

Lived experience of having type 2 diabetes: A phenomenological research in three villages in rural Northern Saudi Arabia

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ABSTRACT

Background: The study was aimed to explore the lived experience among patients with type-2 diabetes living in rural settings. **Methods:** A qualitative phenomenological study design was used in this study. **Results:** First, the patients' reactions were a mixture of denial and shock regarding their diagnosis of diabetes. Second, they faced challenges of having debilitating disease. Third, all were Muslims, and their faith led them to accept their disease as their destiny from Allah. Fourth, they psychologically accepted the disease to gain the physical acceptance of their condition. Finally, the participants demonstrated a degree of adaptation. **Conclusion:** The study findings suggested that type-2 diabetes is viewed as a matter of destiny. Although participants in the current study revealed natural feelings of shock and denial towards their illnesses in the early stages; however, they soon became more familiar with their disease and expressed a feeling of acceptance and adaptation, especially during Ramadan.

Keywords: Lived experience, phenomenology, rural areas, type-2 diabetes

Background

Living with type 2 diabetes can be problematic, as it is necessary to maintain blood glucose constantly. It is also a long-term chronic disease.^[1] Saudi Arabia as a developing country is not the only one that is suffering from this disease.^[2] The reasons may be attributed to the increase of cardiovascular risk factors in the urban areas, because of a decrease in exercise or any activities that target the body fat. Thus, a rich descriptive and interpretative account is required to explore personal experiences of adjustment, while patients, being the experts, can give in-depth and fruitful insights.

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In Saudi Arabia, cultural and psychological barriers may exist among the participants, even though it may, at times, differ. Since the participants live in rural settings, there is a high probability of poor control of their diabetes and difficulties accessing well-equipped hospitals and diabetic centres, leading to a lack of education regarding their disease. The study aim was to explore the lived experience among patients living in rural settings in the north of the Kingdom of Saudi Arabia (KSA) with type 2 diabetes.

Materials and Methods

A qualitative phenomenological research study was conducted. Three villages of Al-Jouf region near Sakaka (a large city in the northern part of Saudi Arabia) were included in the present research: Athfa, Qara, and Soier. A total of 12 participants (both males and females) were selected.

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Sampling technique

A purposive sampling technique was employed in this study; candidates for interviews were proposed by the local Health Affairs Department in Al-Jouf County via the Diabetic Centre in King Abdulaziz Specialist Hospital, Saudi Arabia. When a potential participant was identified, they were first approached informally via home visits or telephone. This was followed by a telephone call to set up a date and venue for the interview. At the first meeting, consent was sought via signature on a consent form.

Research instrument

A semi-structured interview was conducted using an appropriate prompt sheet for participants. The questionnaire comprised of basic demographic questions, questions concerned with the patients' personal experiences with diabetes, and their initial reactions after being diagnosed with diabetes, experience during Ramadan, social interactions involving patients' families, workplaces, and other social activities affect their daily life and existence with diabetes, and their reactions, reflections, and opinions of local health care providers. The interview was concluded by inviting the interviewees to add any further ideas or comments on anything that had been discussed.

Research data collection

At the beginning of each interview the moderator (researcher) explained the full procedure of the study. Once formal written consent was obtained, the audio-recorded interviews were then conducted by the researcher. The interviews began with the introduction of the researcher followed by general questions and then more specific questions to obtain more detailed data. The interviews were acceptable to all participants, and each one lasted between 30 and 45 minutes.

Ethical considerations

An initial ethical approval for this research was obtained from the Faculty of Health and Life Sciences, Research Ethics Committee, De Montfort University (DMU), UK. After approval was received, the Ministry of Health in Saudi Arabia was contacted to obtain permission to implement this study and to contact the district county for additional support.

Research data analysis

The steps involved in qualitative phenomenological research data analysis were adopted and applied as described previously.^[3] All data were transcribed and analysed in Arabic and then the findings were recorded in English as well. These transcripts were analysed using a phenomenological approach.

Results

Data from interviews were analysed under the following categories: Shock, Denial and response, Challenges, Faith, believe and submission, Acceptance and moving on and Adaption and interaction.

Shock, denial and response

One hundred percent of the interviewees expressed shock, when they were told that they had been diagnosed with type 2 diabetes. A follow up question was asked about the reason for this reaction.

QM1 *"...when I heard that I was diagnosed with type two diabetes for the first time, I was shocked and afraid. I felt that my life had changed, dramatically"*.

Some patients believe that alongside their diagnosis of diabetes will come complications like, amputation, failed sight, or renal failure, etc., One lady said:

QF1 *"when I first heard that from the doctor, I recalled the image of the suffering of my best friend and my mother, for a moment I feared: will I lose my sight? Will I lose my leg?... No that can't be?"*

Challenges

Challenges in this case are understood to refer to the mental and physical reaction of a patient's diagnosis with diabetes.

