



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 route 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.

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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 be 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)

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