

Diabetes Self-Management Education; Experience of People with Diabetes

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ABSTRACT

Introduction: Diabetes self-management education (DSME) is a major factor which can affects quality of life of people with diabetes (PWD). Understanding the experience of PWD participating in DSME programs is an undeniable necessity in providing effective DSME to this population. The Aim of the study was to explore the experiences of PWD from a local DSME program in Iran.

Methods: This study applied a descriptive phenomenological approach. The participants were PWD attending a well-established local DSME program in an endocrinology and diabetes center in Isfahan, Iran. Fifteen participants willing to share their experience about DSME were selected through purposive sampling from September 2011 to June 2012. Data were collected via unstructured interviews and analyzed using Colaizzi's approach.

Results: The experience of participants were categorized under three main themes including content of diabetes education (useful versus repetitive, intensive and volatile), teaching methods (traditional, technology ignorant) and learning environment (friendly atmosphere, cramped and dark).

Conclusion: It seems the current approach for DSME cannot meet the needs and expectations of PWD attending the program. Needs assessment, interactive teaching methods, multidisciplinary approach, technology as well as appropriate physical space need to be considered to improve DSME.

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Introduction

Diabetes is one of the main health problems in all countries, which World Health Organization (WHO) mentioned it as a silent epidemic.^{1,2} In Iran, diabetes is headed among non-contagious diseases in the country.³ Epidemiological researches have reported high prevalence rate for Iranians adults.¹ Chronic complications, decreased life expectancy and increased mortality caused by diabetes impose high economic burdens on individuals, families, and the society.⁴

Diabetes is a unique condition that can affect anyone in his or her life.⁵ In this ongoing battle, individuals make several daily decisions regarding nutrition, physical activities and stress management in order to achieve a balance between diabetes and their

lifestyle.⁶ In this struggle, health care providers are not responsible for retinopathy, neuropathy, cardiovascular disease, and even the benefits of glycemic control. They are only responsible for the quality of care, DSME, and support.⁷

DSME is assumed to be fundamental to improve health outcomes for PWD. The ultimate goal of DSME is to support informed decision making, self-care behaviors, problem-solving and active interaction with healthcare providers to improve health status, and quality of life, those living with diabetes.⁸ DSME is one of the main responsibilities of health care providers to empower PWD.^{9,10} As a result, health care providers must endeavor to enhance the quality of the education to ensure that PWD will achieve learning outcomes.⁷

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In order to deliver high quality education, evaluation of DSME is necessary.⁸ Both PWD and diabetes educators are two valuable parts of this process. Most researches have focused on health care providers' perspectives about DSME,^{11,12} while exploring the experiences of PWD has virtually been ignored. This study aims to describe the experiences of PWD attending DSME program in one of the well-known local endocrinology and diabetes centers in Isfahan, Iran.

Materials and methods

This study applied descriptive phenomenology approach consisting of three phases of intuition, analysis, and description.¹³ Phenomenology is the most appropriate way to explore and to understand actual experiences of the participants.¹⁴ In this research, descriptive phenomenology relies on the individuals' experiences about DSME. This study has been approved by Ethics Committee

of Isfahan University of Medical Sciences in Iran to recruit participants from among eligible people. The inclusion criteria included: a) having diabetes; b) attending DSME program at the target endocrinology and diabetes center and c) willingness to participate in the study. The DSME program in the center included 7 two hours group DSME sessions for both Type 1 and Type 2 diabetes. All the participants completed the DSME program between September 2011 and June 2012. The research team considered maximum variation in the recruitment including gender, age, level of education, marital status, job and social and economic status. Finally, fifteen participants were recruited through purposive sampling from September 2011 to June 2012 until saturation was reached.

Saturation in this study was reached when no new codes were identified. Table 1 describes the demographic characteristics of the study participants.

