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“It Feels Good to Know That Someone Cares”: Hispanic Adults’ Motivations for Attending Diabetes Education Classes

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Abstract

Introduction: Diabetes is the leading cause of death in Hispanic communities. Self-management is an important part of diabetes care, and diabetes self-management education (DSME) aims to teach the skills necessary for preventing and delaying complication. However, DSME is underutilized. The purpose of this study was to explore Hispanic adults’ motivations for attending a DSME class to identify effective strategies for promoting class participation and retention.

Method: Nineteen adults participated in seven focus groups conducted in Spanish. Discussions were audio-recorded, transcribed, and translated. Transcripts were content coded by two coders to create a thematic coding scheme.

Results: Five main themes emerged as motivations for attendance: (1) frustration with physiological changes, (2) desire to “do better” because of family experience with death/ complications from diabetes, (3) free access to information that is unattainable elsewhere, (3) a way to take control, and (4) group setting offered valued emotional and informational support as well as peer support for those who were uncomfortable discussing diabetes with family or lived with family who do not support lifestyle changes.

Conclusions: Gaining diabetes self-management knowledge only partly explains the perceived value of classes. Culturally relevant content and appealing to the social supportive aspects of groups may encourage participation.

Keywords

diabetes self-management; education; motivations; barriers; attrition; Hispanic

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Background

Type 2 diabetes mellitus is a controllable chronic condition that affects approximately 29.1 million people in the United States and is the leading cause of cardiovascular disease, stroke, endstage renal disease, and lower limb amputations (Centers for Disease Control and Prevention [CDC], 2014). People of Hispanic descent are at greater risk for developing diabetes compared with Whites, and approximately 13% of Hispanics have diabetes compared with 9.3% of the general population (CDC, 2014). Hispanics with diabetes have higher rates of uncontrolled diabetes than Whites, putting them at an increased risk for developing diabetes-related complications such as vision loss, nerve damage, renal failure, and limb amputations (CDC, 2011). Furthermore, diabetes is one of the leading causes of death in the Hispanic community behind cancer, heart disease, injuries, and stroke (Dominguez et al., 2015; Umpierrez, Gonzalez, Umpierrez, & Pimentel, 2007). Thus, strategies to mitigate these risks are an important part of diabetes care.

Diabetes self-management is a necessary component of diabetes care and plays an important role in glycemic control when administered alongside medical care and management (Haas et al., 2012). Self-management behaviors are aimed at promoting lifestyle changes and include activities such as monitoring diet, engaging in physical activity, checking blood glucose levels, using medications safely, practicing foot care, and recognizing symptoms of complications. Receiving diabetes self-management education (DSME) at initial diagnosis can help people with diabetes cope and learn the skills necessary to successfully conduct self-care. However, the importance of DSME continues beyond initial diagnosis. Receiving education on an ongoing basis can help people with diabetes maintain self-management skills in order to optimize glycemic control throughout a lifetime (American Diabetes Association, 2013). The benefits of DSME can also be ascribed to people with prediabetes, those who have elevated blood glucose levels but are outside the formal range for diabetes diagnosis. Strategies for supporting behavior change in people with prediabetes to prevent the development of diabetes are similar to those that support healthy behaviors in people with diabetes to prevent or delay complications (Haas et al., 2012). Thus, DSME is applicable and helpful to both groups.

DSME is underutilized despite its efficacy in preventing and delaying diabetes-related complications (Powers et al., 2015). In one study among persons who were privately insured in the United States, only 6.8% of patients with a new diagnosis of diabetes participated in DSME or any diabetes care training within the first 12 months of diagnosis (Li et al., 2014). Even among patients who attend DSME classes, attrition rates are often high due to numerous barriers. Known barriers that contribute to the underuse and attrition include competing priorities, transportation barriers, forgetfulness, apathy, low perceived seriousness of diabetes, and lack of accessible services (Gucciardi, Demelo, Offenheim, & Stewart, 2008; Peyrot, Rubin, Funnell, & Siminerio, 2009). Among Hispanics, lack of health insurance, cultural barriers, and limited English proficiency are also barriers to access (Gonzalez, Berry, & Davison, 2013). Given the low attendance and high attrition rates for DSME, there is a need to better understand ways in which diabetes educators can develop effective strategies for encouraging participation and continued attendance. Particularly for

Hispanic populations where rates of uncontrolled diabetes are high, promoting ongoing DSME can be a crucial tool in the overall control of diabetes.

