

Factors influencing adherence to dietary guidelines: a qualitative study on the experiences of patients with type 2 diabetes attending a clinic in Cape Town

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Keywords: diabetes, nutrition, adherence, diet, guidelines

Abstract

Objective: The purpose of this study was to explore the experiences of patients with type 2 diabetes mellitus attending the Groote Schuur Hospital Diabetes Clinic in relation to contextual factors that promote or impede adherence to nutrition care guidelines.

Subjects and setting: Eight diabetic patients (four males and four females) attending the Groote Schuur Hospital Diabetes Clinic who were between 40-70 years old.

Outcome measures: Qualitative analysis of factors influencing adherence to dietary guidelines.

Method: An explorative study, using a qualitative approach with eight semi-structured interviews, was used. Patients were interviewed at the diabetes outpatient clinic in Cape Town. Semi-structured interviews were recorded and transcribed, and thereafter analysed using ATLAS/ti®.

Results: Various themes as to what influences adherence to dietary guidelines emerged. An ecological analysis is offered to understand the different levels of influence on participants' dietary behaviour. The main identified factors at individual level were motivation, individual knowledge, perceptions of moderation, self-responsibility, taste concept or cravings, and temptations. At small group (family and friends) level, family relations with the patients were identified as the main support system used to manage the diabetes. At the organisational or health systems level, long waiting times and the theme of seeing different doctors emerged as problematic factors, but overall, patients were satisfied with the clinic service. At community and policy level, culture and the cost of food were identified as key influential factors with regard to adherence to nutrition care guidelines.

Conclusion: This study shows the usefulness of adopting an ecological model in identifying factors that influenced adherence to dietary guidelines by patients with type 2 diabetes. Some factors acted as enablers and others as barriers. These had an impact on patient adherence to nutrition care guidelines. These factors should be considered by diabetes educators, including dietitians and nurses and doctors, when planning treatment modalities for patients with type 2 diabetes mellitus.

Peer reviewed. (Submitted: 2014-01-17. Accepted: 2014-05-14.) © SEMDSA

JEMDSA 2014;19(2):76-84

Introduction

Type 2 diabetes mellitus is becoming increasingly prevalent worldwide, particularly in developing countries.¹ Females, the elderly, the Indian population and those living in urban areas are most at risk.²

Self-care is an important component in the management of type 2 diabetes mellitus. Self-care management focuses on lifestyle adaptation (diet and physical activity), blood glucose monitoring, medication use, and foot and eye care. Dietary management plays an important role in self-care

management as poor dietary quality leads to poor glucose control, and is associated with increased risk of complications, morbidity and mortality.³

An ecological perspective provides a useful framework in which to examine diabetes self-care management, according to Sallis, Owen and Fisher.⁴ These authors suggest that it may seem "surprising" to consider self-care management from a broader perspective as it is often viewed as an individual responsibility. It is useful to apply this framework to identify factors which affect adherence to dietary management, since the framework addresses multiple levels of influence,

including individual, small group (family and friends), organisational or health systems, and community and policy. Various resources and support should be applied to these levels if successful diabetes management programmes are to result. These include individualised assessment and collaborative goal setting at individual level, family support and encouragement at small group (family and friends) level, group services and programmes that enhance skill and provide support at the organisational or health systems level, and support and resources at the community and policy level.⁴

Research indicates that numerous factors influence adherence to the type 2 dietary guidelines provided by healthcare professionals.⁵ Although the socio-cultural context of the self-management of diabetes has been described in African Americans,^{6,7} a search of the South African literature shows a paucity of information on the contextual experience of adhering to dietary guidelines by people living with type 2 diabetes mellitus.

The aim of this qualitative study was to consider these contextual influences within the perspective of the ecological model, as experienced by a small selected group of people living with type 2 diabetes mellitus. These experiences could contribute to an understanding of what health professionals need to provide in order to deliver effective services and support to patients with type 2 diabetes mellitus.