QM3 *"It is a long psychological struggle against the disease, no one knows who will win in the end."*

Following a special diet which differs from the norm can be one mean by which to overcome the illness. Some patients devised their own diets, to avoid using medications. Others turned to alternative medicine, hoping to overcome the disease as one lady said:

AF6 *"I remember that I was following a special diet... I used to boil a few olive leaves in half a cup of water and drink it after it cooled down. I thought it might work better than the tablets."*

Faith, belief and submission

As most of the Saudi population are Muslims, and worship Allah¹, they believe that disease is their destiny from Allah. When someone is diagnosed with a disease, a moment follows in which every believer realises that this is his/her fate.

QM1 *"Yeah, that was my destiny. I believe that Allah wanted to test my faith and see how patient I would be."*

Some believe that sickness should not be an obstacle. They feel obligated to continue their lives normally to illustrate their faith and submission to Allah as part of Islamic teaching.

Acceptance and moving on

After going through a tough mental experience, patients reported that they tended to pick themselves up and move on. There were steps common to most of the participants, which illustrated acceptance and a desire to move on. One lady stated:

1 Allah is The Islamic God.

SF4 *“my husband noticed that my attention to the house had become less, and at the same time I was feeling fatigued; so, he advised me to start to listen to the doctors and to start using medications, which sounded like the best solution.”*

In addition, some participants started to take doctors' instructions seriously, and started to follow a diet plan and to exercise. In some cases, this may mean depriving themselves of things they love, such as a particular kind of food. One said:

SM4 *“I could not imagine myself not eating Kabsa² every day!!!”*

Adaption and interaction

The participants reported a great degree of satisfaction with the progression of their adaption, because of the support they received from their partners.

SM4 *“when my wife and children discovered that I am a diabetic, they became very careful with me. Sometimes I feel like they treat me like a child. This is so annoying, I hate this.”*

The workplace can pose unique challenges for diabetic people. The nature of the work undertaken could have an impact on the adaption process, as well.

AM6 *“at work I feel embarrassed, particularly when someone brings some food and starts to push me to eat. I know this is a problem. I know they do not bring the right food for me so, I have to bring my own food every day.”*

In Islam there are two main Holy days (Eid³). For Muslims to preserve the sanctity of these days they have to show happiness and share meals, sweets and candies. This is another challenging scenario for diabetic patients to adapt to.

QM1 *“I share in the happiness, but not the meals ...”*

Fasting during Ramadan is considered a divine injunction, whereby one fasts according to Allah's transcriptions in the Qur'an⁴. When participants were asked about their experiences during Ramadan most of them explained that they had accepted their diabetes and all its possible impacts and had been reassured that fasting was not a big issue according to most doctors. However, one woman mentioned that she suffered a lot during Ramadan, and on many occasions became hypoglycaemic.

One participant stated:

AM5 *“In Ramadan my sugar is in a good condition and fasting helps me to control its level.”*

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- 2 Kabsa: Is a traditional Saudi meal consisting of rice and meat.
 - 3 Eid: Is an important religious holiday celebrated by Muslim worldwide.
 - 4 Quran: The Muslim Holy book.

Most participants related that their strong belief provided them with the strength to manage their disease and complete their fast; although they agreed that the Islamic religion does not ask them to do something beyond their ability.

Discussion

What does it mean to be diagnosed with type 2 diabetes?

The implications of being diagnosed with diabetes was established through the experience of the participants, varied from one to another, while they gone through multiple stages. The first stage was being shocked and responding with denial. Shock and denial varied accordingly with how negative the image held or the stories they had heard about the disease. When comparing these findings to the literature review, shock and denial were found another study.^[4]

The second stage is represented as a period of challenge, when rejection of the fact of having the disease began to appear as denial, and thus a battle against it. Patients in both this current study and that of Johansson *et al.* (2009) demonstrate eventual acceptance of the disease and a motivation to live a normal life, along with seeking out health care providers.^[4] However, patients in this current study also demonstrated acceptance by alternative solutions to cure the disease, such as Moxibustion and herbal medicine.

The third stage relates to belief. In the literature review, Aghamohammadi-Kalkhoran (2012) employed hermeneutic phenomenology.^[5] Faith plays a vital role in the perspective of believers of all faiths towards their illnesses. In this current study, the participants demonstrate a stage of having faith in Allah, gaining strength due to their linking the fact of having the disease to the will of Allah, for which they believe they will be rewarded.