Table 1. Demographic characteristics of the participants

| Diabetes type | Age | Sex | Years of diagnosis | Education level | Job | Marital status |
|---------------|-----|-----|--------------------|-----------------|------------|----------------|
| 1 | 36 | F | 3 | Bsc | Housewife | Married |
| 1 | 26 | F | 14 | Bsc | Housewife | Single |
| 1 | 22 | M | 7 | Diploma | Unemployed | Single |
| 2 | 45 | F | 5 | Diploma | Employed | Married |
| 1 | 25 | F | 16 | Msc | Student | Married |
| 1 | 22 | F | 17 | Bsc | Housewife | Married |
| 2 | 54 | M | 10 | Bsc | Teacher | Married |
| 1 | 17 | F | 15 | High School | Student | Single |
| 1 | 16 | F | 16 | High School | Student | Single |
| 1 | 21 | F | 15 | As | Housewife | Married |
| 2 | 47 | M | 5 | High School | Tailor | Married |
| 1 | 30 | M | 15 | Diploma | Employed | Single |
| 2 | 62 | M | 10 | Illiterate | Employed | Married |
| 2 | 36 | M | 1 | Bsc | Employed | Married |
| 2 | 58 | F | 1 | Illiterate | Housewife | Married |

The data were collected using unstructured interviews, which provide more detailed and deeper information on the experiences of the participants.¹² Interviews were conducted in a private and quiet place based on the participants' choice. All the participants signed the consent informed form. All the interviews started with the

initial open question the participants were asked to respond to the initial interview question (Please talk about your experience of being in the diabetes self-management education program). The interviews were followed by the participants' answers.

Finally, 18 interviews from 15 participants (three participants needed

additional interviews) were collected with the average duration of 30 minutes for each interview. Before data analysis the research team identify their personal biases, and assumptions about the DSME program at the target center and put them aside to avoid their personal assumptions on the interview process or data analysis. The data was immediately transcribed verbatim and analyzed based on Colaizzi's seven steps method.¹¹ In first step, the researchers read all the transcripts separately in order to understand the participants' experience related to DSME. Then, they derived words and phrases related to DSME. In third and fourth steps, the researchers tried to give special meaning to the important sentences and arranged them around particular conceptual themes. Then, the research team referred to the main descriptions to establish the reliability. Afterthat, they summarized the comprehensive descriptions of DSME to an actual and essential description. Finally, the categories and description were referred to the participants in order for them to clarify their beliefs about the research findings and to make findings credible.¹¹ In this research, prolonged engagement (to increase credibility), peer review (to enhance data neutrality and objectiveness), monitoring participants (to increase reliability and to increase data neutrality and objectiveness), and depth description of work (to increase transmission) were all used¹² for rigor.

Results

The findings highlighted three main themes regarding PWD experience about DSME, including: Content of diabetes education (useful versus repetitive, intensive and volatile), teaching methods (traditional, technology ignorant) and learning environment (friendly atmosphere, cramped and dark).

1. Content of Diabetes Education

The participants put an emphasis on the educational content rather than anything

else related to DSME. To beginners, the content was useful and for people who had had diabetes for long periods it was rather repetitive. Overall, the participants' expectations of diabetes education at one of the main endocrinology and diabetes centers in Isfahan (Iran) were far from what they had already experienced. PWD complained about their failure to receive new information in diabetes field. Turmoil in the expression of different topics in a session or repeating one topic in several sessions without considering individuals needs was one of their main problems. In addition, participants expressed their dissatisfaction with the intensive and volatile DSME content. Categories of the themes are "useful versus repetitive" and "intensive and volatile".

1-1. Useful versus repetitive

To those who were newly diagnosed with diabetes, the content of the DSME was useful. Novices in living with diabetes explained how they were informed in DSME classes about different aspects of living with diabetes and self-care behaviors.

Participants expressed that DSME classes had answered all of their questions about diabetes. They described the positive experience since DSME changed their perspectives about diabetes from a scary disease to a manageable one.

