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Original article

A focus group study of patient's perspective and experiences of type 2 diabetes and its management in Jordan

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ABSTRACT

Background: Diabetes is increasingly becoming a major health problem in Jordan and glycemic goals are often not achieved.
Objective: To explore the patients' perspectives regarding type 2 diabetes and its management in order to "fine-tune" future pharmaceutical care intervention programs.
Method: Focus groups method was used to explore views from individuals with type 2 diabetes attending outpatient diabetes clinic at the Royal Medical Services Hospital. All interviews were recorded, transcribed and analyzed using a thematic analysis approach.
Results: A total of 6 focus groups, with 6 participants in each one, were conducted. Participants in the present study demonstrated a great information needs about diabetes and the prescribed treatment. Medication regimen characteristics including rout of administration, number of prescribed medications and dosage frequency in addition to perceived side effects represented the major barriers to medication adherence. In addition to demonstrating negative beliefs about the illness and the prescribed medications, participants showed negative attitudes and low self-efficacy to adhere to necessary self-care activities including diet, physical activity and self-monitoring of blood glucose.
Conclusion: Future pharmaceutical care interventions designed to improve patients' adherence and health outcomes in patients with type 2 diabetes should consider improving patients' understanding of type 2 diabetes and its management, simplifying dosage regimen, improving patient's beliefs and attitudes toward type 2 diabetes, prescribed medications and different self-care activities in addition to improving patient's self efficacy to perform different treatment recommendations.

1. Introduction

Diabetes is a major public health concern and financial burden all over the world. The prevalence of diabetes is dramatically increasing globally (Wild et al., 2004), particularly in developing countries including Jordan (Ajlouni et al., 1998). Compared to 108 million people affected by diabetes in 1980, an estimated 422 million adults were found to have diabetes in 2014 (WHO, 2016). The World Health Organization (WHO) data indicates an increase from 1% in 2002 to 7% in 2010 (WHO, 2011) in the proportion of diabetes-related deaths in Jordan. Uncontrolled diabetes leads to long-term microvascular and macrovascular complications including retinopathy, nephropathy, neuropathy and cardiovascular diseases (Kelly and Rodgers, 2000).

Patients' non-adherence to therapeutic regimens and lifestyle advice is a major barrier to achieve the desired glycemic control in order to prevent diabetes related complications (McDonald et al., 2002; Irons et al., 2002). Available data indicates that improving treatment adherence leads to improved clinical outcomes (Rhee et al., 2005). However, information available on treatment adherence in patients with type 2 diabetes is sparse despite its importance (Cramer, 2004). In a study conducted in Jordan, it was found that of the 171 study participants, almost three quarter (72.5%) were classified as non-adherent (Jarab et al., 2014). Factors

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associated with poor adherence to recommended treatment have been assessed in different studies, but the patients' perspective and participation in the treatment decisions and care plan design was remarkably absent (Vermeire et al., 2003). Clarke et al. reported that it is very important to have a patient-centered approach because it is estimated that patients with diabetes are responsible for 95% of their own management and one of the reasons for poor outcomes of diabetes treatments is lack of patients' participation (Clarke et al., 2002). In order to achieve better adherence to prescribed treatment, healthcare professionals need to understand and address factors that enable patients to adhere (Gagliardino and Etchegoyen, 2001). Vermeire et al. reported that the first step to designing effective interventions is to understand those factors that help patients with type 2 diabetes adhere to therapeutic regimens and lifestyle advice (Vermeire et al., 2003). Furthermore, little is known about the barriers that people with diabetes face to incorporate self-care activities into their lifestyles (Nagelkerk et al., 2006).

Qualitative research, including focus group method, enables us to access areas not amenable to quantitative methodology and allows for the introduction of new issues and ideas necessary for the development of effective interventions (Haines and Jones, 1994). In addition to the enhancement of the participation of people who cannot read or write (Kitzinger, 1995), focus group can help the participants exploring their views in a more accessible way than other qualitative research methods such as one-to-one interview (Kitzinger, 2000). Qualitative research in the form of focus group method was chosen in the present study to obtain an in-depth exploration of the patient's perceptions and views in managing type 2 diabetes. There is limited information in the literature on what diabetic patients feel and think in relation to treatment adherence (Vermeire et al., 2003; Benner, 1985). This study, to our knowledge, is the first one that has examined patients' experiences of type 2 diabetes in Jordan. The current study findings should be incorporated into future diabetes care programs which are tailored to patients' needs and designed to improve health outcomes in patients with type 2 diabetes.

2. Aim of the study

To explore the patients' perspectives and experiences of type 2 diabetes and its management, in addition to their views about the barriers to adherence to medications and self-care activities. Findings should be useful in the design of future pharmaceutical care interventions aiming at improving health outcomes in patients with type 2 diabetes.

