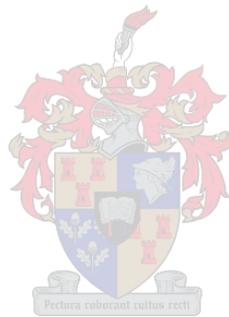


UNIVERSITY OF STELLENBOSCH

**Views of patients on a group diabetic education programme using motivational interviewing in underserved communities in South Africa:
Qualitative study**



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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Abstract

Background

Diabetes is a significant contributor to the burden of disease in South Africa and to the reasons for encounter in primary care. There is little structured and systematic education of patients that supports self-care. This study was a qualitative assessment of a diabetes group education programme in Community Health Centres of the Cape Town Metropolitan District. The programme offered four sessions of group education and was delivered by trained health promoters using motivational interviewing as a communication style. The aim of the study was to evaluate the programme by exploring the experiences of the patients who attended.

Methods

Thirteen individual in depth interviews were conducted. Each patient had attended the educational programme and came from a different health centre in the intervention arm of a larger randomised controlled trial. The interviews were audiotaped, transcribed and then analyzed using the framework approach.

Results

Patients expressed that they gained useful new knowledge about diabetes. The use of educational material was experienced positively and enhanced recall and understanding of information. The general experience was that the health promoters were competent, utilised useful communication skills and the structure of sessions was suitable. Patients reported a change in behaviour especially with diet, physical activity, medication and foot care. There were organizational and infrastructural problems experienced specifically with regards to the suitability of the venue and communication of information regarding the timing and location of the sessions.

Conclusion

This study supports the wider implementation of this programme following consideration of recommendations resulting from patient feedback. However, only patients who attended the educational sessions were interviewed and the results of the larger controlled trial must still be obtained.

Introduction

Diabetes is one of the most common non-communicable diseases globally. In September 2011 the World Health Organization stated that 346 million people have diabetes worldwide. Compared to people without diabetes, diabetics require at least two to three times the healthcare resources. Diabetic care can account for up to 15% of national health care budgets.(1) The number of deaths due to diabetes is expected to double between 2005 and 2030. More than 80% of deaths caused by diabetes occur in low- and middle-income countries.(2)

The Western Cape, South Africa is home to a large population living with diabetes. Self-reported prevalence of diabetes amongst men and woman of 2.4% and 3.7% have been found across the nine provinces of South Africa. The self-reported prevalence of diabetes in men and woman in the Western Cape were 3.2% and 4.9% respectively and only exceeded by KwaZulu-Natal. The prevalence was higher amongst urban residents compared to non-urban.(3) A prevalence of diabetes as high as 10.8% has been found in a study done by Levitt et al amongst the mixed ancestry population group in the urban areas of the Western Cape.(4) It is expected that this number will increase significantly in the future.(5)

The costs of managing diabetes and its complications are high.(6) It is therefore important that management strategies should maximize the effectiveness of treatment and reduce the morbidity and mortality associated with diabetes.

Health centres and clinics in the public health sector are responsible for the health care of most of the people living with diabetes. In South Africa only 16.2% of the population has health insurance. The rest of the population is dependent on the public sector for their health care needs.(7) The metro district health service provides health care to the uninsured population of Cape Town. This service is provided by 45 community health centres. Nine of these facilities provide 24 hour service. Patients are attended to by both clinical nurse practitioners and medical officers.(8) A recent multi-centre prospective study conducted in four provinces of South Africa showed diabetes to be the second most common diagnoses during consultations in patients 15 years and older and fourth most common diagnosis overall. Diabetes was also reported to be the tenth most common reason for encounter for patients 15 years and older in primary care.(9) This highlights how commonly people with diabetes visit primary care in South Africa.

The quality of care is lacking and there is not a well structured education programme in place. Studies have shown a lack of glycaemic control and the prevalence of diabetic complications are indicators of deficient diabetes care at primary level. Levitt et al showed that only 49.4% of diabetic patients in Cape Town had acceptable control. The prevalence of diabetic complications were as follows: retinopathy (any grade) 55.4%, cataracts 7.9%, peripheral neuropathy 27.6%, absent foot pulses 8.2%, amputations 1.4%, persistent proteinuria 5.3% and an elevated albumin-creatinine ratio 36.7%. The high prevalence of suboptimal glycaemic control as well as diabetic complications speaks to the deficiency of efficient preventative diabetes care and the need thereof.(10)

