualitative decision support models included Meta-Analyses, Systematic Reviews, Literature Reviews, Expert Face Validations, Answers from Questionnaires, Expert Panel Discussions, Task Force of Clinical Experts and Consensus Panels (Multimedia Appendix 1). The techniques covered among other things that experts are in charge of proposing features when building qualitative decision support models, and models are based on clinical studies with the highest evidence [26]. In 3 of the 6 (50%) qualitative decision support models, the techniques were a combination of literature reviews and expert panel discussions [41,44,45]. Two of the remaining 3 (67%) qualitative decision support models used only one of the mentioned techniques [42,43], and the applied technique in the last qualitative decision support model (1/3, 33%) was not described in the study [40].

The professionals who had access to 3 of the 6 (50%) qualitative decision support models were health care professionals who undertake wound care for chronic wounds (Multimedia Appendix 2) [41,44,45]. Two of the 6 (33%) qualitative decision support models were designed specifically for registered nurses, licensed practical nurses and specialized nurses who provide critical support for tissue viability services [40,42]. The last qualitative decision support model by Kravitz et al [43] from 2007 was applicable only for surgeons undertaking diabetic foot ulcer surgery (Multimedia Appendix 2).

Table 5. An overview of who the publication authors were, the year the publication was published and where the publication was published.

Reference No.	Publication Authors	Year Published	Country Where Published
[40]	Alvey B, Hennen N, Heard H	2012	US
[41]	Beitz JM, van Rijswijk L	2012	US
[42]	Smith G, Gibson E	2013	Great Britain
[43]	Kravitz SR, McGuire JB, Sharma S	2007	US
[44]	LeBlanc K, Baranoski S, Christensen D, Langemo D, Sammon MA, Edwards K, Holloway S, Gloeckner M, Williams A, Sibbald RG, Regan M	2013	US
[45]	McNichol L, Watts C, Mackey D, Beitz JM, Gray M	2015	US

The accessibility of the inference engines of the 6 qualitative decision support models was high. Health care professionals could follow the decision process from start to finish; furthermore, they were required to take an active part in assessing the wounds.

The focus of each of the 6 qualitative decision support models varied. In the qualitative decision support model of Alvey et al, [40] registered nurses and licensed practical nurses were required to select descriptive information on a wound to let the qualitative decision support model assist them during decision-making. The qualitative decision support models by Beitz and Rijswijk [41] were relevant in three different areas: initially assessing a wound, increasing the wound assessment at every dressing change of surgical and acute wounds, and improving wound assessment for chronic wounds at every dressing change. The qualitative decision support model of Smith and Gibson [42] required the wound care link nurses to decide on characteristics of the wound and thereby receive assistance in decision making. The qualitative decision support model by Kravitz et al [43] required surgeons to choose between proactive (elective) diabetic foot ulcer surgery and reactive (nonelective) diabetic foot ulcer surgery. The qualitative decision support model by LeBlanc et al [44] was designed to be used in multiple health care settings and by all levels of staff and caregivers. The last qualitative decision support model by McNichol et al [45] was also designed to be used by multiple health care professionals, and clinicians could interact with three different models: a skin and pressure ulcer risk assessment algorithm, a prevention of pressure ulcers algorithm, and a treatment of pressure ulcers algorithm.

Diabetic foot ulcer surgery was the focus of 1/6 (17%) studies [43], 4/6 (67%) focused on chronic wounds [41,42,44,45], and the last 1/6 (17%) study focused on pressure ulcers [40].

Discussion

Principal Results

Recent studies have shown that it can be valuable to apply CDSS in clinical settings to increase the quality of care and generate solid bases for evidence-based practice [23,28-31]. Hence, the aims of this systematic literature review were to identify the various models used in CDSS over the past decade that support health care professionals treating chronic wounds, to classify each clinical decision support model and to create an overview. A total of 10 clinical decision support models were identified, 4/10 (40%) of which were quantitative and 6/10 (60%) of which were qualitative [36-45]. The clinical decision support models were targeted at different types of chronic wounds. The degree of accessibility of the inference engines varied. Quantitative decision support models served as the engine and were invisible to the health care professionals. The qualitative decision support models required health care professionals' involvement.

Comparison With Prior Work

Chronic wounds are complicated to treat and challenging for health care professionals. In decision-making situations where health care professionals need advice related to chronic wound treatments, health care professionals are, according to the literature, often forced to rely on their own experience rather than having evidence available that they can follow [21,46]. A cross-sectional survey by Stolt et al [47] measured nurses' knowledge of foot care and concluded that nurses need more knowledge and have clinical knowledge gaps. Several other studies have pointed out that health care professionals' curriculum is lacking when it comes to wound care [21,48-51]. On the basis of the studies included in the present systematic literature review, one might say that the conditions the health care professionals have are not as good as they could be when it comes to performing evidence-based practice [36-45]. The deficient number of studies could indicate that there is a need to develop more clinical decision support models targeted at chronic wounds to increase the quality of care and to support evidence-based wound care practice [21,46,47].

The optimal type of decision support model may not be easy to identify. The techniques applied in the clinical decision support models reviewed here were classified into two groups: 4 studies were based on quantitative models, and 6 studies were based on qualitative models. One of the strengths of the quantitative decision support model classification is that outcomes of statistical processes are objective, reproducible and in accordance with the clinical data [26]. However, applying the models can be somewhat complicated. The qualitative decision support models have different strengths and limitations [26]. One of the strengths of the qualitative approach is that many years of professional experience within a specific domain help experts manage unknown and uncertain situations where they use their clinical knowledge and experience and thereby build up significant judgemental and tacit knowledge [27]. When experts participate in expert panel discussions or consensus panels, it must be assumed that the basis on which they speak is well-founded. However, although experts may have many years of professional experience, there may still be gaps in their knowledge and experience. As such, 6 included qualitative decision support models may lack validity. With data being increasingly available [32,52-54], the argument for using a quantitative approach is strengthened, and one might suggest that future work focuses to a greater extent on quantitative techniques.

It is commonly accepted that accessibility of the inference engine is important [55]. Quantitative and qualitative decision support models differ from each other in this respect. The quantitative decision support models appeared as engines without requiring involvement, whereas the qualitative decision support models required health care professionals to take an active part and be involved. In other words, systems based on qualitative models are more accessible than systems based on quantitative models. Although there are fewer accessible models in quantitative systems, the advantage of using Big Data on large data sets may outweigh the disadvantages related to accessibility [52,53]. Future research should investigate how to compensate for lack of accessibility in quantitative systems by developing methods for augmenting users' understanding of the decision processes.

One might argue that IT systems should be tailored to specific professional groups to address the needs of nurses or doctors optimally, for example [31]. Some systems found in our review focused solely on supporting surgeons, some supported wound specialists and some focused on no specific profession. The heterogeneity of the target group of professionals may be explained by the fact that treating chronic wounds is a multidisciplinary task, requiring the participation of many different professions [16]. Future research should include work on how to balance the two concerns—facilitating the need for multidisciplinary collaboration as well as optimally addressing the specific needs of each professional group.

Limitations

Several of the existing checklists are addressed to conventional study designs such as randomized controlled trials, cohort studies and qualitative semi-structured interviews [56]. However, none of the scientific articles identified in our systematic literature review applied any of the mentioned study designs.

It is a complicated task to build a search strategy which reflects an accurate inventory of what has been done within a research area. Primarily because hits often reflect the conducted search rather than reflecting the reality within a research area. However, there are several initiatives to avoid this problem. In our study, our preliminary search strategy consisted of 4 facets, respectively: Facet 1 (Algorithm), Facet 2 (Wound care), Facet 3 (Clinical decision support system) and Facet 4 (Wound). Facet4 consisted of a mix of MeSH terms and synonyms and these were: “foot ulcer,” “diabetic foot,” “skin ulcer,” “leg ulcer,” “decubitus,” “chronic wound,” “venous foot,” “venous ulcer,” “pressure ulcer,” “ulcer,” “wounds and injuries,” “varicose ulcer,” “ulcer wound,” and “diabetic foot”. Between each of the search terms in Facet 4 the Boolean operator “OR” was inserted to achieve as many hits as possible. When running the search with the 4 facets, we did not receive any hits, maybe because it was too narrow. Hence, we refined our search strategy and made it broader. Subsequently, we removed search query facet 4, so the search strategy instead only consisted of Facet1, Facet2 and Facet3. When running the revised search strategy, we retrieved several hits as depicted in our flowchart (Figure 2). We could have refined our search strategy further, so it only consisted of Facet2 and Facet3, and thereby we would have received more than 9600 hits. One might think that the risk of missing and identifying potential articles is rather high when more than 9600 articles should be read through by the human eye.

We used the classification suggested by Bemmel and Musen [26] of clinical decision support models discriminating between quantitative models and qualitative models. However, other classifications might have been relevant as well.

Conclusions

There were 10 clinical decision support models identified. Of these, 4 (40%) were quantitative decision models and 6 (60%) were qualitative decision support models.

Three (3/4, 75%) of the quantitative decision support models were applicable for all health care professionals who detect, estimate, diagnose and register essential tissue measurements for pressure ulcer diagnosis or who undertake wound care for chronic wounds. The fourth (1/4, 25%) quantitative decision support model was applicable for surgeons who work in a hospital setting. Two qualitative decision support models were designed specifically for registered nurses, licensed practical nurses and specialized nurses such as wound care nurses who provide critical support for tissue viability services. One qualitative decision support model applicable for surgeons who undertake diabetic foot ulcer surgery.

The degree of accessibility of the inference engines varied. The 4 quantitative decision support models served as engines and were invisible to health care professionals. The 6 qualitative decision support models required interaction with health care professionals.

The clinical decision support models were targeted towards different types of chronic wounds. Two (2/4, 50%) of the quantitative decision support models focused on pressure ulcers, while the remaining 2/4 (50%) focused on chronic wounds. One of the 6 (17%) qualitative decision support models explicitly focused on diabetic foot ulcer surgery, 4 (4/6, 67%) focused on chronic wounds, and the last (1/6, 17%) qualitative decision support model focused on pressure ulcers.

More research is needed to develop clinical decision support models targeted at health professionals treating chronic wounds. Given the growing focus on evidence-based care and the availability of increasing amounts of data, the arguments for a quantitative approach to decision models in future work are strengthened. Future research should also address problems with accessibility in quantitative systems by developing methods for augmenting users’ understanding of the processes in the quantitative models.

Acknowledgments

This systematic review study received no financial support for the research, authorship, and publication of this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The table provides an overview of which type and size of data the models were based on, and the applied techniques in the clinical decision support systems.

[PDF File (Adobe PDF File), 38KB - diabetes_v3i2e11_app1.pdf]

Multimedia Appendix 2

An overview of the qualitative decision support models' accessibility of the inference engines, what type of wounds it focuses on and the type of professionals who have access.