3. Methods

3.1. Study site and subjects

Patients attending the outpatient diabetes clinic at the Royal Medical Services Hospital who met the inclusion criteria were provided with an information sheet and asked to sign a consent form if they agreed to participate in the study. All patients who had type 2 diabetes for at least one year and took at least one medication for diabetes control were included in the study. Patients were excluded if they suffered from mental or physical disability.

3.2. Study design

A qualitative research approach i.e. focus group discussions, was adopted in the present research. The focus group discussion was guided by the principal investigator (AJ) with the assistance of (TM), who have a good experience in caring for patients with type 2 diabetes, using a schedule of open-ended questions designed to explore information needs about diabetes and its treatment and barriers to adherence to prescribed medications and different self-care activities as shown in Table 1. The researchers did not have a previous relation with any of the study participants and they were not working in the clinic at which the current study was conducted. Before conducting each focus group, participants were informed that the discussion would be recorded and remain confidential. All focus groups were conducted in Arabic with an average time of 75 minutes for each focus group. AJ demonstrated that the purpose of the research was to gain a better understanding of how they, as patients, understand and cope with diabetes and its management. Typically, 6–8 people are recruited in each group to explore patient experiences of disease and health issues. Based on purposive sampling technique, the process of adding focus groups was carried out until no new information can been attained and theoretical data saturation was reached (Glaser and Strauss, 1967). Accordingly, a total of 6 focus groups with a total of 36 patients were used in the current study.

3.3. Data analysis

The audiotapes from the focus groups were transcribed verbatim and the transcripts were checked for accuracy against the original audiotapes (Boeije, 2002). Transcripts were translated into English and then back translated to Arabic by two independent translators to guarantee content consistency. Each transcript was coded independently by three members of the research team. The data were analyzed using a thematic analysis approach (Kitzinger, 2000; Silverman, 1993). Transcripts of each individual focus group were read, re-read and summary notes were made. Topics raised were grouped under potential thematic categories, which were often renamed, when a more appropriate title emerged. The ideas and issues, which emerged, were grouped into categories and then further grouped into themes. Having carried out this exercise independently, the team members met to discuss and agree a final framework to describe and evaluate the information and views brought forward by the patients.

4. Results

Six focus groups were held with a total of 36 patients. The demographic characteristics of the participants are shown in Table 2. The participants demonstrated a variation among each focus group in relation to gender, age, employment status, disease duration, compelling indications and disease severity. The analysis resulted in the following major themes: knowledge and information needs about diabetes and its management, barriers to adherence to medications and self-care activities, and self-efficacy and beliefs about illness and medications.

Theme 1 Knowledge and information needs

Knowledge about diabetes

Participants demonstrated little knowledge about type 2 diabetes

"Is it the food that we are eating that causes diabetes or is it obesity?" (P15)

"Is it something to do with your pancreas?" (P22)

"...is it something to do with the genes?" (P28)

On the other hand, better knowledge and awareness was demonstrated about poor blood glucose control

"There is a poster here somewhere which says that 75% of people with diabetes die of a heart condition" (P8)

"Diabetes can cause nerve damage and sometimes patients require foot amputation as blood vessels can be damaged and there can be kidney damage" (P15)

Table 1
Open-ended questions used during focus groups interview.

Question 1: What do you know about type 2 diabetes?
Question 2: Why it is important to control blood sugar? How has diabetes affected your health?
Question 3: What type of medications you take to control your blood sugar?
Question 4: How would your medications help you to control your blood sugar?
Question 5: What do you expect from your medications?
Question 6: What makes taking your medications as prescribed difficult?
Question 7: How can you help the medical team to control your blood sugar?
Question 8: How does having diabetes impact your daily life?

Table 2
Characteristics of the participants in the six focus groups (n = 36).

Characteristics	FG1	FG2	FG3	FG4	FG5	FG6	n	%
Gender								
Male	4	4	4	5	4	5	26	72.2
Female	2	2	2	1	2	1	10	27.8
Age								
30–40	1	2	1	1	0	1	6	16.7
41–50	1	2	1	2	2	1	9	25
51–60	2	2	2	1	2	2	11	30.6
61–70	2	0	1	2	2	1	8	22.2
>70	0	0	1	0	0	1	2	5.5
Employment status								
Working	3	5	4	4	4	4	24	66.6
Retired	3	1	2	2	2	2	12	33.3
Duration of diabetes (years)								
<5	2	1	1	1	1	1	7	19.4
5–9	2	3	1	2	2	2	12	33.3
10–15	1	1	1	1	2	3	9	25
>15	1	1	3	2	1	0	8	22.2
Diabetes pharmacotherapy								
Oral tablets only	2	3	4	2	4	3	18	50
Insulin injections only	1	1	1	2	0	1	6	16.7
Oral tablets and insulin injections	3	2	1	2	2	2	12	33.3

FG: focus group.

