CHALLENGES AND OPPORTUNITIES IN DIABETES SELF-MANAGEMENT EDUCATION AND SUPPORT: THE ANALYSES OF DIABETES MOBILE APPLICATIONS AND PROVIDER DOCUMENTATION PATTERNS

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By

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CHALLENGES AND OPPORTUNITIES IN DIABETES SELF-MANAGEMENT EDUCATION AND SUPPORT: THE ANALYSES OF DIABETES MOBILE APPLICATIONS AND PROVIDER DOCUMENTATION PATTERNS

Presented by Qing Ye

A candidate for the degree of

Doctor of Philosophy

And hereby certify that, in their opinion, it is worthy of acceptance.

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Dedicated to

my mom Jun Gu, dad Chuansheng Ye,

my significant other Luke Moss,

and my family and friends,

for their endless love, support, and encouragement.

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ABSTRACT

Diabetes mellitus is one of the most prevalent chronic diseases in the United States. As a disease with long-term complications requiring changes in management, diabetes requires not only education at the time of diagnosis, but ongoing diabetes self-management education. The goal of this dissertation is to identify challenges and opportunities in diabetes self-management education and support through the analyses of diabetes mobile applications and provider documentation patterns.

This dissertation includes three specific areas. First, we compared features of current diabetes mobile apps to the American Association of Diabetes Educators Self-Care Behaviors™ guidelines. A multidisciplinary team analyzed and classified the features of each eligible app based on the guidelines. The results show an unbalanced diabetes mobile apps development trend. Many apps were designed to support the behavior of Healthy Eating, Monitoring, Taking Medication and Being Active. Few apps explore the behavior of Problem Solving, Healthy Coping and Reducing Risks. Second, we identified barriers in features and usability related to the needs of older people with diabetes for diabetes self-management applications. We conducted focus groups with 10 older people with diabetes. The features that participants liked most for the diabetes self-management applications were documentation, information and goal setting. Thematic analysis revealed that usability was their primary concern about diabetes self-management applications in managing diabetes conditions. The average System Usability Scale score was 48 out of 100, which is considered not acceptable. It suggests current diabetes self-management

applications do not provide evidence-based, usable features for diabetes self-management and may not fulfill the needs of older people with diabetes. Third, we collected 200 clinic notes of follow-up visits for 100 adults with diabetes and studied the History of Present Illness (HPI) and Impression and Plan (I&P) sections. The results show that Monitoring was the most common self-care behavior mentioned in both HPI and I&P sections. Being Active was the least common self-care behavior mentioned in the HPI section and Healthy Coping was the least common self-care behavior mentioned in the I&P section. We found providers delivered more information on Healthy Eating to men compared to women in I&P section. Generally, providers delivered diabetes self-management education to people with diabetes regardless of patient characteristics. It indicates a lack of patient-centered education when people with diabetes visit providers for ongoing management.

In summary, the main contribution of this dissertation to the field of health informatics is the identification of challenges and opportunities in diabetes self-management education when people with diabetes, especially for older people, using diabetes mobile apps. It also provides verification whether healthcare providers deliver evidence-based and patient-centered diabetes education during follow-up visiting.

CHAPTER 1 - INTRODUCTION

Diabetes self-management education and support (DSME/S)

There were 34.1 million Americans adults with diabetes mellitus in 2018, including 7.3 million people who were undiagnosed [1]. Diabetes self-management education (DSME) is an organized process of teaching people with type 1 or type 2 diabetes to learn to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences associated with diabetes [2]. Diabetes self-management support (DSMS) is defined as activities that help people with diabetes engage in behaviors needed for daily self-management [3]. Diabetes self-management education and support (DSME/S) is a vital component for the management of people with diabetes [2]. A systematic review reported that DSME/S helped to improve diabetes knowledge, record eating habits and increase the frequency and accuracy of blood glucose monitoring in people with diabetes [4]. It can also help to improve glycemic control [2, 4] and reduce risks for complications from diabetes [5].

Diabetes self-management (DSM) applications (Apps)

Mobile health is defined as "the use of mobile computing and communication technologies in health care and public health" [6]. It can provide chronic disease management assistance outside hospital [7] because DSM is a daily task and requires support between office visits on an ongoing basis. There has been rapid development of health apps in recent years. A new study that was conducted by Research 2 Guidance in 2016 reported that the number of mobile health apps reached 259,000 [8]. With the explosion of health apps, the number

of apps developed for providing assistance to people with diabetes also has increased significantly [9].

Mobile health apps designed to help people with diabetes can be reliable tools for complying with self-management behaviors [10]. These apps can provide features to help people with diabetes to monitor blood sugar levels, carbohydrate intake, activities and insulin dosage. Research has indicated that people with diabetes benefit from using diabetes apps. Hou et al conducted a systematic review to assess the clinical effectiveness of diabetes apps in controlling hemoglobin A1c (HbA1c) [11]. They reported on 10 studies related to type 2 diabetes showed a decrease in HbA1c [11-21]. Similarly, a systematic review of 12 randomized controlled trials by Wu et al reported that using diabetes apps was associated with a significantly reduced HbA1c [12, 14-16, 20, 22-29].

AADE7 Self-Care Behaviors™ guidelines

Based on seven systematic reviews [30-36], the American Association of Diabetes Educators (AADE) Research Committee assessed the state of the evidence regarding the basic self-care behaviors guidelines for people with diabetes in 2007 [37]. The guidelines are the seven principles of AADE7 Self-Care Behaviors™ (AADE7™): Healthy Eating, Being Active, Monitoring, Taking Medication, Problem Solving, Reducing Risks and Healthy Coping [37]. Healthy Eating aims to "assist and facilitate individual lifestyle and eating behavior changes" and "improve metabolic control, a reduced risk in complications and improve health" [30, 38]. Being Active aims to help people with diabetes to lower cholesterol, improve blood pressure, lower stress and anxiety and improve mood through physical activity [31]. Monitoring aims to help the people with diabetes to track and confirm whether blood sugar levels are within target goals [32]. Taking Medication aims

to help keep people with diabetes' blood sugar stable and decrease risk of complications [33]. Problem Solving aims to help people with diabetes develop "a learned behavior that includes generating a set of potential strategies for problem resolution, selecting the most appropriate strategy, applying the strategy, and evaluating the effectiveness of the strategy" [34]. Reducing Risks aims to help people with diabetes to quit smoking, have regular clinic visits and take care of their feet, which would reduce the risk of stroke, loss of vision and nerve damage [35]. Healthy Coping aims to help people with diabetes to deal with "psychological and social factors" that affect "health status and quality of life" [36]. The AADE7™ is a structured, validated and widely accepted patient-centered self-management behaviors guidelines to provide the basis of DSME/S for people with type 1 or type 2 diabetes in the United States [39]. It also can help providers deliver the key points of DSME/S in an organized manner to patients with diabetes. In addition, the American Diabetes Association (ADA) [40] and the American Geriatrics Society (AGS) [41] also recommend the AADE7™ for DSM.

Problem statement

Diabetes is one of the most common chronic diseases in the world. As a disease with long-term complications requiring changes in management, diabetes requires both ongoing DSME/S and education at clinic visits. Mobile apps provide possible solutions to help people with diabetes to follow DSME/S guidelines. However, few studies have systematically examined if diabetes apps followed the evidence-based diabetes self-management guidelines. Also, few studies evaluated the usability of diabetes mobile apps, special for older people with diabetes. Not only using diabetes apps, people with diabetes may receive diabetes education during clinic visits, which is an import source for DSME/S.

However, there have been limited studies analyzing clinic notes of people with diabetes based on DSME/S guidelines and verifying whether healthcare providers deliver patient-centered DSME.

Outline of the dissertation

The dissertation is organized as follows:

Chapter 1 describes the introduction.

Chapter 2 compares the features of current diabetes mobile applications to the AADE7™ guidelines.

Chapter 3 identifies barriers in features and usability related to the needs of older people with diabetes self-management application.

Chapter 4 investigates the frequency distribution of information providers delivered to people with diabetes during clinic visits based on the AADE7™ guidelines. It also verifies whether the healthcare providers delivered diabetes education to people with diabetes based on patient characteristics.

Chapter 5 summarizes the main contributions.

CHAPTER 2 - AN ANALYSIS OF DIABETES MOBILE APPLICATIONS FEATURES COMPARED TO AADE7™: ADDRESSING SELF-MANAGEMENT BEHAVIORS IN PEOPLE WITH DIABETES

Problem statement

Diabetes mobile apps have been designed to improve knowledge of diabetes and self-management behaviors. However, very few studies have evaluated the coherence between features of diabetes apps and the evidence-based guidelines such as from the AADE. Chomutare et al analyzed the functions of 101 DSM apps from Apple iPhone, Google Android, BlackBerry, and Nokia Symbian [42]. The authors found that features of diabetes apps on the online market did not cover evidence-based recommendations. The results showed that the four most popular features were insulin and medication recording (62%), data export and communication (60%), diet recording (47%), and weight management (43%) [42]. They found a lack of other important features such as diabetes education, social media integration and alerts [42]. Similarly, in 2013, Breland et al compared features of 227 DSM apps from Apple App Store to the AADE7™ [43]. They found that the apps followed only some of the seven self-management behaviors by AADE7™ [43]. Out of 227 apps, 109 apps provided features for Self-monitoring, 106 apps for Medication, 102 apps for Healthy Eating, 67 apps for Problem Solving, 56 apps for Being Active [43]. Only 27 apps addressed Reducing Risks and 13 apps dealt with Healthy Coping [43]. However, Breland et al's study did not examine the entirety of the mobile apps for adherence to

AADE7™. Instead, they only reviewed the App Store description of the 227 apps. Because Chomutare et al mentioned that there were differences between the actual features in the apps and features promoted in the description pages in their limitations [42], Breland et al's results may have been different if all 277 apps were downloaded for review.

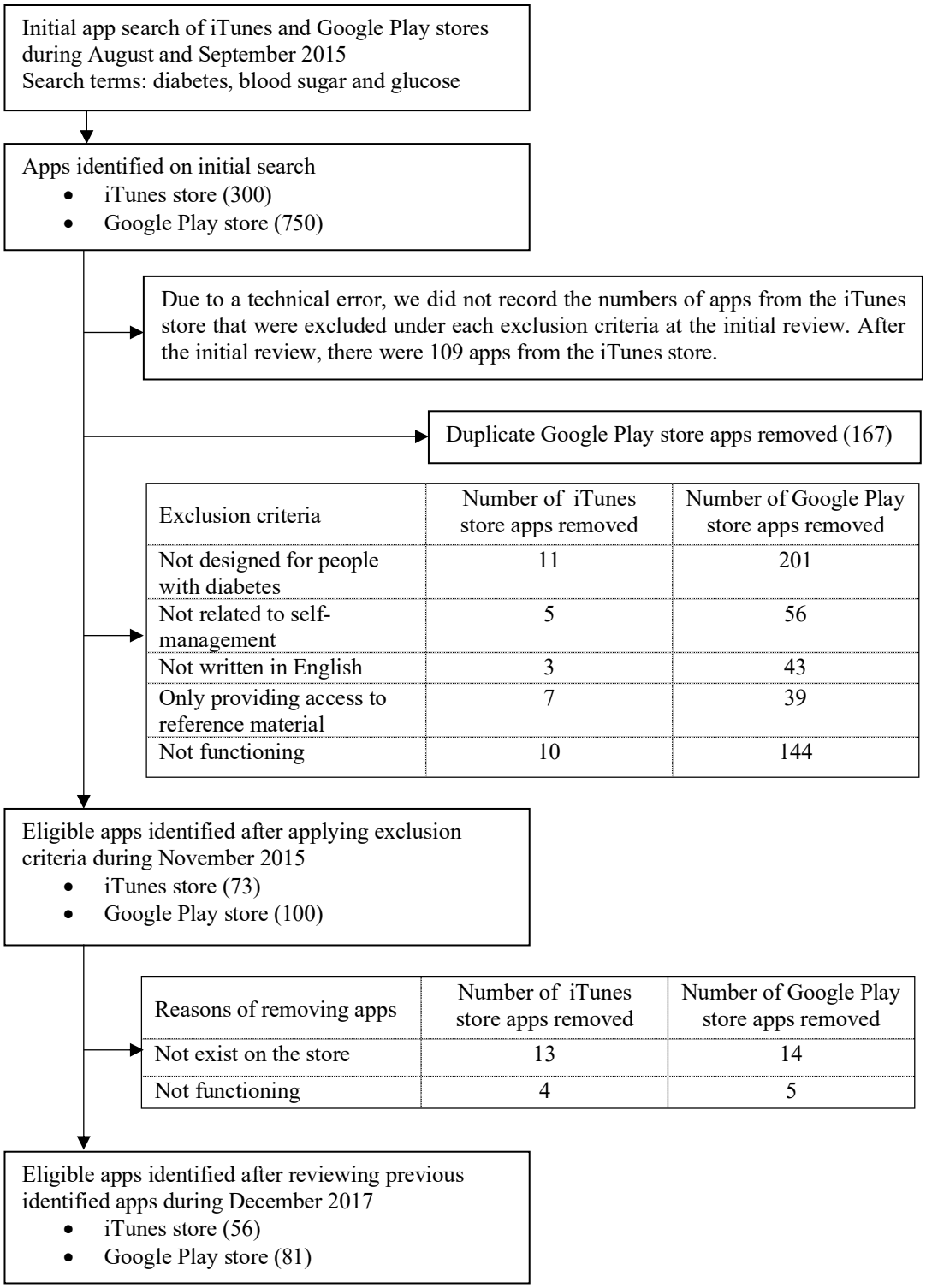
The objective of this study was to compare features of DSM apps that are currently available on the main app stores to the evidence-based AADE7™.

Methods

Identification of apps

From the Statistics Portal in March 2017, there were 2,800,000 apps on Google Play, 2,200,000 apps on iTunes Store and 669,000 apps on Windows Store [44]. iTunes and Google Play are the two largest app stores and were therefore selected to search DSM apps. We chose iPad apps from the iTunes store because the iPad screen size may be easier to read for older people with diabetes with limited visual acuity and motor control [45]. A multi-disciplinary team of a usability expert (MSK), a diabetes education researcher (SAB), an endocrinologist (UK), an epidemiologist (EJS), and a mobile health intervention developer (QY) conducted a multi-step review process (Figure 1). First, based on the use of search terms in other studies, three terms "diabetes,"[7, 42, 43, 46-49] "blood sugar," [48] and "glucose" [42, 48] were used respectively in both the app stores. Second, titles and descriptions of the retrieved apps were reviewed for select eligible DSM apps. Based on previous literature [48, 50], we developed the exclusion criteria. The apps were excluded if they (1) were not designed for people with diabetes, (2) were not related to self-management, (3) were not written in English, (4) only provided access to reference material,

Figure 1 DSM apps study flow chart.



