

Research Article

Participant Explanations for Non-Completion of a Diabetes Self-Management Education Program

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The purpose of this study was to identify reasons for non-completion of an accredited diabetes self-management education program offered at a hospital-based diabetes and nutrition center in a Southeastern state. A cross-sectional study design was used to implement an anonymous survey which was mailed to patients with diabetes who started, but did not complete diabetes self-management education classes during a one year time period. The survey was designed to gain information regarding participants' rationale for not completing classes, things that would have influenced participants to continue classes, and what they liked about the classes that they did complete. Data were analyzed for the final sample size of 98 participants. The most commonly reported reason participants gave for why they stopped coming to classes was they thought they had completed. Other reasons included not being able to afford the cost, logistical issues, and competing obligations. Participants' responses to the survey question about what would have caused them to continue attending were categorized as personal, economic, logistical, and other reasons. Participants gave many open-ended answers to the survey question about what they liked about the classes that included the class content, instructors, and peer support. Identifying patient barriers and facilitators to participation in diabetes self-management education classes can assist educators to address these issues and promote patient involvement. In this study, a need was identified to emphasize the importance of diabetes self-management education follow-up visits.

Keywords: Health behavior; Diabetes; Self-management education; Chronic disease management

Abbreviation

T2DM: Type 2 Diabetes Mellitus

Introduction

The upward trend in diabetes prevalence continues to be a concern in the United States. A recent study reported the prevalence of diabetes as 12% to 14% with the highest rates among African, Asian, and Hispanic Americans. Significant increases in diabetes have occurred across age, gender, race, educational level, and income categories [1]. Initial and ongoing diabetes self-management education is essential for these people who face daily and evolving health issues related to diabetes [2]. The American Diabetes Association recognizes diabetes self-management education as one of the cornerstones of diabetes care and recommends that all people with diabetes participate in diabetes self-management education to develop the knowledge, skills, and abilities needed to manage diabetes [3]. Multiple research studies have concluded that diabetes self-management education leads to improvements in outcomes including diabetes knowledge and glycemic control [4-7]. However, a joint position statement from the American Diabetes Association, American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics, reported that only 6.8% of people with newly diagnosed diabetes who had private health insurance and 4% of Medicare patients participated in diabetes self-management education within 12 months of diagnosis [2].

Literature Review

Literature indicates people do not receive or complete diabetes education programs due to a number of factors. People living with diabetes may not understand the necessity and effectiveness of diabetes self-management education or healthcare providers may fail to discuss the importance of self-management education with patients leading them to believe that it is not important or that what they are currently doing is sufficient for self-management [8]. Providers may have confusion regarding when people should be referred for diabetes self-management education, how the process works, or reimbursement [8-9]. Schafer and colleagues reported that physicians significantly influence patients' decisions to participate in diabetes education [9]. Access to diabetes self-management education may be limited due to financial barriers and lack of or poor insurance reimbursement for diabetes education [2,8,10-11]. Expense of travel to and from classes was also discussed as a financial barrier [12].

Many personal issues for non-attendance of diabetes education classes exist. These include lack of transportation or access to classes, long travel times to classes, competing family commitments or work schedules, and disabilities or comorbidities that make attendance difficult [2,9,12]. In a previous study, participants reported that diabetes had low priority in their lives because they were too busy or not in the mood for classes and other things were more important [9]. Finally, diabetes education classes are often offered in group settings

and some participants do not feel comfortable in the group format [12].

Perhaps some of the most difficult reasons to address for non-attendance are attitudes regarding diabetes and diabetes education. In one qualitative study, participants stated that they did not realize the importance of diabetes self-management skills and if they are not doing well, they did not want to go to classes where they may be reprimanded for not managing properly [8]. Another qualitative study reported that participants avoided diabetes education classes because they did not want to hear other people's struggles, learn about the bad things that could happen to them, or they lacked the desire to make behavior changes to manage diabetes. A commonly reported reason for non-attendance was feeling that their current knowledge and self-management practices were sufficient [9]. In the study by Schafer and colleagues more than half of the participants stated they did not need to attend classes because their knowledge of diabetes was sufficient [12]. Finally, people living with diabetes may have negative attitudes about diabetes education classes. Participants reported they thought there was too much discussion about issues that were not relevant to their self-management [9]. Other reasons participants chose not to participate in diabetes education included negative feelings regarding the classes, feared excessive demands to self-manage diabetes, and thought the content of the classes would be too difficult [12].