[PDF File (Adobe PDF File), 33KB - diabetes_v3i2e11_app2.pdf]

References

1. Frykberg RG, Banks J. Challenges in the Treatment of Chronic Wounds. Adv Wound Care (New Rochelle) 2015 Sep 01;4(9):560-582 [FREE Full text] [doi: 10.1089/wound.2015.0635] [Medline: 26339534]
2. Harding KG, Morris HL, Patel GK. Science, medicine and the future: healing chronic wounds. BMJ 2002 Jan 19;324(7330):160-163 [FREE Full text] [Medline: 11799036]
3. Nussbaum S, Carter M, Fofe C, DaVanzo J, Haught R, Nusgart M, et al. An Economic Evaluation of the Impact, Cost, and Medicare Policy Implications of Chronic Nonhealing Wounds. Value in Health 2017;21(1):27-32. [doi: 10.1016/j.jval.2017.07.007]
4. Järbrink K, Ni G, Sönnergren H, Schmidtchen A, Pang C, Bajpai R, et al. The humanistic and economic burden of chronic wounds: a protocol for a systematic review. Syst Rev 2017 Dec 24;6(1):15 [FREE Full text] [doi: 10.1186/s13643-016-0400-8] [Medline: 28118847]
5. Khalil H, Cullen M, Chambers H, Carroll M, Walker J. Reduction in wound healing times, cost of consumables and number of visits treated through the implementation of an electronic wound care system in rural Australia. Int Wound J 2016 Oct;13(5):945-950. [doi: 10.1111/iwj.12414] [Medline: 25662780]
6. Hjort A, Gottrup F. Cost of wound treatment to increase significantly in Denmark over the next decade. J Wound Care 2010 May;19(5):173-4, 176, 178, 180, 182, 184. [doi: 10.12968/jowc.2010.19.5.48046] [Medline: 20505590]
7. Jørgensen SF, Nygaard R, Posnett J. Meeting the challenges of wound care in Danish home care. J Wound Care 2013 Oct;22(10):540-2, 544. [doi: 10.12968/jowc.2013.22.10.540] [Medline: 24142076]
8. Woo KY, Botros M, Kuhnke J, Evans R, Alavi A. Best practices for the management of foot ulcers in people with diabetes. Adv Skin Wound Care 2013 Nov;26(11):512-24; quiz 225. [doi: 10.1097/01.ASW.0000436385.24508.d5] [Medline: 24149666]
9. Falanga V. Wound healing and its impairment in the diabetic foot. The Lancet 2005 Nov 12;366(9498):1736-1743. [doi: 10.1016/S0140-6736(05)67700-8] [Medline: 16291068]
10. Bekara F, Vitse J, Fluieraru S, Masson R, Runz AD, Georgescu V, et al. New techniques for wound management: A systematic review of their role in the management of chronic wounds. Arch Plast Surg 2018 Mar;45(2):102-110 [FREE Full text] [doi: 10.5999/aps.2016.02019] [Medline: 29506339]
11. Han G, Ceilley R. Chronic Wound Healing: A Review of Current Management and Treatments. Adv Ther 2017 Mar;34(3):599-610 [FREE Full text] [doi: 10.1007/s12325-017-0478-y] [Medline: 28108895]
12. Dumville JC, Deshpande S, O'Meara S, Speak K. Foam dressings for healing diabetic foot ulcers. Cochrane Database Syst Rev 2011 Sep 07(9):CD009111. [doi: 10.1002/14651858.CD009111.pub2] [Medline: 21901731]
13. Han G, Ceilley R. Chronic Wound Healing: A Review of Current Management and Treatments. Adv Ther 2017 Mar;34(3):599-610 [FREE Full text] [doi: 10.1007/s12325-017-0478-y] [Medline: 28108895]
14. Stoekenbroek RM, Santema TB, Legemate DA, Ubbink DT, van DBA, Koelemay MJW. Hyperbaric oxygen for the treatment of diabetic foot ulcers: a systematic review. Eur J Vasc Endovasc Surg 2014 Jun;47(6):647-655 [FREE Full text] [doi: 10.1016/j.ejvs.2014.03.005] [Medline: 24726143]
15. Dumville JC, O'Meara S, Deshpande S, Speak K. Hydrogel dressings for healing diabetic foot ulcers. Cochrane Database Syst Rev 2011 Sep 07(9):CD009101. [doi: 10.1002/14651858.CD009101.pub2] [Medline: 21901730]
16. Alexiadou K, Doupis J. Management of diabetic foot ulcers. Diabetes Ther 2012 Nov;3(1):4 [FREE Full text] [doi: 10.1007/s13300-012-0004-9] [Medline: 22529027]
17. Bergin SM, Wraight P. Silver based wound dressings and topical agents for treating diabetic foot ulcers. Cochrane Database Syst Rev 2006 Jan 25(1):CD005082. [doi: 10.1002/14651858.CD005082.pub2] [Medline: 16437516]
18. Dumville JC, O'Meara S, Deshpande S, Speak K. Alginate dressings for healing diabetic foot ulcers. Cochrane Database Syst Rev 2012 Feb 15(2):CD009110. [doi: 10.1002/14651858.CD009110.pub2] [Medline: 22336860]
19. Cruciani M, Lipsky BA, Mengoli C, de LF. Granulocyte-colony stimulating factors as adjunctive therapy for diabetic foot infections. Cochrane Database Syst Rev 2013 Aug 17(8):CD006810. [doi: 10.1002/14651858.CD006810.pub3] [Medline: 23955465]
20. Selva OA, Solà I, Barajas-Nava LA, Gianneo OD, Bonfill CX, Lipsky BA. Systemic antibiotics for treating diabetic foot infections. Cochrane Database Syst Rev 2015 Sep 04(9):CD009061. [doi: 10.1002/14651858.CD009061.pub2] [Medline: 26337865]
21. Schaarup C, Pape-Haugaard L, Jensen MH, Laursen AC, Bermark S, Hejlesen OK. Probing community nurses' professional basis: a situational case study in diabetic foot ulcer treatment. Br J Community Nurs 2017 Mar;22 Suppl 3(Sup3):S46-S52. [doi: 10.12968/bjcn.2017.22.Sup3.S46] [Medline: 28252333]

22. Buntin MB, Burke MF, Hoaglin MC, Blumenthal D. The benefits of health information technology: a review of the recent literature shows predominantly positive results. Health Aff (Millwood) 2011 Mar;30(3):464-471. [doi: 10.1377/hlthaff.2011.0178] [Medline: 21383365]
23. Bright TJ, Wong A, Dhurjati R, Bristow E, Bastian L, Coeytaux RR, et al. Effect of clinical decision-support systems: a systematic review. Ann Intern Med 2012 Jul 03;157(1):29-43. [doi: 10.7326/0003-4819-157-1-201207030-00450] [Medline: 22751758]
24. Coiera E. Guide to health informatics. In: London: Arnold Busck; ISBN. London: Arnold; Oct 31, 2003:A.
25. Sim I, Gorman P, Greenes RA, Haynes RB, Kaplan B, Lehmann H, et al. Clinical decision support systems for the practice of evidence-based medicine. J Am Med Inform Assoc 2001;8(6):527-534 [FREE Full text] [Medline: 11687560]
26. Bemmel JV, Musen M. Handbook of Medical Informatics. The Netherlands: Heidelberg, Springer Berlin; 2002:3518.
27. Shortliffe E, Buchanan B, Feigenbaum E. Knowledge engineering for medical decision making: A review of computer-based clinical decision aids. Proc. IEEE 1979 Sep;67(9):1207-1224. [doi: 10.1109/PROC.1979.11436]
28. Kawamoto K, Houlihan CA, Balas EA, Lobach DF. Improving clinical practice using clinical decision support systems: a systematic review of trials to identify features critical to success. BMJ 2005 Apr 02;330(7494):765 [FREE Full text] [doi: 10.1136/bmj.38398.500764.8F] [Medline: 15767266]
29. Delaney BC, Fitzmaurice DA, Riaz A, Hobbs FD. Can computerised decision support systems deliver improved quality in primary care?. Interview by Abi Berger. BMJ 1999 Nov 13;319(7220):1281 [FREE Full text] [doi: 10.1136/bmj.3197220.1281] [Medline: 10559035]
30. Blum D, Raj SX, Oberholzer R, Riphagen II, Strasser F, Kaasa S, EURO IMPACT, European Intersectorial Multidisciplinary Palliative Care Research Training. Computer-Based Clinical Decision Support Systems and Patient-Reported Outcomes: A Systematic Review. Patient 2015 Oct;8(5):397-409. [doi: 10.1007/s40271-014-0100-1] [Medline: 25432150]
31. Garg AX, Adhikari NKJ, McDonald H, Rosas-Arellano MP, Devereaux PJ, Beyene J, et al. Effects of computerized clinical decision support systems on practitioner performance and patient outcomes: a systematic review. JAMA 2005 Mar 09;293(10):1223-1238. [doi: 10.1001/jama.293.10.1223] [Medline: 15755945]
32. Staszewska A, Zaki P, Lee J. Computerized Decision Aids for Shared Decision Making in Serious Illness: Systematic Review. JMIR Med Inform 2017 Oct 06;5(4):e36 [FREE Full text] [doi: 10.2196/medinform.6405] [Medline: 28986341]
33. Thomas KW, Dayton CS, Peterson MW. Evaluation of internet-based clinical decision support systems. J Med Internet Res 1999;1(2):E6 [FREE Full text] [doi: 10.2196/jmir.1.2.e6] [Medline: 11720915]
34. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 2009 Jul 21;6(7):e1000097 [FREE Full text] [doi: 10.1371/journal.pmed.1000097] [Medline: 19621072]
35. Prospero Registration. 2017. Schaarup C URL: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017068495 [accessed 2018-04-14] [WebCite Cache ID 6yg4KgleE]
36. Veredas FJ, Luque-Baena RM, Martín-Santos FJ, Morilla-Herrera JC, Morente L. Wound image evaluation with machine learning. Neurocomputing 2015 Sep;164:112-122. [doi: 10.1016/j.neucom.2014.12.091]
37. Forsberg JA, Potter BK, Wagner MB, Vickers A, Dente CJ, Kirk AD, et al. Lessons of War: Turning Data Into Decisions. EBioMedicine 2015 Sep;2(9):1235-1242 [FREE Full text] [doi: 10.1016/j.ebiom.2015.07.022] [Medline: 26501123]
38. Mukherjee R, Manohar DD, Das DK, Achar A, Mitra A, Chakraborty C. Automated tissue classification framework for reproducible chronic wound assessment. Biomed Res Int 2014;2014:851582 [FREE Full text] [doi: 10.1155/2014/851582] [Medline: 25114925]
39. Veredas F, Mesa H, Morente L. Binary tissue classification on wound images with neural networks and bayesian classifiers. IEEE Trans Med Imaging 2010 Feb;29(2):410-427. [doi: 10.1109/TMI.2009.2033595] [Medline: 19825516]
40. Alvey B, Hennen N, Heard H. Improving accuracy of pressure ulcer staging and documentation using a computerized clinical decision support system. J Wound Ostomy Continence Nurs 2012;39(6):607-612. [doi: 10.1097/WON.0b013e31826a4b5c] [Medline: 22948492]
41. Beitz JM, van RL. Developing evidence-based algorithms for negative pressure wound therapy in adults with acute and chronic wounds: literature and expert-based face validation results. Ostomy Wound Manage 2012 Apr;58(4):50-69 [FREE Full text] [Medline: 22466133]
42. Smith G, Gibson E. The development of an algorithm to support nurses choosing dressings for chronic exudate. Wounds UK 2013;9(2):67.
43. Kravitz SR, McGuire JB, Sharma S. The treatment of diabetic foot ulcers: reviewing the literature and a surgical algorithm. Adv Skin Wound Care 2007 Apr;20(4):227-37; quiz 237. [doi: 10.1097/01.ASW.0000266643.97417.eb] [Medline: 17415031]
44. LeBlanc K, Baranoski S, Christensen D, Langemo D, Sammon MA, Edwards K, et al. International Skin Tear Advisory Panel: a tool kit to aid in the prevention, assessment, and treatment of skin tears using a Simplified Classification System ©. Adv Skin Wound Care 2013 Oct;26(10):459-76; quiz 477. [doi: 10.1097/01.ASW.0000434056.04071.68] [Medline: 24045566]
45. McNichol L, Watts C, Mackey D, Beitz JM, Gray M. Identifying the right surface for the right patient at the right time: generation and content validation of an algorithm for support surface selection. J Wound Ostomy Continence Nurs 2015;42(1):19-37 [FREE Full text] [doi: 10.1097/WON.0000000000000103] [Medline: 25549306]