Exclusion criteria	Number of iTunes store apps removed	Number of Google Play store apps removed
Not designed for people with diabetes	11	201
Not related to self-management	5	56
Not written in English	3	43
Only providing access to reference material	7	39
Not functioning	10	144

Reasons of removing apps	Number of iTunes store apps removed	Number of Google Play store apps removed
Not exist on the store	13	14
Not functioning	4	5

or (5) were not functioning at the time of the study. Third, the eligible apps from the iTunes store were downloaded on an iPad (4th generation). The eligible apps from the Google Play store were downloaded on a Nexus 7 and a Galaxy tab SM-T230. The author who conducted the initial review (QY) applied the exclusion criteria and identified 173 apps that were potentially eligible for the study. All authors then systematically analyzed and discussed features of each app during eight group meetings conducted over a period of three months. We tested the functionality and features of all the apps by creating a user account if required, and entering typical DSM information such as glucose level, weight and medications. We collected iTunes apps between August 31 and September 1, 2015 and Google Play apps between October 13 and October 15, 2015. We recorded each app's name, description, whether it is designed for type 1 or type 2 diabetes, price, vendor, URL, number of ratings of current version and all versions, average rating of current version and all versions, and mobile operating systems (e.g., iOS, Android). Because we used three search terms individually for both the iTunes and Google Play stores, some apps appeared multiple times. We identified and removed these duplicate apps to avoid double counting when we computed the total eligible apps for this study. Considering that there were mobile apps removed from iTunes and Google Play stores, we checked the availability and applied the exclusion criteria on the 173 apps. Then we updated the feature analysis data on the eligible apps during December 2017.

Feature analysis using AADE7™

Mobile apps are designed using specific elements or "features" to support user needs. Based on the description of each of the seven self-care behaviors in AADE7™ web page, we created a feature list which was categorized by seven self-care behaviors of AADE7™.

After eligible apps were download and tested, we recorded and classified the features of every app on the basis of the feature list. Features related to DSM but not listed in AADE7™, were recorded and classified into an "Others" category. We grouped the features in the "Others" category. We employed two types of descriptive statistics to analyze features against the AADE7™. First, we computed the unique number of apps that provide any number of features related to AADE7™. For example, an app was counted once for Healthy Eating category regardless of whether the app had one or five features that belonged to Healthy Eating. Second, we also counted the total number of features under an AADE7™ category across the apps. For example, we counted 45 features under Problem Solving. There were 38 features for "alert and reminder for abnormal data," five features for "self-monitoring," and two features for "discuss possible solutions with others."

Interview with diabetes physicians and educators

We conducted interviews with diabetes physicians and educators individually for addressing the reasons why few apps supported the features related to Problem Solving, Reducing Risks and Healthy Coping. The interview questions included how long they had worked in diabetes care or education, if they had ever recommended DSM apps to people with diabetes and their opinions on the research results. The interviews were recorded for retrospective analysis.

Results

Identification of apps

We retrieved 300 apps from the iTunes store and 750 apps from the Google Play store. After a multilevel review process, 173 apps were found eligible during November 2015 and 137 apps during December 2017 for this study. There were 56 apps from the iTunes store and 81 apps from the Google Play store (Figure 1). There were two apps designed for type 1 diabetes, nine apps designed for type 2 diabetes, 19 apps designed for both type 1 and type 2 diabetes, and 107 apps did not report in their description information about the type of diabetes for which they were designed. Out of 137 apps, most apps were free (71%, 97/137). The median price of paid apps was $2.99. The price ranged from $0.99 to $14.99 for paid apps.

Feature analysis using AADE7™

We analyzed features of the eligible apps based on the AADE7™ during November 2015 and December 2017. As shown in Table 1, we found that many apps were designed to support behaviors of Healthy Eating (72% in 2015, 77% in 2017), Monitoring (73% in 2015, 76% in 2017), Taking Medication (53% in 2015, 58% in 2017) and Being Active (39% in 2015, 45% in 2017). On the other hand, few apps were designed to provide features that support the behaviors of Problem Solving (20% in 2015, 31% in 2017), Healthy Coping (9% in 2015, 10% in 2017) and Reducing Risk (6% in 2015, 5% in 2017).

Table 1 Number of apps providing features related to each behavior of AADE7™.

AADE7™ behaviors	Number from November 2015(%)	Number from December 2017(%)
Healthy Eating	125(72)	105(77)
Being Active	67(39)	62(45)
Monitoring	126(73)	104(76)
Taking Medication	92(53)	79(58)
Problem Solving	35(20)	42(31)
Reducing Risks	10(6)	7(5)
Healthy Coping	15(9)	14(10)

Table 2 presents the feature list in each self-care behavior and the number of features related to the AADE7™ across the 137 apps. There were several features that were covered well by current DSM apps, including "count carbohydrates" and "monitor eating" under Healthy Eating, "keep track of activities" under Being Active, "record blood sugar levels" and "record height or weight or BMI" under Monitoring and "keep track of medications" under Taking Medication. There were several features that are suggested by AADE7™ with zero count, indicating that no apps provided any of those features. For example, "report smoking behavior" under Reducing Risks were not provided in any apps.

Table 2 Number of features related to AADE7™ across the 137 apps.

AADE7™ Behaviors	Number of Features across the apps
Healthy Eating (316)	Count carbohydrates* (79), Monitor eating (58), Measure each serving*(46), Read food labels*(45), Provide Recipes (20), Prevent high or low blood sugar*(19), Provide knowledge of healthy eating (13), Set goals for healthy eating*(12), Remind to eat (9), Develop an eating plan*(7), Share record of eating, send it through Email, forum (5), Provide restaurants information (3).
Being Active (99)	Keep track of activities*(54), Check blood sugar levels before and after exercise*(18), Provide knowledge of exercise (8), Set exercise goal (7), Remind to do exercise (7), Send record of exercise through forum and email (3),

	Start exercising*(1), Do exercise at personal pace*(1), Mix it up*(0), Choose activities*(0), Find a friend to exercise with*(0), Take a class*(0), Join an adult league*(0).
Monitoring (322)	Record blood sugar levels*(97), Record height or weight or BMI (54), Set goals (44), Record blood pressure, pulse (41), Record lab test results (25), Remind to check blood sugar*(24), Send record of blood sugar through forum and email (15), Prepare solutions when the numbers are out of the target range*(7), Provide knowledge of blood sugar (7), Record other vital signs(4), Record the spot of blood sugar testing or insulin injection (3), Learn how to use a blood sugar (glucose) meter*(1).
Taking Medication (164)	Keep track of medications (68) Manage medication list*(45), Calculate recommended insulin dosage (20), Remind to take medication (13), Send record of medication through forum and email (10), Provide knowledge of medication (5), Record medicine adherence (2), Clinical goal of medication*(1).
Problem Solving (45)	Alert and reminder for abnormal data (38), Self-monitoring*(5), Discuss possible solutions with others*(2), Take action*(0), Learn from experience*(0), Try new solutions*(0).
Reducing Risks (16)	Visit the eye doctor at least once a year*(4), Take care of the feet*(4), Provide knowledge of reducing risks (3), See the doctor regularly*(2), See the dentist every six months*(1), Listen to the body*(1), Provide forum topics include diabetes complication (1), Report smoking behavior*(0).
Healthy Coping (14)	Record mood (8), Attend support groups*(5), Do exercise*(1), Participate in faith-based activities or meditation*(0), Pursue hobbies*(0).
Others (93)	Share general reports, forum topics include diabetes management (61), General reminder (14), Provide knowledge related to diabetes(13), Export data (4), Record emergency contact information (1).

The number in the parentheses after each of the seven behaviors indicates the sum of features that related to each of the seven self-care behaviors. The number in the parentheses after each feature indicates the sum of each feature category across the entirety mobile apps.
* indicates features from AADE7™.

Interview with diabetes physicians and educators

The author (QY) conducted six interviews with two diabetes physicians and four diabetes educators during November 2016. The interviews lasted between 15 and 30 minutes. The median experience working with people with diabetes was 15 years for this group, and ranged from 14 months to 29 years.

Based on these interviews, we summarized the main reasons for lack of features addressed in DSM apps.

Regarding Problem Solving, the interviewees summarized four main reasons why features related to Problem Solving have been less developed in DSM apps.

First, features related to Problem Solving are more likely to be based on qualitative information rather than quantitative data, and as such may be hard to incorporate in a mobile app for DSM. An example of comments from interviewees:

- "Healthy Eating, Being Active, Monitoring and Taking Medication, are all the things that you can write down. For Problem Solving, that's not easy to pinpoint."

Second, there may be too many variables in the decision making process to address Problem Solving in DSM. An example of comments from interviewees:

- "(Why did you not have breakfast?) Because I got up later. (Why did you get up late?) Because I have three kids. You need to consider many variables in the problem tree."

Third, the interviewees also identified that Problem Solving, especially in chronic diseases, is best done with direct interaction between the learner and the educator. An example of comments from interviewees:

- "There is no human interaction to support your need."

Fourth, online search engines are easily accessible for information regarding diabetes. Many people with diabetes may be using these search engines to address Problem Solving related to DSM. The interviewees thought that when compared to the online search engines, the DSM apps failed to provide effective support for solving problems. This may be related to ease of query, and to simultaneous suggestions of possible answers within a few seconds. An example of comments from interviewees:

- "When they had problem, Google was even faster than the app."

Regarding Reducing Risks, the interviewees summarized four main reasons why the features related to Reducing Risks have been less developed in DSM apps.

First, again, as in Problem Solving, features related to Reducing Risks are not based on quantitative data. An example of comments from interviewees:

- "It's not like black and white concrete information. It's not based on numbers."

Second, regular follow up, and evaluation of comorbidities is part of Reducing Risks. Many people with diabetes use other tools like calendars and notebooks to set up reminders. An example of comments from interviewees:

- "I see many people with diabetes set reminders in [their] calendar."

Third, Reducing Risk needs appropriate suggestions from providers. Many people with diabetes may be unaware of their role in this process. An example of comments from interviewees:

- "For example, [the person who is] quitting smoking needs to find other alternatives to replace cigarettes. [The person who involved in] Nicotine replacement therapy need suggestions from physicians."

Fourth, many people with diabetes may lack information or resources to address risks associated with diabetes, and as such, cannot participate actively in an app feature for Reducing Risks. An example of comments from interviewees:

- "I have not seen patients response well. For example, see the dentist. The patients need to pay."

Regarding Healthy Coping, the interviewees summarized three main reasons why the features related to Healthy Coping have been less developed in DSM apps.

First, every person with diabetes deals with not just chronic medical condition, but may be facing distinctly different social, financial and psychological stresses in life. The interviewees thought this would make it difficult to develop a DSM app with the features related to Healthy Coping. An example of comments from interviewees:

- "It is not easy to develop such an app."

Second, Healthy Coping requires self-care and establishment of a support network. The lack of an emotional connection when using mobile apps may be a drawback. This feature would be hard to incorporate in a mobile app also. An example of comments from interviewees:

- "We should consider the emotional needs. To develop an app on Healthy Coping, [a] video conference with [a] group [of] people may help."

Third, the interviewees pointed to health disparities in diabetes, and suggested developers need to consider cultural variations in coping with life stress, including chronic diseases like diabetes. An example of comments from interviewees:

- "Different cultures have different attitudes towards healthy coping. For example, Asian and African are different from American."

Discussion

This study revealed that, compared to the AADE7™, there was an unbalanced feature development of current DSM apps. We found that many DSM apps provided features related to Healthy Eating, Monitoring, Taking Medication and Being Active behaviors, which were positive aspects. However, few apps offered features related to Problem Solving, Reducing Risks and Healthy Coping behaviors, which need to be developed in future DSM apps. This result was similar to Breland et al's study, which reported that many apps supported features for Healthy Eating (44.9%), Being Active (24.7%), Self-Monitoring (48%), Medication (46.7%) and Problem Solving (29.5%) [43]. On the other hand, few apps supported features related to Reducing Risks (11.9%) and Healthy Coping (5.7%) [43]. Our result was consistent with studies by Eng and Lee [7] and Arnhold et al [10]. Eng and Lee's study reviewed 516 diabetes apps for iPhone. They found the largest percentage of diabetes apps (33%) provided features for health tracking, based on quantitative data entry, such as tracking insulin doses, activity and blood sugar levels [7]. Arnhold et al's study analyzed 656 diabetes apps from iTunes and Google Play stores. Their results showed that 348 (53%) apps provided the feature of documentation focused on recording and monitoring eating habits, physical activity and medical therapy [10]. Our

study also found that features related to Healthy Eating, Monitoring, Taking Medication and Being Active were frequently developed in mobile apps. Compared to the features analysis data from November 2015 and December 2017 (Table 1), the unbalanced feature development trend did not change much.

Reasons why few apps supported the features related to Problem Solving, Reducing Risks and Healthy Coping need to be defined. Breland et al suggested that the two behaviors of Reducing Risks and Healthy Coping are usually addressed by direct interaction with diabetes educators [32].

This was also identified by interviewees in our study. Another possible reason may be that it is hard to incorporate qualitative information into mobile apps which are easily designed for quantitative data. We found features with high appearance, such as "count carbohydrates" (79/316, 25%) under Healthy Eating, "keep track of activities" (54/99, 55%) under Being Active, "record blood sugar levels" (97/322, 30%) under Monitoring and "keep track of medications" (68/164, 41%) under Taking Medication are all quantitative and therefore easy to enter into an app. Emotional needs and human interactions in management of diabetes may be hard to replace by apps. For example, quitting smoking needs interaction between patients and physicians so that physicians can provide professional guidance [51]. For people with diabetes, emotional interaction, such as face-to-face communication in support groups, may be a more effective method to cope with stress compared to a mobile app [52]. However, features such as interactive video for supporting emotional interaction may be incorporated into DSM apps as recommended in our study by interviewees. Another reason why people with diabetes may not use mobile apps for Problem Solving, Reducing Risks and Healthy Coping could be there are alternate

efficient methods to fulfill same features other than using apps. For Problem Solving, people with diabetes could use a search engine to find answers for their questions, such as searching on Google when they have low blood glucose after exercise.