Some studies have started to uncover the components of DSME programs that promote positive outcomes for populations from diverse backgrounds. One systematic review found hospital-based DSME programs were more effective than community-based programs in achieving positive outcomes such as blood glucose control, physical activity, and diet changes (Gucciardi, Chan, Manuel, & Sidani, 2013). However, DSME programs in the United States are moving toward community-based models so there is a need to learn strategies for optimizing success in community-based programs. Ferguson, Swan, and Smaldone (2015) demonstrated in a metaanalysis that DSME delivered in primary care settings to Hispanic patients is effective at promoting glycemic control. Thus, community-based, primary care health centers may be appropriate settings for DSME delivery.

One way to better understand ways to structure DSME to promote attendance is to explore the perspectives of patients who already attend DSME classes. According to the theory of planned behavior, the intention to perform a behavior is informed by (1) an individual's attitudes toward the behavior, (2) subjective norms, and (3) perception of behavioral control (Ajzen, 1991). The theory of planned behavior is a popular framework used to guide health interventions. In the context of DSME, class participants' motivations for attending class may be informed by their attitudes toward the class, normative opinions about the costs or benefits of attending, and perception of individual ability to attend class when desired. Thus, the purpose of the current study was to explore the experiences of Hispanic patients in a clinic-based DSME program and their motivations for attending classes in order to identify areas where interventions can be strengthened to address attrition and low attendance. The theory of planned behavior was used as a guide for understanding participants' motivations for participating in a clinic-based DSME by exploring their attitudes and perceptions toward attending DSME classes.

Method

The DSME Class

Patients who attended a clinic-based DSME series were recruited to participate in focus groups. The DSME series was delivered in a university-affiliated federally qualified health center in Orange County. This clinic serves a largely Hispanic, medically underserved, population with more than 90% of patients falling below 200% of the federal poverty level. Hispanic patients make up more than 70% of the overall clinic population. Some patients were referred to the class by their primary care physician if they had a diagnosis of prediabetes or diabetes. Other patients were invited to attend the class based on abnormal hemoglobin A1C values. Eventually, new participants were recruited through word of mouth from existing attendees.

The DSME consisted of a free 24-week course series where patients met in a group format on Wednesday evenings for 2 hours once a month. The first hour of class involved a lecture-based discussion drawing from diabetes-related content endorsed by the American Diabetes Association. The second hour included a healthy cooking demonstration led by a

professional chef and taste testing. All lectures were presented in Spanish by program volunteers using Power-Point slides, which were developed by volunteers under the supervision of Family Medicine medical residents. A physician remained on hand during the lecture portion to answer medically related questions. Spanish-language handouts were given to patients to take home. Presentation topics included the following: Diabetes Basics, Nutrition, Importance of Exercise, Heart Conditions, Diabetic Medications, Complications in Diabetes, and Mental Health.

At the beginning of each class session, program volunteers greeted patients on arrival to the clinic, checked their vital signs, and provided lecture handouts. Participants were asked to write down a learning goal for the month on an index card. A brief amount of time was spent discussing the previous month's goals, and participants shared what they learned and how they felt achieving their goals. A 2-minute group exercise and 30-minute lecture followed the brief discussion. Then, participants broke into small groups for to review the day's lecture and share anecdotes. Finally, the class session concluded with a cooking demonstration featuring recipes using diabetes friendly ingredients in common Hispanic dishes. Participants also had an opportunity dialogue about foods and share recipes.