46. Haram R, Ribu E, Rustøen T. The views of district nurses on their level of knowledge about the treatment of leg and foot ulcers. J Wound Ostomy Continence Nurs 2003 Jan;30(1):25-32. [doi: 10.1067/mjw.2003.4] [Medline: 12529591]
47. Stolt M, Suhonen R, Puukka P, Viitanen M, Voutilainen P, Leino-Kilpi H. Nurses' knowledge of foot care in the context of home care: a cross-sectional correlational survey study. J Clin Nurs 2015 Oct;24(19-20):2916-2925. [doi: 10.1111/jocn.12922] [Medline: 26179162]
48. Gottrup F. Education in Wound Management in Europe with a Special Focus on the Danish Model. Adv Wound Care (New Rochelle) 2012 Jun;1(3):133-137 [FREE Full text] [doi: 10.1089/wound.2011.0337] [Medline: 24527293]
49. Timmons J. Wound care education needs a boost. Br J Community Nurs 2006 Mar;11(3):S3. [doi: 10.12968/bjcn.2006.11.Sup1.20590] [Medline: 16607240]
50. Declaration Professional Bachelor's Degree in Nursing. 2014 URL: https://www.retsinformation.dk/Forms/R0710.aspx?id=181963 [accessed 2018-06-13] [WebCite Cache ID 708ltr3o2]
51. Chamanga ET. Community nurses' experiences of treating patients with leg ulcers. J Clin Nurs ?34, ISSN 2014;28(6):28.
52. Kruse CS, Goswamy R, Raval Y, Marawi S. Challenges and Opportunities of Big Data in Health Care: A Systematic Review. JMIR Med Inform 2016 Nov 21;4(4):e38 [FREE Full text] [doi: 10.2196/medinform.5359] [Medline: 27872036]
53. Kruse CS, Goswamy R, Raval Y, Marawi S. Challenges and Opportunities of Big Data in Health Care: A Systematic Review. JMIR Med Inform 2016 Nov 21;4(4):e38 [FREE Full text] [doi: 10.2196/medinform.5359] [Medline: 27872036]
54. Wang W, Krishnan E. Big data and clinicians: a review on the state of the science. JMIR Med Inform 2014 Jan 17;2(1):e1 [FREE Full text] [doi: 10.2196/medinform.2913] [Medline: 25600256]
55. Nielsen J. Usability Engineering. San Francisco, Califlsevier Ltd: Morgan Kaufmann; 1993:E.
56. Enhancing the QUlity and Transparency OF health Research.: Network E; 2017. URL: http://www.equator-network.org/about-us/ [accessed 2018-06-13] [WebCite Cache ID 708mQmxqD]

Abbreviations

CDSS: Clinical Decision Support Systems
CINAHL: Cumulative Index of Nursing and Allied Health Literature
CONSORT: Consolidated Standards of Reporting Trials
EMBASE: Excerpta Medica Database
MEDLINE: Medical Literature Analysis and Retrieval System Online
MeSH: Medical Subject Headings
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO: Prospective Review Database

Edited by G Eysenbach; submitted 30.06.17; peer-reviewed by JH Lee, J Staley, R Robinson; comments to author 22.11.17; revised version received 17.04.18; accepted 03.05.18; published 21.06.18.

Please cite as:
Schaarup C, Pape-Haugaard LB, Hejlesen OK
Models Used in Clinical Decision Support Systems Supporting Healthcare Professionals Treating Chronic Wounds: Systematic Literature Review
JMIR Diabetes 2018;3(2):e11
URL: http://diabetes.jmir.org/2018/2/e11/
doi:10.2196/diabetes.8316
PMID:30291078

Original Paper

Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study

Michelle L Litchman[1,2*], PhD, FNP-BC, FAANP; Linda S Edelman[1*], RN, PhD; Gary W Donaldson[1,3*], PhD

[1]College of Nursing, University of Utah, Salt Lake City, UT, United States
[2]Utah Diabetes and Endocrinology Center, Salt Lake City, UT, United States
[3]Department of Anesthesiology, University of Utah, Salt Lake City, UT, United States
*all authors contributed equally

Corresponding Author:
Michelle L Litchman, PhD, FNP-BC, FAANP
College of Nursing
University of Utah
10 South 2000 East
Salt Lake City, UT, 84112
United States
Phone: 1 801 585 9612
Email: michelle.litchman@nurs.utah.edu

Abstract

Background: Successful diabetes management requires ongoing lifelong self-care and can require that individuals with diabetes become experts in translating care recommendations into real-life day-to-day diabetes self-care strategies. The diabetes online community comprises multiple websites that include social media sites, blogs, and discussion groups for people with diabetes to chat and exchange information. Online communities can provide disease-specific practical advice and emotional support, allow users to share experiences, and encourage self-advocacy and patient empowerment. However, there has been little research about whether diabetes online community use is associated with better diabetes self-care or quality of life.

Objective: The aim of this study was to survey adults with diabetes who participated in the diabetes online community to better understand and describe who is using the diabetes online community, how they are using it, and whether the use of the diabetes online community was associated with health indicators.

Methods: We recruited adults diagnosed with diabetes who used at least one of 4 different diabetes-related online communities to complete an online survey. Participants' demographics, reported glycated hemoglobin (HbA$_{1c}$), health-related quality of life (SF-12v2), level of diabetes self-care (Self-Care Inventory-Revised), and diabetes online community use (level of intensity and engagement) were collected. We examined the relationships between demographics, diabetes online community use, and health indicators (health-related quality of life, self-care, and HbA$_{1c}$ levels). We used binary logistic regression to determine the extent to which diabetes online community use predicted an HbA$_{1c}$ <7% or ≥7% after controlling statistically for other variables in the model.

Results: A total of 183 adults participated in this study. Participants were mostly female (71.6%, 131/183), white (95.1%, 174/183), US citizens (82.5%, 151/183), had type 1 diabetes (69.7%, 129/183), with a mean age of 44.7 years (SD 14) and diabetes duration of 18.2 years (SD 14.6). Participants had higher diabetes self-care (P<.001, mean 72.4, SD 12.1) and better health-related quality of life (physical component summary P<.001, mean 64.8, SD 19; mental component summary P<.001, mean 66.6, SD 21.6) when compared with norms for diabetes. Diabetes online community engagement was a strong predictor of A$_{1c}$, reducing the odds of having an A$_{1c}$ ≥7% by 33.8% for every point increase in diabetes online community engagement (0-5). Our data also indicated that study participants are oftentimes (67.2%, 123/183) not informing their healthcare providers about their diabetes online community use even though most (91.2%, 161/181) are seeing their healthcare provider on a regular basis.

Conclusions: Our results suggest that individuals highly engaged with diabetes online community are more likely to have better glycemic levels compared with those with lower engagement. Furthermore, diabetes online community users have high health-related quality of life and diabetes self-care levels. Supplementing usual healthcare activities with diabetes online community use may encourage knowledge and support among a population that needs to optimize its diabetes self-care. Further studies are needed to determine how diabetes online community engagement may affect health outcomes.

(JMIR Diabetes 2018;3(2):e8) doi:10.2196/diabetes.8603

KEYWORDS

diabetes; online peer support; social media; eHealth; quality of life; self-care; A1c

Introduction

Background

The internet is increasingly used as a source of health information. In fact, 79% of adults in the United States use the internet and, of those, 59% are looking for health information [1]. It is observed that 23% of individuals with chronic conditions look online to find someone with similar health concerns [2]. Websites that allow interaction and crowdsourcing the collective wisdom of others [3] can help patients manage their own health by providing tools for health promotion and disease self-care, decision support, support for behavior change, and access to online communities [4]. Online communities can support health literacy by crowdsourcing information to support medical decision making [5,6]. Although many patients are using online information and communities to improve health [7] and engagement, how online activity affects health outcomes is poorly understood, and measuring meaningful eHealth engagement can be difficult [8].

As diabetes is a complex condition, some people with diabetes find patient peers helpful in providing support for managing their disease. Engagement in peer health is defined as the interaction, education, and support offered by peers with the same condition to promote self-care. Peers who receive special training can provide assistance in day-to-day chronic disease management, encourage appropriate clinical care, and offer ongoing social and emotional support [9,10]. Trained peers with diabetes have provided formal face-to-face support or discussion groups [10,11], phone calls [10,12,13], text support, and home visits [10]. Diabetes-related peer health has been associated with increased knowledge [14,15], self-efficacy [11,12,16], patient activation [11,16], communication with physicians, healthier eating habits [11,17], and improved hemoglobin A_{1c} [13,15-24]. Importantly, reciprocal peer support has been found to be better than nurse care management with regard to glycated hemoglobin (HbA_{1c}) reduction [13]. The American Diabetes Association and American Association of Diabetes Educators recognize peers as an important factor in diabetes self-care [25,26]. However, the informal or unstructured peer support provided by the diabetes online community (DOC) has not been fully addressed.

Diabetes Online Community

The DOC is a grassroots online community developed for the purpose of sharing knowledge and support based on the user's experience of living with diabetes. Individuals involved in the DOC were initially those living with diabetes themselves, although the community has expanded and now includes family, friends, healthcare providers, and industry representatives [27]. DOC provides a vehicle for individuals to learn practical diabetes self-care techniques from experienced peers with shared experiences [27-29], and can be a source of confidence in diabetes self-care [30], inspiration, motivation, and encouragement [31], all of which support health literacy. The DOC includes blogs, video vlogs, discussion boards, and diabetes-specific (ie, Reality Check, TuDiabetes, Diabetic Connect, Beyond Type 1, Diabetes Daily) and general social media sites (ie, Facebook, Twitter, Instagram).