Limitations of the Study

Due to the explorative nature of the study, there were several limitations. First, the initial 1,050 apps were collected during 2015. Given the rapid rate of app development, there are new DSM apps available on iTunes and Google Play stores. The results of this study may not perfectly match the current app stores. Second, we used AADE7™ to analyze features of DSM apps considering that both the ADA [40] and the AGS [41] recommend the AADE7™ for DSM; there may be other valid guidelines used by app developers. Third, we excluded apps that provided access to reference material only. These apps may be likely to address certain aspects of the guidelines. For example, there is an app with an e-book providing coping strategies for people with diabetes.

Conclusions

This study found that features of current DSM apps from two main app stores did not have balanced development compared to the DSM guidelines from AADE7™. Healthy Eating, Being Active, Monitoring and Taking Medication are covered well by current DSM apps. Few apps provided features supporting Problem Solving, Reducing Risks and Healthy Coping behaviors. These three behaviors are essential behaviors of AADE7™ for successful DSM. Future diabetes apps should incorporate balanced features from the

AADE7™ to better support changing self-management behaviors of people with diabetes. More research is needed on how we can target future app development to include features that support qualitative data entry rather than limiting apps to quantitative data.

CHAPTER 3 - EXPERIENCE OF DIABETES SELF-MANAGEMENT WITH MOBILE APPLICATIONS: A FOCUS GROUP STUDY AMONG OLDER PEOPLE WITH DIABETES

Problem statement

Based on the 2011-2014 National Health and Nutrition Examination Survey and 2015 U.S. Census Bureau data, there were 12 million people aged 65 years or older with diagnosed and undiagnosed diabetes in the US indicating 25.2% of people aged 65 years or older had diabetes [1].

Older people with diabetes exhibit not only clinical but also functional heterogeneity which complicates their long-term care [53, 54]. DSM educates people with diabetes on how to manage their own diabetes and avoid complications [55]. Appropriately designed DSM may help people with diabetes to improve knowledge of DSM behaviors, such as healthy eating, regular physical exercise, and medication adherence, leading people with diabetes to improve long-term outcomes [9, 56, 57].

Current DSM apps are not designed according to evidence-based guidelines of diabetes management. Breland et al [43], examined 227 DSM apps according to AADE7™ guidelines. The AADE7™ guidelines addressed by DSM apps were Healthy Eating (44.9%), Being Active (24.7%), Self-Monitoring (48.0%), Medication (46.7%), Problem Solving (29.5%), Reducing Risks (11.9%), and Healthy Coping (5.7%) [43]. Chomutare et al [42], analyzed 101 DSM apps in four leading platforms, including Apple iPhone, Google

Android, BlackBerry, and Nokia Symbian. They compared features of diabetes mobile apps with evidence-based recommendations with the following features: (1) self-monitoring: (1.1) blood glucose, (1.2) weight, (1.3) physical activity, (1.4) diet, (1.5) insulin and medication and (1.6) blood pressure; (2) education; (3) disease-related alerts and reminders; (4) integration of social media functions; (5) disease related data export and communication and (6) synchronization with personal health record (PHR) systems or patient portals [42]. They found most DSM apps provided the following 6 features: (1) insulin and medication, 63 (62%), (2) disease-related data export and communication, 61 (60%), (3) self-monitoring: diet, 47 (47%), (4) self-monitoring: weight, 43(43%), (5) self-monitoring: blood pressure, 36 (36%) and (6) self-monitoring: physical activity, 34 (34%) [42]. Few DSM apps provided the following 4 features: (1) synchronization with personal health record (PHR) systems or patient portals, 17 (17%), (2) integration of social media functions, 17 (17%), (3) education, 16 (16%) and (4) disease-related alerts and reminders, 8 (8%) [42]. These 4 features were missing from the DSM apps [42].

Additionally, current DSM apps have not shown acceptable usability for older people with diabetes. *Usability* is defined as "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" [58]. According to the Agency for Healthcare Research and Quality (AHRQ) report in 2012, lack of usability was a barrier "for using health information technology applications to enable patient-centered care" [59]. Arnhold et al conducted an expert-based usability evaluation of 66 DSM apps from Apple App Store and Google Play Store [10]. The results showed that diabetes apps with limited features showed moderate to good usability for people aged 50 or older with diabetes [10]. Comparatively,

diabetes apps with multiple features showed worse usability for people aged 50 or older [10].

The objective of this study was to identify the needs for evidence-based features and to determine usability barriers in older people with diabetes when they used DSM apps.

Methods

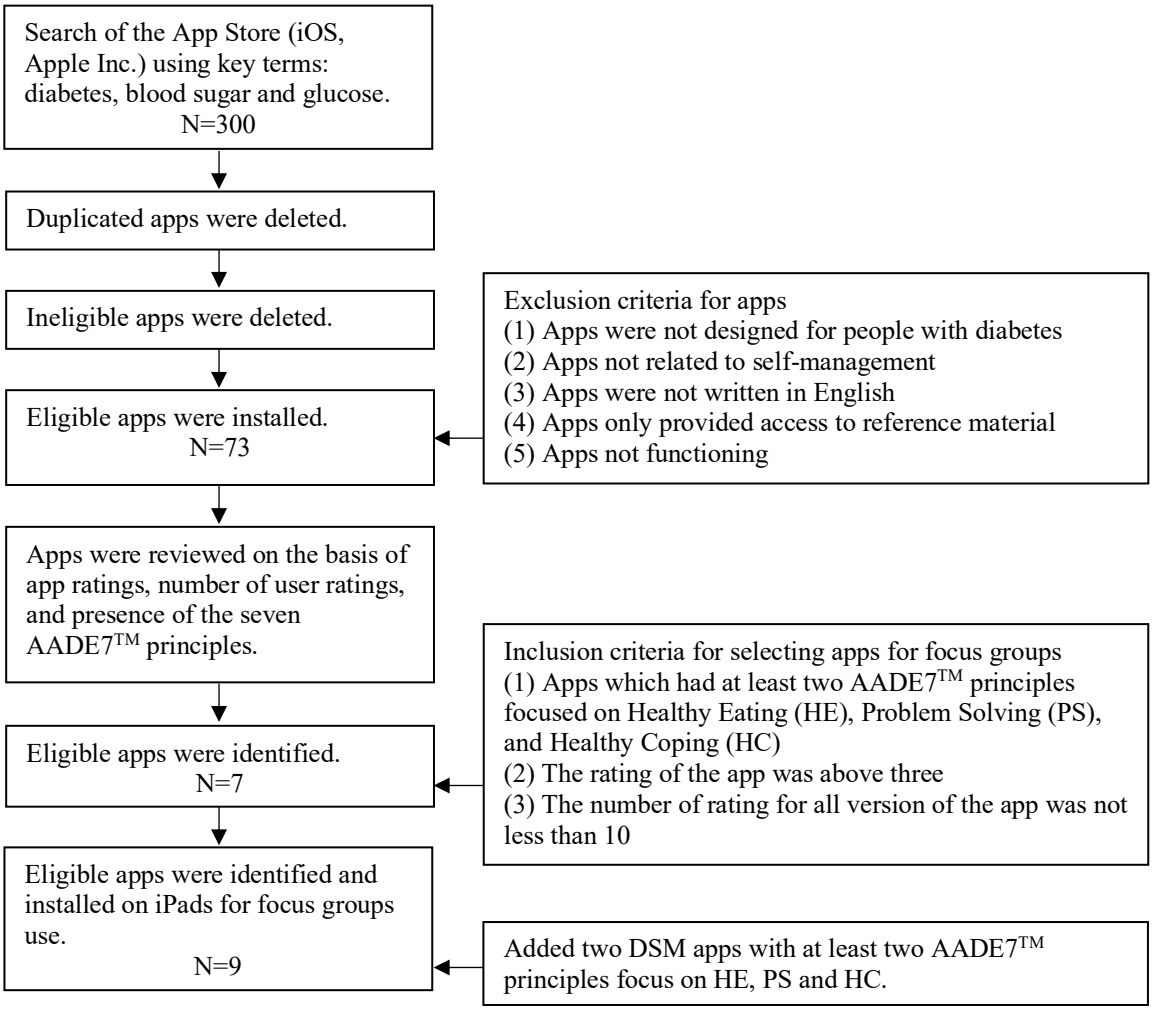
Study design

We conducted 2 focus groups at the Cosmopolitan International Diabetes and Endocrinology Center at University of Missouri Health Care to measure perception of DSM apps with participants. Considering the level of involvement and group interaction, Kitzinger recommended that a focus group should include 4 to 8 participants [60]. In our study, we recruited 5 participants in each focus group. Based on the data saturation theory, we would conduct an additional focus group depending on whether new themes were being identified [61]. Each participant answered a questionnaire about preferences, concerns and needs to examine features and usability of the designated apps. Participants, then completed app specific DSM task sets. Each focus group was conducted over 2 hours. Short breaks were included after participants completed each app's task to allow for questions and discussion. Each section was recorded and transcribed. We used a mixed-methods approach [62] to identify the gap between needs of features and usability for DSM apps and those offered by current DSM apps. This study was approved by the University of Missouri Healthcare Institutional Review Board.

Selection of diabetes self-management apps

We searched the App Store (iOS, Apple Inc.) from September 2015 to November 2015. Figure 2 shows the flow chart for selection of DSM apps. Each focus group had 4 unique apps and one common app which is a reference app. The DSM apps inclusion criteria were

Figure 2 Flow Chart for Selection DSM Apps.



as follows: (1) app provided at least two AADE7™ principles focused on Healthy Eating, Problem Solving and Healthy Coping because Healthy Eating was very frequently discussed during patient visits, in consultation with an experienced endocrinologist (UK), Problem Solving and Healthy Coping were less developed in current mobile apps based on our previous study (Table 3); (2) the rating of the app was above three and (3) the number of ratings for all version of the app was not less than 10. We selected the AADE7™ as the guideline for feature analysis because the American Diabetes Association (ADA) [40] and the American Geriatrics Society (AGS) [41] both recommend the AADE7™ for DSM.

Table 3 Summary of apps' name, ratings/number of ratings, principles and used for focus group.

App	Name of Apps	Ratings/ Number of Ratings - All Version	Presence of seven principles by AADE7™ Self-Care Behaviors	Principles addressed by DSM tasks	Focus Group used
1	mySugr Diabetes Logbook	No Customer Ratings.	HE, BA, M, TM, PS, HC	HC	1
2	GoMealsHD	3+/1717	HE, BA, M, PS	HE	1
3	DiabetesConnect	4+/73	HE, BA, M, TM, PS, HC	PS	1
4	Diabetes Pilot HD	4+/13	HE, BA, M, TM, PS	HE	1
5	Tactio Health	3+/992	HE, BA, M, PS, HC	HC	2
6	Diabetes App Lite	4/1124	HE, BA, M, TM, PS	HE	2
7	Ezbds	5/21	HE, BA, M, TM, PS	PS	2
8	Daily Carb Premium for iPad	No Customer Ratings. Free version 4/11.	HE, PS	HE	2
9 †	Diabetes in Check	4/991	HE, BA, M, TM, PS, RR, HC	HE, PS, HC	1, 2

Note: Healthy Eating (HE), Being Active (BA), Monitoring (M), Taking Medication (TM), Problem Solving (PS), Reducing Risks (RR) and Healthy Coping (HC). † indicates common app for both focus groups.

Questionnaire development

An interdisciplinary research team designed a questionnaire through literature review and discussion. The questionnaire included 5 sections: participant characteristics, DSM tasks, System Usability Scale (SUS) [63], 12 app specific questions and two open-ended questions (Table 4). The section of participant characteristics include demographics, diabetes history, the Single Item Literacy Screener (SILS, 1-5) [64] and experience of smart mobile device and diabetes apps. The SILS is a validated single-question instrument and was used to identify patients with limited reading ability who need help reading health-related materials [64]. SILS scores greater than 2 indicate some difficulty with reading health-related material [64]. The section of DSM tasks include 9 different app-specific DSM task sets. The tasks were designed to assess if the apps supported the 3 AADE7™ principles: Healthy Eating, Problem Solving, and Healthy Coping.

We designed scenario-based tasks [65]. For example, "Mr. David had type 2 diabetes. He used GoMealsHD on iPad to record what he ate for lunch today". The example tasks are listed in Table 4. The section of SUS included 10 questions to measure usability for each app. A score from 0 to 50 is regarded as not acceptable, a score from 50 to 62 is considered as low marginal, a score from 63 to 70 is high marginal and a score from 70 to 100 is acceptable [66]. The section of app-specific questions involved 6 questions for each of the 4 unique apps and 12 questions for the common app. The section on open-ended questions comprised 2 questions to identify participants' overall opinion about the current diabetes apps and factors they considered important when downloading diabetes apps.

Table 4 Focus group questionnaire.

Participant Characteristics
Demographics
1. Age
2. Sex
3. Race
Diabetes History
4. What type of diabetes do you have?
5. How long have you had diabetes?
6. In the past week, did you get insulin injections?
Single item literacy screener (SILS)
7. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
Experience of smart mobile device and diabetes apps
8. How long have you used smart mobile devices such as iPad, iPhone, Samsung Galaxy S, Samsung Galaxy tab, Amazon Fire, Nokia Lumia and HTC One?
9. Have you used diabetes apps to help you manage your condition?
10. If yes, what diabetes apps have you installed and kept for regular usage? Please explain why you decided to keep the apps.
11. If yes, what diabetes apps have you downloaded but uninstalled later? Please explain why you decided to abandon the apps.
DSM Tasks
Example of DSM tasks for GoMealsHD :
Task 1: Open the app
Task 2: Review the app (1 minute)
Task 3: Click “Browse Foods”, type “green beans” in the search bar
Task 4: Click “Green Beans, Cut”
Task 5: Select “Lunch” and “1 serving”, click “Add”, then click “OK”
Task 6: Close the app
System Usability Scale (SUS) - 10 questions
1. I think that I would like to use this application frequently.
2. I found the application unnecessarily complex.
3. I thought the application was easy to use.
4. I think that I would need the support of a technical person to be able to use this application.
5. I found the various functions in this application were well integrated.
6. I thought there was too much inconsistency in this application.
7. I would imagine that most people would learn to use this application very quickly.