Program volunteers were crucial to the operation of the class. Volunteers consisted of undergraduate and post-baccalaureate students interested in health careers in underserved communities. Every month prior to each scheduled class session, volunteers were assigned a list of class participants to provide reminder phone calls. During class the sessions, volunteers took an active role in facilitating group discussions, taking patient vital signs, helping with cooking demonstrations, and answering questions from participants.

Focus Groups and Analyses

Seven focus groups lasting approximately 1 hour each were conducted between January 2014 and August 2014. The focus group methodology was appropriate for this study because verbal discussions can accommodate different literacy levels and use the group dynamic to encourage participation from those who do not want to be interviewed alone or feel they have nothing to contribute (Kitzinger, 1995). Furthermore, the participants were already accustomed to the group format and interaction with one another from the classes.

All participants were consented and no incentives were offered but healthy snacks and water were provided. The inclusion criteria for the study were as follows: (1) Spanish speaking, (2) 18 years of age or older, and (3) attended at least one prior DSME class. All focus groups were led by an experienced qualitative researcher with the help of a certified Spanish interpreter. Discussions were audio-recorded, transcribed verbatim in Spanish, and translated to English by a certified Spanish interpreter. The University of California, Irvine Institutional Review Board approved this study.

The English translations of the transcripts using content analysis were analyzed in Atlas-Ti software. Two independent raters went through each transcript and coded line-by-line to extract ideas and themes. After each transcript was completed, the raters compared their list of codes, and all discrepancies in the coding were discussed until consensus was reached. Using this method ensured that 100% consensus on codes was reached. All codes were then

sorted into categories and themes and illustrative quotes relevant to those themes were extracted. Categories and themes were discussed and organized into a hierarchical coding tree (Hsieh & Shannon, 2005; Patton, 2002).

Results

A total of 19 people participated in the focus groups. The mean age was 54.2 years; most were female (63.2%), married, or in a domestic partnership (57.9%); had less than high school education (57.9%); had some form of health insurance (63.2%); had their HbA1C levels tested within the past 3 months (63.2%); attended at least three class sessions (94.4%); and had a mean of 7.7 years since first diagnosis of diabetes.

Diabetes Is Frustrating and Life Changing

When asked to share the reasons why they attended the DSME classes at the clinic, many participants voiced their frustration with having the diagnosis. Many participants relayed that the health complications and lifestyle changes associated with having diabetes were “frustrating” and “life changing.” For many, the psychological challenges of managing diabetes and dealing with a diabetes diagnosis were more burdensome than the physical or health challenges. Several people discussed the difficulty of resisting “the temptations of food and drink,” particularly during the holiday season and large family gatherings. One woman stated that she cooked and ate separately from other family members at home in order to avoid being tempted to eat the foods that other family members are able to and want to eat. Some participants said that it required “perseverance” and “strong will” to eat healthy and maintain control over diabetes and that the constant vigilance over their diet was a source of stress.

Desire to “Do Better”

For some participants, attendance at DSME classes was driven by the desire to “do better” than others in their family who had diabetes. Many participants shared that other family members had diabetes and attributed their premature deaths, amputations, blindness, or other complications to having diabetes. One female participant stated,

All my cousins have diabetes. One died, the other has no legs, and the other can't see. They didn't go anywhere. They didn't speak to anyone. So I take advantage of the fact the classes are offered. I take initiative to help myself and help my family.

Some participants also stated that going to classes helped them feel like they were engaging in self-care and that it “feels good” to do so. One male participant stated that just by attending DSME classes he felt “75% better” about his diabetes and that he looks forward to the classes and “waits for the month to pass to return to the class.”

Access to Information

Having a venue to access trusted medical information about diabetes in Spanish was a valuable resource for many participants. The majority of participants mentioned that they appreciated that the classes were free to attend. The majority of participants also spoke about their desire to seek information and “learn new things.” Many people did not feel they had

many avenues for obtaining information elsewhere, including from their physicians. One man stated that although he liked his physician he did not feel he was able to get sufficient information about diabetes management from his physician because time constraints at visits did not allow him to ask all the questions that he wanted to ask. Several people saw the DSME classes as a way to obtain additional strategies to complement the medical advice they received from their physicians. For one woman despite having a family history of diabetes, she had limited knowledge of what diabetes actually was:

I had no idea what diabetes was even though my mother had it. So, after coming to class, I realized what I did not know. I was not on the track I wanted to be on. I learned about things I did not know.