"Classes changed my attitude towards diabetes. It was so useful for me who had just got diabetes for a year. For example, topics such as nutrition and diet recommendations were very useful." (Male, T2DM, 36 years old)

Not surprisingly, to those who have lived with diabetes for more than 10 years, the content was repetitive and too general. This group of participants complained that the DSME classes are being held without considering their individual needs. They indicated that participation in these classes is a requirement to be eligible for receiving health care service from the target endocrinology and diabetes center and they did not consider their needs to have been

accounted for in the classes. Therefore, the participants asked for specific information addressing their daily challenges in diabetes management.

"Classes are useful for beginners, those who have just been diagnosed with diabetes. However, for people like me who has had diabetes for 15 years it is all too repetitive. I need new and more specific information. I participate in these classes just out of obligation and to receive care from the physicians of this center." (Female, T1DM, 22 years old)

Some participants also discussed the repetition of the content in different DSME sessions:

"One thing that happened in many classes was that topics were not classified. I mean that some topics were just repeated in different sessions. For example, according to the given topic which specified what would be talked about in this session, that is how anti hyperglycemic medications control blood sugar, the diabetes educator actually talked about diabetes complications!" (Female, T2DM, 36 years old)

1-2. Intensive and volatile

To beginners of living with diabetes, the number of provided topics and subjects in each session (each of which lasts 1.30 -2 hours) was quite intensive. They discussed the imbalance between their needs and the number concepts delivered. PWDs, particularly old adults, also mentioned their difficulties in remembering the concepts and integrating the information into their diabetes self-care. Participants asked for educational materials that they could take home to refer to when it was necessary.

"The number of sessions was few for all these things that should be learned about diabetes. Five sessions are way too few. Furthermore, the concepts discussed in classes get out of our mind too early. Well, we are old and we forget things too quickly. I wish that they give us booklets of the topics for each session to take home and look at in case we forgot them." (Female, T2DM, 58 years old).

2. Teaching methods

The second theme emerging from the data was teaching methods. Some participants

were dissatisfied with the traditional approach of the educator. To them, the use of lecture as the only method in all sessions is not an appropriate way for adult learning. They also valued the importance of using technology. Most participants asked for a change in teaching methods, which they believed, was "traditional" and "technology-ignorant".

2-1. Traditional

All participants in various parts of the interview expressed their dissatisfaction with having one instructor for all the sessions. They mentioned an interdisciplinary team involving experts from various professions would lead to providing more updated and specific information.

"If they use experts for each field it would be very good. To be honest, these classes did not add too much to what I already knew. I think an expert in the subject area should present each topic. For example, a nutritionist should present nutrition. If it could be like that, I think it would become better. Here, the diabetes educator just tells us to do exercise but they do not say what kind of exercise we need to do." (Male, T2DM, 47 years old)

On the other hand, young adults suggested using interactive teaching methods where the diabetes educator could perform as a facilitator during the learning process.

"We have got tired of listening to lectures. We want to talk with each other and to learn from each other. For example, I want to see a person like me, to see what he/she does when he/she has a problem controlling his/her blood sugar. I wish they held classes in a way that we could learn from each other". (Female, T1DM, 17 years old)

2-2. Technology ignorant

Ignoring the use of technology in the DSME sessions was another significant point that had been brought up in the interviews. PWD stated that in the era of technology using audiovisual materials would certainly help with improving their learning. They advocated the use of technology that would

make their learning more tangible and stable.

"If they show concepts on charts, diagrams or with pictures, it would be more understandable to us. I think if seeing and hearing are both involved simultaneously, the instructions could be more effective. Showing films and slides I think it is far better. I forget all of what I learned. I do not know maybe I am the reason, but I can't have forgotten it all this soon. If the learning were deep enough and if they taught us deeply enough by effective methods, I do not think we forget them quickly. So if I am to forget it all, what is the point of these classes? They, should find a solution for this problem" (Female, T2DM, 45 years old)

3. Learning Environment

Learning environment was another important theme to influence individuals' learning about diabetes management. Although the participants emphasized "the friendly atmosphere" of the diabetes classes, they did mention how poor light and limited physical space of the class had affected their learning process. They all agreed that the class was friendly but the space was "cramped and dark".