A recently published systematic review identified two main themes from published studies on non-attendance of diabetes education courses. The themes were classified as those who could not go and those who would not go. Those who could not go identified logistical barriers, competing commitments, and medical or financial reasons. Those who would not go did not perceive any benefit, felt they had enough information on self-management care, had negative feelings or were in denial about their condition, and experienced language, literacy, or cultural issues [13]. Similarly, a recent qualitative study identified two main categories for non-attendance at diabetes education classes. Schwennesen and colleagues categorized reasons for non-attendance into individual and organizational explanations. Individual explanations included illness, lack of perceived benefit, and timing of invitation to join classes. Organizational explanations included program scheduling issues such as interference with work or family life [14].

All of the reviewed literature addressed reasons for non-participation in diabetes education classes, but there is scant information about those who begin, yet do not complete classes. The purpose of this mixed method, descriptive study was to identify reasons for non-completion of a diabetes self-management education program with a high attrition rate. The diabetes education center staff approached the researchers about conducting a survey to determine reasons for non-completion in order to implement measures to decrease the non-completion rate.

Methods

Study aims

The aims of this study were to explore the reasons why an attrition level of greater than 80% has been observed in an outpatient diabetes education center associated with a regional hospital in

the Southeastern United States (US). Aim 1 intended to examine prevalence of rationale for not completing the classes. Aim 2 intended to explore and report open-ended response for: a) reasons that would have caused participants to continue the classes and b) what they did like about the education/classes they completed. Aim 3 intended to examine associations between demographic and medical history variables to see if participants' characteristics could explain or predict the most prevalent reasons for not completing.

A cross-sectional, descriptive study design was used to implement a brief, anonymous survey which was mailed to patients with diabetes who started, but did not complete diabetes self-management education classes in 2014. Approval for the study was granted by the Institutional Review Boards of the hospital and university.

Participants and recruitment

Adults with either type 1, type 2, or prediabetes who enrolled and attended at least one class or session during the year 2014, but did not complete the entire set, were invited to participate in the study. Women with gestational diabetes were excluded. The setting for the study was an American Diabetes Association accredited outpatient diabetes and nutrition center associated with a 350-bed regional hospital in the Southeastern US. The hospital and diabetes and nutrition center draw from rural and underserved areas with minority populations at greater risk and higher diabetes prevalence than the national and state rates. The diabetes self-management education program includes three group classes and culminates with a one-on-one meeting with a registered dietician for personal goal-setting and planning. Patients attend one class per week for three consecutive weeks then meet with a registered dietician for a follow-up visit two to four weeks later. Patients are followed monthly for a year after completing the classes. The Center provided approximately 715 initial education visits in 2014; with approximately 500 of those enrolling in the diabetes self-management education program, but 420 did not complete the full program.

Questionnaire development and measures

Content for the survey questions was derived from a review of the literature on diabetes education attrition/non-participation and open-ended, unstructured interviews with four diabetes educators. The one-page, anonymous questionnaire included sections for demographic and medical history variables; reasons they stopped coming to the classes; open-ended comments on what would have caused them to continue; and open-ended comments on what things they liked most about the classes they did attend. The questionnaire reading level was edited to a 7th grade reading level and was pre-tested among center diabetes educators and a few diabetes patients for face and content validity. A one-time mail out was sent to all 420 non-completers from the 2014 diabetes self-management education classes. A cover letter from the center director, the IRB study information letter, and a postage-paid envelope addressed to the center was included with the survey. The survey packet was prepared by study personnel, but staff from the diabetes education center addressed and mailed the letters to protect patient identity.

Data analyses

Using IBM SPSS Statistics Software Version 21, descriptive statistics (means and frequencies) were generated to report

Table 1: Sample Demographics.

Characteristic	n	%
Gender		
Female	60	61
Male	37	38
Age-mean (range)		56 (18-79)
Ethnic Background		
Black/African American	39	40
White/Caucasian	54	55
Other	2	4
Education Level		
High school	46	47
College	22	22
Graduate school	12	12
Health Insurance		
Yes	92	94
None	6	6
Type Diabetes		
Type 2	80	82
Type 1	8	8
Length of time with Diabetes		
Less than 1 year	15	15
1-10 years	53	54
Greater than 10 years	26	27
Result of last Hgb A1_c		
Less than 7	45	46
Greater than 7	30	31
Don't know	21	21

participant demographic and medical history variables; correlations were generated to describe associations among variables. Aim 1 was addressed with frequencies for each of the 13 provided reasons they indicated for why they stopped coming to the classes (participants could check multiple options as their most important reasons they stopped). These were then individually coded into a yes/no dichotomy for item analysis purposes.