Method

Sample and setting

The Diabetes Clinic at Groote Schuur Hospital is a tertiary level government clinic where patients are referred if they have poor glucose control. Patients are referred for insulin therapy management by doctors from a primary or secondary institution. Usually from a low socio-economic background, the patients are often unemployed, with a poor educational background, and are mainly of mixed and Asian ethnicity.⁸

Patients were purposefully selected from the diabetes outpatient clinic on a Thursday. Inclusion criteria were a type 2 diabetes mellitus diagnosis, having previously been seen by a dietitian for individual dietary counselling, being English or Afrikaans speaking, aged 40 years and older, and male or female. Patients with type 1 diabetes mellitus were excluded from the study.

Eight participants, ranging in age from 40-70 years, were selected. Most of them were aged 60 and older. Four were English and four Afrikaans speaking. Four were males, and four females. Seven had had diabetes for approximately 10 years. One of the patients had had it for 30 years. Seven of the participants had been educated to grade 12 level or below. One had been educated to higher than grade 12 level. Unintentionally,

seven of the participants (with the exception of one) were Muslims. The remaining participant was Christian. Five of the patients had attended the clinic for over five years, two for more than 10 years, and one for less than one year. The number of times that they had been seen by the dietitian was dependent on the number of visits to the clinic and the availability of the dietitians. Half attended the clinic twice a year, and the other half 3-4 times a year.

Qualitative procedures and analysis

Ethical approval was obtained from the University of Cape Town Human Research Ethics Committee for this study (Ref Number 217/2011). Semi-structured interviews, lasting approximately one hour, were conducted face to face to explore the views and attitudes of patients on, and experiences of, the nutrition guidelines.

The interview questionnaire (Figure 1), was developed through a review of the relevant literature, discussions with experts and two pilot sessions. Following recruitment and completion of the consent process, an appointment was made with the patients for an interview at a venue of their choice. The interviews were conducted by the principal investigator, audio-recorded and transcribed verbatim into English later. Analysis and interpretation of the data was carried out using ATLAS.ti® version 1.

Stages in the analysis process included:

- The principal investigator read the transcripts and started coding the data in the first transcript with descriptive labels.
- These codes were placed in subcategories as common themes were identified. The codes and subcategories were then used as the basis for the analysis of the remaining transcripts. If new codes emerged, all of the documents were rechecked and coded accordingly. Codes were analysed and reviewed by an experienced qualitative investigator, before being finalised.
- The next level of analysis entailed placing the codes into four main categories according to the levels in the ecological model, e.g. individual, small group (family and friends), organisational or health systems, and community or policy.⁹
- Finally, reports were created showing the frequency with which the codes were used to label data segments (quotations) in the main categories. This step assisted in identifying the most common experiences of participants at the different ecological levels.

Figure 1: The interview questionnaire

Patients with diabetes interview schedule**Assess perceptions of care received by patients with type 2 diabetes attending Groote Schuur Hospital outpatient clinic with regard to healthcare professionals (with the exception of dietitians)**

How do you feel about visiting the clinic? (Probe by asking: "Why?")

- When you visit the clinic, with which staff members do you spend the most time?
- What happens during this time?
- What information is usually given to you during this time? (Probe by asking: "Is anything else you would like to add? i.e. Were you told what to eat and what not to eat?")
- How do you feel about these sessions? (Probe by asking: "Why?")
- How do you experience your interaction with different staff members at the clinic?
- How do these interactions influence the way in which you manage your diabetes?
- When you leave the clinic, do you feel that your expectations of care have been met? (Probe by asking: "Why?")

Assess perceptions of nutrition care received as part of diabetes care from the dietitian

- Tell me about the food information that you have received here at the clinic?
- Who gave it to you?
- Can you recall what information was given to you? e.g. Was it written? (If printed or written, do you still have the diet sheets?). Was it oral? In what language was it given?
- How do you feel about the information that was given to you? (Probe to ascertain if it was appropriate, and easy to understand and follow.)
- What were your feelings about implementing the information when it was given to you?
- How did you feel about it when you went home and had to put it to use?
- What was the most useful food information given to you, and by whom?
- What food and nutrition information would you like to receive from the clinic? In what format? In what language? From whom?