A few people mentioned that the DSME classes were also a venue where they felt free to ask for clarification about common myths surrounding diabetes, such as the belief that anxiety or being frightened (*susto* in Spanish) caused diabetes. For example, one woman shared that she believed she contracted diabetes when she was in an automobile accident that frightened her. Topics around cultural mythologies were seen as something that was not appropriate to discuss with a personal physician in a medical setting.

A Way to Take Control

Many participants attributed their struggles with glycemic control to various factors. Several participants stated their belief that it is difficult to adhere to a culturally acceptable diet while making dietary changes, citing the Hispanic foods such as *chicharrones* (fried pork belly or pork rinds), tortillas, and a traditional breakfast of bread and hot chocolate. These participants desired to make dietary changes but found it difficult to do so within the parameters of the cuisine with which they were familiar. Some participants described having to cook traditional meals for their family members who were not always supportive of making dietary changes. One woman further described the difficulty of eating healthy foods with limited financial resources:

[It] is difficult because usually you base the meal you have on what's available. You usually eat what's available. And if there's something that's very abundant, you tend to use it over and over you end up using something that's most abundant, getting the most out of it, and maybe it's not the healthiest thing.

These factors contributed to participants' lack of perceived day-to-day control over diabetes but some people said that attending DSME classes was a way to take control because it was something that they could do for themselves. For some, going to class provided an external source of motivation to face those day-to-day challenges and engage in steps toward making dietary changes. One woman shared, "When I attend classes, I am motivated. I am in control. Then, I leave it and I fall into the same trap."

Peer Social Support

Related to the theme of taking control is the theme of peer social support. Many participants stated that they attended classes for the informal emotional and information support. This referred to the support that they received from one another or from the program volunteers and medical resident physicians. Some people felt the classes were like support groups.

Many people enjoyed having the opportunity to meet others who had the same struggles and experiences. Sometimes groups of friendships developed and often conversations with other peers before or after class provided an opportunity to share new recipes, information, or emotional encouragement. One elderly woman described the group as giving her an “injection of energy to know that I can do it, even at my age.” The psychological aspect of “knowing that someone cares” was uplifting and motivating to some participants. This sentiment is summed up in this quote by a female participant:

[The volunteers] leave behind doing other things in order to be with us. And I tell myself that it is great that there are people who worry about us. It motivates you; it makes you think that life has meaning. It makes you feel good. The illness is still here, but knowing that someone cares about you helps.

Two participants additionally suggested that classes were a space to seek support when they were unable to receive support from their families. These participants felt uncomfortable sharing the details of their condition with family members because they felt “judged” or “isolated” because others did not understand their struggle. For them, having a space where they felt included and supported was an important part of their emotional wellness.

Discussion

Findings from the focus group discussions offer insights into the factors that motivate participants to engage in and return to DSME classes at the clinic. Two major themes reflected participants’ attitudes. One theme revolved around the idea of fulfilling a desire to engage in self-improvement, which was related to the theme of feeling frustrated by diabetes. Many participants expressed having difficulty coping with the physiological changes associated with diabetes and viewed attending DSME classes as a way to learn new coping skills. The findings reflected participants’ positive attitudes toward DSME and the belief that they can benefit from acquiring information taught in the classes. Participants also viewed DSME classes to be a reliable source of information.

A second theme of gaining control over diabetes is related to the concept of perceived behavioral control in the theory of planned behavior. The idea of gaining control is akin to the concept of self-efficacy, or the belief of one’s ability to engage in a specific task. For some participants, attending classes gave them a sense of control over their condition and promoted feelings of self-efficacy despite the daily challenges associated with dietary and lifestyle changes. Self-efficacy is an important precursory to self-care and has been found to be associated with better self-management behaviors across both race/ethnicity and literacy levels (Sarkar, Fisher, & Schillinger, 2006). For example, a study found that among low-income, minority populations, having a higher sense of self-efficacy was significantly associated with better glycemic control, diet, and exercise (Walker, Smalls, Hernandez-Tejada, Campbell, & Egede, 2014).