The DOC can be accessed through stand-alone interactive websites or social media sites. DOC users can actively contribute to discussions or passively view posts without contributing to the discussion [32]. DOC users engage in peer health [33,34] to gain practical advice [35-38], emotional support [35-41], shared experience [37-39], and improved coping [42] and empowerment [40]. There is limited data on negative patient outcomes related to DOC use [43]; however, misinformation on social media sites is infrequent [35,36,44,45] and quickly corrected by other members in the discussion group [35,39].

Currently, we are not aware of any research examining the relationship between DOC engagement and health behaviors.

Objective

The overarching purpose of this study was to better understand DOC users and how DOC engagement is related to self-reported health outcomes. The specific aims of this exploratory and descriptive study were threefold: (1) to describe DOC users in terms of demographics, diabetes type, and diabetes-related treatment; (2) to describe intensity of use and levels of engagement of DOC users; and (3) to examine the relationship between DOC use (intensity and engagement) and health-related quality-of-life, self-care behaviors, and HbA_{1c} levels.

Methods

Study Design

We conducted an exploratory cross-sectional study of a convenience sample of DOC users using an online survey posted to 4 distinct DOC social media sites. First, we conducted a small pilot study of DOC users (n=5) and asked for input from 2 diabetes specialty healthcare providers to guide survey development, and to address usability and technical functionality. The final 129-item survey included questions about demographic information, health history, eHealth app use, DOC intensity and engagement, health-related quality of life (HRQoL) [46], and diabetes self-care behaviors [47]. We used Research Electronic Data Capture (REDCap) Survey software (Nashville, TN) to administer the survey. REDCap survey is a secure, Web-based study management system.

Sample

Adult DOC users (18 years and older) with a diagnosis of type 1 or type 2 diabetes, or Latent Autoimmune Diabetes of Adulthood (LADA) who could read English, were eligible for the study. Any participant who identified themselves as having gestational diabetes, being a caregiver for someone with diabetes (ie, parent of a child with diabetes), or younger than 18 years were excluded from the analyses. The study was approved by the University of Utah Institutional Review Board, Salt Lake City, UT. The study was also approved by the administration team from TuDiabetes and Diabetic Connect; the other 2 sites were Facebook and Twitter.

Recruitment and Setting

We recruited adult DOC users in 2 waves. We selected the initial site, TuDiabetes, because it was hosted by a nonprofit organization, the Diabetes Hands Foundation, that did not allow advertisements. TuDiabetes members were screened by an administrator before they could join, posts could be viewed by members without logging in to their account. TuDiabetes had more than 35,000 members with diabetes at the time of the study. Initially, we posted a synopsis of the study with a link to the survey on the principal investigator's TuDiabetes profile page, which was shared by key opinion leaders and mentioned in the TuDiabetes online newsletter. The first question of the survey asked individuals if they consented to participate in the study and provided a link to further information about the study purpose and method.

A second wave of recruitment included Diabetic Connect, a for-profit organization, which was selected because of its growing diabetes-specific social media presence. Facebook and Twitter were also used for recruitment, given the number of groups, pages, and tweet chats focused on diabetes. Data collection occurred over a 7-month period.

Measures

The online survey was divided into 6 sections: (1) demographics, (2) health history, (3) eHealth use (including reasons to join a diabetes social network, DOC intensity, DOC engagement, and internet social capital), (4) HRQoL, (5) diabetes self-care behaviors, and (6) source credibility. Moreover, 5 validated instruments were used and included the SF-12v2 [46,48], an adapted version of the Facebook intensity scale [49], an adapted version of the internet social capital scale [50], Self-Care Inventory-Revised (SCI-R) [47], and the source credibility scale [51]. This paper will examine demographics, health history, eHealth use as noted below (that includes reasons to join a DOC, DOC intensity, and DOC engagement, but does not include internet social capital), HRQoL, and diabetes self-care behaviors. Details for each measure are noted below.

Demographics

A total of 11 demographic items focused on gender, marital status, education level, employment, annual household income, age, ethnicity, race, country or state, living setting, and insurance status.

Health History

A total of 8 self-reported items focused on diabetes type, diabetes duration, current diabetes treatments, most recent HbA_{1c} level, type of medical practice, and type of healthcare provider used for diabetes care, frequency of diabetes provider visits, and presence of diabetes-related complications.

eHealth Use

A total of 22 items, individually scored, were asked to measure how participants navigate the DOC and if the participants' healthcare provider knew about and supported their DOC use.

Reasons to Join the Diabetes Online Community

A total of 13 items were developed based on an anecdotal dLife (Diabetes Life) report [52] that addressed the reasons why someone with diabetes should join the DOC. Items were dichotomous, allowing a yes or no response.

Diabetes Online Community Intensity

The DOC intensity scale is an 8-item tool adapted from the Facebook intensity scale [49] to measure how often and for how long individuals are engaged in the DOC, and to determine the emotional connectedness and integration into daily activities. Scores range from 0 to 5, with higher scores indicating more DOC intensity. Cronbach coefficient for DOC intensity was .85.

Diabetes Online Community Engagement

The DOC engagement scale is a 5-item tool developed by the authors and informed by a qualitative analysis [36] to measure engagement or interaction with other DOC users. Specifically, this tool was used to measure whether or not participants shared clinical information, requested or provided clinical guidance or feedback, or received or provided emotional support. Scores range from 0 to 5, with higher scores indicating more DOC engagement. Cronbach coefficient for DOC engagement was .73.

Health-Related Quality of Life

SF12-v2 is a 12-item tool used to measure physical and mental health status. A 4-week recall was used in this study. Norm based scoring (mean 50, SD 10) was used for this analysis [46]. Cronbach coefficient for SF-12v2 was .88 (physical=.77 and mental=.86).

Diabetes Self-Care

SCI-R is a 15-item tool used to measure diabetes self-care behaviors and can accommodate natural variation in treatment plans for patients with type 1 and type 2 diabetes. Scores range from 0 to 100 [47]. Cronbach coefficient for the SCI-R was .68.

Analysis

In a survey study such as ours, precision of parameter estimation is the key sample size criterion. We defined excellent precision operationally as an 80% probability of obtaining 95% confidence intervals for the mean, with half-width no greater than 0.15 SD. This criterion provides interval estimation with symmetric uncertainty that is smaller than Cohen familiar standard for a "small" effect. Under the 2-sided *t*-distribution, a sample size of 189 was required to meet this criterion, which conservatively guided our recruitment of a sample of 207. The final sample of 183 participants successfully achieved an 80.5% probability of 95% CI precision limited to 0.151 SD units.

Survey responses were identified by a participant number code, and all the study-related files were maintained in REDCap. Data were screened for multiple entries. In accordance with standard scoring methods, missing data were imputed with appropriately scaled item means in the calculation of total scores for the validated scales. All other missing data were excluded pairwise. Missing data made up less than 10% of each analysis. We performed statistical analysis using SPSS 21 (IBM) [53] and used exploratory data analysis to screen for errors, determine frequencies, and identify normality of distribution patterns. Cronbach alpha was calculated for each validated measure.

The primary goal was to gather detailed data on DOC users, both demographically and in terms of intensity and engagement in using the DOC, and to describe any relationship between DOC use and health indicators (HRQoL, self-care, and HbA_{1c} levels). To address our first aim, we ran frequencies for each demographic variable and used analysis of variance and Chi-square tests to examine if there were differences in demographic variables based on diabetes type. To address our second aim, scores for DOC intensity and DOC engagement were averaged. Analyses were conducted to determine relationships between, and interactions among, demographic variables, health history, eHealth use, DOC intensity, DOC engagement, HRQoL, and diabetes self-care behaviors, to address our third aim. This included correlations between DOC intensity, DOC engagement, HRQoL, and diabetes-self-care, as well as between the support participants received from their healthcare providers related to their DOC use, DOC intensity, and DOC engagement scores. A one sample *t* test was used to compare the studied sample with norms for diabetes related to health status [46] and diabetes self-care [47].

Variables that predicted the dichotomous outcome of HbA_{1c} <7% or ≥7%, based on the American Diabetes Association's recommendations for an HbA_{1c} <7% [54], were examined in a simultaneous model among DOC users. To explore this, variables were analyzed based on researcher and DOC key opinion leader knowledge of the DOC in an initial stepwise logistic regression. Stepwise logistic regression allowed us to refine the variables and to remove nonsignificant variables. We then used a simultaneous logistic regression in the final predictive model. For inference, alpha was set at .05.

Results

Recruitment

There were 1501 unique DOC site visitors who viewed the online recruitment post and 207 unique participants who completed the survey. Of those, 183 met the inclusion criteria, giving us a recruitment rate of 12.2%. Table 1 shows participant demographic data. Participants were more likely to be female, white, living in the United States in a suburban setting, well educated, employed, and to have type 1 diabetes. Participants with type 1 diabetes were younger than those with type 2 diabetes (*P*<.001), or those with LADA (*P*=.002).

Health History

Most of the participants reported receiving care for their diabetes at an endocrinology office (68.1%, 124/182), although those with type 2 diabetes were more likely to be seen by a family practice provider than those with type 1 diabetes (*P*<.001). Participants saw their healthcare providers at least quarterly (63.5%, 115/181) or every 6 months (23.8%, 43/181).

Participants had an average of 1.2 diabetes-related complications; there was a positive correlation between number of diabetes-related complications and diabetes duration (*r*=.369, *P*<.001). Those with type 1 diabetes were more likely to report depression (*P*=.01), heart disease (*P*=.01), and eye disease (*P*<.001) than those with type 2 diabetes or LADA. Over half (59.0%, 108/183) of individuals reported diabetes-related complications. Most commonly reported diabetes-related complications included depression (32%, 59/183), cardiovascular disease (27%, 49/183), retinopathy (21%, 38/183), and neuropathy (19%, 35/182). Diabetes treatments varied, although majority of the participants were using intensive insulin management (85%, 155/183). Of those undergoing intensive insulin management, 54.8% (81/147) were using an insulin pump, whereas 25.2% (37/147) were using a continuous glucose monitor. Respondents with type 1 diabetes had a longer diabetes duration than those with type 2 diabetes or LADA (*P*<.001).

eHealth Use

Participants used an average of 2.6 devices to access the internet. The majority (96.2%, 175/183) of participants spent their time reading (91.3%, 167/183), responding (74.3%, 136/183), and creating original posts (59.6%, 109/183). The time for which participants had been using DOC ranged from less than 1 year (32%, 58/183) to 1 to 3 years (37.7%, 69/183), or more than 3 years (30.4%, 56/183). The majority of respondents had not told their healthcare providers about their DOC use (67.2%, 123/183). Of those who did tell their healthcare providers about their DOC use, 60% (36/60) were supported to continue doing so, 1.9% (3/183) were not supported, and 10.9% (20/183) were not sure if their provider supported their use of the DOC.

Reasons to Join a Diabetes Online Community

A majority of the participants found participating in the DOC beneficial as it related to knowledge attainment, support, and empowerment; see Table 2. DOC users who found a benefit in their participation with the DOC reported higher DOC intensity and DOC engagement; see Table 3.

Table 1. . Demographics by type of diabetes.