Explore internal and external barriers or enablers to the implementation of dietary guidelines or nutrition intervention received as part of the nutrition care process

(This objective will mostly be covered by the previous questions)

- Lastly, please tell me again about everything that makes it difficult for you to follow the dietary advice given to you by the clinic.
- What (at home and at the clinic) will make it easier for you to follow the advice?
- Did you ask to be seen by a dietitian, or were you referred to her or him? (If "yes", how many times? If referred, who referred you? If it was your own request, why did you ask to see a dietitian?)

Results**Individual level**

Although patients mostly reported adherence to the diabetic dietary guidelines, analysis of the data showed many instances of poor dietary practice:

"I only use canola, but only a little bit. I use only canola margarine; not the hard one. That's the bad one" (and then later in the interview): "I will first ask my sisters, are the pies ok? Not too fatty, not too oily, no? Then I will eat them". – P1

Analysis and interpretation of the interview data revealed the following barriers and enablers experienced by participants at several different levels of influence when trying to adhere to the recommended nutrition guidelines. Most participants indicated that they thought that it was ultimately the responsibility of the individual to follow the dietary guidelines given to them:

"It's always up to the person himself. They can give you as much information and give you literature. But you know it's up to you, as a person. I mean they can just do what they can do, and what they are supposed

to do. More than that, they can't do. They can't force you". – P3

Most participants reported a preference for specific foods, especially those high in fat and sugar. The craving for these foods was often a barrier to adherence to the nutrition guidelines:

"I had a gassy cold drink with sugar. I know that it is wrong. It's just the craving. Somebody else drinks it, and you also want it. I don't drink sugar-free stuff but I think it's time I get myself used to it". – P3

"I say: 'I'm just going to eat a small piece, man. I must taste it. It tastes ok. Ok, right, I will leave it'. I said to them now: 'We are not by the eating department, we are by the tasting department'. You know what I'm saying? If the *koeksister* tastes nice, you cannot eat five, you can only eat one". – P7

The majority of the participants mentioned fear of death, their relations with others and achieving a goal or result as motivating factors that helped adherence to the nutrition care guidelines:

"I think it will be different from now on. Before (having a goal), I didn't care. I just had this thing that you

got to go, you got to go, whether it's with or without sugar. And people try to give you a better life, to make your life better, but if you have to go, you have to go; whether or not you take insulin, or whether or not you take tablets. You got to die. You got to die". – P5

The "death concept" emerged as a common theme to motivation, which could either be seen as an enabler or barrier to adherence to the nutrition care guidelines. Fear of death, or experiencing the complications of disease, in particular with regard to amputation, was apparent in half of the subjects for whom fear acted as an enabler for them to adhere to the nutrition care guidelines. Some patients felt that death was inevitable. They believed that they were going to die, irrespective of whether or not they ate properly. Two of the patients cited willpower and determination as the main reasons behind their actions, derived from religious beliefs or a highly regulated upbringing.

When patients were asked to recall the nutrition information that they had received from the clinic, reference was made to particular aspects of the diet in relation to specific types of food. The reports reflected some understanding of their prescribed diet since they could not recall all of the prescribed guidelines that were advised by the dietitian. This suggests that they had a poor understanding of the definition of diabetes. Only one participant understood what it was. Those who had some idea were confused in other respects, e.g. misinterpreting the relationship between glucose and insulin in the body:

"Diabetes is to do with your glucose levels; insulin levels at least. There's too much glucose in your body that eats up insulin, right? And that's why you need to get artificial insulin in you, because your pancreas doesn't function 100%. So the medication they give you is to help your pancreas manage your insulin levels". – P3

Small group (family and friends) level

The majority of patients reported that they received support from their families, albeit sometimes in the form of admonishment:

"My son, I'm living with him. He always (offers) care and support: 'Mummy, do this. Mummy, be careful'." – P5

Nevertheless, half of the patients who received family support also cited lack of support with regard to certain aspects of their lives, especially with regard to meal preparations. Cooking a separate meal for patients with diabetes was considered to be inconvenient:

"To me, it's my wife's job. By the time I get home, I forget whatever I was told. Even the wife. She will listen to you now; for that week you are going to eat healthy. You are not going to eat anything that you really want to eat, because she wants to give you healthy food.

