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Original Paper

DiaFit: The Development of a Smart App for Patients with Type 2 Diabetes and Obesity

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Abstract

Background: Optimal management of chronic diseases, such as type 2 diabetes (T2D) and obesity, requires patient-provider communication and proactive self-management from the patient. Mobile apps could be an effective strategy for improving patient-provider communication and provide resources for self-management to patients themselves.

Objective: The objective of this paper is to describe the development of a mobile tool for patients with T2D and obesity that utilizes an integrative approach to facilitate patient-centered app development, with patient and physician interfaces. Our implementation strategy focused on the building of a multidisciplinary team to create a user-friendly and evidence-based app, to be used by patients in a home setting or at the point-of-care.

Methods: We present the iterative design, development, and testing of DiaFit, an app designed to improve the self-management of T2D and obesity, using an adapted Agile approach to software implementation. The production team consisted of experts in mobile health, nutrition sciences, and obesity; software engineers; and clinicians. Additionally, the team included citizen scientists and clinicians who acted as the de facto software clients for DiaFit and therefore interacted with the production team throughout the entire app creation, from design to testing.

Results: DiaFit (version 1.0) is an open-source, inclusive iOS app that incorporates nutrition data, physical activity data, and medication and glucose values, as well as patient-reported outcomes. DiaFit supports the uploading of data from sensory devices via Bluetooth for physical activity (iOS step counts, FitBit, Apple watch) and glucose monitoring (iHealth glucose meter). The app provides summary statistics and graphics for step counts, dietary information, and glucose values that can be used by patients and their providers to make informed health decisions. The DiaFit iOS app was developed in Swift (version 2.2) with a Web back-end deployed on the Health Insurance Portability and Accountability Act compliant-ready Amazon Web Services cloud computing platform. DiaFit is publicly available on GitHub to the diabetes community at large, under the GNU General Public License agreement.

Conclusions: Given the proliferation of health-related apps available to health consumers, it is essential to ensure that apps are evidence-based and user-oriented, with specific health conditions in mind. To this end, we have used a software development approach focusing on community and clinical engagement to create DiaFit, an app that assists patients with T2D and obesity to better manage their health through active communication with their providers and proactive self-management of their diseases.

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KEYWORDS

mHealth; diabetes; obesity; apps

Introduction

Between 1980 and 2014, the number of Americans diagnosed with diabetes increased fourfold [1]. Almost 90% of individuals with type 2 diabetes (T2D) are obese, and the global epidemic of T2D is largely explained by the dramatic increase in both the incidence and prevalence of obesity over the past 40 years. The excess lifetime medical spending for individuals with T2D is up to US \$211,400 [2], and aggregate obesity-related medical care costs in the United States reached a staggering US \$147 billion in 2008.

Poor nutrition, low levels of physical activity, and sedentary lifestyles contribute greatly to T2D and obesity [3-10]. Current national estimates show that close to 64% Americans are trying to lose weight, and that nearly half are actively engaged in a weight loss program [11]. However, primary care providers are traditionally not trained to provide expertise pertaining to physical activity and nutrition, which could aid in weight loss and improved glucose control. Therefore, it is essential to develop comprehensive novel approaches that complement clinical care, to help patients with T2D and obesity manage their conditions, and to reduce long-term T2D and obesity complications. Longer-term lifestyle interventions and behavioral modifications have been found to reduce body weight and T2D complications, including: self-monitoring of weight, dietary intake, activity, and blood glucose; and medication compliance [12]. However, these interventions are often costly and resource intensive, and lack sustainability components. Management of T2D and obesity is self-directed, as individuals need to make day-to-day decisions related to controlling their chronic diseases [13]. Cost-effective and sustainable interventions to improve T2D and obesity-related outcomes could be achieved at a relatively low cost [14], and could save hundreds of thousands of dollars at the individual level and hundreds of billions of dollars at a national level [2].

The ubiquitous nature of the Internet and mobile technologies makes them potential cost-effective and sustainable tools to improve health knowledge and outcomes for chronic diseases, such as T2D and obesity. According to the PEW Research Center, 70% of Americans have access to high-speed Internet at home [1] and 64% have access to a smartphone [15]. Growing evidence indicates that digital media (apps in particular) have the potential to be effective and scalable approaches to deliver health behavior interventions across the socioeconomic gradient [2,3,14,16-18]. However, research assessing the quality of health-related apps suggests that many of these apps lack the evidence-based standards necessary in health care [4-9]. A possible explanation for this lack of standards is that most apps are not necessarily developed with the end-user in mind, and their implementation is undertaken without patient or expert (eg, physician) input.

The primary goal of this paper is to present DiaFit, a T2D and obesity-focused iOS app, and its implementation process, involving its potential end users. The app was developed to help patients self-manage T2D and obesity, and allow physicians to keep track of their patients' progress. The majority of iOS apps targeting diabetes lack evidence-based support, functionalities,

and interfacing with devices that support standard wireless communication protocols (eg, Bluetooth, Bluetooth Low Energy [BLE], or ANT+) [6,10,11]. This limitation forces patients with T2D and obesity to use multiple apps to address the various aspects of their chronic conditions. This scenario is far from ideal, since each app is designed differently and typically comes with a learning curve before the app can be used adequately. Moreover, dealing with multiple apps might prevent the user from understanding the interactions between nutrition, medication, and glucose levels. Therefore, we developed DiaFit, an app that allows a user to store their dietary intake, physical activity log, medication use, blood glucose values, and general well-being in one app. DiaFit permits seamless uploads via Bluetooth when possible. Finally, there is evidence that when building such mobile apps, patients and physicians should be involved, in particular for health-related apps that are aimed at older adults [10]. Therefore, DiaFit was developed in close collaboration with key stakeholders, including a primary care physician, citizen scientists, and people with diabetes and/or obesity; all of whom acted as potential users. Citizen scientists are defined as lay people who engage in scientific research. In our project these individuals were paid for their time and their contributions were considered just as important as those of traditional scientists. The aim of this paper is to present the software implementation process of DiaFit, alongside the app itself.

Methods

Agile Software Development

For the purposes of this paper, the terms *client* and *stakeholder* are used interchangeably, and refer to physicians and citizen scientists. To ensure that a given software meets the needs of the client, development requires significant communication between the development team and the client [12]. When following a traditional waterfall software development lifecycle model [13], the initial phase of software production aims at producing a software requirement specification document [12]. This document describes the software simply, unambiguously, and entirely, from its architectural design to its simplest functionalities and behaviors. This approach is not well-suited for rapid software development [19]. Moreover, this approach significantly delays the presentation of functional prototypes to the stakeholders. Therefore, we followed best practices in software engineering by using an Agile software development methodology [19]. Using Agile, we followed adaptive planning and evolutionary development principles, aiming to deliver the software product early with continuous improvement.

We aimed to develop a fully integrative app that could be used to help patients manage their T2D and obesity, in a primary care setting and under the supervision of a primary care provider. We assembled a key stakeholder team comprised of citizen scientists (RB, CM, CRD), an internal medicine physician (ER), researchers in biomedical informatics, nutrition, and obesity science (FM, MC), and a software development team (TM, ZL). The citizen scientists were paid volunteers from the University of Florida Clinical and Translational Science Institute citizen scientist program. All citizen scientists had a chronic disease;

either obesity and/or diabetes. The citizen scientists acted as de facto customers for the DiaFit software, whereas the clinician had both a customer and consultant role in the project.

We followed an Agile software development methodology [19], with an emphasis on the following principles of the Agile manifesto:

1. Continuous and regular delivery of software components to allow the users to provide feedback early in the process, and to engage the intended users.
2. A project involving highly motivated individuals.
3. Regular face-to-face meetings.
4. Frequent and close cooperation between the stakeholders and continuous refinement of the design.
5. Functional software as main metric for progress.

6. Simplicity (ie, make the software as simple as possible, in collaboration with the stakeholders).

7. Pair-programming, whereby two programmers work together on a part of the code, with one programmer writing the code (the driver) and the other programmer assessing for correctness (the observer).

Requirements and Preference Elicitations

During the initial phase of the project we reviewed the limitations of existing apps (see *Comparison With Prior Work* in the *Discussion* section) [6,10,11]. We then identified the key elements necessary for the self-management of T2D and obesity, and how they could be addressed effectively using a mobile health (mHealth) approach. This phase led us to a first set of basic software requirements, resulting from best practices for T2D and obesity management, and the end-user software requirement elicitation process. The initial set of requirements generated is summarized in [Table 1](#).

Table 1. Basic requirements.

Requirement	Functional Requirement
The patient-user should be able to use application on an iPhone	DiaFit runs on the following devices running iOS 9.2 or newer: iPhone 5 to iPhone 6s Plus
The patient-user should have secure access to their account	DiaFit requires username and password for access. Passwords are saved via the keyed-hashed message authentication code - secure hash algorithm 1 random <i>salted</i> for each password, and standard encryption protocol
The patient-user should be able to track their eating habits	DiaFit provides user with access to a large nutrition database for logging dietary intake
The patient-user should be able to measure calorie intake	DiaFit calculates the calorie intake of the user, utilizing the food consumption that is input by the user, and the nutritional database
The patient-user should be able to measure carbohydrates, proteins and fats	DiaFit provides a graphical breakdown of the macronutrients consumed by the user, based on food consumption that is input by the user, and the database information
The patient-user should be able to measure calorie expenditure	DiaFit supports Fitbit devices, Apple watch, or the iPhone on which the DiaFit app is installed, and provides the following calorie expenditure: (1) energy requirement estimate [20], calculated using the data that is input by the user; and (2) physical activity energy expenditure estimate, calculated utilizing the information gathered by the device selected by the user
The patient-user should be able to track blood glucose	DiaFit allows the user to track their glucose by inputting their current glucose value, utilizing any type of glucometer
The patient-user should be able to keep track of their medication	DiaFit provides data entry for the user to manually enter any medication and, if desired, create a reminder based on the time that medicine is taken

DiaFit was implemented using iOS, so the software engineering team chose Apple's Swift 2 programming language. This approach allowed for a tight integration with the current (and future) functionalities of Apple Healthkit (a platform for collecting data from various health and fitness apps in iOS). We used a serverless back-end developed with Amazon Web Services (AWS) Lambda and AWS DynamoDB database. The use of AWS Lambda allowed the app to have high availability and scalability without provisioning or managing servers. AWS also provided Health Insurance Portability and Accountability Act compliance, as well as Family Education Rights and Privacy Act and Federal Information Security Management Act compliance, if needed. We used the United States Department of Agriculture National Nutrient Database Application Program Interface (API) [21] to allow the users to search for their food consumed, and allow the app to calculate and save the nutritional

information. The architecture of DiaFit is described in [Figure 1](#).