"My eyesight is not as good as it was. I have kidney problems and loss of feeling in the feet." (P17)

Knowledge about the medications

The patients expressed a range of information needs related to medication regimens including: type, therapeutic effect, potential side effects and dosing of the prescribed medications

"How many types of tablets are there?" (P11)

"Are they of different strengths? What do the medications do for you?" (P17)

"I don't know when to take my medicines, I just swallow them" (P5)

"They work and they do help you to reduce your glucose levels but the side effects are not explained to you and I think the combination of oral tablets also made my mood swings bad" (P3)

"I think it should be explained more to you when is the best time to take your individual tablets" (P20)

The patients in the focus groups highlighted the need to understand the rationale behind the prescribed treatment i.e. some patients are prescribed lifestyle change while others need medications.

"I don't understand that. Some people are just on diet and others are on insulin" (P24)

Theme 2 Barriers to adherence to medications

In addition to poor knowledge, therapeutic regimen characteristics constituted a major barrier to medication adherence for the study participants. Focus group participants in the present study showed many concerns regarding insulin injection and would have preferred a non parenteral route of administration. Many patients related the reason for non-adherence to the high number of the prescribed medications and the multiple dosing frequencies, while others related non-adherence to the sideeffects of the prescribed medications.

Route of administration

"I would almost prefer it if it wasn't for the needle. If there was another way of taking it" (P35)

Frequency of administration

"This is where we are ignorant. I have to take some in the morning and some in the evening but you are saying take one daily dose" (P4)

"If it could be made that you could take all your medicines in one go that would be better than having different periods".

Polypharmacy

"At the end of the day I feel I am taking so many tablets" (P19)

However, other participants gave important suggestions to help in taking prescribed medications as recommended

"I put mine in a box Monday, Tuesday and Wednesday etc. and then I know that I have taken them if they are empty" (P9)

"I sit down and do my tablets for a week and then I know what I am running short of and I order them on a Monday" (P21)

"I take mine from a medical box and they are all set out" (P26)

Theme 3 Self-efficacy

Some patients exhibited high self-efficacy by emphasizing the importance of individual responsibility to follow the treatment recommendations and to achieve the desired clinical outcomes

"It is also about taking responsibility for your own health. You go to the doctor or the nurse and they tell you what to do but in reality the health service is getting to the stage where you are going to have to take responsibility for your own health" (P1)

"It's up to yourself if you take your medication or not" (P33)

However, the patients in general showed low self-efficacy in following the different aspects of lifestyle advice and self-care

activities including diet, exercise and self-monitoring of blood glucose.

"I would need someone to nearly come and do it for me because I would only monitor my blood sugars about 3 times a week" (P7)

"It is very difficult to control what you eat. You more or less have to set your limits and that is where the people round you come in and that can encourage you to eat even more.

"I find I am too tired to do exercise. I can't motivate myself" (P22)

"Once I sit down that is it"(P23)

Theme 4 Health beliefs

Beliefs about illness

Participants showed negative illness beliefs illustrated by negative attitudes to the illness and the impact of diabetes on their daily life

"It is endless, you have it for the rest of your life, and it does not go away" (P4)

"I know that it does progress no matter what you do" (P14)

"It means your life is governed by other people who say to do this and do that" (P23)

"But it can be very depressing. I am on tablets for depression" (P29)

Beliefs about medications

Patients' concerns about diabetes medications varied. This included concerns about side effects of the medications, lack of confidence in the effectiveness of diabetes medications and fears from insulin injections

"I am concerned about them because when you take a cocktail of about 20 tablets a day and according to the manufacturer each one has the potential for so many side-effects" (P11)

"I would prefer not to have to take medication. I would try to control it with diet and exercise" (P32)

"It is the night mare; it is the injection" (P23)

5. Discussion

The focus group interviews, which are discussed in the current study, represent qualitative research method that is based on group interactions to develop and refine interventions via exploring patients' experiences of disease and health issues (Vermeire et al., 2001). In a focus group, participants are encouraged to exchange information on each others experiences and points of view, talking to each other, asking questions and listening to what others say, which help them articulate their own issues (Kitzinger, 1994). The rationale is that under the guidance of a focus group leader, group members can describe the reasoning behind their actions, perceptions, beliefs and attitudes in ways that would be less easily accessible in a one-to-one interview (Farmer et al., 2005).