8. I found the application very cumbersome to use.
9. I felt very confident using the application.
10. I needed to learn a lot of things before I could get going with this application.

App Specific Questions

1. Healthy Eating
    a. Do you think this app will help you gain the skill of counting carbohydrates?
    b. Do you think this app will help you gain the skill of reading food labels?
    c. Do you think this app will help you gain the skill of setting goals for healthy lifestyle?
2. Problem Solving
    a. Do you think this app will help you learn how to recognize and react to high and low blood sugar level?
    b. Do you think this app will help you learn how to deal with the situation when you have a hard time finding healthy food choice?
    c. Do you think this app help you to recognize and react to taking too much diabetes medication or getting flu?
3. Healthy Coping
    a. Do you think this app will help you connect to people or support groups to deal with stress, anxiety or depression?
    b. Do you think this app will help you exercise and meditate to deal with stress, anxiety or depression?
    c. Do you think this app will help you to pursue hobbies to deal with stress, anxiety or depression?
4. What features do you like most about this diabetes app? Please explain why you like it most?
5. What features do you like least with this diabetes app? Please explain why you like it least?
6. Do you have any specific comments about this app?

Open-Ended Questions

1. What are the biggest issues of the current diabetes apps in managing diabetes conditions?
2. When you decide to download diabetes apps, what do you look for? Take a piece of paper and jot down three features that are important to you when you download diabetes apps?

Data collection

Focus groups were recruited by an experienced endocrinologist (UK) and conducted in December 2015. Each focus group was facilitated by one researcher (SB) who has experience with focus group facilitation. Three other researchers (QY, MK, UK) observed and interacted with the focus groups. Each focus group lasted approximately 2 hours. Participants completed the DSM tasks and questionnaires. The sessions were recorded using a digital voice recorder Olympus WS-110.

Data analysis

We used descriptive statistics to analyze participant characteristics, SUS scores and app-specific questions related to Healthy Eating, Problem Solving and Healthy Coping. For each app, we counted the "yes" numbers for each app-specific question. For example, when 5 participants from focus group one used app 3, they answered the 3 questions related to Problem Solving. For each question related to Problem Solving, we counted the number of participants who answered "yes" and the number of participants who answered the question. We divided the number of participants who answered "yes" by the number of participants who answered the question to compute the approval (yes) rates of each app's specific questions. Then, for each app-specific question, we computed the average of approval (yes) rate to obtain the mean rate of approval.

Thematic analysis was used to evaluate qualitative data, including the following questions: (1) "What features do you like most about this diabetes app? Please explain why you like it most?" (2) "What features do you like least with this diabetes app? Please explain why you like it least?" (3) "Do you have any specific comments about this app?" (4) "What are the biggest issues of the current diabetes apps in managing diabetes

conditions?" (5) "When you decide to download diabetes apps, what do you look for? Take a piece of paper and jot down 3 features that are important to you when you download diabetes apps?" Audio-recordings were transcribed verbatim. The written responses and transcription were collectively analyzed. We read and re-read the text to ensure familiarity with answers, coded question-related text, arranged codes into categories, created themes according to categories and counted frequency of themes [67, 68].

Results

Description of selected diabetes self-management apps

Among the 73 eligible apps, no apps were designed specifically for older people with diabetes. We found 7 apps based on the DSM apps inclusion criteria. We added 2 DSM apps (mySugr Diabetes Logbook and Daily Carb Premium for iPad) with at least 2 AADE7^{TM} principles focused on Healthy Eating, Problem Solving and Healthy Coping. Table 3 summarizes of the 9 apps used for focus groups by name, average rating/number of ratings for all versions, the presence of 7 principles by AADE7^{TM} and principles addressed by DSM tasks. All 9 apps provided at least 2 principles out of the 3 pre-identified principles of Healthy Eating, Problem Solving and Healthy Coping. When we created DSM tasks, apps 2, 4, 6, 8 and 9 were used for Healthy Eating tasks; apps 3, 7 and 9 were used for Problem Solving tasks and app 1, 5 and 9 were used for Healthy Coping tasks. Except for app 9, only apps 1, 3 and 5 provided features of Healthy Coping. We assigned Healthy Coping tasks on apps 1 and 5 for 2 focus groups respectively. Then we created the list of the other 6 apps (apps 2, 3, 4, 6, 7 and 8) based on the number of ratings for all versions. For the balance of DSM apps used in 2 focus groups, the apps with ranks 1, 3 and 5 were

used in focus group one and the apps with ranks 2, 4 and 6 were used in focus group two, respectively. App 9 was used in both focus groups.

Participant characteristics

The 10 participants' ages ranged from 56 to 82 years and the mean age was 69 years. There were 6 males and 4 females. All participants were white, 82.4% of the population in Missouri are white according to the American Community Survey Profiles Report in 2015 [69]. Six participants had Type 1 diabetes and 4 had Type 2 diabetes. The average duration of diabetes was 27 years. Nine participants received insulin injections. Only one participant had a SILS score greater than 2, indicating the participant had some difficulty with reading printed health-related material. The average SILS score of all participants was 1.8, indicating that 9 participants did not have some difficulty with reading printed health-related material. Seven participants had used smart mobile devices for more than 12 months; however, 90% of participants had never used diabetes apps to help them manage their conditions.

SUS scores

All participants used 5 apps and answered the SUS after using each app. Each participant answered a total of 50 SUS questions for 5 apps. Ten participants answered a total of 500 SUS questions for 5 apps. Out of 500 questions, there were 12 questions that participants did not answer. We used common point imputation to handle the 2.4% (12/500) of missing data [70]. The average score of SUS of all apps was 48. The highest mean score was 56 (SD=36) for app 8 and the lowest mean score was 41 (SD=24) for app 5 (Table 5). Four apps (apps 3, 4, 6 and 8) were "low marginal" and 5 apps (apps 1, 2, 5, 7 and 9) were "not acceptable" according to acceptability ranges.

Table 5 Overall System Usability Scale (SUS) score for each app evaluated, acceptability ranges.

App	Name of App	SUS Average Score	SD	Acceptability Ranges
1	mySugr Diabetes Logbook	43	14	Not acceptable
2	GoMealsHD	49	28	Not acceptable
3	DiabetesConnect	51	29	Low marginal
4	Diabetes Pilot HD	51	26	Low marginal
5	Tactio Health	41	24	Not acceptable
6	Diabetes App Lite	55	38	Low marginal
7	Ezbds	43	28	Not acceptable
8	Daily Carb Premium for iPad	56	36	Low marginal
9	Diabetes in Check	48	32	Not acceptable

App-specific questions related to Healthy Eating, Problem Solving and Healthy Coping

The appearance of features in 9 apps that were evaluated by participants based on questions of Healthy Eating, Problem Eating and Healthy Coping of the AADE7™ are shown in Table 6. App 9 was used by 10 participants since it was the common app used for focus group one and two. The other 8 individual apps were used by 5 participants. For example, 5 participants who used app 2 answered the Healthy Eating question "Do you think this app will help you gain the skill of counting carbohydrates?" Out of 5 participants, 3 participants answered "yes" and 2 participants answered "no". Some participants did not answer the questions. For example, there were 4 participants who used app 4 who answered the Healthy Eating question "Do you think this app will help you gain the skill of counting carbohydrates?" Out of 4 participants, 3 participants answered "yes", and one participant did not answer.

Table 6 details the percentages of mean rate of approval for 9 individual app-specific questions related to Healthy Eating, Problem Solving and Healthy Coping. For example, 69% of the participants agreed that apps (apps 2, 4, 6, 8 and 9) provided the feature for counting carbohydrates. Overall, the percentages of *counting carbohydrates* (69%),

reading food labels (50%) and *setting goals for healthy lifestyle* (60%) that related to Healthy Eating were all above 50%. However, for features of Problem Solving, only *learn how to recognize and react to high and low blood sugar level* (70%) was over 50%. The percentages of *learn how to deal with the situation when you have a hard time finding healthy food choice* (34%) and *recognize and react to taking too much diabetes medication or getting flu* (45%) that related to Problem Solving were below 50%. The percentages of *dealing with stress, anxiety or depression by connecting to people or support groups* (40%), *exercise and meditation* (10%) and *pursuing hobbies* (28%) that related to Healthy Coping were all below 50%.

Table 6 The appearance of features related to Healthy Eating, Problem Solving and Healthy Coping based on a specific app.

AADE7™ Behavior	App-Specific Questions	App	Name of App	Approval (yes) rate	Mean rate of approval (%)
Healthy Eating	Do you think this app will help you gain the skill of counting carbohydrates?	9	Diabetes in Check	9/10	69
		4	Diabetes Pilot HD	3/4	
		2	Go Meals HD	3/5	
		6	Diabetes App Lite	3/5	
		8	Daily Carb Premium for iPad	3/5	
	Do you think this app will help you gain the skill of reading food labels?	9	Diabetes in Check	3/5	50
		6	Diabetes App Lite	3/5	
		4	Diabetes Pilot HD	1/2	
		2	Go Meals HD	2/5	
		8	Daily Carb Premium for iPad	2/5	
	Do you think this app will help you gain the skill of setting goals for healthy lifestyle?	9	Diabetes in Check	7/10	60
		2	Go Meals HD	3/5	
		6	Diabetes App Lite	3/5	
		8	Daily Carb Premium for iPad	3/5	
		4	Diabetes Pilot HD	1/2	
Problem Solving	Do you think this app will help you learn how to recognize and react to high and low blood sugar level?	7	Ezbds	4/5	70
		9	Diabetes in Check	7/10	
		3	Diabetes Connect	3/5	
	Do you think this app will help you learn how to deal with the situation when you have a hard time finding healthy food choice?	7	Ezbds	1/2	34
		9	Diabetes in Check	1/3	
		3	Diabetes Connect	1/5	
	Do you think this app help you to recognize and react to taking too	3	Diabetes Connect	3/5	45
		9	Diabetes in Check	1/2	

	much diabetes medication or getting flu?	7	Ezbds	1/4	
Healthy Coping	Do you think this app will help you connect to people or support groups to deal with stress, anxiety or depression?	9	Diabetes in Check	1/2	40
		5	Tactio Health	1/2	
		1	mysugr	1/5	
	Do you think this app will help you exercise and meditate to deal with stress, anxiety or depression?	9	Diabetes in Check	3/10	10
		5	Tactio Health	0/4	
		1	mysugr	0/5	
	Do you think this app will help you to pursue hobbies to deal with stress, anxiety or depression?	9	Diabetes in Check	2/5	28
		5	Tactio Health	1/4	
		1	mysugr	1/5	

Features participants favored most

When asked what features participants favored most about the specific diabetes app, the rank of themes were documentation, information, and goal setting. The followings were the frequencies of the themes: documentation, 16; information, 10 and goal setting, 4.

The documentation feature helps people with diabetes to observe and record daily behavior. It also provides the relationship between behaviors and blood glucose levels, allowing people with diabetes to analyze factors that affect blood glucose levels. Example comments:

- "It helps to keep a running count of your daily carbs."
- "I would use maybe more daily. Because this applies to your every day, I mean, you're supposed to learn how many carbs are in this. "
- "I like that label. Add several items at one time. Add sports is nice. Add more than one condition of mood. It's good for mood."

The information feature offers knowledge that helps people with diabetes to modify self-behavior. Participants' comments included information for food choices, stress relief, and self-management of diabetes. Example comments:

- "For a beginner, it would probably help knowing the values of different foods for glucose management."
- "It has a good variety of food combination to pick from."

The goal-setting feature offers motivation for people with diabetes to control their daily self-behaviors. People with diabetes could also use apps to check whether they achieved the goals. Goal setting includes setting a target for blood glucose, weight and calories, etc. Example comment:

- "It also had goal setting. On the chart it has like when you put in your, was it the water, you could see it go up to what your budget was, kind of your goal."

Features that participants liked the least

When asked what features participants liked the least about the specific diabetes app, the rank of themes for the features were poor screen design and documentation. The followings were the frequencies of the themes: poor screen design, 5 and documentation, 2.

Screen design issues the participants commented on included small font, small button and the small space between buttons. Example comments:

- "Small print in food selections."
- "Too small buttons makes it hard for me to tap the buttons."
- "The small spaces between buttons; easy to make mistakes."

Documentation issues included the recording and monitoring of carbohydrate counting, physical activity and blood glucose, etc. Examples comments:

- "One thing I didn't like about it was the weights in kilograms, not pounds."
- "Medical record only has one insulin entry"

Participants' comments about every DSM app

Table 7 summarized the negative, positive and neutral themes of participants' comments about every DSM app. There were 11 themes, including 7 negative themes, 3 positive themes and one neutral theme. The total number of comments was 70, which contained 47 negative comments, 21 positive comments and 2 neutral comments. Out of 70 comments, 54 comments related to usability, which covered *complicated* (n=19), *not useful* (n=10), *difficult to use* (n=9), *poor screen design* (n=2) and *easy to use* (n=14). Approximately 60% of answers were associated with a negative impression of usability. Examples comments:

- "It could be very beneficial if it was less complicated and usable on an app"
- "I just keep track of mine on a tablet, notebook, which is much easier than going in on the app. I doubt if I would even use this"

Table 7 Summary of the negative, positive and neutral themes of participants' comments about every DSM app.

Negative Themes	Positive Themes	Neutral Themes
Complicated† (19)	Easy to use† (14)	Cost (2)
Not useful† (10)	Helpful (6)	
Difficult to use† (9)	Function rich (1)	
No back button (4)		
No save button or small save button (2)		
Poor screen design† (2)		
No verbal input method (1)		
Total (47)	Total (21)	Total (2)

Note: The number in parentheses represents the number of comments. † indicates themes related to usability.