Additionally, we are in the process of incorporating the RxNorm API [22] into DiaFit. This addition will allow the user to access the RxNorm medication database in order to facilitate and increase the accuracy of medication entry, versus the current option of free text input. DiaFit will be made available through GitHub, under the GNU General Public License agreement, version 3 [23]. By making DiaFit open source, the diabetes community at large will have the opportunity to contribute to, refine, and expand the functionalities of the tool, promoting cooperation and innovation. Following the Agile software development methodology, the software team started the implementation of DiaFit with partial requirements, which was generated after the initial preference elicitation meeting with

the physician and citizen scientists. Using Agile allowed us to present incomplete, albeit functional, versions of DiaFit to the stakeholders of DiaFit. Therefore, an effort was made to ensure modularity of the various components of the app.

Additional requirements were identified in subsequent meetings, referred to as *sprints* in the Agile methodology, with the stakeholders of the DiaFit project. We incorporated a validated measure of well-being (Diabetes-Specific Patient-Reported Outcome Quality of Life [24]) and patient-physician communication functionality, through direct secure messaging in DiaFit. Patient-reported outcomes (PROs) are important validated measures that can be used to measure the quality of life of patients [25], and therefore provide a method to track changes. However, a tradeoff needs to be made between obtaining data through phone prompts and interfering with patients' lives. PROs can only be collected via direct manual entry of the data in the app, so we worked with citizen scientists to assess how often PROs should be elicited. Consensus was reached on PROs being entered by patients in DiaFit 1.0 when

they chose to, rather than have an app prompt requesting the data from the user. Additional focus groups in a primary care setting allowed us to answer this question more accurately. Moreover, the team acknowledged that an essential functionality of DiaFit should be the ability to seamlessly upload data pertaining to physical activity and glucose to DiaFit, via Bluetooth and BLE. These requirements are summarized in Table 2.

Conceptually, the interactive process between the research team, software team, and the *clients* is summarized in Figure 2. The specifications were obtained through a continuous and highly interactive process led by the development team, primarily via face-to-face weekly meetings with the research team, and from face-to-face monthly meetings with the physician and citizen scientists. Intermediate DiaFit versions were first presented to the research team for evaluation and feedback. Release was then presented to the *clients*, then tested for usability and functionality.

Table 2. Additional partial requirements.

Requirement	Functional Requirement
The patient-user should be able to monitor their well-being	DiaFit prompts the user weekly for Short Form (9 questions) Diabetes-Specific Patient-Reported Outcomes Quality of Life (National Institutes of Health [NIH] Patient-Reported Outcomes Measurement Information Systems [PROMIS]) [24], and stores PRO responses
The patient-user should be able to track physical activity with a variety of wearables	DiaFit allows user to synchronize with iPhone Apple step counter, iWatch, and FitBit devices, and stores steps in a database
The patient-user should be able to track blood glucose	DiaFit allows the user to track their glucose by automatically detecting if glucose data has been saved to Apple Health by a Bluetooth glucometer (ie, the wireless smart glucose-monitoring system from iHealth)
The patient-user should be able to receive feedback from their physicians	DiaFit allows patient-user to give access data logs to physician-user
The physician-user should be able to see summary statistics of their patients	DiaFit provides physician view
The physician-user should be able to send encouragement messages to patient-user	DiaFit provides secure messaging interface
The patient-user should be able to read physician-user messages	DiaFit provides secure access to messages

Figure 1. Architecture of DiaFit. API: Application Program Interface; DB: database; USDA: United States Department of Agriculture.

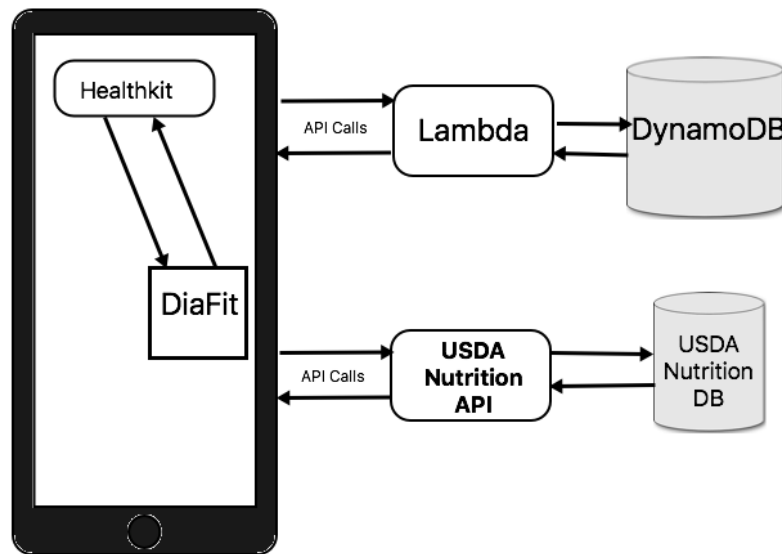
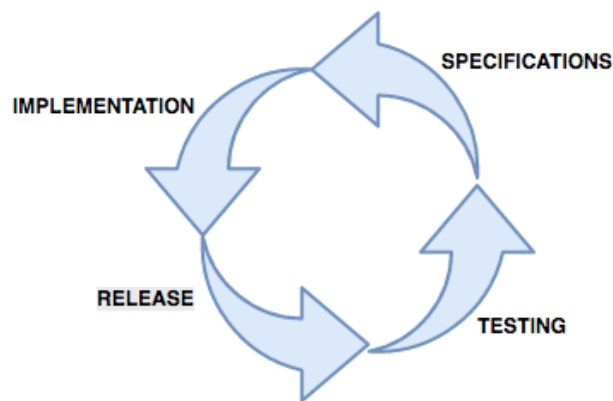


Figure 2. Agile methodology for DiaFit development.



Results

Dimensions

DiaFit incorporates account information and the following dimensions: nutrition, physical activity, blood glucose, medication, and Diabetes-Specific Patient-Reported Outcomes Quality of Life [24], as well as measures of subjective [26] and objective socioeconomic status information for research purposes. For privacy reasons, data entry is entirely voluntary, and participants may choose to leave fields blank. DiaFit

supports Bluetooth data uploads for physical activity and glucose monitoring.

Icon, Login, and Account Information

DiaFit’s icon was developed with the larger group of citizen scientists (Figure 3). The objectives were to have a meaningful icon for the intended users, as well as an icon that is found quickly on a phone, to increase the likelihood of app use, and thus adherence. The login screen is pictured in Figure 4. The basic demographics that we included in our account information screen (Figure 5) include gender, age, height, weight, marital status, and employment status.

Figure 3. DiaFit icon.

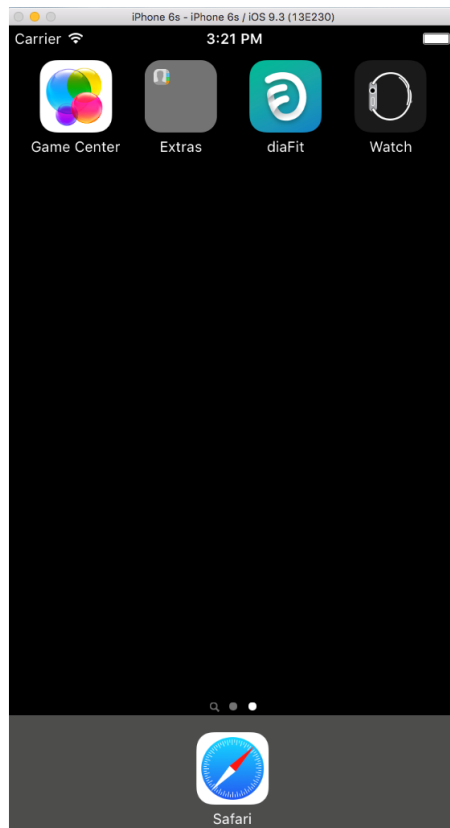


Figure 4. Login/sign-in.

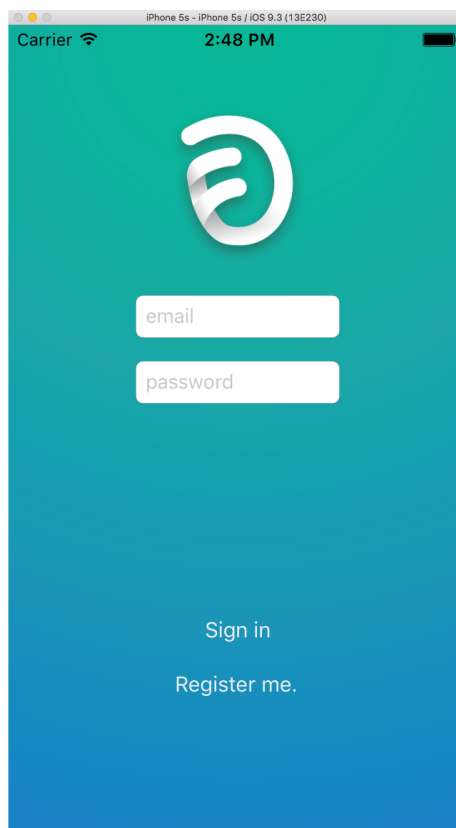


Figure 5. Account information.