The fourth stage is acceptance and moving on. All participants accepted their condition and began to act accordingly, although the period of acceptance varies from four to six months among participants. Similarly, a study demonstrates that in the state of accepting the disease, patients follow up doctors' instructions and diet plans and exercise to overcome the disease and live a normal life.^[4] In another study, participants demonstrated a different form of acceptance. They kept to medical advice, diet and exercise only when they felt that their blood sugar level was high.^[5] This might be considered a wrong behaviour since they changed their diets for the purpose of reducing blood sugar only temporarily, and then back to their earlier dietary habits and activity levels.

The final stage is adapting to the new situation. Participants show strength and courage in overcoming diabetes by refusing to surrender. This is due to the desire to live a normal live and giving and sharing as human beings. Participants in Johansson *et al.* (2009) study soon began to adapt to the disease, driven by the power to fight it and not become their illness.^[4] This is in

line with this current study, where adaption required changing the basis of the participants' daily life.

How do people with type 2 diabetes perceive their future in relation to their disease?

Most of the participants did not demonstrate concern about their future because they accepted the disease as a part of their lives, and they expressed their satisfaction, based on their religious background. By contrast, George and Thomas's (2010) study demonstrates that the participants felt considerably threatened by their illness and had no future goal, even simply waiting to die.^[6] However, in Haltiwanger's (2012) study some of the participants tended to take more responsibility with regard their future, but without any clear goal, due to depression.^[7] The satisfaction with the present and future based on religious background in this study is supported by the studies conducted in Iran and Australia, respectively.^[5,8]

What is the meaning of living in rural setting and having diabetes?

The villages that were the subject of this research had poor healthcare services and some healthcare providers have the minimum level of qualifications. Diabetic villagers who wish to have decent services must travel very long distances to find the service they need and looked for their healthcare elsewhere. According to Skinner *et al.* (2013) study (which was conducted in rural settings in Australia), poor access to medical specialists is considered a great challenge among those who have previously lived in the countryside.^[9]

The second phase is related to personal adaption to the disease. This has been supported by the following several studies.^[10-13] These studies established that the prevalence of type 2 diabetes among rural areas is lower than in urban regions. The reasons behind this have been identified as life in open areas enforcing continuous activity, while outdoor activities (such as cultivation or looking after sheep) have a considerable impact on burning calories and consuming dietary fat.

How do those diagnosed with diabetes make sense of the information they are given to manage their condition?

Initially, most patients suffer from psychological depression, due to the shock. Therefore, the physical condition of patients began to deteriorate. They then realised that it was time to visit the doctor and follow his advice. Following this advice, and changing their lifestyle, had a positive impact on the health of most patients. Although the participants in the present study noted a shortage of healthcare providers, they demonstrated self-awareness concerning their illness. This has been supported by Holmstrom *et al.*'s (2003) study, in which the researchers concluded that patients' understanding of their condition must be taken as a departure point when creating a learning situation.^[14]

How do those diagnosed with diabetes perceive the directions they receive from healthcare providers to change their self-care behaviour?

In this study, changing their lifestyle was not easy for most of the participants, with many refusing to change their diet. They began to avoid situations in which they became nervous and anxious. Similarly, a study found that participants experienced great challenges in adapting to their new life.^[15] Likewise, several patients managed to change their social life to control over their illness. The reasons behind this attitude could be feelings of annoyance based on other influences, such as family, friends and colleagues. This is in line with Johansson *et al.* (2009) study, because, from the moment they were diagnosed, her participants demonstrated similar feelings towards the people around them, who began to act differently in an attempt to take care of them.^[4]

What are the implications of having diabetes during Ramadan?

Ramadan might appear difficult for a diabetic, due to fasting, which can cause hypoglycaemia. However, most participants fast during Ramadan, motivated by their beliefs. The majority stated that they faced no problems fasting during Ramadan. These findings are supported by those of Peterson *et al.* (2012), where participants shared similar perceptions of Ramadan, due to having the same religious background (i.e., Islam). Although they faced difficulties interacting with healthcare providers, because of the differences in religious background, they soon adapted and became more familiar with it.^[8]

Conclusion

These findings have the potential to enrich the understanding of health researchers in Saudi Arabia in relation to the practical issues concerning type 2 diabetes. There is an underlying desire in Saudi Arabia to excel, and therefore this presents an opportunity to educate the population concerning healthcare, moving from the dependence on doctors, to a greater emphasis on self-care. Hence, such programmes as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) [which was invented in the UK and is widely used by the National Health Service (NHS)] contain a successful training course for people with type 2 diabetes. DESMOND is a family of self-management programmes for people at risk of, or with, type 2 diabetes.