Concerns participants had about the current diabetes apps

After using all 9 DSM apps, participants were asked about any concerns they had about the current diabetes apps. The frequencies of themes were *easy to use* (n=5), *time consuming* (n=2), *cost* (n=2), *verbal input method* (n=2), *documentation* (n=1), *data forwarding* (n=1), *screen design* (n=1), *help features* (n=1) and *back button* (n=1). *Easy to use* was given the

highest priority by participants and accounted for 31% in total themes. Examples comments:

- "Easy selection of data for input"
- "Being able to use the app easily and quickly"

Features important to the participants in deciding to download diabetes apps

When asked about features important to the participants in deciding to download diabetes apps, *easy to use* (n=5) was the most important. *Documentation* (n=4), *cost* (n=3), *useful* (n=2), *speed of app* (n=1), *memory size of app* (n=1), *goal setting* (n=1) and *features rich* (n=1) were also mentioned. Usability factors, which included *easy to use* and *useful*, represented 39% of responses through 18 themes. Example comment:

- "Easy to use without using lots of time. Something that works the way I think"

We compared the themes on features and usability between focus group one and focus group two for new information. We confirmed there was no new information developed in focus group two. This indicated a data saturation and we decided not to pursue an additional focus groups.

For app 9, we compared the SUS score, approval (yes) rate of app specific questions and themes of last 5 questions of the questionnaire between focus group one and two. There were no major difference of the SUS score, approval (yes) rate of app specific questions and themes.

Discussion

This study had demonstrated that current DSM apps fail to address the evidence-based DSM guidelines from AADE7™ which are supported by the American Diabetes Association (ADA) [40] and the American Geriatrics Society (AGS) [41]. We found that most apps provided features related to Healthy Eating. Few apps offered features related to Problem Solving and Healthy Coping. This result is in accordance with the findings of our previous DSM apps features study. In the DSM apps features study, 137 DSM apps from iTunes and Google Play app stores were analyzed. The results showed many apps explored behaviors of Healthy Eating (77%), Monitoring (76%), Taking Medication (58%) and Being Active (45%), but few apps explored the behaviors of Problem Solving (31%), Healthy Coping (10%) and Reducing Risk (5%). Breland et al [43], analyzed 227 DSM iPhone apps. Their study showed that 44.9% of apps promoted features of Healthy Eating, 29.5% of apps provided features of Problem Solving and only 5.7% of apps offered features of Healthy Coping. The possible reason for few apps having features of Problem Solving may be that suggestions for Problem Solving are made by providers in current healthcare practices. Similarly, Healthy Coping skills are usually addressed by diabetes educators [71]. Another possible reason for few apps having features of Healthy Coping may be that it is hard to incorporate in mobile apps because there are few methods to treat depression by apps [43]. According to AADE7™, the action for optimization of Healthy Coping may include being active, participating in faith-based activities or meditating, pursuing hobbies and attending support groups [72]. If DSM apps could be designed to assist users to transfer interventions into practice, they will promote Problem Solving and Healthy Coping.

Our study suggested that usability is our older users' main concern. In our research, the themes related to usability accounted for a large percentage of comments. The technology acceptance model suggests that user acceptance of new technology depends on a user's perception of usefulness and ease of use of a system [73]. However, current DSM apps did not offer acceptable usability. Arnhold et al reported worse usability of diabetes apps with multiple features for people aged 50 or older with diabetes [10]. Demidowich et al reported that 4 of 42 Android DSM apps had composite usability score (scale 1-30) above 20 [48]. Our findings are similar to the results supported by Arnhold et al [10]. and Demidowich et al [48]. Even though we pre-selected the most representative DSM apps, almost half of apps' SUS scores were not acceptable and more than half of SUS scores were low marginal for older people with diabetes in our study.

A study by Isakovic et al [74], discusses the importance of involving end users when designing an app. Designers should consider the special needs of older people with diabetes. For example, older users may have visual impairment leading to difficulty in using the apps with dense design such as small font, buttons and small space between symbols as indicated by the participants in this study. Some studies provided user interface design recommendations for older people as follows: (1) "use the home screen menu", (2) "use the back button", (3) "use scrolling when the app requires it", (4) "keyboard usage should be minimized", (5) use wording that is understandable by older people, (6) enough spacing between buttons and items, (7) use button with text and (8) avoid interactive element on the edge of the screen [75, 76].

Limitations of the Study

Our study has some limitations. First, all participants were white. Second, there were more participants with type 1 diabetes than type 2 diabetes in our study. Although the life expectancy of people with type 1 diabetes has increased significantly [77], type 2 diabetes is more common in the older age group [78]. Third, the sample of DSM apps selected in the study only covered iOS apps and did not contain apps from Android platform.

Conclusions

This study suggests current DSM apps do not provide meaningful features for self-management and may not fulfill the needs of older people with diabetes. There is a need to conduct a systematic features analysis of current diabetes apps for older people with diabetes against evidence-based guidelines. Future DSM apps should be designed following evidence-based guidelines and user interface design recommendations for older people [75, 76].

CHAPTER 4 - EVALUATION OF PROVIDER DOCUMENTATION PATTERNS AS A TOOL TO DELIVER ONGOING PATIENT-CENTERED DIABETES EDUCATION AND SUPPORT

Problem statement

The AADE, ADA and Academy of Nutrition and Dietetics recommend that patients should visit a certified diabetes educator (CDE) when first diagnosed with diabetes and then annually to monitor their condition [79]. Additional visits with a CDE are recommended if they experience complications or any time there is transition in their care [79]. Health education is the cornerstone of a well-developed healthcare system. However, in the United States (US), access to diabetes education may be limited because of several barriers. Despite known benefits, Medicare as well as most private insurance companies in the US provide DSME/S to only a small percentage of people with diabetes [80]. Consequently, only 5% of Medicare beneficiaries and 6.8% of privately insured people with newly diagnosed diabetes participate in DSME/S [81, 82]. The reasons behind limited utilization of DSME/S may include poor understanding of the necessity and effectiveness of DSME/S, confusion regarding when and how to make referrals for physicians and lack of access to DSME/S services and support from family [83]. Limitation in number of visits to a CDE prevents patients from getting timely and continuous support from the CDEs [84, 85].

Considering the access barriers to DSME/S by a CDE, the diabetes education that healthcare providers deliver during clinic visits may be the only source for DSME/S for

many people with diabetes. Furthermore, a 2006 survey in the US, conducted by the Department of Health and Human services, showed that receiving diabetes education and knowledge about the disease from providers was the most preferred method by people with diabetes [86]. However, in a busy clinical environment, it is a challenge for providers to deliver DSME/S effectively during the limited visiting time [87-89]. Based on the statistics portal "Statista", only 11% of the US primary care physicians spent 25 or more minutes with each patient in 2018 [90]. Administrative and documentation responsibilities may be another hindrance. After adopting a structured and standard electronic health record (EHR), the time that providers spent in consultation was decreased by 8.5% [91]. Within the limited clinic time, a provider must review and document numerous clinic note sections [92]. Consequently, the remaining time may be fragmented, and insufficient for providers to educate patients on individual DSME/S topics.

Patient-centered DSME is defined as "diabetes education that begins from the patients' experience of their diabetes, their perspectives on its management and its outcomes, and seek to increase the patients' involvement in the management of their disease." [93] In collaboration with health providers, patients and families, patient-centered education provides the needed information to help patients make medical decisions and personalized self-management plans [94, 95]. Patient-centered education can benefit patients with diabetes, including improvement of blood glucose, total cholesterol and body mass index (BMI) [96-99].

There have been limited studies analyzing the clinic notes of people with diabetes [100-104]. These studies focused on applying natural language processing (NLP) for information extraction, such as identifying people with type 2 diabetes with a specific

phenotype [100], estimating the occurrence of hypoglycemia [101] and extracting the lab test results [104]. However, limitations exist when NLP techniques were used in these studies, such as disagreement with manual classification [103], decreasing accuracy with semantically complex sentences [102, 104], having difficulty distinguishing acronyms and abbreviations with different meanings [105] and demonstrating successes in specific research settings [106]. Considering the lack of NLP applications for information discovery in diabetes education using EHR physician note sections, we opted to manually code clinic notes in this study as a feasibility study. We chose two sections in clinic notes, History of Present Illness (HPI) and Impression and Plan (I&P), to analyze the information providers deliver to people with diabetes. HPI and I&P are preferably not auto-populated, and are the sections where providers document patients' previous self-management behaviors (HPI section) and suggestions for conducting self-management (I&P section) [107]. Increasingly, completed clinic notes are available for review by the patient and may provide an additional opportunity for diabetes education and support [108].

The objective of this study was to investigate the frequency distribution of information providers deliver to people with diabetes during clinic visits based on the AADE7™ guidelines by analyzing the HPI and I&P sections in clinic notes. We also aimed to investigate whether the providers delivered DSME/S to people with diabetes based on patient characteristics of sex, age group, geographic region, type of diabetes, history of diagnosis of diabetes, comorbidities (e.g., hypertension, hyperlipidemia and coronary artery disease), insulin treatment, BMI and HbA1c.

Methods

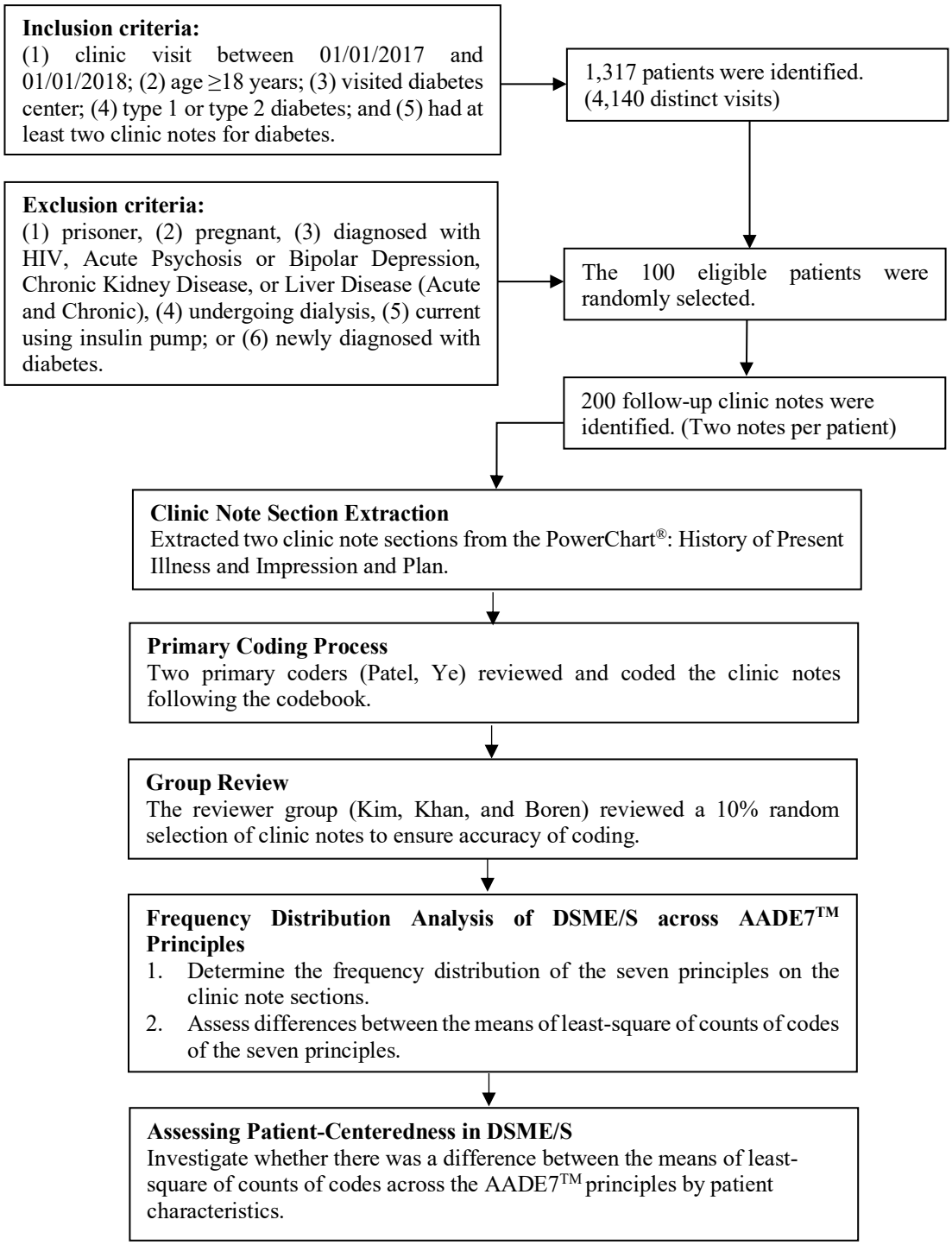
Study design

We conducted this qualitative study at the Cosmopolitan International Diabetes and Endocrinology Center (CIDEC) at University of Missouri Health Care (UMHC). Using a codebook created based on the AADE7^{TM}, we first conducted a multi-step deductive thematic analysis via a systematic group review process to determine the frequency distribution of the counts of codes based on the AADE7^{TM} in the designated clinic note sections. Additionally, we conducted inferential statistics based on the counts of codes. We used generalized linear mixed model (GLMM) [109, 110] to assess differences between the means of least square of counts of codes of the seven AADE7^{TM} principles. Then, we conducted an inferential statistics analysis to verify whether providers delivered DSME/S to people with diabetes based on patient characteristics. Patient characteristics collected included sex, age group, geographic region, type of diabetes, history of diagnosis of diabetes, hypertension, hyperlipidemia, coronary artery disease, insulin treatment, BMI and HbA1c. Figure 3 depicts the data collection and data analysis process.

Study setting and investigators

Cosmopolitan International Diabetes and Endocrinology Center at UMHC is recognized nationally for excellence in patient care and multidisciplinary research programs. During 2017, there were almost 6,600 visits for adults with type 1 or type 2 diabetes to the Diabetes Center. All patient information is maintained in EHRs, PowerChart, a secure Cerner-based program with access to all providers, and also to patients via a patient portal, HEALTHConnect. UMHC maintains PowerInsight, Cerner's clinical reporting platform

Figure 3 Clinic notes collection and analysis process. We identified 100 patients' 200 clinic notes after application of inclusion and exclusion criteria. Clinic note sections extracted from the PowerChart were coded and reviewed following the codebook to determine the frequency distribution of the American Association of Diabetes Educators Self-Care Behaviors™ (AADE7™) principles on clinic notes. We used the generalized linear mixed model (GLMM) to assess differences between the means of least square of counts of codes of the seven AADE7™ principles. We also used GLMM to investigate whether there was a difference in documentation pattern across the AADE7™ principles by patient characteristics.



for the EHR [111], which allows effective patient selection for the data collection required by this study. The study team had interdisciplinary expertise including diabetes education, health informatics and clinical endocrinology.