Characteristics	Type 1 diabetes (n=129)	Type 2 diabetes (n=33)	LADA[a] (n=21)	Total	*P* value
Age in years, mean (SD)[b]	41 (13.6)	51.2 (11.4)	52.6 (13.7)	44.7 (14.0)	<.001
Diagnosis (duration in years), mean (SD)[b]	22.5 (14.6)	6.4 (5.7)	10.4 (10.2)	18.2 (14.6)	<.001
Gender, n (%)[c]					.09
Male	31 (24.4)	14 (42.4)	4 (20)	49 (26.8)	
Female	96 (75.6)	19 (57.6)	16 (80)	131 (71.6)	
Ethnicity, n (%)[c]					.27
Hispanic or Latino	6 (4.7)	0 (0.0)	0 (0)	6 (3.3)	
Not Hispanic or Latino	121 (95.3)	33 (100)	21 (100)	175 (95.6)	
Race, n (%)[c]					.73
American Indian or Alaskan Native	2 (1.6)	0 (0.0)	0 (0)	2 (1.1)	
Asian	2 (1.6)	0 (0.0)	1 (5)	3 (1.6)	
African American	2 (1.6)	0 (0.0)	0 (0)	2 (1.1)	
White	122 (95.3)	33 (100.0)	19 (95)	174 (95.1)	
Country, n (%)[c]					.64
United States	108 (84.4)	27 (81.8)	16 (76.2)	151 (82.5)	
Not United States	20 (15.6)	6 (18.2)	5 (24)	31 (16.9)	
Living setting, n (%)[c]					.03
Rural	16 (12.4)	11 (33.3)	6 (28.6)	33 (18.0)	
Suburban	78 (60.5)	16 (48.5)	8 (38.1)	102 (55.7)	
Urban	35 (27.1)	6 (18.2)	7 (33.3)	48 (26.2)	
Income, n (%)[c]					.58
Less than US $30,000	28 (23)	12 (36.4)	3 (16.7)	43 (23.5)	
US $30,000-$49,999	20 (16.4)	5 (15.2)	5 (27.8)	30 (16.4)	
US $50,000-$74,999	24 (19.7)	6 (18.2)	4 (22.2)	34 (18.6)	
Education, n (%)[c]					.001
Some high school	2 (1.6)	0 (0.0)	0 (0)	2 (1.1)	
High school graduate	5 (3.9)	6 (18.2)	0 (0)	11 (6.0)	
Some college	13 (10.2)	7 (21.2)	8 (38.1)	28 (15.3)	
Associate’s degree	11 (8.6)	6 (18.2)	3 (14.3)	20 (10.9)	
Bachelor’s degree	54 (42.2)	8 (24.2)	4 (19)	66 (36.1)	
Graduate degree	43 (33.6)	6 (18.2)	6 (28.6)	55 (30.1)	
Employment, n (%)[c]					.19
Student	12 (9.3)	2 (6.1)	1 (5)	15 (8.2)	
Unemployed	8 (6.2)	5 (15.2)	1 (5)	14 (7.7)	
Working part-time	20 (15.5)	4 (12.1)	3 (15)	27 (14.8)	
Working full-time	67 (51.9)	13 (39.4)	10 (50)	90 (49.2)	
Retired	9 (7)	6 (18.2)	5 (25)	20 (10.9)	
Disabled	13 (10.1)	3 (9.1)	0 (0)	16 (8.7)	
Insurance, n (%)[c]					.63
Insured	111(92.5)	32(97)	19 (95)	162 (88.5)	

Characteristics	Type 1 diabetes (n=129)	Type 2 diabetes (n=33)	LADA[a] (n=21)	Total	*P* value
Uninsured	9 (7.5)	1 (3)	1 (5)	11 (6.0)	
Treatment, n (%)[c]					<.001
No medications	0 (0)	3 (10)	0 (0)	3 (1.6)	
Oral agents only	0 (0)	15 (45)	0 (0)	15 (8.2)	
One injection[d]	0 (0)	7 (21)	3 (14)	10 (5.5)	
Intensive insulin	129 (100)	8 (24)	18 (86)	155 (84.7)	
Type of practice, n (%)[c]					<.001
Endocrinology	101 (78)	8 (24)	15 (75)	134 (67)	
Internal medicine	14 (11)	8 (24)	0 (0)	22 (11.9)	
Family practice	12 (7)	15 (46)	3 (15)	30 (16.2)	
Community clinic	2 (2)	1 (3)	1 (5)	4 (2.2)	
Other	0 (0)	1 (3)	1 (5)	2 (1.1)	

[a] Latent autoimmune diabetes of adulthood.

[b] Analysis of variance.

[c] Chi-square.

[d] One injected medication (ie, basal insulin, incretin mimetic) with or without oral medications.

Table 2. . Reasons to join a diabetes online community (DOC); N ranges from 169 to 176.

Reason to join a DOC	n (% stating yes)
The DOC helped me learn research and treatment alternatives	146 (83.4)
The DOC allows me to help others	142 (80.9)
The DOC helped me learn new diabetes management strategies	139 (80.3)
The DOC helps me feel understood	138 (79.3)
The DOC helped me get answers to many of my diabetes questions	133 (76.0)
The DOC helps me feel less alone	128 (75.7)
The DOC helps me feel more empowered	128 (73.1)
The DOC allows me to make new friends	113 (66.1)
The DOC helped me learn about potential side effects of drugs or devices	112 (64.0)
The DOC helped me learn things that my healthcare provider did not know	102 (60.0)
The DOC helps me feel support through rough times	99 (57.9)
The DOC helped me learn strategies to improve insurance coverage for diabetes-related medications or supplies	84 (47.7)
I discussed a topic I learned about on the DOC with my healthcare provider	82 (48.5)

Table 3. Relationship between diabetes online community (DOC) benefits, intensity, and engagement; N ranges from 169 to 176.

DOC benefit	DOC intensity		DOC engagement	
	Mean (SD)	*P* value	Mean (SD)	*P* value
Feel understood		<.001		<.001
Yes	3.0 (0.65)		2.7 (1.6)	
No	2.1 (0.64)		1.2 (1.3)	
Feel less alone		<.001		<.001
Yes	3.0 (0.62)		2.7 (1.7)	
No	2.2 (0.60)		1.4 (1.2)	
Feel more empowered		<.001		<.001
Yes	3.0 (0.63)		2.8 (1.6)	
No	2.1 (0.60)		1.0 (1.1)	
Feel support through rough times		<.001		<.001
Yes	3.1 (0.62)		2.92 (1.6)	
No	2.4 (0.70)		1.57 (1.5)	
Learn new diabetes management strategies		<.001		<.001
Yes	2.9 (0.67)		2.6 (1.6)	
No	2.1 (0.64)		1.4 (1.4)	
Learn research and treatment alternatives		<.001		<.001
Yes	2.9 (0.66)		2.6 (1.7)	
No	2.1 (0.70)		1.0 (0.98)	
Get answers to diabetes questions		<.001		<.001
Yes	3.0 (0.65)		2.7 (1.6)	
No	2.2 (0.67)		1.4 (1.4)	
Learn about potential side effects of drugs or devices		<.001		<.001
Yes	3.0 (0.65)		2.8 (1.6)	
No	2.3 (0.68)		1.5 (1.4)	
Learn things that my healthcare provider didn’t know		<.001		<.001
Yes	3.0 (0.68)		2.8 (1.6)	
No	2.4 (0.70)		1.5 (1.4)	
Learn strategies to improve insurance coverage for diabetes-related medications or supplies or tools		<.001		.003
Yes	3.0 (0.66)		2.7 (1.7)	
No	2.5 (0.72)		2.0 (1.6)	
Discussed a topic learned from DOC with my healthcare provider		<.001		<.001
Yes	3.0 (0.68)		3.2 (1.6)	
No	2.5 (0.68)		1.6 (1.4)	
Help others		<.001		<.001
Yes	2.9 (0.66)		2.7 (1.6)	
No	2.1 (0.74)		0.70 (0.88)	

Diabetes Online Community Intensity

The average DOC intensity scale score was 2.76 (SD .73) on a scale of 0 to 5. There was a difference in the intensity with which participants were using the DOC when comparing the 4 diabetes treatments ($F_{3,177}$=3.5, *P*=.02). Respondents who were on no medications (mean 3.1, SD 0.80) or on intensive insulin management (mean 2.8, SD 0.71) had higher DOC intensity scores when compared with those taking oral agents only (mean 2.3, SD 0.69). DOC intensity scores varied based on whether or not DOC users had told their healthcare providers about their DOC use, and if it was supported ($F_{3,170}$=11.3, *P*<.001). Specifically, DOC intensity scores were higher in those participants who had told their healthcare providers about their DOC use and felt supported (mean 3.2, SD 0.64) or were not sure (mean 3.2, SD 0.57) than those who had never told their healthcare providers about their DOC use at all (mean 2.6, SD 0.71). Type of diabetes or length of time using the DOC was not associated with DOC intensity. DOC intensity and DOC engagement were positively correlated (*r*=.572, *P*<.001).

Diabetes Online Community Engagement

The average DOC engagement score was 2.24 (SD 1.69) on a scale of 0 to 5. DOC engagement scores were related to healthcare provider knowledge and support of DOC use ($F_{3,170}$=11.0, *P*<.001). DOC engagement scores were higher for those who had told their healthcare providers about their DOC use and were unsure if they were supported (mean 2.9, SD 1.3) or felt supported (mean 3.6, SD 1.4) than for those who had never told their healthcare providers about their DOC use at all (mean 1.9, SD 1.6). DOC engagement scores were higher the longer someone had participated in the DOC. Those who had participated in the DOC for 4 or more years (mean 2.86, SD 1.7) were more engaged than those who had participated for less than 3 months (mean 1.50, SD 1.5, *P*<.001). There was no difference in DOC engagement scores for those who were insured or uninsured or by type of diabetes. Furthermore, there was no correlation between DOC engagement and age, diabetes type, or diabetes duration.

Health-Related Quality of Life

The SF-12v2 physical component summary mean score was 64.8 (SD 19) and the mental component mean summary score was 66.57 (SD 21.1); both were higher (*P*<.001, one sample *t* test) than previously reported physical component summary norms of individuals with diabetes [46]. The SF-12v2 physical component summary score negatively correlated with age (*r*=−.177, *P*=.02). The physical component summary and mental component summary were not related to diabetes type, DOC engagement, and DOC intensity.

Diabetes Self-Care Behaviors

On average, DOC participants had high self-care scores (mean 72.4, SD 12.0) compared with mean scores found in other samples of adults with type 1 and type 2 diabetes (*P*<.001, one-sample *t* test) [47]. Diabetes self-care behavior scores were lower in those who reported depression (reported depression mean 68.9, SD 13.8; reported no depression mean 74.1, SD 10.8, *P*=.007). There were positive correlations between self-care scores and DOC engagement scores (*r*=.170, *P*=.02), DOC intensity scores (*r*=.236, *P*=.002), and SF-12v2 mental component summary scores (*r*=.301, *P*<.001). There was a negative correlation between self-care scores and HbA_{1c} (*r*=−.157, *P*=.04). Correlation between diabetes self-care, HRQoL, DOC intensity, and DOC engagement is noted in Table 4.