The screenshot shows the 'Account' page of the DiaFit app. The page has a teal header with a hamburger menu icon on the left and the title 'Account' in the center. Below the header, there are seven white input fields with rounded corners, each containing a label and a value. The labels and values are: 'Name' (N/A), 'What is your gender?' (Male), 'What is your age?' (36), 'What is your height?' (4'6), 'What is your weight?' (151), 'What is your marital status?' (N/A), and 'What is your current employment status?' (N/A). At the bottom of the page, there are two buttons: 'Save Profile' on the left and 'Sign Out' on the right. The status bar at the top shows 'Carrier', signal strength, Wi-Fi, and the time '2:26 PM'.

Key Functionalities

The key functionalities of DiaFit were the following:

1. Access to a large nutrition database, which includes food items, calories, and breakdown in macronutrients, sodium, and fiber (Figures 6 and 7). Although micronutrients are an important aspect of a healthy diet, our discussions with the citizen scientists suggested that this would likely lead to information overload, and may not be critical to our target end-users.
2. Physical activity tracking and seamless data entry. For the first version of the DiaFit app, the software team focused on integration with iPhone activity data, Apple watch, and Fitbit devices (Figure 8).
3. Glucose monitoring, either through manual input or Bluetooth seamless upload with iHealth glucose monitors. Another feature of glucose entry is the possibility to differentiate fasting glucose versus nonfasting glucose, which can be specified by the user (Figure 9).
4. Medication use via manual data entry, although DiaFit is being improved with an RxNorm API (Figure 10).
5. PROs (Figure 11), using an NIH PROMIS short form quality of life assessment tool. These functionalities are described in Figures 4-11.

6. Simplicity was also identified as a key, albeit nonfunctional, requirement of DiaFit. Indeed, with an aging population with T2D and obesity, it is critical to make the app as simple as possible [10], which led our design choices. We opted for a slider menu (Figure 6) to allow for easy navigation through the various components of DiaFit, and we also opted for limited nutritional variables (beyond macronutrients) versus other popular nutrition/physical apps such as myfitnesspal.

Additionally, simple graphic capabilities were added to allow the user to track changes and see improvement over time. To continue our development process, our citizen scientists are undergoing software testing of the app and reporting bugs, frequency of bugs, and needed user interface changes through a Web-link.

Physician View

Finally, DiaFit offers a physician view, which allows the monitoring of patient improvements remotely and asynchronously (Figure 12). The physician side of the app also offers basic secure messaging capabilities, allowing a physician to easily and securely send a text-based message to a patient. We are also working on adding machine learning-based automated messaging capabilities to DiaFit, which will be available in the next release of the app.

Figure 6. Slider menu.

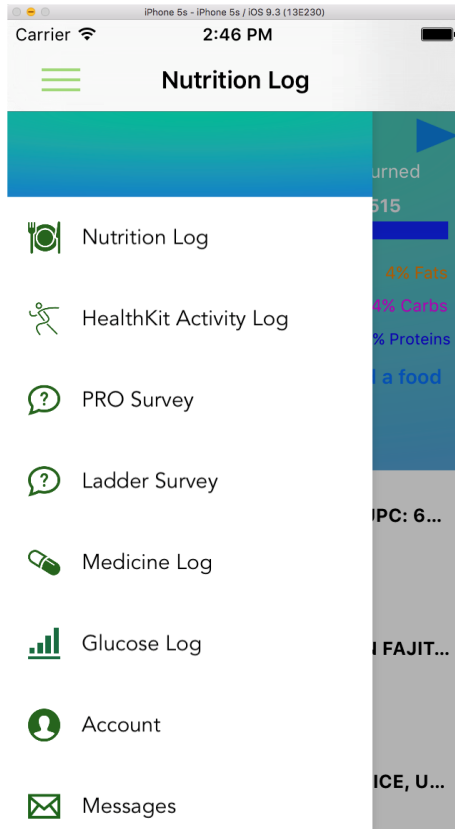


Figure 7. Nutrition tracking.

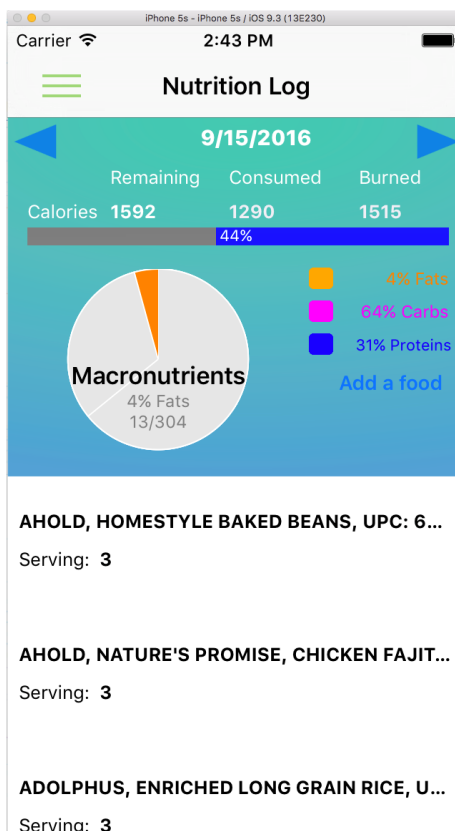


Figure 8. Physical activity log.

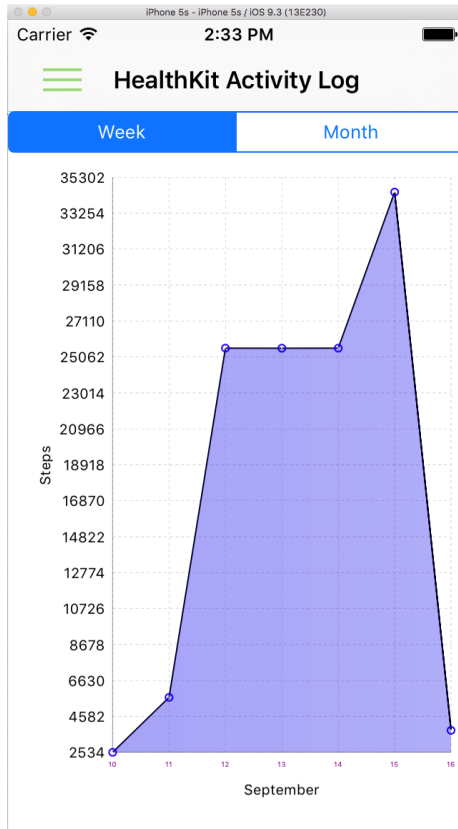


Figure 9. Glucose log.

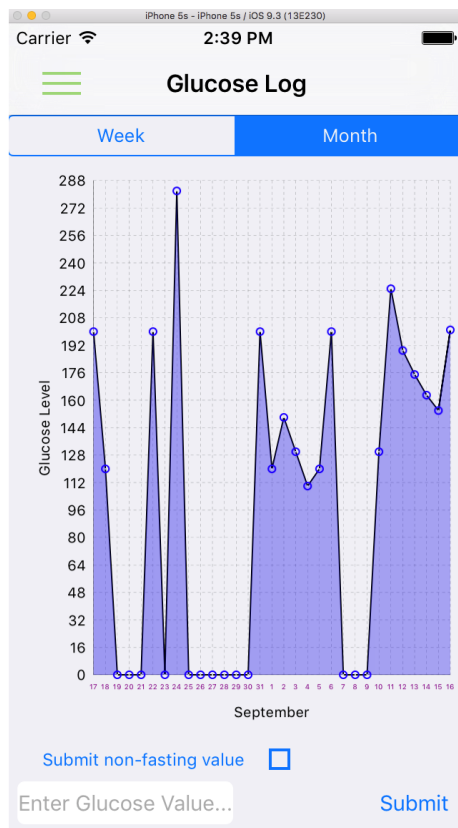


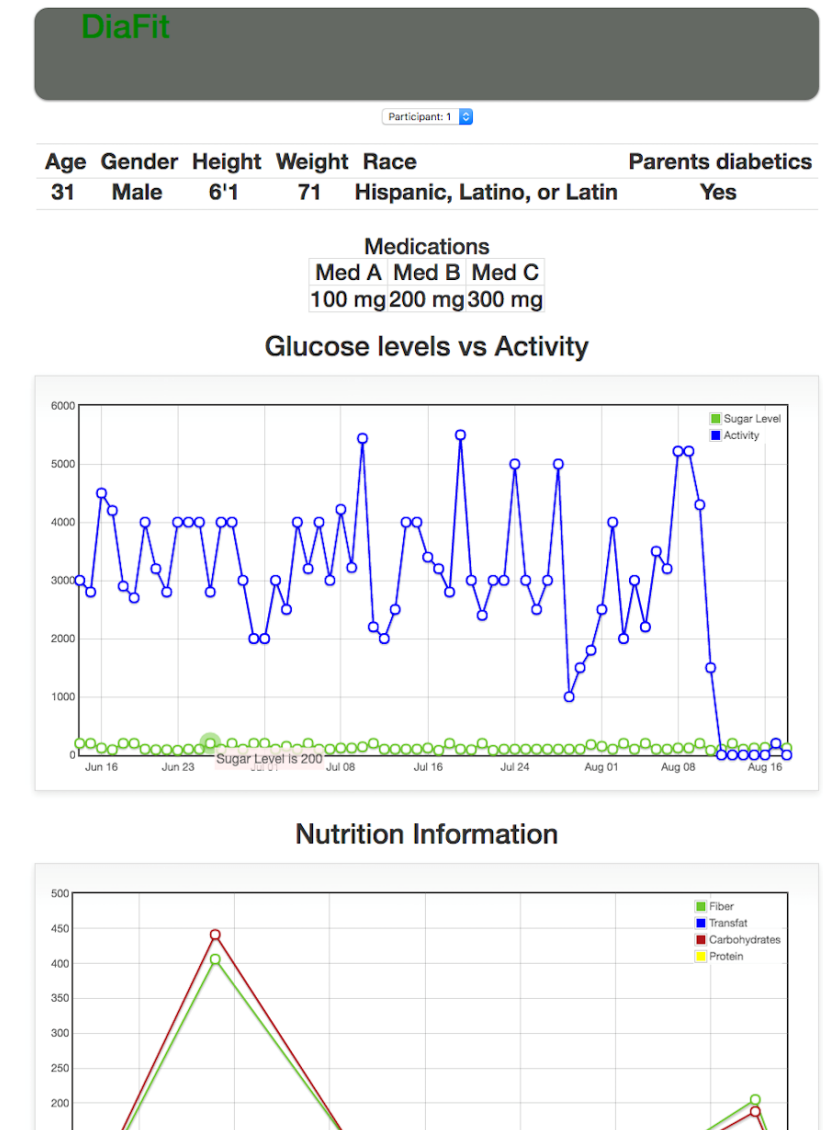
Figure 10. New medication entry.