And after that, you know, then you just eat what they eat, because they *dik* (tired) of giving you special food. Then they go back to: 'Ja man, ek het nie nou tyd nie' ('Yes, man. I don't have time now'). And tomorrow, we start again, and then it fades and you just take what you get". – P3

Organisational or health systems level

Participants identified several factors that conveyed how they perceived organisational resources and support with regard to self-management of their diabetes mellitus.

Most patients were positive about attending the clinic. They reported feeling eager, motivated and excited. However, inconvenience and long waiting times were also mentioned.

Although some respondents said that they had resigned themselves to waiting, others were frustrated at having to do so:

"I come here in the morning, go for my blood tests, and then go to get my folder. There's a long wait. I think that brings your sugar and blood and everything up". – P3

Generally, the patients were positive, satisfied or happy after leaving the clinic. When asked about overall satisfaction with the care received at the clinic, comparisons were made to other institutions visited previously and the poor service received there.

The majority of patients were satisfied with their check-ups with the doctors, and reported having a good relationship with them. Doctors were viewed as supportive in the management of their condition.

Patients who were dissatisfied with their check-ups cited poor patient-provider relations. For example, one complained about the appearance of the doctors, comparing them to "hippies":

"They look so playful. They don't look like doctors with the white coats, you know". – P6

A theme that emerged from discussions was that all of the patients had been seen by different doctors. Half of them found this to be problematic and said that they would prefer to be seen by only one doctor.

The majority of patients reported no problems with the other staff members at the clinic. However, only a few found the nurses, in particular, to be friendly and helpful. Some patients had issues with staff members being too authoritarian, inattentive or not understanding them:

"They give me this stuff. I can't eat it. They don't understand. Because the nurses give me a lot of things I can't eat, they don't understand. They are strict: 'You must eat this'. I don't like it". – P1

Many patients were satisfied with the service provided by dietitians. Generally, they felt that dietitians were experts in their field and provided them with information that was helpful, sound and interesting:

“Very good in the sense that they tell you what you can buy and what you cannot buy, and so you don't waste time in the supermarket. It's so invaluable. You know where research is being done. They tell you exactly (what you should and shouldn't buy) because you don't know if your sugar is going to spike if you eat something, or if it's going to stay stable”. – P8

However, there were a few exceptions. One patient did not want to see the dietitian because of to her age and religion. She felt that the dietitian would not be able to change her diet, and that it was unnecessary since her glucose was well controlled:

“I don't want to see a dietitian because I don't eat the stuff that they give me because I am a Muslim. Also because at my age, I don't think I will be able to change my diet. I think my diet is fine. The doctor showed me on the computer. Since 2009, my sugar has been so good, very well, even this morning”. – P1

Community and policy level

Lack of availability of appropriate cultural food

The cultural barriers were very specific as the majority of the patients were Muslim and of mixed ancestry. The strongest theme that emerged was a preference for traditional food.

Other cultural factors revolved around social events (weddings, birthdays and funerals), celebrations and religious practices. Ramadan (fasting) was mentioned several times in the interviews. This was found to be a barrier to adherence to the nutrition care guidelines because of the presence of “forbidden” food:

“And you know that next month is another month in our lives, when all those things are on the table”. – P7.

“Oh. I try. But my sugar goes haywire. You go to a wedding, ahhh, and you eat all those things: the sorghi, the vermicelli, the samoosas, the pie. And especially if you're hungry, and your sugar is 20, and you are already cockeyed, and you just want to sleep”. – P9

Food insecurity

Half of the patients mentioned that their economic status made it difficult for them to adhere to the dietary guidelines:

“As money gets less with the month, your diet also drops, and then you just lapse”. – P3

Other community and policy factors that affected attendance at the clinic included transport, traffic issues and work commitments.