Finally, the theoretical concept of subjective norms was reflected in the theme of social support. For most participants, the feeling of self-efficacy was encouraged by the social support they received from the volunteers and physicians who lead the classes, and from peers who attended. Social support is associated with a positive change in diabetes-related

lifestyle behaviors, such as physical activity and monitoring diet that can come from family, friends, and other nonkin (Levy-Storms & Lubben, 2006; Rosland et al., 2014; Wen, Shepherd, & Parchman, 2004). For those who may not receive sufficient support at home or from family members, having a source of nonkin support may be beneficial to diabetes self-management. For example, because of the perceived sense of social support, participants in this study found the DSME classes to be a safe space for discussion on topics that were perceived to be inappropriate in a medical setting.

Drawing on the findings of this study, specific strategies for diabetes educators, nurses, or other health professionals who work with Hispanic patients in DSME settings were offered. One aspect of the class that garnered positive response from participants was that classes were conducted by a native Spanish speaker as opposed to an English speaker with the aid of a Spanish translator. Materials such as presentations and handouts were tailored toward Hispanic audiences by addressing culturally specific ideas such as *susto* and incorporated discussion of cultural foods and diets. Specific attention to cultural tailoring as opposed to simply translating materials into Spanish can foster an environment where participants feel included and valued.

Another strategy included the service of volunteers. While diabetes care education should be delivered by properly trained diabetes educators, there are opportunities for volunteers to help in DSME classes, and participants confirmed that the volunteers were a valuable aspect of the program. Volunteers placed reminder phone calls to patients and interacted with patients before, during, and after class. This helped create a sense of trust, caring, and inclusiveness, and participants felt that volunteers cared about their well-being. This emotional connection should not be downplayed because it highlights the fact that social support can include both informational as well as emotional support.

As previously discussed, DSME is often underused due to lack of access (Gucciardi et al., 2008; Peyrot et al., 2009). The classes described in this study were free of charge and held at the primary care clinic in the evening hours to make it more accessible to people who worked during the day. Attendance at every class in the series was encouraged to achieve maximum benefit but flexible enrollment was offered so that participants could drop in at any point in the series and could attend as many classes as they chose. These strategies potentially helped the participants increase their feelings of behavioral control. Purposeful planning to make DSME classes as accessible as possible to participants who may not have flexible schedules can remove some barriers allowing them to attend the classes.

Finally, there are creative ways to build a peer support component into the class without taking time away from the delivery of important education materials. Some ideas include collecting healthy recipes from participants for a communal cookbook, allocating a portion of each class to share challenges and successes in small groups, or implementing a buddy system where participants team up with a peer to share glucose logs and have mutual accountability. Diabetes educators can consider building peer social support structures into classes that offer culturally relevant information and employing motivated volunteers to help foster a positive, trusting environment as strategies to recruiting and retaining patients in DSME classes.

Limitations

There are several limitations to this study. Because recruitment occurred only from a clinic-based DSME class, the views of these patients may not be generalizable to other settings. This is also a population that is already connected to medical care and, thus, may be particularly motivated to acquire information and skills related to diabetes care. Different strategies may be needed to engage people with diabetes who are not already connected to care.

Conclusion

DSME is a critical part of diabetes care but is underused by Hispanic patients with diabetes. Understanding the motivations of patients who attend DSME classes may help diabetes educators develop strategies for recruitment and retention. One of the most significant points is that many participants talked about the DSME classes as encompassing more than just a place to access information but also a space where the interaction with peers, educators, and volunteers was just as valuable. This group dynamic is important and highlights the need for diabetes education to focus not just on delivering factual information but also on nurturing a group environment that fosters inclusiveness.

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