The screenshot shows a mobile application interface for entering new medication information. The title bar at the top reads "New Medication". The form includes three input fields: "Medication Name:", "Dose:", and "Time:". Below these fields is a checkbox labeled "Do you want a reminder?". At the bottom of the form are two buttons: "Cancel" and "Save". The background of the form is a teal-to-blue gradient.

Figure 11. Patient-reported outcomes survey.

The screenshot shows a mobile application interface for a patient-reported outcomes survey. The title bar at the top reads "PRO Survey". The main question is "What is your overall quality of life?". Below the question is a scale from 0 to 10, with the text "0 is as bad as it can be, 10 is as good as it can be". The scale consists of radio buttons for each number from 0 to 10. At the bottom of the form is a "Next" button. The background of the form is a teal-to-blue gradient.

Figure 12. Physician view of DiaFit.



Discussion

Principal Results

The 2 main objectives of the DiaFit project were to (1) develop an evidence-based app that allows patients with T2D and obesity to manage their chronic conditions, and (2) ensure that the app is developed with the end-user in mind by involving them in the entire development of the product, rather than only in the testing phase (as is commonly done). To achieve this, we assembled a team of highly motivated individuals comprised of biomedical informaticians, nutrition and obesity science researchers, software engineers engaged in app development, a primary care physician, and citizen scientists with a strong interest in mHealth as a tool to address chronic conditions. To the best of our knowledge, this is the first attempt at assembling such a diverse team that included all stakeholders in the development of an app for the management of chronic conditions. It is important to note that our approach differed from that of focus groups, and that all team members acted as de facto collaborators on this project, bringing in a diverse range of expertise and perspectives. Although we included

evidence-based components in the development of DiaFit, we cannot yet state that we have successfully created an evidence-based app because the effectiveness of the app has not yet been tested. Thus, whether we have succeeded in making the app evidence-based will need to be tested in future studies, and currently remains outside the scope of this paper.

The initial meeting with all DiaFit constituents occurred in late January 2016. The design and implementation phase started in late March 2016 due to the difficulty of recruiting motivated iOS developers. Finally, the deployment of the current version of DiaFit occurred mid-August 2016. The main barrier to accelerating the development process proved to be scheduling. Coordinating meetings with several citizen scientists who work full time, and a physician with long clinical hours, resulted in the research and development teams deciding to have partial team meetings to elicit feedback for improvement. However, the high motivation of all involved parties ensured that deadlines were met, and deliverables were presented on time to DiaFit stakeholders.

Limitations and Lessons Learned

The development of DiaFit presented several challenges. Primary care physicians are significantly time-constrained. Therefore, careful planning is necessary to schedule Agile sprints early at the beginning of the project. We had not accounted for planning issues adequately at the beginning of this project, and subsequently lost a significant amount of time in early stages. Given the necessity for short time periods between meetings (ie, short Agile sprints), the development process should clearly lay out bimonthly meetings from the initial phase of the project, rather than letting development drive meeting times. However, our initial delays were mitigated by very strong clinical support for DiaFit. Having a clinician championing such a project is essential, not only to ensure sufficient feedback, but also to increase chances of adoption at later time points. Based on the expertise of our team, we decided to focus our efforts on iOS development and ignored the large Android market. With a growing segment of the population speaking Spanish, we also need to make the app available in Spanish. We are currently in version 1 of the app, and have not yet moved on to the staging that incorporates automated messaging, which would help the patients handle interactions related to diet, physical activity, and their glucose responses, which would be beneficial for self-management of T2D or obesity. Finally, DiaFit has not yet been tested as part of a pragmatic trial in a primary care setting with patients and physicians. However, prior work on mHealth strategies for diabetes management suggests that DiaFit could have a significant positive impact on patients' lives [11]. Development of DiaFit for Android, a Spanish version of DiaFit, and assessment of the DiaFit in a primary care setting (internal medicine) are planned as part of our future work.

Comparison with Prior Work

Most apps developed for managing T2D and obesity do not include all variables that need to be addressed for these chronic

conditions. Such apps typically address one dimension only, such as glucose monitoring or nutrition tracking, and often omit key functionalities that facilitate data entry and adherence, such as Bluetooth compatibility [6,10,11]. Moreover, to the best of our knowledge, no diabetes-related app attempts to link nutrition, physical activity, glucose monitoring, and medication use with PROs, thus missing critical patient feedback for quality of life with a chronic condition. App creation also lacks patient and physician involvement [10], and therefore lacks essential feedback from the targeted users. Finally, very few apps on the market are available open source, despite several attempts at democratizing health data, such as the Open mHealth initiative [27].

Conclusions

Despite the presence of >100,000 health and fitness-related apps in the Apple store alone, apps tend to be of poor quality with regards to clinical evidence. Very little effort has been placed in developing apps while including the potential end-users (eg, patients and physicians or health care professionals) in the process. In this paper, we presented the iterative process and design of the DiaFit process development, an app created to help patients with T2D and obesity manage their conditions more effectively. The process was based on the creation of a team representing all constituents of the DiaFit project, and we involved them as clients in an Agile software development project. We believe that this approach will allow academicians interested in mHealth strategies to close the gap between *fun* apps and evidence-based apps, and allow mHealth to reach its goal of revolutionizing health care by improving scalability of access. Finally, we hope that providing DiaFit as an open source solution to diabetes and obesity management will lead the community to improve and grow its functionalities to better serve patients.

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Conflicts of Interest

None declared.

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Abbreviations

API: application program interface

AWS: Amazon Web Services

BLE: Bluetooth Low Energy

mHealth: mobile health

NIH: National Institutes of Health

PRO: patient-reported outcome

PROMIS: Patient-Reported Outcomes Measurement Information Systems

T2D: type 2 diabetes

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Original Paper

Use of Social Media in the Diabetes Community: An Exploratory Analysis of Diabetes-Related Tweets

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Abstract

Background: Use of social media is becoming ubiquitous, and disease-related communities are forming online, including communities of interest around diabetes.

Objective: Our objective was to examine diabetes-related participation on Twitter by describing the frequency and timing of diabetes-related tweets, the geography of tweets, and the types of participants over a 2-year sample of 10% of all tweets.

Methods: We identified tweets with diabetes-related search terms and hashtags in a dataset of 29.6 billion tweets for the years 2013 and 2014 and extracted the text, time, location, retweet, and user information. We assessed the frequencies of tweets used across different search terms and hashtags by month and day of week and, for tweets that provided location information, by country. We also performed these analyses for a subset of tweets that used the hashtag #dsma, a social media advocacy community focused on diabetes. Random samples of user profiles in the 2 groups were also drawn and reviewed to understand the types of stakeholders participating online.

Results: We found 1,368,575 diabetes-related tweets based on diabetes-related terms and hashtags. There was a seasonality to tweets; a higher proportion occurred during the month of November, which is when World Diabetes Day occurs. The subset of tweets with the #dsma were most frequent on Thursdays (coordinated universal time), which is consistent with the timing of a weekly chat organized by this online community. Approximately 2% of tweets carried geolocation information and were most prominent in the United States (on the east and west coasts), followed by Indonesia and the United Kingdom. For the user profiles randomly selected among overall tweets, we could not identify a relationship to diabetes for the majority of users; for the profiles using the #dsma hashtag, we found that patients with type 1 diabetes and their caregivers represented the largest proportion of individuals.

Conclusions: Twitter is increasingly becoming a space for online conversations about diabetes. Further qualitative and quantitative content analysis is needed to understand the nature and purpose of these conversations.

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KEYWORDS

social media; Twitter, DSMA; diabetes community; spatiotemporal analysis; content analysis

Introduction

Use of social media is becoming ubiquitous among US individuals; according to the Pew Research Center, at least 76% of adults who are Internet users use some form of social networking site such as Facebook or Twitter [1]. Surveys have shown that 7 out of 10 US adults with chronic diseases are (1) looking online for health information about medical problems, treatments, and drugs; (2) consulting online reviews about treatments; and (3) learning about others' personal health experiences [2].

Although Facebook is still the most popular social media channel, use of additional social media channels in the US population is increasing; for example, in 2014 an estimated 23% of online adults reported that they use Twitter [3]. In particular, patients and caregivers with diabetes started to congregate and participate in online conversations about diabetes on Twitter [4], engage in virtual communication and sharing, and find peer support online.