For Aim 2, qualitative research methods were applied to comments participants gave in the open-ended questions regarding what would have caused them to continue and what they liked about the classes they did attend. Two researchers independently examined each comment and proposed a set of themes from among the responses to each of the two open-ended questions; they subsequently met and came to consensus on a common set of themes per question. Next, they independently examined each response and assigned it to the agreed themes, and then discussed their assigned themes and came to consensus on where each response would fit among the themes. After theme-coding per item, each theme was quantified in that frequencies were calculated to identify prevalence of each of the items regarding what would have caused them to continue and what they liked about the classes they did attend.

Aim 3 was addressed through generation of correlations among demographic and medical history variables and the items for reasons they stopped attending, as well as the coded responses to the questions regarding what would have caused them to continue and what they liked most about the classes they did attend. Pearson correlations were used among continuous variables; Spearman correlations were used among categorical variables. T tests were also used to explore differences in means for continuous variables across the dichotomous yes/no for the variables noted in Aim 1.

Results

A total of 420 surveys were mailed to patients who enrolled in, but did not complete the diabetes education course. Of those surveys, 12 were returned undeliverable. Fifty-two surveys were completed and returned. Due to the low response rate (12%), IRB approval was granted to conduct follow-up telephone calls to the target population to gain additional responses via structured interview. An intern at the Diabetes and Nutrition Center randomly selected 102 patients from the list of 420 non-completers and asked them to answer questions over the telephone. Participants were assured that no names would be included on the survey and study personnel did not have access to the list of non-completers; only the intern saw the list. All non-completers were not contacted due to lack of time and resources. Of the 102 participants contacted by phone, 50 additional participants responded for a response rate of 24%. Fifty-two indicated they already mailed in the survey, didn't answer the phone after three attempts, or were unwilling to respond.

Participant characteristics

Data from 102 surveys were collected. Four participants did not meet inclusion criteria so the final sample size was 98. Participants ranged in age from 18 to 79 and the majority were female (n=60) and of either Black/African American (n=39; 40%) or Caucasian (n=54; 55%) race. See Table 1 for descriptive characteristics of the sample.

Aim 1 results: Participants were asked to check the most important reasons they stopped coming to classes from a list that allowed multiple responses. Analysis of data from this question revealed several missing responses. After examining surveys of those who did not respond to this question, participants listed reasons they stopped coming in the "What would have caused you to continue attending section". These reasons they stopped coming were coded in two additional categories (thought they had completed and other) for the "reasons stopped coming" question and added to the other responses for this question.

The most commonly reported reason for stopping was not on the provided list, but 33 participants wrote in or verbally reported when called they thought they had completed all the classes. Twelve participants reported they already knew everything that was being taught. A comprehensive list of reasons for stopping is provided in Table 2.

Aim 2 results: Researchers independently evaluated responses and developed categories for the open-ended questions about what would have caused participants to continue attending classes and what were the things participants liked most about the classes they did attend. Following individual analysis, researchers jointly reviewed responses and came to a consensus on categories for the

Table 2: Reasons Stopped Coming to Classes.

Reason	n
Did not have time	8
Location and time not convenient	8
Could not afford the cost or copay	8
Did not feel comfortable with the educators	2
Did not feel supported	1
Already knew everything they were teaching	12
Not ready to make changes to manage diabetes	5
Classes were not important to me	2
Had no way to get to the classes	4
Speak a language that is not English	1
Had to care for family first	5
Thought I had completed the classes	33

Table 3: Reasons to Continue.

Reason to Continue	n
Economic	
Insurance coverage	12
Transportation to classes	6
Class Logistics	
Different class times	6
Different class length	5
Classes being one-on-one	1
Being able to relate to others in class	3
Better customer service	2
Personal	
Change to curriculum	12
Absence of family/personal/child care issues	8
Not relocating	3
If classes were offered when I'm not out of town	3
Work schedule not interfering with class schedule	3
Curriculum	
If the curriculum was easier	4
Other	17
Nothing	6

two questions. Categories and responses for what would have caused participants to continue attending are displayed in Table 3.

The most frequently reported things that would have caused participants to continue attending were categorized as personal (n=29; 30%). Participants reported that if the curriculum would have been different, they would not have moved or been out of town, or if they did not have family, personal, or work-related conflicts they would have continued attending. Insurance coverage and transportation to classes were categorized as economic factors that would have caused participants (n=18; 18%) to continue attending. Responses (n=17; 17%) related specifically to the diabetes classes were categorized as class logistics and included things such as different class times, lengths, and format; better customer service; and being able to

relate to others in the class. Four participants commented that if the curriculum was easier or food tracking wasn't so difficult, they would have continued. Six participants said nothing would have caused them to continue. Lastly, participants (n=17; 17%) gave reasons that were classified as other and included responses such as they would have come, but they forgot or they would have come if their doctor would have told them to do so.