Glycated Hemoglobin A1c Levels and Predictors

The majority (59.6%, 109/183) of survey respondents reported an HbA_{1c}<7%. There was no difference in HbA_{1c} levels between US users and non-US users, insured and uninsured users, or type of diabetes. After conducting an initial stepwise logistic regression, the final predictive binary logistic regression model (see Table 5) was employed to explain the HbA_{1c} category of <7% or ≥7% while controlling for all other variables in the model. The odds ratio for age was significant, with every 1-year increase in age yielding 34% reduction in the odds of having an HbA_{1c}≥7%. Diabetes duration generated a 1.46 odds ratio of having an HbA_{1c}≥7%. DOC engagement was a strong predictor of HbA_{1c} level; every single point increase in DOC engagement yielded a 33.8% reduction in the odds of an individual having an HbA_{1c}≥7%. There was a 2.7 times increase in the odds of having an HbA_{1c}≥7% among participants who reported that DOC helped them learn about strategies to improve insurance coverage for diabetes-related medications, supplies, and technology devices (coded yes or no).

Table 4. Correlation matrix for health indicators.

Health Indicator		1	2	3	4	5
1	DOC[a] intensity	1.00				
2	DOC engagement	.572[c]	1.00			
3	Physical HRQoL[b]	−.043	.102	1.00		
4	Mental HRQoL	−.076	.074	.651[c]	1.00	
5	Diabetes self-care	.236[d]	.170[e]	.097	.301[d]	1.00

[a] DOC: diabetes online community.

[b] HRQoL: health-related quality of life.

[c] Significance at the <.001 level.

[d] Significance at the <.01 level.

Table 5. Final model explaining risk of glycated hemoglobin $A_{1c} \geq 7\%$.

Variable	Beta	SE	*P* value[a]	Exp (B)=odds ratio	95% CI for Exp (B)
DOC[b] engagement[c]	−.413	.132	.002	0.662	0.511-0.857
Diabetes diagnosis duration[d]	.377	.108	<.001	1.459	1.180-1.803
Learned insurance coverage strategies	.987	.406	.02	2.684	1.212-5.944
Help others	−.952	.557	.09	0.386	.0130-1.150
Support through rough times	.808	.441	.07	2.243	0.946-5.320
Age in years	−.035	.014	.01	.966	0.940-0.992
Constant	.349	.793	.66	1.417	

[a] *P* value of Wald ratio.

[b] DOC: diabetes online community.

[c] Mean score of 5 dichotomous variables, coded 0 to 5.

[d] Length of time in years since diabetes diagnosis using a square root transformation to address a positive skew.

Discussion

The purpose of this study was to explore who uses the DOC, how they use it, and whether DOC use is associated with specific health indicators. Below we discuss the significant findings that support both the importance of the DOC for specific populations with diabetes and the positive association of DOC use with health indicators. We also discuss implications for clinical practice.

Principal Findings

We found an overwhelming representation of type 1 diabetes within this sample of DOC users, even though type 1 diabetes makes up only 5% to 10% of all diagnosed cases of diabetes [55]. This overrepresentation may be due to the fact that one of our recruitment sites, TuDiabaetes, had mostly individuals with type 1 diabetes using their website. An alternative explanation is that individuals with type 1 diabetes must utilize intensive insulin management techniques, whereas individuals with type 2 diabetes may not. Intensive insulin management may drive an additional need for knowledge and support, leading patients to DOC. Furthermore, those with type 1 diabetes have more exposure to technology, given that they typically are diagnosed much younger and typically use a glucometer. Those with type 1 diabetes in this sample were younger and potentially more likely to use social media in general [56]. Finally, because there are fewer individuals with type 1 diabetes compared with type 2 diabetes in the general population, those with type 1 diabetes may not be able to connect with another person with their same condition offline and this may lead them to seek others like themselves online [2]. Diabetes research conducted in other online communities, such as PatientsLikeMe, have found more respondents with type 2 diabetes, suggesting that other factors such as DOC site user characteristics and site purpose may influence who participates [57]. There was no significant difference between type of diabetes as it related to DOC engagement or HbA_{1c}.

The majority of the participants had not told their healthcare providers about their DOC use. Although our findings support the idea that DOC use is supplementary to, not in place of, regular healthcare provider visits, research has shown that healthcare providers may be hesitant to suggest DOC use due to concerns about misinformation [58,59], fear of a power imbalance from the traditional hierarchy of medicine [60,61], or fear of a challenge to their authority [62]. It is important for healthcare providers to be aware of the DOC and how health-related social media is driving a more patient-centered healthcare system [63,64] by putting the patient’s preferences and values about how they want to receive healthcare front and center [65], consistent with the eHealth-enhanced chronic care model [66]. Furthermore, healthcare providers should be learning how they can engage with DOC themselves while supporting their patients with diabetes to use the DOC [28,31,67]. If healthcare providers discuss and support DOC use with their patients, patients may be encouraged to access quality online diabetes self-care information and support. In this way, the DOC could be a complementary resource for information to support health literacy not found in the traditional healthcare model.

DOC intensity varied by treatment. Those with no medications or on intensive insulin management used DOC more intensely than those on oral agents. This is perhaps due to the fact that individuals on no medications may be accessing the DOC to educate themselves with hopes of halting the progression of their diabetes, whereas those on intensive insulin management require more education, skills, and support to manage their diabetes than those on oral agents only. Similar to other research, our study found associations between intensity of DOC use and feeling supported in disease management [68]. We did not find differences in DOC intensity between insured and uninsured participants; conversely, other research has shown that individuals with chronic conditions who were uninsured were more likely than those who were privately insured to be frequent users of online health information [69].

Our research indicates that DOC users have higher HRQoL when compared with HRQoL norms for the general population [46]. Individuals who seek online health information report being happier and healthier when compared with those who seek offline health information [70]. DOC users can quickly access health-related information they desire in multiple formats (ie, discussion board, blog, Tweetchat, etc), allowing them to easily review crowdsourced information from individuals living with diabetes, learn the same information in a variety of ways [8] from different DOC users to address learning style preferences, and focus on topics based on need and interest. The ability to obtain health information from the DOC in multiple ways supports a patient-centered approach to enhancing health literacy. The DOC also provides an avenue for individuals with diabetes to provide social support to one another. Social support, which has been linked to HRQoL scores [71], allows individuals to feel less alone in their diabetes. Individuals reported a sense of social connectedness, which strongly predicts altruism [72]. Altruism has been identified as a factor in participating in chronic disease online communities [73-75], which may enhance the social learning process.

This is the first study to demonstrate that engaging in the DOC is associated with positive health benefits for people with diabetes. DOC engagement is related to better glycemic levels, diabetes self-care, and HRQoL. DOC engagement allows individuals to share personal experiences, exchange emotional support, and gain expertise in day-to-day management techniques through crowdsourced information by peers. Although it is important to note that directionality and causation cannot be determined in this model, there is evidence to suggest that DOC engagement may lead to improved HbA_{1c} levels. Individuals who have an HbA_{1c}≥7% and longer diabetes duration may be engaging in the DOC to connect with others due to diabetes burnout. Furthermore, individuals who already had an HbA_{1c}≥7% may have sought support from the DOC to learn strategies to improve insurance coverage of diabetes-related expenses so they could in turn improve their diabetes management. Longitudinal research is necessary to understand glycemic levels as it relates to specifics of DOC use, such as learning how to improve insurance coverage for diabetes-related expenses.

Individuals with diabetes who are actively engaging in the DOC are actively participating in their own healthcare. Patient activation, known to decrease healthcare costs, is gauged by knowledge, skills, and confidence one has to manage his or her own health [76], which is associated with engagement in online communities [77]. In this study, DOC engagement was associated with increasing diabetes-related knowledge and skills, self-care, and empowerment, supporting the notion of high patient activation. Health literacy may also improve with increased diabetes-related knowledge. Research has shown that the interaction between patient activation and health literacy is associated with better glycemic levels [78]. Furthermore, patients who actively participate in medical decisions have improved glycemic levels [79]. Additional research is needed to distinctly identify how DOC impacts glycemic levels, patient activation, and health literacy.

DOC engagement was higher for DOC users whose healthcare providers supported them in their DOC use. Although it is important to note that a causal inference cannot be made, this finding has potential clinical implications in that DOC engagement may supplement current diabetes care and lead to improved glycemic levels. Participation in the DOC requires no resource allocation from the current healthcare system, although it is only available to those with internet access and a sufficient level of health literacy to use it. Despite documented benefits of face-to-face peer health [11-13,80], there are currently no professional recommendations for individuals to use peer health via the DOC to supplement their diabetes care.

Limitations

We recruited our sample from the DOC, and therefore, caution must be exercised when generalizing because of the possibility of bias due to sample self-selection. Individuals who responded to the survey may be more engaged with the DOC or have better glycemic levels. The majority of individuals in this sample identified themselves as using intensive insulin management, which does not reflect the treatment intensity seen in the general population. We had a response rate of 12.2% based on the number of times the study recruitment post was viewed by unique site visitors. Although the recruitment percentage may appear low, a response rate of <.1% is not unusual for online surveys [81]. The respondents were overwhelmingly white, college-educated females living in the United States, which may not be an accurate reflection of the entire DOC population, and is not an accurate reflection of the general population with diabetes. For example, individuals who are American Indian or Alaskan Native, black, and Hispanic are more likely to have diabetes than those who are white [82]. Finally, this study only looked at adult DOC users, and findings should not be generalized to individuals with gestational diabetes, minors, or caregivers participating in the DOC.

Self-reporting of HbA_{1c} may affect reliability of data; however, research that validated self-reported HbA_{1c} with laboratory values has shown that self-reported diabetes data are accurate >92% of the time [83]. Similar HbA_{1c} results have been found among international DOC users, in which the average HbA_{1c} was 6.9% [84]. In addition, some DOC participants have been found to share their HbA_{1c} levels with others online [84], and have gone as far as including a photograph of their lab record. Transparency in sharing health information, as seen in recent #wearenotwaiting and #OpenAPS movements on Twitter and other social media sites [85], may improve reliability in reporting, although we did not request HbA_{1c} documentation for this study.

The nature of this research cannot determine causality. We do not know if the high DOC engagement results in high self-care and optimal glycemic levels, or vice versa, or if common unknown causal factors induce the association. Prospective studies, specifically randomized control trials, are warranted to better understand DOC and its impact on health outcomes.

Conclusions

Our study found that higher engagement with the DOC was associated with HbA_{1c} levels <7%, although we cannot determine directionality of this relationship. We also found that DOC users are generally proactive in diabetes self-care behaviors and that there was a strong sense of community among DOC participants. Participants found DOC peer health to be beneficial with regard to knowledge attainment and support, factors known to enhance health literacy. Our survey indicated that DOC users are often not informing their healthcare providers about their participation with the DOC. Our findings suggest that healthcare providers should be familiar with DOC and ask their patients about use of online sources for diabetes self-care information and support. Supplementing usual healthcare activities with DOC use may encourage knowledge and support among a population that can benefit greatly from optimizing diabetes self-care. This study adds to the body of knowledge in diabetes care and online communities for chronic disease management. Further studies to determine how DOC use affects health outcomes, and how health behaviors contagiously spread throughout the DOC, would be enlightening.