Discussion

This study revealed several enablers and barriers at various levels of the ecological model that affected adherence by patients with type 2 diabetes mellitus to the dietary guidelines.

Individual level

Self-care management should be considered as “beyond the self”, e.g. not only the patient's sole responsibility.⁹ Patients in this study felt that the responsibility of adherence to the dietary guidelines was theirs alone. This finding is similar to that reported in a veteran study in which patients with diabetes were satisfied with the advice received, but indicated that lack of adherence with the nutrition care guidelines was their own fault.¹⁰ It could be argued that patients who believe that diabetes management is their responsibility only might not seek assistance from family, friends or health professionals.

The concept of temptation, perceptions of moderation and cravings were evident barriers in this study. This is consistent with the findings of the study by Kavookjian et al.¹¹ Although most patients reported good eating habits, they also admitted to eating unhealthy foods that they craved. Eating food that tastes good was a common theme and was given as a reason for not adhering to the dietary guidelines.

The “death concept” mentioned by patients in this study was also a barrier to adherence to the nutrition care guidelines since patients said that death was inevitable whether or not the recommended diet was followed. Similarly, Jones et al found that patients' perceptions that type 2 diabetes mellitus was unmanageable and ultimately led to death had a negative impact on self-care.¹² This is a notable finding, since it informs the healthcare professional at the outset that such a patient might be more resistant to change.

Knowledge of the definition of diabetes and how it should be self-managed was poor in this study, especially with regard to being able to define healthy eating guidelines. This finding is consistent with that in a study by Gazmararian, Ziemer and Barnes, who found that the definition of diabetes provided by patients was insufficient.¹³ However, having a good knowledge of diabetes alone does not necessarily translate to improved self-management.¹⁴ Aljaseem, Peyrot, Wissow and Rubin reported increased levels of confidence with regard to patients' ability to adhere to treatment with increased knowledge, although this did not necessarily mean increased adherence.¹⁵ Therefore, it can be assumed that the poor knowledge demonstrated in this study could have been a contributory factor to patients' self-management practices. Following assessment, nutrition knowledge was found to be

unsatisfactory in healthcare professionals in a study in the Western Cape, particularly with regard to diabetes.¹⁶ This emphasises the need for nutrition education sessions with healthcare professionals, such as doctors and nurses.

Small group (family and friends) level

With regard to the small group (family and friends) level, Mbhenyane et al identified the role of family members as a barrier to adherence to the nutrition care guidelines in the form of "peer pressure".¹⁷ This was also demonstrated in this study, where patients felt pressure to adhere to the norms and practices of their families. A patient in this study recommended the involvement of family members in counselling sessions. Similarly, Weiler and Crist reported on similar recommendations by patients with type 2 diabetes mellitus.¹⁸

Organisational or health systems level

At organisational or health systems level, long waiting times were considered to be frustrating, although some patients had resigned themselves to waiting in this study. Abdulhadi et al also reported long waiting times to be stressful and unacceptable to patients, who although dissatisfied with having to do so, felt that they had to accept the situation because they were receiving a free healthcare service. However, patient dissatisfaction contributes to individual stress, and affects health quality assurance or quality management.¹⁹

Participants' experience of the healthcare team was mostly positive. Patients found the healthcare team members to be supportive through the provision of information and a service. This encouraged them to improve their self-care management. The findings of this study seem to support those of Abdulhadi et al and Berry et al, in which the importance of the doctor-patient relationship with regard to nutrition management was emphasised. In this study, the majority of patients received dietary guidelines from their doctors.^{19,20} However, this is contrary to the findings of Poshkiparta, Kasila and Kiuru; and Parker, Steyn, Levitt and Lombard.^{16,21} It was found in both studies that doctors did not play a pivotal role with regard to nutrition management, owing to lack of time and resources. However, the details pertaining to the nutrition information provided by healthcare professionals in this study were not assessed. Therefore, a conclusion cannot be made in this regard. The patients in this study were satisfied with the advice received from dietitians and found the information to be useful. In our study, the role of dietitians was not undermined by patients, which occurred in the study by Parker, Steyn Levitt and Lombard.¹⁶ Programmes that emphasise the importance of behavioural