Areas for future research

The results could provide invaluable information to primary healthcare physician to implement an educational program about diabetes, which may be viewed as a supplementary aid to medical treatment. This study would be useful in identifying peoples' attitudes towards having diabetes and the reasons behind these attitudes. In addition, it might provide guidance to cater educational programs. Finally, it can contribute to the current body of literature relevant to diabetes.

Limitations

This study is not without its limitations. First, this study focussed on a small sample, which may not be broadly reflective of variations within other Saudi rural areas. Thus, further study is needed to identify perceptions of the examined phenomena in other populations. Second, the sample was based on purposive sampling, a non-probability method. This sampling strategy may limit the generalizability of the results. Moreover, due to the qualitative nature of this study, it is also difficult to generalise the results. Third, using the research methodology of phenomenology, the findings are limited to the study participants and should be generalised with some caution.

Key points of the research

The initial implication of having type 2 diabetes in rural areas in Saudi Arabia is that it is viewed as being a matter of destiny. Although the participants in the current study reveal natural feelings of shock and denial towards their illnesses in the early stages, they soon became more familiar with their disease and expressed a feeling of adaptation, for example during the spiritual seasonal occasion of Ramadan. However, an obstacle for all participants was poor access to medical specialist centres, along with a shortage of expert healthcare providers. More attention must therefore be paid to those who are suffering from type 2 diabetes and living in rural areas in order to enable them to increase their self-management.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

References

1. Despina LA, Wakefield BJ. Making sense of blood glucose data and self-management in individuals with type 2 diabetes mellitus: A qualitative study. *J Clin Nurs* 2020;29:13-4.
2. Aldossari KK, Aldiab A, Al-Zahrani JM, Al-Ghamdi SH, Abdelrazik M, Batais MA, *et al.* Prevalence of prediabetes, diabetes, and its associated risk factors among males in Saudi Arabia: A population-based survey. *J Diabetes Res* 2018;2018:2194604.
3. Berenguera A, Molló-Inesta À, Mata-Cases M, Franch-Nadal J, Bolibar B, Rubinat E, *et al.* Understanding the physical, social, and emotional experiences of people with uncontrolled Type 2 diabetes: A qualitative study. *Patient Prefer Adherence* 2016;10:2323-32.
4. Johansson K, Ekebergh M, Dahlberg K. A lifeworld phenomenological study of the experience of falling ill with diabetes. *Int J Nurs Stud* 2009;46:197-203.
5. Aghamohammadi-Kalkhoran M, Valizadeh S, Mohammadi E, Ebrahimi H, Karimollahi M. Health according to the experiences of Iranian women with diabetes: A phenomenological study. *Nurs Health Sci* 2012;14:285-91.
6. George SR, Thomas SP. Lived experience of diabetes among older, rural people. *J Adv Nurs* 2010;66:1092-100.
7. Haltiwanger EP. Experience of mexican-american elders with diabetes: A phenomenological study. *Occup Ther Health Care* 2012;26:150-62.
8. Peterson S, Nayda R, Hill P. Muslim person's experiences of diabetes during Ramadan: Information for health professionals. *Contemporary Nurse* 2012;41:41-7.
9. Skinner T, Allen P, Peach E, Browne JL, Pouwer F, Speight J, *et al.* Does the shortage of diabetes specialists in regional and rural Australia matter? Results from Diabetes MILES--Australia. *Diabetes Res Clin Pract* 2013;100:222-9.
10. Ben Romdhane H, Grenier FR. Social determinants of health in Tunisia: The case-analysis of Ariana. *Int J Equity Health* 2009;8:9.
11. Ben Romdhane H, Ben Ali S, Aissi W, Traissac P, Aounallah-Skhiri H, Bougatef S, *et al.* Prevalence of diabetes in Northern African countries: The case of Tunisia. *BMC Public Health* 2014;14:86.
12. Bouguerra R, Alberti H, Salem LB, Rayana CB, Atti JE, Gaigi S, *et al.* The global diabetes pandemic: The Tunisian experience. *Eur J Clin Nutr* 2007;61:160-5.
13. Atre S, Deshmukh S, Kulkarni M. Prevalence of type 2 diabetes mellitus (T2DM) in India: A systematic review (1994-2018). *Diabetes Metab Syndr* 2020;14:897-906.
14. Holmström I, Halford C, Rosenqvist U. Swedish health care professionals' diverse understandings of diabetes care. *Patient Educ Couns* 2003;51:53-8.
15. Ahlin K, Billhult A. Lifestyle changes - A continuous, inner struggle for women with type 2 diabetes: A qualitative study. *Scand J Prim Health Care* 2012;30:41-7.