The results of the present study show that knowledge deficit, together with the therapeutic regimen complexity, made it very difficult for patients to adhere to the prescribed therapy. Consistent with the findings of others (Vermeire et al., 2003; Vinter-Repalust et al., 2004), participants in the present study demonstrated a poor knowledge and significant information needs about type 2 diabetes and its management. Coates et al. found that lack of knowledge was one of the reasons why patients do not manage their diabetes effectively (Coates and Boore, 1996). A recent focus group study showed unmet information needs among Australian patients with type 2 diabetes (Carolan et al., 2015). Although behavioral change and effective self-management is not guaranteed by knowledge alone, the assessment of diabetes-related knowledge is an important first step from which to individualize diabetes education programs and make evaluations of their effectiveness (Garcia et al. (2001); Nau and Ponte (2001)).

Consistent with the current study findings, research has also clearly indicated that polytherapy regimens (Donnan et al., 2002; Melikian et al., 2002), perceived adverse effects (Melikian et al., 2002; Grant et al., 2003; Islam et al., 2017), higher dosing frequency (Paes et al., 1997; Rubin, 2005), and receiving insulin (Cramer, 2004; Vermeire et al., 2003; Jarab et al., 2014; Lerman, 2005) have a negative impact on medication adherence in diabetic patients. In a study of 18 focus groups conducted by Hayes et al., type 2 diabetes patients were concerned about the inconvenience which results from frequent dosing requirements, which in turn leads to missed doses (Hayes et al., 2006). They suggested a sustained release tablet so that they can take their medication once daily. The patients also demonstrated a desire to avoid insulin injection and polypharmacy. The complicated therapeutic regimen has been identified as a barrier to medication adherence in a focus group of pregnant Zimbabwean women (Mukona et al., 2017). All these findings are consistent with the present research results.

Many participants in the present study demonstrated low self-efficacy. Research has indicated that self-efficacy is an important predictor of a range of health behaviors including adherence with the prescribed medications in a variety of chronic conditions such as diabetes (Littlefield et al., 1992). Research has also indicated that it is generally much more difficult to achieve and maintain adherence with lifestyle regimens than with prescribed medications (Poirier et al., 2006). As demonstrated in the present study, negative attitudes to different aspects of self-care activities, combined with low self-efficacy, were dominant factors affecting adherence to lifestyle advice and self-care activities. Self-efficacy has been found to predict adherence with diet recommendations (Sarkar et al., 2006), exercise regimens and self-monitoring of blood glucose (Horne and Weinman, 1999). Another recent focus group study emphasized on the importance of improving self-efficacy among patients with type 2 diabetes in Germany (Grammes, 2017).

Qualitative studies have also indicated that health beliefs are important predictors of adherence to therapeutic regimens (Vermeire et al., 2003; Vinter-Repalust et al., 2004). Patients in this study demonstrated negative beliefs about their illness and their medications, both of which have been suggested as strong predictors of medication non-adherence (Vermeire et al., 2003; Jarab et al., 2012).

In summary, the current explorative study findings should provide useful to determine the elements of future effective and specific pharmaceutical care programs designed to improve blood glucose control and other clinical and humanistic outcomes in patients with type 2 diabetes.

6. Conclusions

The patients generally demonstrated poor knowledge about type 2 diabetes which may influence their approach to their disease management. The patients also demonstrated clear information needs relating to the prescribed medications including: effect, dosing, potential side effects and the time required to achieve the desired blood glucose control. Meeting these information needs via individualized patients educational programs should be considered by future effective pharmaceutical care interventions. It was apparent from concerns regarding dosing frequency, and the number of drugs being prescribed for some patients, that medication regimen should be rationalized where possible. Insulin injection was not a popular treatment choice. The study also revealed that patients had negative beliefs about their medications, represented by concerns about the effectiveness of the prescribed medications. Much concern about the possible sideeffects of the medications was demonstrated by the patients. Such concerns have been reported in the literature to influence patients' adherence to medications and therefore need to be addressed. Although some patients demonstrated positive illness beliefs of the awareness of the disease severity and the susceptibility to develop com-

plications in the case of poor control, many patients demonstrated negative illness beliefs and attitudes. Such concerns and beliefs should again be addressed in future intervention programs. Adherence to lifestyle advice was influenced by negative attitudes to lifestyle change, lack of awareness about the importance of different elements of lifestyle advice and low self-efficacy. These barriers provide a target for future diabetes care programs.

Ethics approval

Ethical approval to carry out the study was obtained from the Institutional Review Board (IRB), King Hussein Hospital, Royal Medical Services, Amman, Jordan.

Study limitations

Final themes were not validated by the participants and the analysis of the transcripts could have been influenced by the prior perceptions of the researchers. Furthermore, participants in the focus group study may adjust their own behavior in response to their impressions of other group members.

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Conflicts of interest

None to declare.

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