Participants responded with more comments for the question that asked what they liked about the diabetes classes they attended than any other question on the survey. A total of 212 comments were made regarding what they liked. Responses were separated into eight categories. Participants commented they liked the course content (n=71; 33%) and the instructors (n=29; 14%). Other responses were categorized as outcomes and included learning outcomes (n=27; 13%), clinical outcomes (n=7; 3%), and general outcomes (n=2; 1%). Learning outcomes included comments about learning how to eat, how much to eat, how to control blood glucose, and what causes changes in blood glucose levels. Clinical outcomes included participant comments that they liked the classes because it helped them lose weight and lower hemoglobin A1C levels. General outcomes comments were, "I learned a lot" and "I learned how to carry on by myself". Seventeen participants commented they liked the customer service and these comments were categorized as logistics. Peer support was another category identified by researchers. Comments in this category (n=13; 6%) included, "I liked the fellowship", "I liked the sharing from others, it helped me know I'm not alone", and "I liked sharing and listening to others". Eighteen participants offered areas for improvement or negative comments in the liked section. Finally, a miscellaneous category was created that included comments such as, "Fun", "helpful", and "loved, loved, loved everything about the classes".

Aim 3 results: Using Spearman's rho correlation, significant associations between some demographic variables were identified. Duration of diabetes (r=.247, p=.018), gender (r=.257, p=.012), and age (r=-.327, p=.001) were significantly associated with hemoglobin A1C. Type of diabetes was significantly associated with participant age (r=-.230, p=.025).

Spearman's rho correlations were also evaluated for demographic variables and reasons participants stopped attending diabetes education classes. Educational level was significantly associated with "did not feel comfortable with the educators" (r=.238, p=.019), "not ready to make changes to manage diabetes" (r=.201, p=.049), and "had no way to get to classes" (r=-.230, p=.023). A Chi square test of independence indicated that those participants with a graduate level education were most likely to report not feeling comfortable with the educators, $\chi^2(5, N=97) = 15.97, p=.007$. Those with a lower educational level were significantly more likely to have no way to get to diabetes classes, $\chi^2(5, N=97) = 12.46, p=.029$.

Hemoglobin A1C was significantly correlated with "had no way to get to classes" (r=.317, p=.002) and Chi square revealed that those who did not know their last hemoglobin A1C value were the most likely to have no way to get to diabetes classes, $\chi^2(3, N=96) = 18.09, p < .001$. An independent t-test indicated that age also was significantly correlated with "had no way to get to classes" (95) = 2.13, p=.036

Duration of diabetes was significantly associated with “did not feel comfortable with the educators” ($r=.235, p=.022$). The Chi square test revealed that those who had diabetes greater than 15 years were most likely to not feel comfortable with the educators, $X^2(5, N=94) = 17.17, p=.004$.

Discussion

Aim 1 discussion and implications

The most prevalent reason participants indicated they stopped coming to classes was they thought they had completed the classes. This may indicate an area for increased communication or clarification between center staff and patients. Patients may have attended all three weeks of classes, but if they do not meet with the registered dietician for a follow-up visit, they are considered a non-completer. These follow-up visits are scheduled before the patients leave the center. Clarification should be provided for patients that the follow-up visit is required for completion of the program at this time. Patients receive a reminder phone call about the follow-up appointment. This is another opportunity to remind them that the follow-up appointment is required for completion of the program.

Other reasons participants stopped coming to the diabetes education classes are similar to those found in previous literature and included lack of insurance, cost of the classes, lack of transportation, and competing demands such as work or family. Similar to findings by Schafer and colleagues and Horigan and colleagues, several participants in this study stopped coming because they felt they already knew how to manage diabetes or the classes were not important to them [12-13]. A recent survey that examined trends in diabetes-related knowledge, perceptions, and behaviors found that while knowledge levels have increased, perceived risk has remained stagnant indicating that people may not apply the knowledge to themselves [15]. Although these patients have the knowledge, they may not be ready to apply that information to themselves. Diabetes educators should explore perceptions and feelings of those who have been diagnosed for longer periods of time to identify reasons for non-completion of diabetes self-management education programs. A discussion between patients and healthcare providers can outline benefits of structured diabetes education and identify specific educational needs for these patients [16]. Reaching these patients who feel they already know how to self-manage or are not interested in the classes may require a more patient-centered approach [13]. In the current study, approximately half the participants indicated their Hemoglobin A1C level was less than 7; therefore, they may feel they have all the information needed to manage diabetes leading them to miss important information such as problem-solving and prevention of complications.