Acknowledgments

This research was supported by predoctoral grants from the Jonas Center for Nursing Excellence/John A. Hartford Center and the Noorda Family Foundation/University of Utah Hartford Center of Geriatric Nursing Excellence. Additionally, this work was supported by a research grant from Sigma Theta Tau International, Nu Nu Chapter. The authors would like to acknowledge the other members of Litchman’s dissertation committee: Ginny Pepper, Joy Pierce, Scott Wright, and Erin Rothwell; and the key informants within the diabetes online community who made this study possible. The authors would also like to thank Holly Witteman, PhD, who edited an earlier version of this manuscript.

Conflicts of Interest

None declared.

References

1. Fox S. The Social Life of Health Information, 2011. Pew Research Center. 2011. Health topics URL: http://www.pewinternet.org/2011/05/12/health-topics/ [WebCite Cache ID 6xx5tRYH3]
2. Fox S. Peer-to-peer healthcare. Pew Research Center. 2011. URL: http://www.pewinternet.org/2011/02/28/peer-to-peer-health-care-2/ [WebCite Cache ID 6xx5yKMXp]
3. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [doi: 10.2196/jmir.1030] [Medline: 18725354]
4. US Department of Health and Human Services. Health.gov. Washington, DC: Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services; 2006. Expanding the reach and impact of consumer e-health tools URL: https://health.gov/communication/ehealth/ehealthTools/default.htm [accessed 2018-03-24] [WebCite Cache ID 6yAi7V31c]
5. Rubenstein EL. Crowdsourcing health literacy: the case of an online community. 2013 Presented at: Proceedings of the 76th ASIS&T Annual Meeting: Beyond the Cloud: Rethinking Information Boundaries; November 1-5, 2013; Montreal, Quebec, Canada p. 1-5. [doi: 10.1002/meet.14505001119]
6. Willis E. The making of expert patients: the role of online health communities in arthritis self-management. J Health Psychol 2014 Dec;19(12):1613-1625 [FREE Full text] [doi: 10.1177/1359105313496446] [Medline: 23988679]
7. Eysenbach G. What is e-health? J Med Internet Res 2001;3(2):E20 [FREE Full text] [doi: 10.2196/jmir.3.2.e20] [Medline: 11720962]
8. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. Health Promot Pract 2013 Jan;14(1):15-23. [doi: 10.1177/1524839911405850] [Medline: 21558472]
9. Brownson CA, Heisler M. The role of peer support in diabetes care and self-management. Patient 2009 Mar 01;2(1):5-17. [doi: 10.2165/01312067-200902010-00002] [Medline: 22273055]
10. Fisher EB, Boothroyd RI, Coufal MM, Baumann LC, Mbanya JC, Rotheram-Borus MJ, et al. Peer support for self-management of diabetes improved outcomes in international settings. Health Aff 2012 Jan;31(1):130-139 [FREE Full text] [doi: 10.1377/hlthaff.2011.0914] [Medline: 22232103]
11. Lorig K, Ritter PL, Villa FJ, Armas J. Community-based peer-led diabetes self-management: a randomized trial. Diabetes Educ 2009;35(4):641-651. [doi: 10.1177/0145721709335006] [Medline: 19407333]
12. Heisler M, Piette JD. “I help you, and you help me”: facilitated telephone peer support among patients with diabetes. Diabetes Educ 2005;31(6):869-879. [doi: 10.1177/0145721705283247] [Medline: 16288094]
13. Heisler M, Vijan S, Makki F, Piette JD. Diabetes control with reciprocal peer support versus nurse care management: a randomized trial. Ann Intern Med 2010 Oct 19;153(8):507-515 [FREE Full text] [doi: 10.7326/0003-4819-153-8-201010190-00007] [Medline: 20956707]
14. Brown SA, Garcia AA, Kouzekanani K, Hanis CL. Culturally competent diabetes self-management education for Mexican Americans: the Starr County border health initiative. Diabetes Care 2002 Feb;25(2):259-268 [FREE Full text] [Medline: 11815493]
15. Lujan J, Ostwald SK, Ortiz M. Promotora diabetes intervention for Mexican Americans. Diabetes Educ 2007;33(4):660-670 [FREE Full text] [doi: 10.1177/0145721707304080] [Medline: 17684167]

16. Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VB, et al. Online diabetes self-management program: a randomized study. Diabetes Care 2010 Jun;33(6):1275-1281 [FREE Full text] [doi: 10.2337/dc09-2153] [Medline: 20299481]
17. Ayala GX, Ibarra L, Cherrington AL, Parada H, Horton L, Ji M, et al. Puentes hacia una mejor vida (Bridges to a Better Life): outcome of a diabetes control peer support intervention. Ann Fam Med 2015 Aug;13 Suppl 1:S9-17 [FREE Full text] [doi: 10.1370/afm.1807] [Medline: 26304977]
18. Moore K, Mengel M. Expanding the team: the use of volunteers in a diabetes education program. Diabetes Educ 2002;28(4):554-8, 560, 562 [FREE Full text] [doi: 10.1177/014572170202800409] [Medline: 12224195]
19. Gilmer TP, Philis-Tsimikas A, Walker C. Outcomes of Project Dulce: a culturally specific diabetes management program. Ann Pharmacother 2005 May;39(5):817-822. [doi: 10.1345/aph.1E583] [Medline: 15769828]
20. Liebman J, Heffernan D, Sarvela P. Establishing diabetes self-management in a community health center serving low-income Latinos. Diabetes Educ 2007 Jun;33 Suppl 6:132S-138S [FREE Full text] [doi: 10.1177/0145721707304075] [Medline: 17620392]
21. Thompson JR, Horton C, Flores C. Advancing diabetes self-management in the Mexican American population: a community health worker model in a primary care setting. Diabetes Educ 2007 Jun;33 Suppl 6:159S-165S [FREE Full text] [doi: 10.1177/0145721707304077] [Medline: 17620396]
22. Two Feathers J, Kieffer EC, Palmisano G, Anderson M, Sinco B, Janz N, et al. Racial and Ethnic Approaches to Community Health (REACH) Detroit partnership: improving diabetes-related outcomes among African American and Latino adults. Am J Public Health 2005 Sep;95(9):1552-1560. [doi: 10.2105/AJPH.2005.066134] [Medline: 16051927]
23. Markowitz JT, Laffel LM. Transitions in care: support group for young adults with Type 1 diabetes. Diabet Med 2012 Apr;29(4):522-525 [FREE Full text] [doi: 10.1111/j.1464-5491.2011.03537.x] [Medline: 22150392]
24. Philis-Tsimikas A, Fortmann A, Lleva-Ocana L, Walker C, Gallo LC. Peer-led diabetes education programs in high-risk Mexican Americans improve glycemic control compared with standard approaches: a Project Dulce promotora randomized trial. Diabetes Care 2011 Sep;34(9):1926-1931 [FREE Full text] [doi: 10.2337/dc10-2081] [Medline: 21775748]
25. Funnell MM, Brown TL, Childs BP, Haas LB, Hosey GM, Jensen B, et al. National standards for diabetes self-management education. Diabetes Care 2012 Jan;35 Suppl 1:S101-S108 [FREE Full text] [doi: 10.2337/dc12-s101] [Medline: 22187467]
26. Beck J, Greenwood DA, Blanton L, Bollinger ST, Butcher MK, Condon JE, 2017 Standards Revision Task Force. 2017 National Standards for Diabetes Self-Management Education and Support. Diabetes Educ 2018 Feb;44(1):35-50. [doi: 10.1177/0145721718754797] [Medline: 29346744]
27. Litchman ML, Rothwell E, Edelman LS. The diabetes online community: older adults supporting self-care through peer health. Patient Educ Couns 2018;101(3):518-523. [doi: 10.1016/j.pec.2017.08.023] [Medline: 28947360]
28. Cooper A, Kar P. A new dawn: the role of social media in diabetes education. J Diabetes Nurs 2014;18(2):68-71 [FREE Full text]
29. Farrell H. Diabetes Online Community #DOC. Nurs Gen Pract 2014;7(4):8-10.
30. Shaffer-Hudkins E, Johnson N, Melton S, Wingert A. Social media use among individuals with diabetes. Int J Commun Health 2014;4:38-43 [FREE Full text]
31. Collins SE, Lewis DM. Social media made easy: Guiding patients to credible online health information and engagement resources. Clinical Diabetes 2013;31(3):137-141. [doi: 10.2337/diaclin.31.3.137]
32. Sparud-Lundin C, Ranerup A, Berg M. Internet use, needs and expectations of web-based information and communication in childbearing women with type 1 diabetes. BMC Med Inform Decis Mak 2011 Jul 07;11:49 [FREE Full text] [doi: 10.1186/1472-6947-11-49] [Medline: 21736713]
33. Armstrong N, Powell J. Patient perspectives on health advice posted on Internet discussion boards: a qualitative study. Health Expect 2009 Sep;12(3):313-320. [doi: 10.1111/j.1369-7625.2009.00543.x] [Medline: 19555377]
34. Jennings A, Powell J, Armstrong N, Sturt J, Dale J. A virtual clinic for diabetes self-management: pilot study. J Med Internet Res 2009;11(1):e10 [FREE Full text] [doi: 10.2196/jmir.1111] [Medline: 21821504]
35. Armstrong N, Koteyko N, Powell J. 'Oh dear, should I really be saying that on here?': issues of identity and authority in an online diabetes community. Health (London) 2012 Jul;16(4):347-365. [doi: 10.1177/1363459311425514] [Medline: 22067915]
36. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J Gen Intern Med 2011 Mar;26(3):287-292 [FREE Full text] [doi: 10.1007/s11606-010-1526-3] [Medline: 20945113]
37. Ravert RD, Hancock MD, Ingersoll GM. Online forum messages posted by adolescents with type 1 diabetes. Diabetes Educ 2004;30(5):827-834. [doi: 10.1177/014572170403000518] [Medline: 15510534]
38. Zhou X, Sun S, Yang J. Sweet Home: Understanding diabetes management via a Chinese online community. 2014 Presented at: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; April 26 - May 1, 2014; Toronto, Ontario, Canada p. 3997-4006. [doi: 10.1145/2556288.2557344]
39. Gilbert K, Dodson S, Gill M, McKenzie R. Online communities are valued by people with type 1 diabetes for peer support: how well do health professionals understand this? Diabetes Spectrum 2012 Aug 15;25(3):180-191. [doi: 10.2337/diaspect.25.3.180]