There is growing interest in studying disease-related communities of interest online. Studies in the scientific literature have analyzed content of a small number of tweets within a short time period; for example, studies have looked at the use of Twitter by local health departments for dissemination of information about diabetes [5,6] and have performed content analysis and user profile classification with hundreds of diabetes conversations on Twitter [7,8], but we are unaware of research studies that have formally tried to perform large-scale evaluation of Twitter metrics among communities of interest focused on diabetes.

Our objective was to examine diabetes-related participation on Twitter by describing the frequency and timing of diabetes-related tweets, the geography of tweets, and the types of participants over a 2-year sample of 10% of all tweets. The results will help us better understand the extent to which patients, caregivers, and medical practitioners participate in social media discussions related to diabetes.

Methods

Data Collection

We used a dataset that contains 29.6 billion tweets obtained during 2013 and 2014 collected through the Twitter stream application programming interface (API) with Gardenhose access, which collects 10% of all public communications on Twitter (secured through a formal agreement with the University of Michigan School of Information). We identified tweets with diabetes-related search terms and hashtags based on suggestions from providers and patients in the diabetes community using the following query terms and hashtags: "glucose," "blood glucose," "diabetes," "insulin pump," "insulin," "#diabetes," "#t1d," "#type1diabetes," "#type1," "#t2d," "#type2diabetes," "#type2," "#bloodsugar," "#dsma" (Diabetes Social Media Advocacy is an online advocacy group which holds a weekly "tweetchat" to provide peer support to individuals with diabetes), "#doc" (diabetes online community), "#bgnow" (blood glucose now, in which individuals share their blood sugars),

"#wearenotwaiting" (a phrase coined by the diabetes community related to the need for rapid access to technology solutions), "#showmeyourpump" (a tweet campaign that occurred when a Miss America contestant decided to wear her insulin pump visibly), "CWD2014" (children with diabetes, a diabetes conference for children and families with diabetes), "dblog"(diabetes blog), and "diyps" (a do-it-yourself artificial pancreas project).

Spatiotemporal Analysis

For each tweet retrieved, we extracted its text content, the username of the tweet, the tweet's posted date and time, the geolocation information of the tweet if available, and whether the tweet is a retweet. We assessed the frequencies with which the retrieved tweets are used across different terms and hashtags. With the posted date information of each tweet, we examined the trend of volume of extracted tweets in each month. We conducted an analysis with 2 subsets: all users with a diabetes-related tweet and users who posted at least once with the #dsma hashtag.

User Identities Analysis

We then examined the identities of two subsets of users. We randomly sampled 500 users from the entire dataset. There were 1424 individuals who had tweeted at least once with the hashtag #dsma; we chose to focus on a smaller subset, those who had tweeted at least 3 times with hashtag #dsma (n=416), because it would identify more active members of the community and it represented a sample similar in number to our overall diabetes sample. A medical student reviewed each of the Twitter profiles to identify individuals' relationship to diabetes, which was categorized into one or more of the following 15 categories: physician, nurse, dietitian, diabetes educator, researcher, individual with type 1 diabetes, individual with type 2 diabetes, individual with diabetes not specified, caregiver/parent/guardian of an individual with diabetes, spouse/significant other of an individual with diabetes, friend of an individual with diabetes, individual who works with a diabetes-related company, health care organization, diabetes medical/device company, and other/unknown. A second individual reviewed another 50 randomly selected profiles for both subsets of users. There was interrater agreement on 44 of the 50 categorizations for the all-user subset. The Cohen kappa was .58. In the subset of #dsma users, there was interrater agreement on 40 of the 50. The Cohen kappa was .71.

Results

Of the 29.6 billion tweets in our entire dataset, there were 1,368,575 diabetes-related tweets, based on the selected diabetes terms and hashtags. One-third of these tweets (454,261) were retweets.

Table 1 shows the number and percentage of tweets and the number and percentage of users tweeting with specific search terms or hashtags in our dataset. The most common tweets were the terms including the term or hashtag diabetes, followed by insulin and glucose, and then finally references to the type of diabetes (ie, type 1 or type 2 diabetes).

Table 1. Number and percentage of tweets by terms or hashtags and the number and percentage of users tweeting with those terms or hashtags.

Term	Tweets n (%)	Users n (%)
Diabetes	1,200,268 (87.7)	748,001 (89.6)
#Diabetes	165,868 (12.1)	67,229 (8.1)
Insulin	83,820 (6.1)	59,728 (7.2)
Glucose	60,033 (4.4)	46,357 (5.6)
#Doc	27,616 (2.0)	16,457 (2.0)
#Dsma	11,757 (0.9)	1424 (0.2)
Blood glucose	10,212 (0.7)	6904 (0.8)
#T1d	9040 (0.7)	3835 (0.5)
#Dblog	5711 (0.4)	1132 (0.1)
Insulin pump	5179 (0.4)	4061 (0.5)
#Type1	3211 (0.2)	1800 (0.2)
#Type2	2905 (0.2)	1468 (0.2)
#Bgnow	2470 (0.2)	753 (0.1)
#Type1diabetes	1812 (0.1)	1248 (0.1)
#Bloodsugar	1718 (0.1)	1213 (0.1)
#Type2diabetes	1388 (0.1)	1035 (0.1)
#T2d	935 (0.1)	452 (0.1)
#Showmeyourpump	932 (0.1)	645 (0.1)
#Wearenotwaiting	327 (<0.1)	183 (<0.1)
#Diyps	132 (<0.1)	50 (<0.1)
#Cwd2014	7 (<0.1)	7 (<0.1)

Figure 1 shows the monthly breakdown of diabetes-related tweets over the 2-year period. The peak occurred in November 2013 on World Diabetes Day, with over 70,000 diabetes-related tweets (representing 10% of tweets). Figure 2 shows the total number of tweets for community using the #dsma hashtag. Both figures show increasing trends of the tweets volume.

Figure 3 shows the monthly distributions of diabetes-related tweets, which were most frequent in November, likely attributable to World Diabetes Day. For tweets using the #dsma hashtag, Figure 4 shows January had the largest proportion. Figures 5 and 6 show that the proportion of diabetes-related tweets was higher during the weekdays compared with the weekend days; mean tweets per weekday were significantly higher than for weekends (2011 per weekday vs 1684 per weekend, $P < .001$). In contrast, the majority of #dsma tweets were posted on Thursdays (Twitter API returns coordinated universal time) due to the fact that there is an online chat organized by a community of individuals with diabetes and caregivers that uses the #dsma hashtag for participating in the conversations at 9 PM eastern standard time every Wednesday night.

Approximately 2% (26,763) of tweets carried geolocation information. Table 2 shows the number of geotagged tweets for countries with at least 100 geotagged tweets, which would likely bias toward English-speaking countries because of our query terms. The United States ranked first, followed by Indonesia, United Kingdom, Venezuela, and Mexico. Figure 7 displays the locations of the geotagged tweets on a world map. For the United States, the participation appeared to be located particularly on the east coast and midwest with pockets on the west coast.

Of the 500 users randomly selected from the diabetes-related tweets, 471 of them were categorized as other/unknown. Table 3 shows the breakdown of categories. There were just 29 users for whom an identity could be assigned, including 12 health care organizations and a handful of patients with type 1 or type 2 diabetes and health care providers. In contrast, only 15.6% of #dsma members' identities were either not related to diabetes or unknown based on their Twitter profile information. The majority of individuals tweeting with #dsma had type 1 or type 2 diabetes or were caregivers. A very small percentage of individuals were health care professionals, and there was less company and health care stakeholder participation than with the general diabetes-related tweets.

Table 2. Frequency of the geotagged diabetes tweets in countries with more than 100 appearances.

Country	Number of geotagged diabetes tweets
United States	10,047
Indonesia	5355
United Kingdom	1897
Venezuela	1172
Mexico	1042
Brazil	816
Malaysia	611
Canada	590
Philippines	439
Ghana	350
Spain	325
Nigeria	299
Argentina	260
Chile	223
India	220
Australia	218
Dominican Republic	199
Netherlands	189
South Africa	185
Colombia	167
Singapore	147
Ireland	107
Sweden	105

Table 3. Categories of individuals who tweeted with diabetes-related tweets and #dsma tweets.

Users' relationship to diabetes	Users who have posted diabetes-related tweets n (%)	Users who have posted #dsma tweets n (%)
Individual with type 1 diabetes	2 (0.4)	220 (52.9)
Individual with type 2 diabetes	1 (0.2)	26 (6.3)
Individual with diabetes (type not specified)	4 (0.8)	39 (9.4)
Caregiver/parent/guardian	0	38 (9.1)
Spouse/significant other	0	3 (0.7)
Friend	0	1 (0.2)
Nurse	2 (0.4)	9 (2.2)
Physician	3 (0.6)	6 (1.4)
Diabetes educator	0	11 (2.6)
Dietician	2 (0.4)	2 (0.5)
Researcher	2 (0.4)	4 (1.0)
Diabetes company	1 (0.2)	7 (1.7)
Diabetes company employee	0	22 (5.3)
Health care organization	12 (2.4)	6 (1.4)
Other/unknown	471 (94.2)	65 (15.6)

Figure 1. Timeline of tweet volume for all diabetes-related tweets.