Subjects

Patient selection was conducted using PowerInsight, a secure portal which provides reports based on specific search criteria, such as medical record number, age, sex, admit date and time, diagnosis description, diagnosis code, provider, reason for visit and clinic locations. We included patients who were 18 years or older and presented to CIDEC between January 1, 2017, 12:00 AM and January 1, 2018, 12:00 AM. Patients who were diagnosed with type 1 or type 2 diabetes, and had at least two clinic notes for follow-up of diabetes during the study period were included. Patients were excluded if they were incarcerated, were pregnant, had known diagnosis of HIV, acute psychosis or bipolar depression, chronic kidney disease, liver disease or were undergoing dialysis. People with diabetes who were using insulin pumps were excluded since focused DSME/S is provided prior to initiating pump therapy and at each visit through a dedicated insulin pump clinic. We also excluded initial visit for diabetes because providers may provide more comprehensive DSME/S themselves or refer people who are newly diagnosed with diabetes to diabetes educators.

When computing the sample size for this study, we considered the qualitative nature of the study. We considered 200 notes of 100 patients which account for approximately 7.6% of the total patients who were 18 years or older at the study site to be an adequate sample size to answer the research questions we aimed to address in this pilot study. Based on the data saturation theory [112], we would add more patients into this study to increase the sample size if the frequency distribution of the seven principles changed significantly

during review process. All data was de-identified to protect individually identifiable health information. This study was approved by the University of Missouri Institutional Review Board.

Clinic note section extraction

From PowerInsight, information regarding patients' medical record number, sex, age, zip code, diagnosis description, diagnosis code, provider and reason for visit was obtained. We removed duplicate records, applied the exclusion criteria and selected 100 patients using simple random sampling. Utilizing PowerChart, the two clinic note sections—HPI and I&P—were extracted, de-identified and copied into a Microsoft Word document for review and manual coding. Data regarding specific patient characteristics including BMI, HbA1c, and information regarding comorbid conditions including hypertension, hyperlipidemia and coronary artery disease were collected. We also included information whether they were taking insulin, and sharing glucose monitoring data with the providers at the time of the visit.

Codebook development

We adopted deductive thematic analysis [113] for our study. Deductive thematic analysis is a theory-driven approach, and its codes and themes were developed by existing concepts [67]. Based on previous experience with a codebook used in our "Diabetes Mobile App Features Analysis Study" [114-116], the study team had developed a codebook by consulting the AADE7^{TM} guidelines for the most up-to-date education items [117]. The research team (Kim, Khan, Boren and Ye) reviewed and revised the codebook to ensure the final code set captures consistent and comprehensive diabetes education items for this study (Table 8).

Table 8 Codebook for clinic notes analysis and count in 200 clinic notes.

Category	ID	Code	Count
1. Healthy Eating (257)	1.1	Develop an eating plan (how to plan a week of eating overall or how to plan each meal)	19
	1.2	Set goals for healthy eating	29
	1.3	Remind to eat	0
	1.4	Provide Recipes	0
	1.5	Count carbohydrates	31
	1.6	Read food labels	1
	1.7	Prevent high or low blood sugar	42
	1.8	Measure each serving (know how much you should eat and don't overdo it)	2
	1.9	Monitor eating (record what you eat and how much you eat)	97
	1.10	Provide knowledge of healthy eating	35
	1.11	Provide restaurants information	0
	1.12	Share record of eating through forum or email	1
2. Being Active (113)	2.1	Set exercise plan/goal	24
	2.2	Remind to do exercise	3
	2.3	Choose activities (think of things you like to do)	7
	2.4	Start exercising (take it slow – start with five or 10 minutes of the activity and work your way up to 30 minutes at a time, five days a week)	7
	2.5	Do exercise at personal pace (don't overdo it! While you exercise, you should be able to talk, but not sing)	19
	2.6	Check blood sugar level before and after exercise	0
	2.7	Keep track of activities	44
	2.8	Find a friend to exercise with	0
	2.9	Take a physical exercise class	1
	2.10	Join adult leagues	0
	2.11	Mix activities up (try a few different things so you don't get bored)	2
	2.12	Provide knowledge of exercise	6
	2.13	Share record of exercise through forum or email	0
3. Monitoring (1,808)	3.1	Learn how to use the glucometer	3
	3.2	Learn tips for the best/easiest way to monitor	3
	3.3	Learn when to check the blood sugar	145
	3.4	Learn what the results of blood sugar mean	68
	3.5	Learn what to do if the results of blood sugar are off target	81
	3.6	Learn how to record blood sugar results and keep track over time	13
	3.7	Set goals for blood sugar	21
	3.8	Monitor blood sugar levels	267
	3.9	Record the spot of blood sugar testing or insulin injection	0
	3.10	Provide knowledge of blood sugar	10
	3.11	Monitor lab test results (other than blood sugar, cholesterol, and urine testing)	246
	3.12	Monitor vital signs (other than blood pressure and pulse)	0
	3.13	Monitor heart health (blood pressure, pulse, weight, BMI, and cholesterol level)	471
	3.14	Monitor kidney health (urine and blood testing)	244
	3.15	Monitor eye health (eye exams)	119
	3.16	Monitor foot health (foot exams and sensory testing)	45
	3.17	Share record of blood sugar through forum or email	72
4. Taking Medication (680)	4.1	Learn why take these medications	3
	4.2	Learn what will these medications do for patients	3
	4.3	Learn how to fit medications into the schedule	3
	4.4	Learn the side effects of these medications	55
	4.5	Learn what to do for side effects of medications	10
	4.6	Remember to take medications at the right time every day	4

	4.7	Remind to take medication	2
	4.8	Manage medication list	348
	4.9	Calculate recommended insulin dosage	199
	4.10	Rotate the sites if inject insulin (if the patient injects insulin, rotate the sites every day from the fattier part of the patient's upper arm to outer thighs to buttocks to abdomen)	2
	4.11	Record medicine adherence	49
	4.12	Provide knowledge of medication	2
	4.13	Share record of medication through forum or email	0
5. Problem Solving (361)	5.1	Don't beat self up (managing diabetes doesn't mean being "perfect.")	0
	5.2	Analyze the day	124
	5.3	Learn from experience (Figure out how to correct the problem in a way that works best for the patient, and apply that to similar situations moving forward)	29
	5.4	Discuss possible solutions	120
	5.5	Try the new solutions (try the new solutions and then evaluate whether they are working for the patient)	88
	5.6	Use an alert or reminder for abnormal data	0
6. Reducing Risks (441)	6.1	Don't smoke	18
	6.2	See the doctor regularly (plan to see the doctor about every three months, unless told otherwise)	186
	6.3	Visit the eye doctor at least once a year	110
	6.4	See the dentist every six months	5
	6.5	Take care of the feet	41
	6.6	Listen to the body (if the patient doesn't feel well, or something just doesn't seem right, contact the doctor to help figure out what's wrong, and what the patient should do about it)	11
	6.7	Provide knowledge of reducing risks	41
	6.8	Share information with a diabetes forum or American Diabetes Association website, etc., with the patient	0
	6.9	Vaccination	29
7. Healthy Coping (75)	7.1	Do exercise (when the patient is sad or worried about something, suggest going for a walk or bike ride. Research shows when people are active, the brain releases chemicals that make them feel better)	2
	7.2	Participate in faith-based activities or meditation	0
	7.3	Pursue hobbies	10
	7.4	Attend support groups	20
	7.5	Thinking positive	4
	7.6	Being good to self	13
	7.7	Record mood	25
	7.8	Share knowledge of healthy coping	1

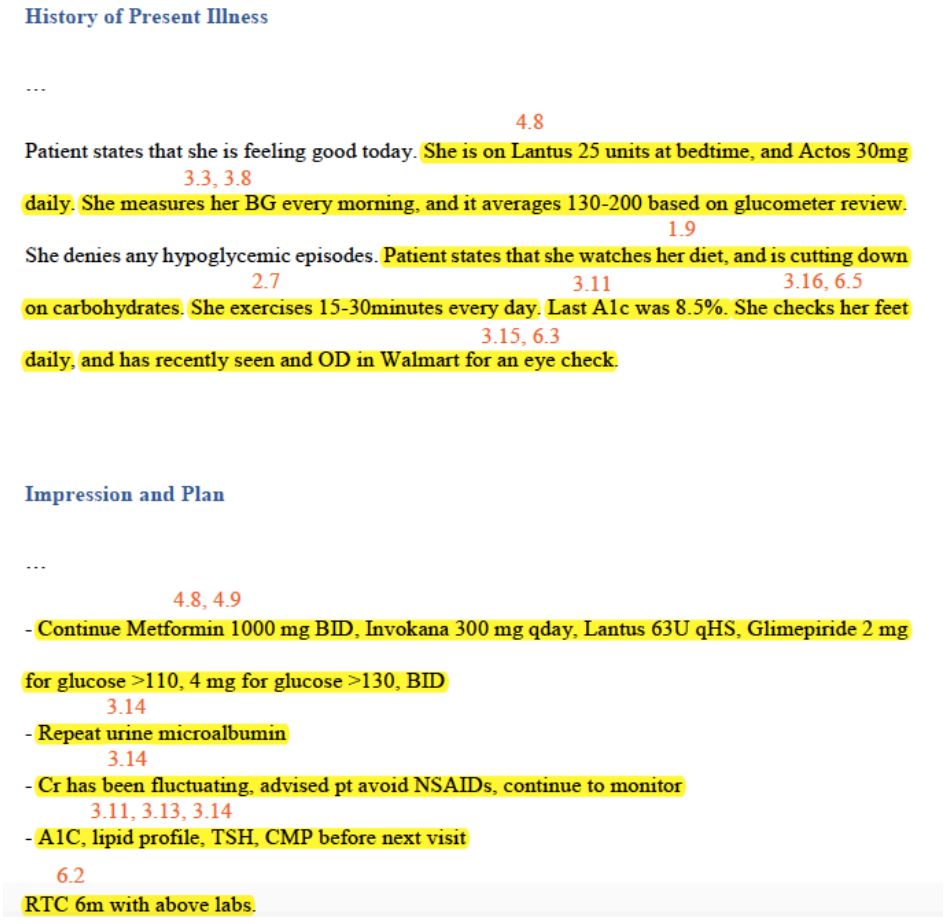
Note: The total count of codes is 3,735. The most commonly occurring principle is Monitoring and least commonly occurring principle is Healthy Coping.

Coding process

We employed a multi-step coding process over a 10-week period along with bi-weekly group reviews [118]. Patel and Ye served as the primary coders. Three research group members (Kim, Khan and Boren) served as reviewers of the primary coding to ensure

accuracy. The coding algorithm involved the following steps: (a) identifying either sentences or words of education items as a unit of analysis in the clinic note sections, (b) determining the codes that matched the concept of the education items from the codebook, (c) marking the code IDs on the extracted clinic note sections and (d) entering IDs and comments into a spreadsheet for a retrospective analysis. Figure 4 shows examples of the coding process from two patients' clinic notes.

Figure 4 Examples of the coding process from two patients' clinic notes. Using a codebook based on the American Association of Diabetes Educators Self-Care Behaviors™ (AADE7™), we identified either sentences or words as a unit of analysis and marked the code IDs.



Frequency distribution analysis of DSME/S across AADE7™ principles

To describe occurrence of each of the seven principles among the clinic notes, we first counted the number of the codes for each note and then calculated the mean counts of codes for each patient as "codes per visit". For example, if the code "3.13- Monitor heart health" occurred three times in the patient's first clinic note and two times in the patient's second clinic note, we would consider the code "3.13" occurred an average of 2.5 times per visit for this patient. Then, we counted the number of each code across the 200 clinic notes (Table 8). Additionally, we summed the counts of codes per visit based on each principle of the AADE7™ for each patient. We described the distribution of the counts of codes based on each of the seven principles. We also tried to understand whether the counts of codes were different from one another of the AADE7™ principles by conducting pairwise comparisons. We used the GLMM [109, 110] to test for a statistically significant difference between the means of least squares of the counts of codes of each pair of AADE7™ principles by two note sections of HPI and I&P. Considering the following factors, we used GLMM [109, 110] to investigate the differences of the counts of codes: (a) the outcome is the discrete counts, (b) the distribution of the counts of codes is negative binomial and (c) the counts of codes from seven principles for each patient are repeated measures. We performed GLMM using PROC GLIMMIX of SAS (Version 9.4 SAS Institute Inc NC).

Assessing patient-centeredness in DSME/S

We investigated whether there were differences for counts of codes based on patient characteristics for sex (male vs female), age group (18-64.9 vs ≥ 65), geographic region (urban vs rural), type of diabetes (type 1 vs type 2), history of diagnosis of diabetes (<5 years vs ≥5 years), hypertension (Yes vs No), hyperlipidemia (Yes vs No), coronary artery

disease (Yes vs No), insulin treatment (Yes vs No), BMI (<30 vs ≥30) [119] and HbA1c (<8% vs ≥8%) [120]. To investigate the patient-centeredness in DSME/S, we again used the GLMMs [109, 110] to test for statistically significant differences between the means of least squares across seven principles by patient characteristics. For example, in HPI section, we computed the means of least squares of the counts of codes for male and female in the Healthy Eating principle individually. Then we compared the two means of least squares to verify whether there was a statistically significant difference. We performed GLMMs using PROC GLIMMIX of SAS (Version 9.4 SAS Institute Inc NC).

Results

Sample size

Our dataset included analysis from 200 distinct clinic notes, two notes from each of 100 patients. We calculated the counts of codes of each of the seven principles for HPI and I&P sections in sets of 20 patients' notes (40 clinic notes). We then computed the frequency distribution of each individual principle in the notes. Figure 5 shows the frequency distribution (percentages) of the seven principles for each set of 20 patients' notes in HPI section. Figure 6 shows the findings for each set of 20 patients' notes in I&P section. We found that the frequency distribution of the seven principles did not change significantly in both HPI and I&P sections across each set of 20 patients' notes. Based on the data saturation theory as applied to the qualitative nature of the study [112], this indicated that adding additional samples into this study beyond the 100 patient dataset would be redundant.