A systematic review that synthesized minority views on barriers and facilitators of T2DM self-management found that patients had high regard for healthcare professionals who provided patient-centered care and communicated in meaningful ways [17]. Rather than providing structured classes only, patient-driven classes where patient questions and concerns are the focus could be offered. Patients who feel they know everything being presented in diabetes education classes may have educational needs that are different from the topics being presented in structured classes. Collaborative goal-setting can ensure that both patient and provider goals are addressed

while promoting patient engagement in self-management.

Aim 2 discussion and implications

Currently, the diabetes and nutrition center in this study only offers in-person diabetes education classes. Offering alternative approaches to education such as internet-delivered education has been suggested in the literature and may be a method to address the personal and logistical reasons for non-completion of diabetes education classes [8,13]. Alternative approaches can provide the flexibility patients need to fulfill personal obligations while still caring for themselves. Alternate educational approaches may also address economic issues. For patients who do not have transportation to educational classes, receiving education over the internet or by viewing DVDs may be options. Ineffective multidisciplinary approach and communication have previously been identified as barriers to diabetes education [8]. This was supported in the current study by participant comments stating they would have continued diabetes education classes if their physician would have told them to do so. Schafer and colleagues stated that physicians who wish to motivate patients for diabetes education should openly encourage them to participate in diabetes education and clarify that patients can profit from education even if diabetes is well-controlled [9].

Missed appointments are also an issue in chronic disease management including diabetes [18]. Some participants in the current study reported they just forgot about attending the classes or follow-up appointment. The importance of communication between patients and healthcare providers cannot be overstated. The value of diabetes self-management education should be communicated to patients at the time of diagnosis as well as over time especially as changes occur. Rodriguez indicated that more communicative relationships between patients and healthcare providers contribute to increased diabetes self-management practices [19]. Schafer and colleagues found a strong association between physician referral and diabetes education participation [12].

Aim 3 discussion and implications

Examination of the associations between demographic and medical history variables revealed interesting findings. Those patients with higher educational levels and longer duration of diabetes felt less comfortable with the educators and reported not being ready to make changes in their lives. A recent survey that examined trends in diabetes-related knowledge, perceptions, and behaviors found that while knowledge levels have increased, perceived risk has remained stagnant indicating that people may not apply the knowledge to themselves [15]. This may be one explanation for why those with higher educational levels and longer duration of diabetes reported feeling less comfortable with educators and not being ready to make changes. Although these patients have the knowledge, they may not be ready to apply that information to themselves. Diabetes educators should explore perceptions and feelings of those who have been diagnosed for longer periods of time to identify reasons for non-completion of diabetes self-management education programs.

Limitations

Limitations to this study are recognized. First, a low response rate was achieved even after multi-modal implementation of the data collection. With just under 25% response, it is possible that bias exists

since a majority of those who did not complete the program did not complete the survey. A second limitation is that the generalizability of results is limited since the study was conducted at one hospital-based diabetes outpatient education center in the Southeastern US. A third limitation has to do with the potential for response biases including recall bias and social desirability; respondents may not have recalled how they felt over the past year about why they stopped attending, may have responded to some questions in a way that would be seen favorably by center staff, or both. It is hoped that the anonymity of the study prevented or reduced the risk of social desirability bias.

Lastly, the most prevalent reason stated for not completing was that they thought they had completed. The protocol at the center includes several communications about the structure of the entire program and information about completing all facets. It is unclear why over a quarter of those who responded to the study indicated they were not aware they had not finished. Perhaps enhanced communication is needed to clarify the follow-up appointment is required for program completion.

Implications for Diabetes Educators

Understanding barriers to DSME can assist diabetes educators to identify patients who are at high-risk for non-completion of educational programs. Varying reasons for non-completion require implementation of multiple strategies to address the barriers. Findings from this study indicate that strategies targeted toward convenient and alternate educational delivery methods, enhanced communication between educators and patients, and partnerships between primary care providers and diabetes educators may improve participation in DSME. Retention of patients within programs should be a primary focus of program planning and evaluation.

Conclusion

Understanding patient views of barriers to completing diabetes education programs may improve communication and understanding between patients and providers and could enhance participation in diabetes education programs. An important finding from this study is the need for enhanced communication between diabetes educators and patients regarding components of the program and expectations for follow-up visits after completion of the diabetes educational classes.

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