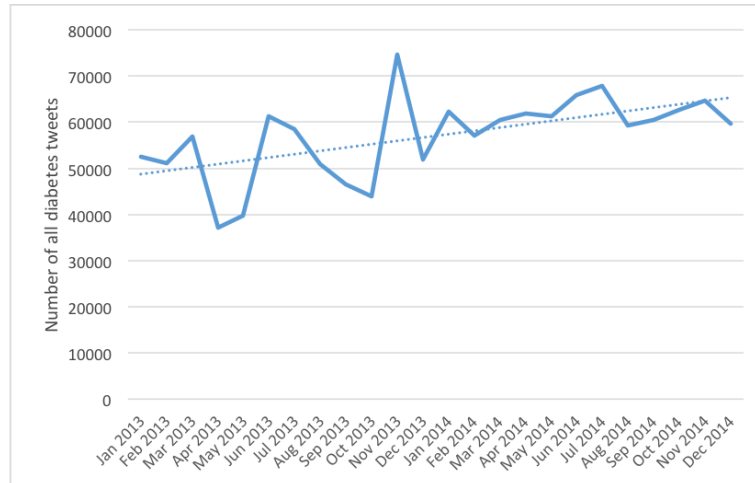


Figure 2. Timeline of tweet volume for tweets using the hashtag #dsma.

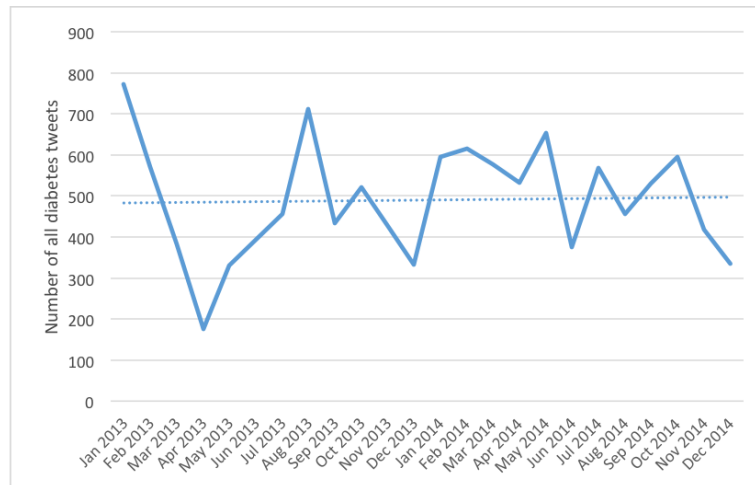


Figure 3. The proportion of tweets by month across the 2-year period for all diabetes-related tweets.

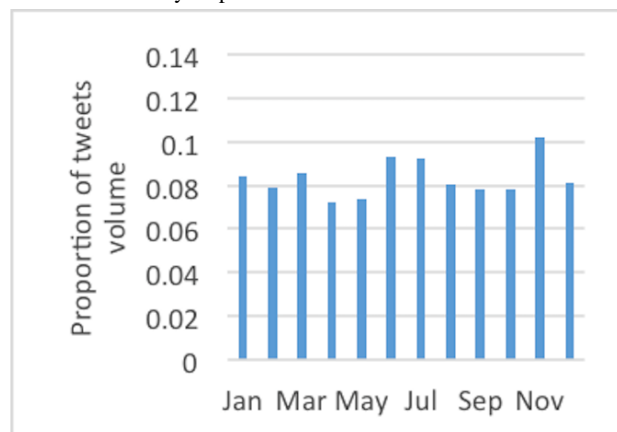


Figure 4. The proportion of tweets by month across the 2-year period for #dsma tweets.

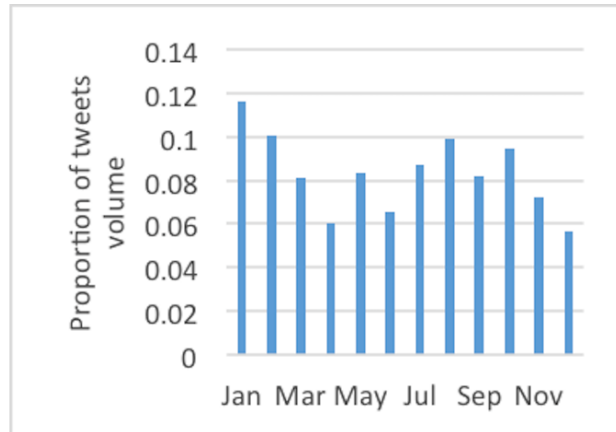


Figure 5. The proportion of tweets by day of the week across the 2-year period for all diabetes-related tweets.

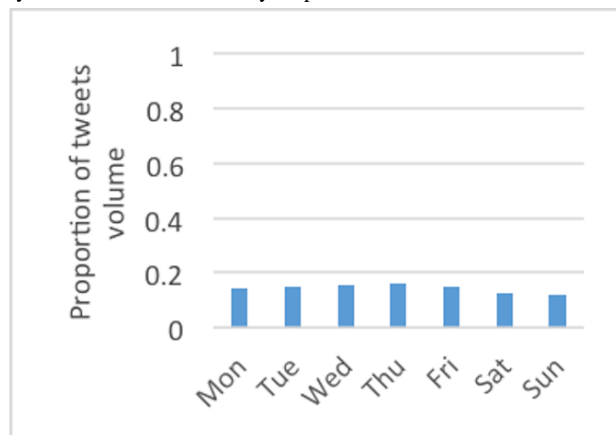


Figure 6. The proportion of tweets by day of the week across the 2-year period for #dsma tweets.

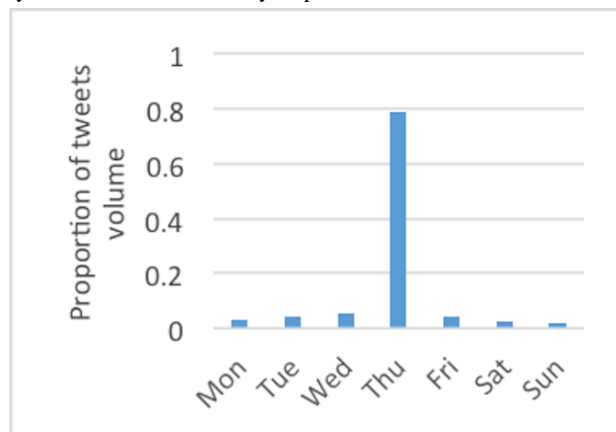
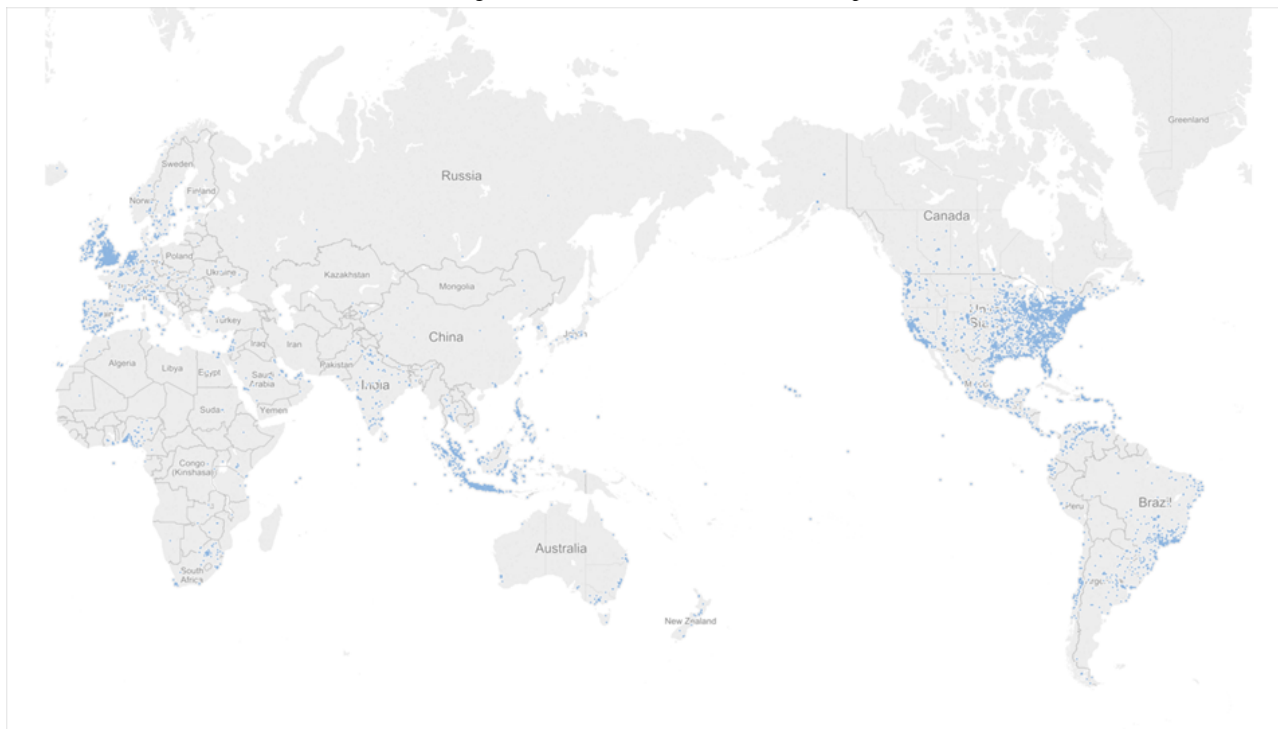


Figure 7. Visualization of diabetes-related tweets with geolocation information. Each blue dot represents one tweet.



Discussion

Principal Findings

We describe the frequency, timing, and location of diabetes-related tweets on Twitter using a large comprehensive dataset of 10% of all tweets over a 2-year period. The large and increasing volume of tweets demonstrates that social media is a growing and robust medium where communications related to diabetes are taking place; in addition, the location of tweets indicates that they are happening at a global scale.

In terms of participants on Twitter, we did not identify clear diabetes stakeholders from our random sampling of users from the pool of all diabetes-related tweets. However, when we focused on users from the #dsma community, we did find a significant proportion of patients with type 1 diabetes represented, demonstrating that they are using the medium and hashtag to communicate with a larger virtual community about diabetes during their weekly tweetchat. We found that a very small percentage of participants were health care providers, which may be consistent with the fact that #dsma is a

patient-focused chat but may also underscore the fact that physicians are reluctant participants or prefer to hide their physician or health care provider identities with regard to social media [9].