40. Oh HJ, Lee B. The effect of computer-mediated social support in online communities on patient empowerment and doctor-patient communication. Health Commun 2012;27(1):30-41. [doi: 10.1080/10410236.2011.567449] [Medline: 21797714]
41. Zrebiec JF, Jacobson AM. What attracts patients with diabetes to an internet support group? A 21-month longitudinal website study. Diabet Med 2001 Feb;18(2):154-158. [Medline: 11251681]
42. Zrebiec JF. Internet communities: do they improve coping with diabetes? Diabetes Educ 2005;31(6):825-8, 830-2, 834, 836. [doi: 10.1177/0145721705282162] [Medline: 16288090]
43. Hilliard ME, Sparling KM, Hitchcock J, Oser TK, Hood KK. The emerging diabetes online community. Curr Diabetes Rev 2015;11(4):261-272 [FREE Full text] [Medline: 25901500]
44. Hoffman-Goetz L, Donelle L, Thomson MD. Clinical guidelines about diabetes and the accuracy of peer information in an unmoderated online health forum for retired persons. Inform Health Soc Care 2009 Mar;34(2):91-99. [doi: 10.1080/17538150902865136] [Medline: 19412842]
45. Cole J, Watkins C, Kleine D. Health advice from Internet discussion forums: how bad is dangerous? J Med Internet Res 2016 Jan 06;18(1):e4 [FREE Full text] [doi: 10.2196/jmir.5051] [Medline: 26740148]
46. Ware JE, Kosinski M, Turner-Bowker DM, Gandek B. User's Manual for the SF-12v2 Health Survey. Lincoln, Rhode Island: QualityMetric Incorporated; 2007.
47. Weinger K, Butler HA, Welch GW, La Greca AM. Measuring diabetes self-care: a psychometric analysis of the Self-Care Inventory-Revised with adults. Diabetes Care 2005 Jun;28(6):1346-1352 [FREE Full text] [Medline: 15920050]
48. Ware JE, Kosinski M, Turner-Bowker DM, Gandek B. How to Score Version 2 of the SF-12 Health Survey. Lincoln, RI: QualityMetric Incorporated; 2002.
49. Ellison NB, Steinfield C, Lampe C. The benefits of Facebook “friends”: social capital and college students' use of online social network sites. J Comput Mediat Commun 2007;12(4):1143-1168. [doi: 10.1111/j.1083-6101.2007.00367.x]
50. Williams D. On and off the 'net: scales for social capital in an online era. J Comput Mediat Commun 2006 Jan;11(2):593-628. [doi: 10.1111/j.1083-6101.2006.00029.x]
51. McCroskey JC, Teven JJ. Goodwill: a reexamination of the construct and its measurement. Commun Monogr 1999;66(1):90-103. [doi: 10.1080/03637759909376464]
52. Hernandez M. dLife. 2011. Ten reasons why you should join a diabetes social network URL: http://dlife.com/diabetes/type-1/manny_hernandez/join-a-diabetes-social-network [accessed 2018-03-16] [WebCite Cache ID 6xx6zdjLM]
53. IBM Corp. IBM SPSS Statistics for Windows. Version 21.0 ed. Armonk, NY: IBM Corp; 2012.
54. American Diabetes Association. Standards of Medical Care in Diabetes-2016 Abridged for Primary Care Providers. Clin Diabetes 2016 Jan;34(1):3-21 [FREE Full text] [doi: 10.2337/diaclin.34.1.3] [Medline: 26807004]
55. US Department of Health & Human Services, National Diabetes Information Clearinghouse. Diabetes in America, 2nd ed. Washington, DC: National Institute of Diabetes and Digestive and Kidney Diseases; 2014.
56. Greenwood S, Perrin A, Duggan M. Pewinternet.: Pew Research Center: Pew Research Center's Internet and American Life Project; 2016. Social Media Update 2016 URL: http://www.pewinternet.org/2016/11/11/social-media-update-2016/ [accessed 2018-03-16] [WebCite Cache ID 6xx7Sm4mB]
57. Schroeder EB, Desai J, Schmittdiel JA, Paolino AR, Schneider JL, Goodrich GK, et al. An innovative approach to informing research: gathering perspectives on diabetes care challenges from an online patient community. Interact J Med Res 2015 Jun;4(2):e13 [FREE Full text] [doi: 10.2196/ijmr.3856] [Medline: 26126421]
58. Ahmad F, Hudak PL, Bercovitz K, Hollenberg E, Levinson W. Are physicans ready for patients with internet-based health information? J Med Internet Res 2006 Sep 29;8(3):e22. [doi: 10.2196/jmir.8.3.e22]
59. Moick M, Terlutter R. Physicians' motives for professional internet use and differences in attitudes toward the internet-informed patient, physician-patient communication, and prescribing behavior. Med 2 0 2012 Jul;1(2):e2 [FREE Full text] [doi: 10.2196/med20.1996] [Medline: 25075230]
60. Snow R, Humphrey C, Sandall J. What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. Br Med J Open 2013 Nov 14;3(11):e003583 [FREE Full text] [doi: 10.1136/bmjopen-2013-003583] [Medline: 24231459]
61. Murray E, Pollack L, White M, Lo B. Clinical decision-making: physicians' preferences and experiences. BMC Fam Pract 2007 Mar 15;8:10 [FREE Full text] [doi: 10.1186/1471-2296-8-10] [Medline: 17362517]
62. Murray E, Lo B, Pollack L, Donelan K, Catania J, Lee K, et al. The impact of health information on the Internet on health care and the physician-patient relationship: National U.S. survey among 1050 U.S. physicians. J Med Internet Res 2003;5(3):e17 [FREE Full text] [doi: 10.2196/jmir.5.3.e17] [Medline: 14517108]
63. van der Eijk M, Faber MJ, Aarts JW, Kremer JA, Munneke M, Bloem BR. Using online health communities to deliver patient-centered care to people with chronic conditions. J Med Internet Res 2013 Jun;15(6):e115 [FREE Full text] [doi: 10.2196/jmir.2476] [Medline: 23803284]
64. Hawn C. Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. Health Aff (Millwood) 2009;28(2):361-368 [FREE Full text] [doi: 10.1377/hlthaff.28.2.361] [Medline: 19275991]
65. Institute of Medicine Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001.

66. Gee PM, Greenwood DA, Paterniti DA, Ward D, Miller LM. The eHealth Enhanced Chronic Care Model: a theory derivation approach. J Med Internet Res 2015;17(4):e86 [FREE Full text] [doi: 10.2196/jmir.4067] [Medline: 25842005]
67. Smith SM, Paul G, Kelly A, Whitford DL, O'Shea E, O'Dowd T. Peer support for patients with type 2 diabetes: cluster randomised controlled trial. Br Med J 2011 Feb 15;342:d715 [FREE Full text] [Medline: 21324992]
68. Cobb NK, Graham AL, Bock BC, Papandonatos G, Abrams DB. Initial evaluation of a real-world Internet smoking cessation system. Nicotine Tob Res 2005 Apr;7(2):207-216 [FREE Full text] [doi: 10.1080/14622200500055319] [Medline: 16036277]
69. Bundorf MK, Wagner TH, Singer SJ, Baker LC. Who searches the internet for health information? Health Serv Res 2006 Jun;41(3 Pt 1):819-836 [FREE Full text] [doi: 10.1111/j.1475-6773.2006.00510.x] [Medline: 16704514]
70. Cotten SR, Gupta SS. Characteristics of online and offline health information seekers and factors that discriminate between them. Soc Sci Med 2004 Nov;59(9):1795-1806. [doi: 10.1016/j.socscimed.2004.02.020] [Medline: 15312915]
71. Aalto AM, Uutela A, Aro AR. Health related quality of life among insulin-dependent diabetics: disease-related and psychosocial correlates. Patient Educ Couns 1997 Mar;30(3):215-225. [Medline: 9104378]
72. Putnam R. Social capital: measurement and consequences. Can J Policy Res 2001;2(1):41-51.
73. Reeves D, Blickem C, Vassilev I, Brooks H, Kennedy A, Richardson G, et al. The contribution of social networks to the health and self-management of patients with long-term conditions: a longitudinal study. PLoS One 2014;9(6):e98340 [FREE Full text] [doi: 10.1371/journal.pone.0098340] [Medline: 24887107]
74. Oh S. The characteristics and motivations of health answerers for sharing information, knowledge, and experiences in online environments. J Am Soc Inf Sci 2011 Nov 01;63(3):543-557. [doi: 10.1002/asi.21676]
75. van Uden-Kraan F, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. Qual Health Res 2008 Mar;18(3):405-417. [doi: 10.1177/1049732307313429] [Medline: 18235163]
76. Hibbard JH, Greene J, Overton V. Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'. Health Aff 2013 Feb;32(2):216-222. [doi: 10.1377/hlthaff.2012.1064] [Medline: 23381513]
77. Grosberg D, Grinvald H, Reuveni H, Magnezi R. Frequent surfing on social health networks is associated with increased knowledge and patient health activation. J Med Internet Res 2016 Aug 10;18(8):e212 [FREE Full text] [doi: 10.2196/jmir.5832] [Medline: 27511272]
78. Woodard LD, Landrum CR, Amspoker AB, Ramsey D, Naik AD. Interaction between functional health literacy, patient activation, and glycemic control. Patient Prefer Adherence 2014;8:1019-1024 [FREE Full text] [doi: 10.2147/PPA.S63954] [Medline: 25092966]
79. Greenfield S, Kaplan SH, Ware Jr JE, Yano EM, Frank HJ. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. J Gen Intern Med 1988;3(5):448-457. [Medline: 3049968]
80. Rashidi K, Safavi M, Yahyavi H, Farahani H. The impact of peers' support on the hemoglobin A1C and fasting blood sugar level of patients with type 2 diabetes. Indian J Med Spec 2017;8(1):7-12. [doi: 10.1016/j.injms.2016.10.001]
81. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res 2004 Dec 29;6(3):e34 [FREE Full text] [doi: 10.2196/jmir.6.3.e34] [Medline: 15471760]
82. Centers for Disease Control and Prevention. CDC. 2017. National Diabetes Statistics Report URL: https://www.cdc.gov/features/diabetes-statistic-report/index.html [accessed 2018-03-16] [WebCite Cache ID 6xx7ej9PG]
83. Schneider AL, Pankow JS, Heiss G, Selvin E. Validity and reliability of self-reported diabetes in the Atherosclerosis Risk in Communities Study. Am J Epidemiol 2012 Oct 15;176(8):738-743 [FREE Full text] [doi: 10.1093/aje/kws156] [Medline: 23013620]
84. Weitzman ER, Adida B, Kelemen S, Mandl KD. Sharing data for public health research by members of an international online diabetes social network. PLoS One 2011 Apr 27;6(4):e19256 [FREE Full text] [doi: 10.1371/journal.pone.0019256] [Medline: 21556358]
85. Omer T. Empowered citizen 'health hackers' who are not waiting. BMC Med 2016 Aug 17;14(1):118 [FREE Full text] [doi: 10.1186/s12916-016-0670-y] [Medline: 27530970]

Abbreviations

DOC: diabetes online community
HRQoL: health-related quality of life
LADA: Latent Autoimmune Diabetes of Adulthood
REDCap: Research Electronic Data Capture
SCI-R: Self-Care Inventory-Revised

Edited by G Eysenbach; submitted 29.07.17; peer-reviewed by P Gee, M Hilliard, T Oser, H Akram, T Bose; comments to author 15.09.17; revised version received 31.01.18; accepted 18.02.18; published 24.04.18.

Please cite as:
Litchman ML, Edelman LS, Donaldson GW
Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study
JMIR Diabetes 2018;3(2):e8
URL: http://diabetes.jmir.org/2018/2/e8/
doi:10.2196/diabetes.8603
PMID:30291079

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org