change to ensure patient adherence to nutrition care guidelines elaborate that various skills and behaviour must be taught to patients to help them to cope with the complexities of diabetes. These skills need to be demonstrated, rehearsed, monitored, revised and tested in order to be effective. Support provided in various forms has been successful in interventions, particularly in low-income areas. Follow-up telephone calls with nurses using tailored information has also been shown to be valuable in improving self-efficacy and reducing levels of depression and glucose levels.⁹ Group medical visits, as well as peer support groups, have also resulted in an improvement in haemoglobin A_{1c} (HbA_{1c}) levels.^{9,22}

Community and health policy level

Food accessibility, specifically relating to financial constraints, was found to be a barrier to adherence to the nutrition care guidelines by most of the patients in this study. This is similar to the findings of other studies.^{14,23,24} Patients in this study could not afford to buy appropriate recommended food since most of them were unemployed, or of pensionable age with a limited allowance.

Cultural influences were apparent at social gatherings and religious celebrations, with regard to traditional food. Preferences for particular food derive from an individual's cultural upbringing.¹⁷ In this study, social events acted as a barrier to adherence to the nutrition care guidelines, owing to the abundant availability of forbidden food and the notion of temptation. Patients preferred receiving dietary advice from healthcare professionals whom they thought understood their eating habits. It is also important that individual assessments are performed to identify the cultural perceptions of patients, as well as their views on disease management. If a patient's perceptions conflict with the position advocated by conventional medicine providers, this should be addressed by healthcare providers through discussions and responses to patient questions, and in keeping with the former's knowledge of the disease.⁹

Conclusion and recommendations

The findings of this study illustrate the usefulness of adopting an ecological framework to explore factors that influence adherence to nutrition care guidelines in patients with type 2 diabetes mellitus. It is apparent that the individual does not function on his or her own, but is affected by various layers and linkages. Berry et al concluded that patients with diabetes should be supported, empowered and encouraged, in order to enable them to develop self-sufficiency.²⁰

Cognisance of cultural backgrounds, and particularly multicultural backgrounds in South Africa, is necessary

so that appropriate guidelines can be incorporated into intervention programmes. Enhancing access to physical activities in communities and work places, and the ability to source reasonably priced healthy foods, could be effective in increasing physical activity and healthy eating. At organisational or health systems level, initiative from top management is required to train staff and develop a system that provides support to patients so that they can manage their disease. Audits of hospital services might be useful in improving the quality of care, and which focus on reducing waiting times in particular.

In order to facilitate family involvement, family-centred support programmes need to be initiated. Ultimately, this could lead to improved health for the entire family, and thus prevent the acquisition of other chronic diseases.

Emphasis should be placed on the benefits of following dietary advice and its effect on glucose control, and on the inevitable reduction of diabetes-related complications. Similarly, the importance of medication compliance and monitoring of glucose needs to be incorporated, together with dietary advice, into collaborative goal setting between the patient and provider to ensure improved HbA_{1c} levels. Care must be taken by health professionals to be less strict in their approach to patients, and not to use "scare" tactics when setting goals. Continuity of care must be instituted to ensure that goals are met and achieved. Follow-up support is an integral aspect of behaviour change.

Perhaps a model that is similar to Wagner's chronic care model^{25,26} could assist with planning interventions for South Africa's healthcare system, and which would integrate clinical components with resources and support to improve self-care skills, and ultimately the quality of life of patients living with diabetes.

Limitations

There were a few limitations in this study. It was a small sample size, most of the patients derived from the same culture, and the patients were elderly and from similar socio-economic groups. More research needs to be conducted on the factors that were identified in this qualitative study that impeded or promoted adherence to nutrition care guidelines in patients with type 2 diabetes, as this would allow transferability of the findings to a larger population.

Conflict of interest

The authors declare no conflict of interest.

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