Strengths and Limitations

Strengths of our study include the ability to extract 10% of all tweets from the Twitter database over an extended time period, the use of geolocated data, and the examination of the identity of participants who are tweeting. However, we must also acknowledge limitations of our study. Because we only had access to a 10% sample, we could not perform social network analysis of the diabetes community on Twitter. We also recognize that there may be limitations with using hashtags to define a community.

Conclusions

Twitter is increasingly becoming a space for online conversations about diabetes. Further qualitative and quantitative content analysis is needed to understand the nature and purpose of these conversations.

Authors' Contributions

YL and JL conceived and led the study, analyzed the data, and drafted the manuscript. QM, DAH, and KZ made intellectual contributions to the study design and assisted in drafting the manuscript. All authors read, revised, and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface

DSMA: Diabetes Social Media Advocacy

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Original Paper

Widely Viewed English Language YouTube Videos Relating to Diabetic Retinopathy: A Cross-Sectional Study

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Abstract

Background: An emergent source of information on health issues is the Internet. One such platform with 1 billion users is YouTube, the global video-sharing service.

Objective: The purpose of this study was to describe the content and characteristics of the most widely viewed YouTube videos related to diabetic retinopathy.

Methods: Videos were sorted according to number of views using the key words “diabetic retinopathy.” For each video, general descriptive information was collected. This information included date and source of upload (news, professional, or consumer), length, and total number of views as of July 18, 2016. Content categories were largely informed by a National Eye Institute fact sheet. Each video was viewed to determine which, if any, of the given content categories were present.

Results: Of the 98 most widely viewed videos related to diabetic retinopathy, 42 were generated by consumers, 40 were generated by professionals, and 16 were generated from news-based sources. The largest number of views were generated from professionals (624,770/994,494, 63.82%). Compared with professional videos, consumer videos were viewed less frequently ($W=622, P=.04$). The main purpose of the majority of videos was to provide information (59/98, 60%), and most of the videos showed or mentioned retinopathy in general (75/98, 77%). Smaller numbers offered information about specific types of retinopathy, namely proliferative (26/98, 27%) and nonproliferative (17/98, 17%). Compared with consumer-generated videos, professional videos were 5.57 times more likely to mention that diabetic retinopathy can go unnoticed (95% CI 1.59-26.15). More than 80% (80/98) of the most widely viewed videos did not address the asymptomatic nature of the disease, only about one-third (33/98) mentioned prevention, and only 58 of the 98 videos (59%) mentioned screening.

Conclusion: Future research is needed to identify aspects of YouTube videos that attract viewer attention and best practices for using this medium to increase diabetic retinopathy screening among people with diabetes.

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KEYWORDS

diabetic retinopathy; social media; YouTube

Introduction

Diabetic retinopathy is the leading cause of blindness in adults of working age in the United States [1]. Almost 1 in 3

individuals aged 40 years and older with diabetes in the United States (28.5%) is afflicted with diabetic retinopathy or vision-threatening diabetic retinopathy [2], and rates are expected to triple between 2005 and 2050 [3]. Compared with

non-Hispanic whites, the crude prevalence for both diabetic retinopathy and vision-threatening diabetic retinopathy is significantly higher for non-Hispanic blacks [2]. Duration of disease is associated with increased risk for developing diabetic retinopathy [1]. The visual impairment or blindness caused by diabetic retinopathy can be delayed or prevented through screening that results in early detection and, when appropriate, treatment with laser photocoagulation of retinal blood vessels. But while the natural history of the disease and how it can be prevented or minimized has been known for decades, only about 60% of people with diabetes receive an annual screening [4]. Rates of diabetic retinopathy screening have been shown to be higher among non-Hispanic whites than ethnic/racial minority groups [5].

People with diabetes are turning to the Internet for information. A study of young adults with diabetes indicated that they frequent websites uploaded by both professionals and consumers [6]. A recent literature review suggested that social media had a positive impact on chronic disease care [7]. In a study of diabetes-related Facebook pages, facets of social media that may have a positive influence on health promotion were examined [8]. Video-sharing platforms offer an array of information ranging from personal experiences to clinical advice on disease management [9], yet we did not identify any published studies on the nature of the most widely viewed YouTube videos on diabetic retinopathy. The purpose of this study was, therefore, to describe the source, content, and selected characteristics of the most widely viewed YouTube videos on this largely preventable disease that causes a substantial burden of vision loss.

Methods

Background

Videos were searched on YouTube.com using Chrome as a browser with a clean search history. The search term “diabetic retinopathy” was used for this study. Video popularity was established by filtering videos by total view count. The cut point of 100 most popular videos was set, and 2 of the videos were excluded because they were not in English. Thus, the final sample included 98 videos. The National Eye Institute (NEI) fact sheet entitled “Facts About Diabetic Eye Disease” was used as a guide in creating categories to code the content of the videos [1]. In addition, categories were added deductively. At the time the categories were created, the NEI fact sheet had been reviewed in September 2015. For each video, general descriptive information was collected. This information included source of the upload, date of upload, length, and total number of views as of July 18, 2016.

Consumer videos were defined as those uploaded by a user with no depicted professional affiliations. Professional videos were defined as those posted by a trained health professional. News clips included any news from a television network or Internet-based news station. One author (AB) coded the entire sample of 100 videos. To demonstrate interrater reliability, 10 videos were chosen using a random number generator and were then coded by both AB and CHB. For the 10 videos that were doubly coded, Cohen’s kappa was .8 and percentage agreement

was 90% for one category (“Purpose of the video was to provide information about diabetic retinopathy”); for all other categories, there was 100% agreement.

Content categories were coded as “yes—mentioned” or “no—not mentioned” for each topic category. The categories used to code the videos were as follows: (1) gender of person providing information in the video (4 categories: no people shown, men shown, women shown, and both men and women shown), (2) purpose of the video was to provide information about diabetic retinopathy, (3) showed or mentioned diabetic retinopathy, (4) showed or mentioned proliferative diabetic retinopathy, (4) showed or mentioned nonproliferative diabetic retinopathy, (5) mentioned screening for diabetic retinopathy, (6) mentioned macular degeneration, (7) mentioned vision loss or blindness, (8) mentioned cataracts, (9) mentioned pain (if any) associated with diabetic retinopathy, (10) mentioned anxiety or fear of the diagnosis or screening, (11) mentioned control of diabetes, (12) mentioned symptoms (if any) for diabetic retinopathy, (13) mentioned treatment (if any) for diabetic retinopathy, (14) mentioned prevention (if any) for diabetic retinopathy, (15) mentioned that diabetic retinopathy can go unnoticed, and (16) mentioned retinal detachment.

Statistical Analysis

Analysis was conducted using R version 3.3.0 (The R Foundation). Descriptive statistics were obtained using functions “summ” and “ci” from R package epiDisplay version 3.2.2.0 [10]. Wilcoxon rank-sum test was performed for pairwise comparison on views and lengths of videos between the 3 categories, given that their distributions were not normal. The correlation between the lengths of the videos and their number of views was assessed using Spearman’s rank order correlation coefficient. Logistic regression models were applied when the outcome variable was binary. In the case of gender of person providing information in the videos, where the variable was ordinal with 4 categories, multinomial logistic regression models were applied using the R package mlogit version 0.2-4 [11].

Ethical Approval

The institutional review boards at William Paterson University and Teachers College, Columbia University, do not review studies that do not involve human subjects.

Results

Descriptive statistics for the videos are presented in Table 1. Of the 98 widely viewed videos related to diabetic retinopathy, 42 were generated by consumers, 40 were generated by professionals, and 16 were generated from news-based news sources. Collectively, these videos were viewed almost 1 million times. The largest number of views was generated from professionals (624,770/994,494, 63.82%) followed by consumer videos (256,373/994,494, 25.78%) and news-based videos (113,351/994,494, 11.40%). There was a statistically significant difference between the number of views of consumer videos and professional videos ($W=622$, $P=.04$) but not between consumer videos and news videos ($W=254$, $P=.16$) or between news videos and professional videos ($W=285.5$, $P=.54$). Pairwise comparison of the lengths of videos between each category

found no statistically significant differences (consumer vs news: $W=350.5$, $P=.81$; consumer vs professional: $W=779.5$, $P=.58$; news vs professional: $W=276.5$, $P=.44$). We found no correlation between log-transformed lengths and log-transformed views (Spearman's $\rho = -.0066$, $P=.95$).

The frequency of diabetic retinopathy videos by content and source are displayed in Table 2. In over one-third of the videos, a male was providing information (36/98, 37%). A purpose of the majority of videos was to provide information (59/98, 60%), and most of the videos showed or mentioned retinopathy in general (75/98, 77%). Smaller numbers offered information about specific types of retinopathy, namely proliferative (26/98, 27%) and nonproliferative (17/98, 17%). Other eye complications related to diabetes were rarely mentioned, with macular degeneration and cataracts being mentioned in fewer than 10% of the videos. The majority of videos (56/98, 57%) mentioned vision loss and blindness, but under half mentioned the importance of screening (40/98, 41%). Symptoms (48/98, 49%) and treatment (56/98, 57%) were frequently mentioned,

but prevention for retinopathy was mentioned in only one-third of the videos (33/98, 34%).

The odds ratio of categories of sources of YouTube videos as compared to consumer-generated videos for each content category is presented in Table 3. Findings indicate that, when compared with consumer-generated videos with no people presenting information, news videos were 6.55 times more likely to have a male presenting information (95% CI 1.17-36.61) and 9 times more likely to have males and females both presenting information (95% CI 1.03-78.57). Similarly, when compared with consumer-generated videos with no people presenting information, professional videos were 4.64 times more likely to have males presenting information (95% CI 1.40-15.32) and 7 times more likely than professional videos to have males and females presenting information (95% CI 1.36-36.01). Compared with consumer-generated videos, professional videos were 5.57 times more likely to mention that diabetic retinopathy can go unnoticed (95% CI 1.59-26.15).