Figure 5 Frequency distribution of the American Association of Diabetes Educators Self-Care Behaviors™ (AADE7™) principles for each 20 patients' notes in History of Present Illness (HPI) Section. For the first 20 patients' notes, we calculated the counts of codes of each of the seven principles in HPI section. Then, the counts of codes from one principle was divided by the total counts of codes from the seven principles of the first 20 patients' notes. We calculated the percentages of seven principles the same way for the other 80 patients' notes.

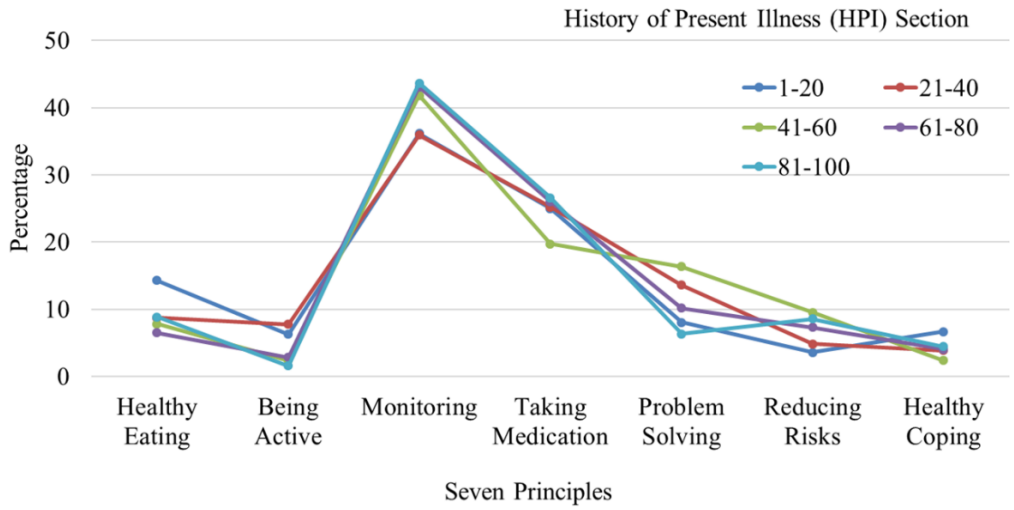
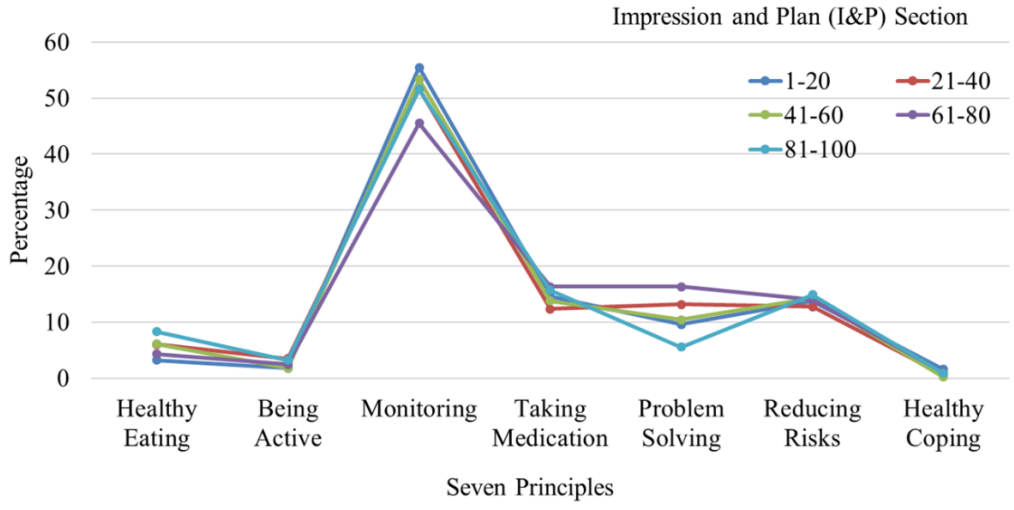


Figure 6 Frequency distribution of the American Association of Diabetes Educators Self-Care Behaviors™ (AADE7™) principles for each 20 patients' notes in Impression and Plan (I&P) Section. For the first 20 patients' notes, we calculated the counts of codes of each of the seven principles in I&P section. Then, the counts of codes from one principle was divided by the total counts of codes from the seven principles of the first 20 patients' notes. We calculated the percentages of seven principles the same way for the other 80 patients' notes.



Subject characteristics

Out of 1,317 patients, 100 patients were randomly selected. There were 68 patients aged between 18 and 64.9 years, and 32 patients aged 65 years and older. There were 52 males and 48 females. Thirty-seven people lived in urban areas and 63 people lived in rural areas. There were 14 people with type 1 diabetes and 86 people with type 2 diabetes. Regarding comorbid conditions, 61 people had hypertension, 40 had hyperlipidemia and 9 had documented coronary artery disease. Seventy-four people took insulin, 72 people were obese and 47 people had an HbA1c over 8%. The average days for interval between two follow-ups were 146 days. Documentation came from nine providers with 3-56 years of experience managing people with diabetes. The average of years in practice managing people with diabetes for the providers is 22 years and standard deviation is 17.79 years, which indicates that they have sufficient clinical experience.

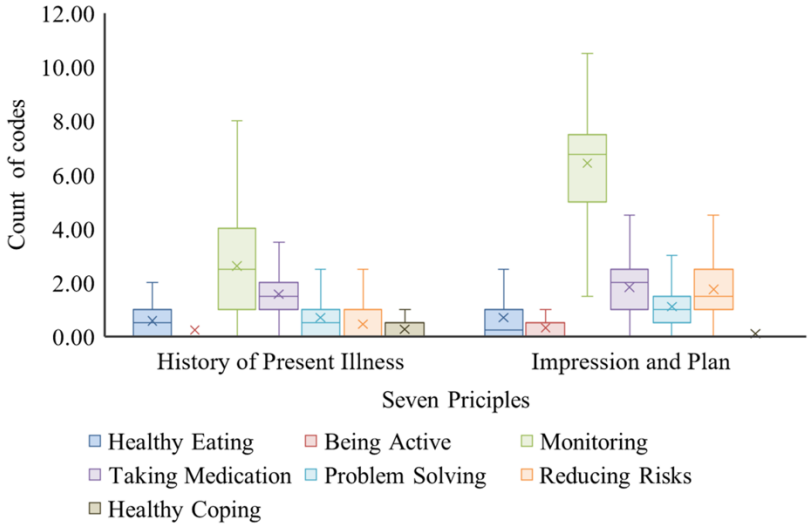
Frequency distribution analysis of DSME/S across AADE7^{TM} principles

The information of DSME/S provided by the providers to people with diabetes was assessed by comparing the counts of codes among the AADE7^{TM} principles. Using the codebook (Table 8), we counted the counts of codes across the 100 patients', 200 clinic notes with 400 note sections. Every clinic note had at least one code. The distribution of counts of codes across the seven principles was not equal. Monitoring (1,808) was addressed most frequently and Healthy Coping (75) were addressed least frequently. We also found the distribution of counts of codes within each principle. Of the total count (3,735), 69% are from 12 codes which were counted more than 100 times. For example, in Monitoring, the codes "3.8- Monitor blood sugar levels" (267), "3.11- Monitor lab test results" (246), "3.13- Monitor heart health" (471) and "3.14- Monitor kidney health" (244)

counted more than 200 times, which contributed 68% of the count in Monitoring. Similarly, in Reducing Risks, “6.2- See the doctor regularly” (186) and “6.3- Visit the eye doctor at least once a year” (110) contributed 67% of the count in Reducing Risks.

Figure 7 shows the box plots along with descriptive statistics of the counts of codes among each of the seven principles by two note sections of HPI and I&P. In HPI section, the order of seven principles by means of the counts of codes was: Monitoring (mean=2.61, median=2.50, SD=1.97), Taking Medication (mean=1.57, median=1.50, SD=0.96), Problem Solving (mean=0.70, median=0.50, SD=0.75), Healthy Eating (mean=0.59, median=0.50, SD=0.63), Reducing Risks (mean=0.46, median=0, SD=0.65), Healthy Coping (mean=0.27, median=0, SD=0.48) and Being Active (mean=0.25, median=0, SD=0.53). In I&P section, the order of seven principles by means of the counts of codes was: Monitoring (mean=6.43, median=6.75, SD=2.36), Taking Medication (mean=1.83, median=2.00, SD=1.08), Reducing Risks (mean=1.75, median=1.50, SD=0.93), Problem Solving (mean=1.11, median=1.00, SD=0.92), Healthy Eating (mean=0.70, median=0.25, SD=0.96), Being Active (mean=0.32, median=0, SD=0.58) and Healthy Coping (mean=0.11, median=0, SD=0.33). Considering the mean of the counts of codes per visit, in HPI section, Monitoring has the greatest and Being Active has the smallest counts of codes per visit. In I&P section, Monitoring still has the greatest counts of codes and Healthy Coping has the smallest counts of codes.

Figure 7 Box plots of counts of codes per visit for each of the American Association of Diabetes Educators Self-Care Behaviors™ (AADE7™) principles. Each box plot includes the upper value within 1.5 times the interquartile range, 75th percentile, 25th percentile, and lower value within 1.5 times the interquartile range. It also includes mean (X) and median (-).



We used GLMM to assess differences between the 21 pairs of means of least square of counts of codes among the seven principles as shown in Table 9. For example, the mean of least square of counts of codes of Heathy Eating principle was compared with those of the other six principles. Because multiple comparisons were conducted, we used adjusted *P* values [121, 122]. In the HPI section, there was a statistically significant difference in the means of least square of counts of codes in 16 pairs of principles, with no statistical difference in five pairs of principles. In I&P section, there was no statistically significant difference between the means of least square of counts of codes of one pair, and for each of the other 20 pairs of principles, the difference between the means of least square of counts of codes was statistically significant. Considering both Figure 7 and Table 9, in HPI section, we found Monitoring has the greatest mean of least square counts of codes, and Being Active and Healthy Coping have the smallest means of least square counts of codes.

In I&P section, we found Monitoring has the greatest mean of least square counts of codes and Healthy Coping has the smallest mean of least square counts of codes. This indicates that providers delivered less information on Being Active and Healthy Coping compared to Monitoring in HPI section and less information on Healthy Coping compared to Monitoring in I&P section.

Table 9 Adjusted *P* values from paired comparison of means of least-square of counts of codes among AADE7™ principles in HPI and I&P sections.

AADE7™ principle	AADE7™ Principle	HPI	I&P
Healthy Eating	Being Active	**<.0001******	**<.0001******
Healthy Eating	Monitoring	**<.0001******	**<.0001******
Healthy Eating	Taking Medication	**<.0001******	**<.0001******
Healthy Eating	Problem Solving	0.8862	**0.0009*****
Healthy Eating	Reducing Risks	0.648	**<.0001******
Healthy Eating	Healthy Coping	**0.0005*****	**<.0001******
Being Active	Monitoring	**<.0001******	**<.0001******
Being Active	Taking Medication	**<.0001******	**<.0001******
Being Active	Problem Solving	**<.0001******	**<.0001******
Being Active	Reducing Risks	**0.0282***	**<.0001******
Being Active	Healthy Coping	0.999	**0.0003*****
Monitoring	Taking Medication	**0.0001******	**<.0001******
Monitoring	Problem Solving	**<.0001******	**<.0001******
Monitoring	Reducing Risks	**<.0001******	**<.0001******
Monitoring	Healthy Coping	**<.0001******	**<.0001******
Taking Medication	Problem Solving	**<.0001******	**<.0001******
Taking Medication	Reducing Risks	**<.0001******	0.9976
Taking Medication	Healthy Coping	**<.0001******	**<.0001******
Problem Solving	Reducing Risks	0.0671	**<.0001******
Problem Solving	Healthy Coping	**<.0001******	**<.0001******
Reducing Risks	Healthy Coping	0.1026	**<.0001******

Note: Asterisk marks mean the level of significance at **** adjusted $P \leq .0001$, *** adjusted $P \leq .001$ and * adjusted $P \leq .05$. In the HPI section, there was no statistically significant difference of the means of least square of counts of codes for the following five pairs of principles: Healthy Eating and Problem Solving, Healthy Eating and Reducing Risks, Being Active and Healthy Coping, Problem Solving and Reducing Risks, Reducing Risks and Healthy Coping. In I&P section, there was no statistically significant difference between the means of least square of counts of codes of Taking Medication and Reducing Risks. For each of the other pair's principles, the difference between the means of least square of counts of codes was statistically significant.
Abbreviations: AADE7™, American Association of Diabetes Educators Self-Care Behaviors™; HPI, History of Present Illness; I&P, Impression and Plan.

Assessing patient-centeredness in DSME/S

We used GLMMs to investigate whether providers deliver patient-centered DSME/S based on patient characteristics across the AADE7™ principles by the patient characteristics in Table 10 and Table 11. Table 10 shows that all the adjusted *P* values in HPI section were >.05, indicating that there was no statistically significant difference across the AADE7™ principles by patient characteristics in the HPI section. For example, for Being Active principle, there was no statistically significant difference of the means of least square of counts of codes between people with BMI <30 and BMI ≥30. We found similar results in sex, age group, geographic region, type of diabetes, history of diagnosis of diabetes, hypertension, hyperlipidemia, coronary artery disease, insulin treatment, BMI and HbA1c across each of the seven principles.

Similarly, Table 11 shows that most adjusted *P* values in I&P section were >.05, showing that there was no statistically significant difference between the means of least square of counts of codes across seven principles by the patient characteristics in I&P section. We found that only the adjusted *P* value between male and female for the Healthy Eating principle was statistically significant (adjusted *P* value=0.0414). The mean of least square of counts of Healthy Eating codes in male was 0.6583 unit higher than female, which means providers delivered more information of the Healthy Eating principle to men compared to women in I&P section. In general, the statistical results show that providers delivered DSME/S similarly regardless of patient characteristics.

Table 10 Adjusted *P* values from comparison of difference between counts of codes across the AADE7™ principles by patient characteristics in HPI section.