3-1. Friendly atmosphere

PWDS discussed the intimate and friendly atmosphere of DSME classes. Because of friendly behavior of the educator, the participants were able to express their fears and concerns about diabetes and its management. Therefore, the friendly and informal atmosphere which was tangible in the class was one of the most positive aspects that the participants mentioned frequently.

"In these classes, we feel so comfortable. To be honest, diabetes educator behaves very well and in a friendly manner. It helps us talk and express our problems. I think everyone feels as I do. Classes were held in a way that everyone asked questions and diabetes educator answered all questions affably". (Male, T2DM, 62 years old)

3-2. Cramped and dark

All participants were dissatisfied with the physical space of the training classes. To

them, the small size and poor light of the class limited their learning experience. Inappropriate physical space even made it almost impossible for them to sit comfortably. Participants voiced their right as a PWD to get education in a better physical condition.

"I think it is our right to benefit from a better physical space which can facilitate our learning. In this small cramped room, we are not even able to sit comfortably. It is too small and dark." (Female, T2DM, 36 years old)

Discussion

The content of DSME is a fundamental part of education which was mentioned by all participants in this study. This finding is similar to other research studies where there is an emphasis on delivering appropriate educational materials to individuals.¹⁵⁻¹⁷ In this study, beginners in living with diabetes were satisfied with the content. Participants in the two studies conducted by Maloney and Weiss and Alagheband et al., also expressed their satisfaction with the education provided.^{18,19} Similar to the findings of this study according to which the content did not meet the expectations of those living with diabetes for several years, the results of several researches showed that individuals have received information less than their expectations.²⁰⁻²³ The different perspectives of the beginners and experienced participants regarding DSME contents has been identified in this study. It seems that providing initial and general information about diabetes management was useful for those who were newly diagnosed with diabetes. However, the rest of participants needed more personalized information to overcome their daily struggles in living with diabetes. This is a fact that DSME needs to be individualized.²⁴⁻²⁶

Another important finding of this study was the intensiveness and volatility of the content. According to them, the presented volume in each session was too heavy and

they forget the concepts too quickly. Likewise, dunning emphasizes effective DSME that PWDs can apply in their real life.²⁷ Increasing the number of DSME sessions and avoiding prolonged sessions are some important principles of adults' education that can facilitate learning processes for people.²⁸ As in this study, the value of teaching methods in maximizing individuals' learning have been discussed in other studies, as well.^{16,29-31} Additionally, using a team approach involving a multidisciplinary team in diabetes education has also been recommended.³⁰

The participants in the current study emphasized receiving information from an expert in the field, which has not been specifically discussed in other studies.

The finding of the study also highlighted that young adults mainly asked for interactive methods while old adults preferred lecturing. This finding is also supported by other studies indicating that interactive teaching methods can improve learning outcomes.^{26,33,34} Inappropriate learning environment has been considered as a barrier to patient education.³⁵ The findings of the present research showed that all participants were dissatisfied with the physical space of the classes. However, they relied on the friendly atmosphere which made them able to share their personal concerns about diabetes freely with the group. This study was a qualitative study conducted with a small sample of PWDs in a local DSEM program in Iran. Therefore, it cannot represent all the DSEM programs that are placed in Iran. In addition, this study focused on participants' experience and did not include the experiences of health care providers which means the providers' expectations, needs and challenges are missed. Future multi-central studies are needed to include both PWDs and health care providers to gain a better insight about DSME in Iran.

Conclusion

DSME is fundamental for improving the quality of life and health of those living

with the illness. However, an effective education requires needs assessment, individualized personalized education, effective teaching methods and application of technology. If a multidisciplinary team can be involved in diabetes education, it could, without doubt, help with delivering information by experts in the specific fields, thus maximizing individuals' learning. It is also necessary to consider individuals' demographic characteristics and learning styles and the type of diabetes.

Health care providers need to reconsider their approach for DSME to meet the needs of the individuals living with the chronic illness. It is obvious that traditional teaching methods and technology ignorance is not an appropriate way for patient education in the 21st century. In addition, the physical space of the learning environment should pay more attention to improve diabetes education.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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