Table 1. Length of videos and the number of views of 98 diabetic retinopathy-related videos in English.

	n	Video length (in minutes)				Number of views				
		Mean (SE)	Median	Range	95% CI	Mean (SE)	Median	Range	95% CI	Total (%)
Consumer	42	10.24 (3.0)	2.90	0.25-97.60	4.04- 16.44	6104 (1578)	3992	1728-68,540	2916-9292	256,373 (26)
News	16	6.49 (2.72)	2.23	0.59-44.48	0.69- 12.29	7084 (1211)	6122	1848-17,760	4503-9666	113,351 (11)
Professional	40	8.26 (2.88)	3.98	0.42-113.02	2.45- 14.08	15,620 (3422)	6194	1758- 119,100	8698-22,540	624,770 (63)
Overall	98	8.82 (1.81)	3.24	0.25-113	5.23- 12.41	10,148 (1620)	5169	1728- 119,100	6933-13,363	994,494 (100)

Table 2. Frequency count of 98 diabetic retinopathy-related videos in English by their sources and contents.

Content category	Source category of videos			Total (N=98) n (%)
	Consumer (n=42) n (%)	News (n=16) n (%)	Professional (n=40) n (%)	
Gender of person providing information in the video				
No people featured	18 (43)	2 (13)	6 (15)	26 (27)
Man featured	11 (26)	8 (50)	17 (43)	36 (37)
Woman featured	10 (24)	3 (19)	10 (25)	23 (24)
Both featured	3 (7)	3 (19)	7 (18)	13 (13)
Purpose of the video was to provide information about diabetic retinopathy				
No	21 (50)	5 (31)	13 (33)	39 (40)
Yes	21 (50)	11 (69)	27 (68)	59 (60)
Shows or mentions retinopathy				
No	11 (26)	4 (25)	8 (20)	23 (24)
Yes	31 (74)	12 (75)	32 (80)	75 (77)
Shows or mentions proliferative retinopathy				
No	29 (69)	15 (94)	28 (70)	72 (74)
Yes	13 (31)	1 (6)	12 (30)	26 (27)
Shows or mentions nonproliferative retinopathy				
No	34 (81)	16 (100)	31 (78)	81 (83)
Yes	8 (19)	0 (0)	9 (23)	17 (17)
Mentions screening				
No	27 (64)	8 (50)	23 (58)	58 (59)
Yes	15 (36)	8 (50)	17 (43)	40 (41)
Mentions macular degeneration				
No	40 (95)	14 (88)	36 (90)	90 (92)
Yes	2 (5)	2 (13)	4 (10)	8 (8)
Mentions vision loss or blindness				
No	21 (50)	5 (31)	16 (40)	42 (43)
Yes	21 (50)	11 (69)	24 (60)	56 (57)
Mentions cataract				
No	39 (93)	16 (100)	37 (93)	92 (94)
Yes	3 (7)	0 (0)	3 (8)	6 (6)
Mentions pain (if any)				
No	39 (93)	16 (100)	39 (98)	94 (96)
Yes	3 (7)	0 (0)	1 (3)	4 (4)
Mentions anxiety or fear of diagnosis or screening				
No	40 (95)	15 (94)	38 (95)	93 (95)
Yes	2 (5)	1 (6)	2 (5)	5 (5)
Mentions control of diabetes				
No	25 (60)	5 (31)	17 (43)	47 (48)
Yes	17 (41)	11 (69)	23 (58)	51 (52)
Mentions symptoms (if any)				

Content category	Source category of videos			Total (N=98) n (%)
	Consumer (n=42) n (%)	News (n=16) n (%)	Professional (n=40) n (%)	
No	24 (57)	6 (38)	20 (50)	50 (51)
Yes	18 (43)	10 (63)	20 (50)	48 (49)
Mentions treatment (if any)				
No	17 (41)	9 (56)	16 (40)	42 (43)
Yes	25 (60)	7 (44)	24 (60)	56 (57)
Mentions prevention for retinopathy				
No	30 (71)	8 (50)	27 (68)	65 (66)
Yes	12 (29)	8 (50)	13 (33)	33 (33)
Mentions that it can go unnoticed				
No	39 (93)	13 (81)	28 (70)	80 (82)
Yes	3 (7)	3 (19)	12 (30)	18 (18)
Mentions retinal detachment				
No	36 (86)	13 (81)	29 (73)	78 (80)
Yes	6 (14)	3 (19)	11 (28)	20 (20)

Table 3. The odds ratios of news and professional videos carrying contents pertinent to certain content compared with consumer-generated videos.

Content category	Odds ratio (95% CI)	P value
Gender of person providing information in the video (reference group: no people featured; reference group: consumer videos)		
News: man featured	6.55 (1.17-36.61)	.032
News: woman featured	2.70 (0.38-18.96)	.318
News: both featured	9.00 (1.03-78.57)	.047
Professional: man featured	4.64 (1.40-15.32)	.012
Professional: woman featured	3.00 (0.84-10.72)	.091
Professional: both featured	7.00 (1.36-36.01)	.020
Purpose of the video was to provide information about diabetic retinopathy		
News	2.20 (0.65-7.44)	.205
Professional	2.08 (0.85-5.09)	.110
Shows or mentions retinopathy		
News	1.06 (0.28-4.00)	.926
Professional	1.42 (0.50-4.00)	.508
Shows or mentions proliferative retinopathy		
News	0.15 (0.02-1.25)	.079
Professional	0.96 (0.37-2.45)	.925
Shows or mentions nonproliferative retinopathy		
News ^a	—	—
Professional	1.23 (0.42-3.60)	.700
Mentions screening		
News	1.80 (0.56-5.77)	.323
Professional	1.33 (0.55-3.24)	.529
Mentions macular degeneration		
News	2.86 (0.37-22.24)	.316
Professional	2.22 (0.38-12.87)	.373
Mentions vision loss or blindness		
News	2.20 (0.65-7.44)	.205
Professional	1.50 (0.63-3.60)	.364
Mentions cataract		
News ^a	—	—
Professional	1.05 (0.20-5.56)	.951
Mentions pain (if any)		
News ^a	—	—
Professional	0.33 (0.03-3.35)	.350
Mentions anxiety or fear of diagnosis or screening		
News	1.33 (0.11-15.81)	.82
Professional	1.05 (0.14-7.85)	.96
Mentions control of diabetes		
News	3.24 (0.95-11.00)	.060
Professional	1.99 (0.83-4.79)	.125
Mentions symptoms (if any)		

Content category	Odds ratio (95% CI)	P value
News	2.22 (0.68-7.25)	.186
Professional	1.33 (0.56-3.18)	.517
Mentions treatment (if any)		
News	0.53 (0.17-1.69)	.284
Professional	1.02 (0.42-2.47)	.965
Mentions prevention for retinopathy		
News	2.50 (0.76-8.19)	.130
Professional	1.20 (0.47-3.09)	.699
Mentions that it can go unnoticed		
News	3.00 (0.54-16.74)	.210
Professional	5.57 (1.44-21.60)	.013
Mentions retinal detachment		
News	1.38 (0.30-6.36)	.676
Professional	2.28 (0.75-6.90)	.146

^aIf all videos belong to a particular category of source of video, then we cannot calculate the odds ratio and the standard error will not be meaningful.

Discussion

Principal Findings

To our knowledge, this is the first study to describe the content of YouTube videos related to diabetic retinopathy. The importance of this eye disease is highlighted by the personal consequences for individuals affected [3], the large increase in incidence projected in the coming decades [3], and by the racial/ethnic disparities in recommended screening [5]. The availability of eye care professionals is unequally distributed throughout the United States [12,13] and individuals with lower levels of education and income have been shown to be less likely to have had an annual eye care visit [14,15]. Audiovisual communications such as YouTube videos are, therefore, a potentially effective approach for helping high-risk individuals make informed decisions about diabetic retinopathy screening.

With pervasive use of mobile technology, efforts using innovative communication methods are emerging. Systematic reviews of mHealth interventions for facilitating self-management of long-term illness [16] and preventive health care [17] have yielded equivocal findings. Nevertheless, there is some evidence for the value of mHealth interventions, for example, to promote lifestyle modifications associated with development of diabetes [18], and digital approaches to diabetic retinopathy screening are emerging as a way to increase access to preventive care [19]. While communication media such as YouTube have the potential to increase awareness and interest

about preventing vision loss caused by diabetic retinopathy and assist individuals in making informed choices about screening and preventive care, our data show that more than 80% of the most widely viewed diabetic retinopathy videos did not address the asymptomatic nature of the disease; only about one-third mentioned prevention, and only 58 of the 98 videos mentioned screening. Thus, while digital media such as YouTube have the potential to contribute to diabetic retinopathy prevention, to realize this will require finding ways to reach consumers, especially racial/ethnic minority groups and those with lower levels of income and education, with communications that not only reach their intended audience but contain clear, accurate, and culturally sensitive messages about the importance of early detection and treatment.

Limitations

This study was limited by the cross-sectional design, the inability to delineate the country of origin of each video, and the fact that it was limited to those videos with contents in English. In addition, the sample size was relatively small and the cut-off point of 100 videos was arbitrary. Despite these limitations, this study begins to fill a gap in the literature related to diabetic retinopathy and YouTube.

Conclusions

Future research is needed to identify aspects of YouTube videos that attract viewer attention and best practices for using this medium for increasing diabetic retinopathy screening among people with diabetes.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
NEI: National Eye Institute

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