Patient Characteristics	Healthy Eating	Being Active	Monitoring	Taking Medication	Problem Solving	Reducing Risks	Healthy Coping
Sex	0.9986	0.996	1	1	1	0.9997	1
Male							
Female							
Age group	1	0.9753	1	1	0.9997	0.9996	0.9961
18-64.9 years							
≥ 65 years							
Geographic region	0.7939	0.215	1	1	0.9991	1	0.7973
Urban							
Rural							
Type of diabetes	0.9505	0.9982	0.9949	1	0.8086	0.9614	0.9923
Type 1							
Type 2							
History of diagnosis of diabetes	1	1	0.9938	1	1	1	0.8593
< 5 years							
≥ 5 years							
Hypertension	1	0.947	0.9676	1	0.9997	0.9938	1
No							
Yes							
Hyperlipidemia	1	0.3629	1	0.9999	0.9886	0.999	1
No							
Yes							
Coronary artery disease	1	0.9985	0.9977	0.9914	1	0.9998	0.9946
No							
Yes							
Insulin treatment	0.9965	0.9965	0.843	0.8627	0.3081	0.9322	0.9993
No							
Yes							
BMI	0.9995	1	1	1	1	1	0.9817
< 30							
≥ 30							
HbA1c	1	1	0.9997	1	0.9996	1	1
< 8%							
≥ 8%							

Note: All the adjusted *P* values are > .05, which means that there was no statistically significant difference between the means of least square of counts of codes across seven principles by the patient characteristics in HPI section.
Abbreviations: AADE7™, American Association of Diabetes Educators Self-Care Behaviors™; BMI, body mass index; HPI, History of Present Illness.

Table 11 Adjusted *P* values from comparison of difference between counts of codes across the AADE7™ principles by patient characteristics in I&P section.

Patient Characteristics	Healthy Eating	Being Active	Monitoring	Taking Medication	Problem Solving	Reducing Risks	Healthy Coping
Sex	**0.0414***	0.246	1	0.9709	1	1	0.9933
Male							
Female							
Age group	1	1	1	1	1	0.9977	1
18-64.9 years							
≥ 65 years							
Geographic region	0.9995	0.9999	1	1	0.9844	1	0.9358
Urban							
Rural							
Type of diabetes	1	0.9988	1	1	0.6209	1	1
Type 1							
Type 2							
History of diagnosis of diabetes	0.9438	0.9623	0.9981	0.9999	0.9973	1	0.0921
< 5 years							
≥ 5 years							
Hypertension	1	1	0.9996	0.4325	1	0.9999	0.8805
No							
Yes							
Hyperlipidemia	0.7451	0.9999	1	0.9997	0.8735	1	0.8459
No							
Yes							
Coronary artery disease	0.9051	0.8937	1	1	1	1	1
No							
Yes							
Insulin treatment	1	0.2287	1	0.4173	0.9912	0.4039	0.1432
No							
Yes							
BMI	1	0.9984	1	1	1	1	0.9998
< 30							
≥ 30							
HbA1c	0.9979	0.9344	0.9995	0.9996	0.9841	0.9993	1
< 8%							
≥ 8%							

Note: Note: Asterisk mark means the level of significance at * adjusted $P \leq .05$. Most adjusted *P* values in I&P section are > .05, which means that there was no statistically significant difference between the means of least square of counts of codes across seven principles by the patient characteristics in I&P section. Only the adjusted *P* value of comparison of the means of least square of counts of codes between male and female for Healthy Eating principle is smaller than .05, which is equal to 0.0414.

Abbreviations: AADE7™, American Association of Diabetes Educators Self-Care Behaviors™; BMI, body mass index; I&P, Impression and Plan.

Discussion

Ongoing DSME/S is a vital component for the management of people with diabetes [2]. The diabetes education that providers deliver during follow-up clinic visits may be the only source for DSME/S for many people with diabetes. In this study, we investigated the frequency distribution of information providers delivered to people with diabetes during follow-up visits based on the AADE7™ guidelines and whether they delivered patient-centered DSME/S based on patient characteristics using GLMMs.

Compared with prior studies of clinic notes of people with diabetes [100-104] that employed NLP techniques, our study adopted manual coding for the clinic notes and conducted regular group reviews. We believe this strategy allowed for the accuracy of coding to be unaffected by complicated sentences, incomplete sentences, acronyms and abbreviations used by healthcare providers (Figure 4). From a practical perspective, manual coding is more efficient for 200 clinic notes and with higher accuracy when comparing to NLP in this pilot study. In many clinic notes, use of EHR templates may result in certain types of documentation becoming more prevalent as an artifact based on construction of the template. This study focused on HPI and I&P sections, which are less likely to be affected by this artifact. In most clinic notes, the providers have to actively document in these two sections, which is more likely to reflect actual clinic interactions.

This study shows the frequency distribution of the AADE7™ principles on clinic notes from follow-up clinic visits. Interestingly, Monitoring appeared to be the most common in both HPI and I&P sections. Being Active was the least common principle in HPI section and Healthy Coping was the least common one in I&P section. Monitoring helps the patient to track and confirm whether blood glucose levels are within target goals [123]. One of the

reasons for providers to focus more on Monitoring may be because of insurance requirements. For example, current Medicare coverage requires that providers should document information about blood glucose data, monitoring frequency and HbA1c to have glucose testing equipment and supplies covered for the recipients [124]. Another reason may be that most patients in this group from a tertiary care center were on insulin, and regular monitoring is needed for appropriate dosing of insulin. Lack of adequate time may be one of the reasons for providers not addressing other principles such as Being Active and Healthy Coping, so Monitoring and Taking Medications become their first option. It is also possible that providers discussed Being Active and Healthy Coping, but because of time constraints, or technological factors, they may not include the discussion in documentation. Additionally, providers may have provided more comprehensive and customized information at an initial visit and may not feel the need to repeat the same information in the follow-up visits. However, the guidelines indicate that it is important to deliver DSME/S at diagnosis, at an annual assessment of education, when new complicating factors occur, and at any transition in care [79, 80]. It may also be difficult to motivate people with diabetes to be active because of factors like increased fatigue, which is common in patients with diabetes [125-128], chronic comorbid condition and social and financial limitations [114].

The Being Active principle can help people with diabetes lower blood sugar, lower cholesterol, improve blood pressure, lower stress and anxiety and improve mood [129]. The Healthy Coping principle provides different ways for people with diabetes to deal with emotional problems, such as stress, depression and anxiety related to diabetes [36, 72]. People with diabetes go through a great deal of social and financial adjustments causing

undue stress in day-to-day life [114]. Stress can impair a person's ability to exercise, check blood glucose regularly or eat healthy foods [130]. This may affect their ability to improve self-management behaviors such as regular exercise, healthy eating or checking blood glucose [131-133]. Healthy Coping skills can help patients to overcome these hurdles [134-138]. Therefore, these two principles deserve more attention by both providers and people with diabetes.

Diabetes is a chronic disease, requiring patient-centered care focusing on personal, medical and social factors. We found that there were almost no differences between the counts of codes across patient characteristics by the AADE7^{TM} principles in HPI and I&P section. The results may indicate that providers deliver standardized DSME/S in follow-up clinic visits. However, our findings may indicate a lack of patient-centered education when people with diabetes visit providers, suggesting that providers may not be addressing important patient characteristics. This was applicable to sex, age group, geographic region, type of diabetes, history of diagnosis of diabetes, hypertension, hyperlipidemia, coronary artery disease, insulin treatment, BMI and HbA1c. This lack of patient-centered education in follow-up visits may be multifactorial, including time limitations during clinic visit, focus on documentation of the visit, lack of knowledge about most recent guidelines and cultural sensitivity of the provider [139]. There were no differences in patient characteristics for frequency of the AADE7^{TM} principles, but it is also possible that there are differences for frequency at subcategory level of the AADE7^{TM} principles by patient characteristics. In the future study, we will compare the differences for frequency at subcategory level.

Patient-centered approach to diabetes requires communication and information sharing between patients and providers. To assess involvement of people with diabetes in DSME/S, we also collected information regarding blood glucose data sharing. In this study, most people with diabetes (88%) shared their glucose data with providers, suggesting their active involvement in Monitoring. We also studied whether there were differences between sex (male vs female) and age groups (18-64.9 vs ≥ 65) with preference of sharing glucose data. There was no statistically significant difference between sex and preference of sharing glucose data (P=0.640, Pearson's χ^2 test [140]). There was no difference between age groups of preference of sharing glucose data (P=0.747, Fisher's exact test [141]). Patients can benefit from sharing glucose data with physicians, which increases patient engagement [142]. Ayuk and Johnson [142] conducted research about remotely monitoring glucose data from people with type 2 diabetes for 90 days for benefits evaluation of remote glucose monitoring and found an increase in frequency of testing blood glucose by 44% at the end of study period. Sharing information also helps providers to have a better understanding of blood glucose trends in order to tailor medical therapy [142, 143]. One method of information sharing in the current era of EHRs is secure access to medical records. At UMHC, HEALTHConnect [144], a patient portal, allows access to laboratory tests and clinic notes to the patient and also allows email communication directly with the provider. In this study, out of 100 people with diabetes, 51 people had an active account. This shows that half of the patients could review their clinic notes and potentially get diabetes education if it is included in the note.

Limitations of the study

Our study has some limitations. First, the study was conducted in the US and may not apply to healthcare settings in other countries. We only collected data from a tertiary referral center (CIDEC) at an academic center (UMHC) that employs a single EHR. Future data analysis should involve clinic notes from multiple institutions to improve external validity. However, the sample size in this pilot study, which was 200 clinic notes from 100 patients, was deemed adequate to identify gaps in the information providers deliver to people with diabetes during clinic visits based on the AADE7^{TM} guidelines. We used the AADE7^{TM} guidelines in our study. We believe AADE7^{TM} guidelines provide equivalent and comprehensive key elements of DSME/S, such as nutrition therapy, physical activity, smoking cessation, psychosocial issues, glycemic management and pharmacologic therapy [145]. However, we recognize there are other diabetes guidelines such as, "Standards of Medical Care in Diabetes" from ADA [145], in the US, and internationally which include excellent recommendations for diabetes self-management. Another limitation may be the influence of difference in levels of expertise for diabetes practice among providers in documentation pattern. The years of practice for the providers in this study managing people with diabetes ranges from 3 to 56 years. The average of years in practice managing people with diabetes for the providers is 22 years and standard deviation is 17.79 years, which indicates they have sufficient clinical and EHR experience. Additionally, clinical encounter includes face-to-face conversations and education which may not be completely reflected in a written note. In this study, two experienced endocrinologists (Khan and Patel) verified the interpretation of abridged contents in clinic notes. Lastly, in this pilot study, we had more people with type 2 diabetes than type 1 diabetes. We did not segregate type

1 diabetes and type 2 diabetes into separate groups. Since these two groups have significant differences in long-term management, future-focused studies are needed in this area.

Conclusions

This study of clinic notes investigated the frequency distribution of DSME/S providers delivered to the people with diabetes during follow-up clinic visits in the US based on the AADE7™ principles. It found that providers focused on Monitoring blood glucose in most notes but may not have addressed important principles like Being Active and Healthy Coping adequately. This approach by providers may have long-term implications particularly in the presence of multiple comorbid conditions in people with diabetes. Generally, we found no difference in DSME/S in the clinic notes based on patient characteristics including sex, demography and comorbid conditions. This may indicate a lack of patient-centered education when people with diabetes visit providers. With the increasing prevalence of diabetes both globally and in the US, further studies are needed to identify the underlying reasons why providers have difficulty delivering ongoing patient-centered education even in a specialty setting and identify whether a separate referral to a diabetes educator was part of follow-up visits. Research involving providers, as well as people with diabetes, is needed to enhance the accuracy of the clinic note. Future studies should focus not only on documentation, but also on the clinic note as a source of individualized DSME/S for people with type 1 or type 2 diabetes who choose to access their clinic notes electronically.

CHAPTER 5 – CONCLUSIONS

This dissertation discussed the challenges and opportunities in diabetes self-management education and support through diabetes mobile apps and clinic notes, which are the import source for DSME/S. A summary of contributions as follows:

First, this dissertation found that current diabetes mobile apps did not provide balanced features compared to the AADE7™ guidelines. Many apps were designed to support the behaviors of Healthy Eating (77%), Monitoring (76%), Taking Medication (58%) and Being Active (45%). On the other hand, few apps explored the behaviors of Problem Solving (31%), Healthy Coping (10%) and Reducing Risks (5%). These three behaviors are essential components for successful diabetes self-management. From interviews, we identified the main reasons why only a few apps support the features related to Problem Solving, Healthy Coping and Reducing Risks. Future diabetes apps should attempt to incorporate features under evidence-based guidelines such as AADE7™ to better support the self-management behavior changes. More research is needed on how we can target future app development to include features, such as Problem Solving, Healthy Coping and Reducing Risks, which support qualitative data entry rather than limiting apps to quantitative data.

Second, this dissertation identified the needs for evidence-based feature and determined usability barriers in older people with diabetes when they used DSM apps. We found that current DSM apps do not provide meaningful features for self-management and may not fulfill the needs of older people with diabetes. The features that participants liked most for the DSM apps were documentation, information and goal setting. Usability was

primary concern for older people when used DSM apps in managing diabetes conditions. However, the usability of current representative diabetes mobile apps for older people is considered not acceptable. Future diabetes apps development should consider the special needs of older people with diabetes. Following user interface design recommendations for older people would be helpful to design senior-friendly diabetes apps.

Third, this dissertation found the frequency distribution of information providers deliver to people with diabetes during clinic visits based on the AADE7^{TM} guidelines by analyzing the HPI and I&P sections in clinic notes. It also found whether the providers delivered DSME/S to people with diabetes based on patient characteristics. During follow-up visits, Monitoring was the most common self-care behavior mentioned in both HPI and I&P sections. Being Active was the least common self-care behavior mentioned in the HPI section and Healthy Coping was the least common self-care behavior mentioned in the I&P section. The results show that providers delivered more information on Healthy Eating to men compared to women in I&P section. Generally, providers delivered DSME/S to people with diabetes regardless of patient characteristics. The results may indicate a lack of patient-centered education when people with diabetes visit providers for ongoing management. Further studies are needed to identify the underlying reasons why providers have difficulty delivering patient-centered education.

In conclusion, the main contribution of this dissertation to the field of health informatics is the identification of challenges and opportunities in diabetes self-management education when people with diabetes, especially for older people, using diabetes mobile apps. It also provides verification whether providers deliver evidence-based and patient-centered diabetes education during follow-up visiting.

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