Self-management means that people have to make choices and decisions about how to manage their life and their diabetes. Optimal patient self-management is dependent on the patients' knowledge and understanding of diabetes. An audit conducted in rural Kwazulu Natal has shown that patients are not equipped with the necessary knowledge to manage their diabetes and prevent complications.(11) Knowledge is the greatest weapon in the fight against diabetes.(12) This is however not the only factor leading to successful self-management. Patients often have knowledge of the correct treatment, but still do not follow it. Patients' understanding of the rationality behind change, intervention and motivation also plays an important role in successful self-management .(13) Successful self-management also requires that health professionals follow a patient-centered approach and behaviour change interventions should be evidence-based.(14) In a study by Assal et al it was found that patients who are knowledgeable and receiving regular counseling are more likely to maintain better glycaemic control.(15) Knowledge and understanding is an essential component to self-management, but there are other factors as well. Importance and confidence have been described as the two dimensions of readiness to change. Patients must not only believe that change is important for them personally, but also feel confident that change is feasible and practical given their abilities and circumstances. Di et al used these principles successfully to demonstrate that a counseling strategy using motivational interviewing to promote the adoption and maintenance of physical activity by a group of type 2 diabetics can be effective.(16)

Motivational interviewing is an approach to behaviour change counseling that is especially helpful for patients resisting change and who are ambivalent.(18) A systematic review by Rubak et al on motivational interviewing revealed that motivational interviewing produced an effect in 74% of randomized control trials reviewed. In none of the studies was motivational interviewing shown to have any adverse effects or be harmful. Three of the seventy two studies reviewed used group motivational interviewing and all of these showed effect. It also showed that the likelihood of an effect increased with the number of encounters. Interestingly the review showed that the effect was not related to the educational background of the counselor as there were no statistically significant differences interviews conducted by psychologists, psychiatrists, physicians or general practitioners. Rubak et al states that, even though it was not shown in their review, it would be reasonable to speculate that interview methodology, experience, training and client-counselor relationships influence effect.(19) A review by Deakin et al evaluated group based training for self-management strategies in people with type 2 diabetes mellitus. They found that group-based training is effective resulting in improvement of fasting blood glucose, glycated haemoglobin, diabetic knowledge and a reduction in systolic blood pressure levels, body weight and the requirement for diabetes medication.(20)

In a qualitative study by Jasnink et al examining how nurses experience lifestyle counseling for diabetics it was found that some nurses reported lacking knowledge in some areas of diabetes, which prevented them from providing adequate lifestyle counseling. Nurses also highlighted a lack of behaviour change counseling skills and mentioned that repeated ineffective education of patients sometimes resulted in reducing their motivation.(17) This highlights the need for an effective and sustainable

training and support programme for the healthcare workers responsible for educating patients.

It is clear that there is a need for a structured and sustainable diabetic educational programme in the Western Cape. No studies have been published on the use of group diabetes education by mid level health workers and whether this can be effective. There are no studies on the use of motivational interviewing in groups in our context. The group education approach makes sense in South Africa where doctors and nurses are scarce and time for individual counselling is very limited. Group education can be delivered by mid level health professionals such as health promotion officers. Ideally such a programme should include training of health promoters in diabetes and communication skills as well as a structured educational programme with appropriate educational materials for the diabetic patients. This study reported here is a component of a randomized control trial which evaluated the effectiveness of a group diabetes education programme using motivational interviewing in underserved communities of South Africa. This study adds value to the project by performing a qualitative assessment of the patient's experience of the intervention.

The aim of this project was to evaluate the effectiveness of a group diabetes education programme in the Western Cape, South Africa through a qualitative exploration of the patients' perspective.

Methods

Study design

The study presented in this research assignment was a qualitative exploration of patients' perspectives of a group diabetes education programme through individual in depth interviews.

Setting

As mentioned in the introduction this assignment was part of another pragmatic cluster randomized control trial evaluating the effectiveness of a group diabetic education program using motivational interviewing. The target population was type 2 diabetic patients attending the 45 health centers in the Western Cape, South Africa. Thirty four health centres were randomly selected from the 45 health centres. Seventeen of the 34 public health centers were randomly assigned to either the intervention or control group. The groups assigned to the intervention group received a structured education programme of four group sessions over a period of a year. The sessions included: understanding diabetes, understanding medication, living a healthy lifestyle and preventing complications. Sessions were presented by trained health promoters to groups of 10-15 patients. Health promoters received a full 4 day training workshop before the start of the educational programme and a further 2 days training was session was held halfway through the programme. Health promoters were trained in their knowledge of diabetes as well as the motivational interviewing style of communication. The control group received usual care.

I am a MMed student specializing in family medicine and currently employed at Khayelitsha District Hospital. I have worked at health centres in the Metropole and through this exposure became aware of the need for diabetes education to improve self care and prevent complications. I was not involved in the training of the health promoters or in any other aspects of the trial and therefore was not attached to any particular outcome or results.

Study population and selection

Patients were purposively selected from the intervention group on the basis of having attended 3-4 of the group educational sessions and having one patient from each of the 17 health centres. Patients had to be able to communicate in English or Afrikaans.

Health promoters from each intervention group were contacted and asked for the names of patients who attended 3-4 of the sessions. This was done because the intention of this study was to explore how patients experienced the educational sessions. These patients were then randomly selected and invited for an interview. The first patient to agree from each health centre was then interviewed.

Data collection

Data was collected through individual in depth interviews. An interview guide was used to ensure that interviews were aligned with the purpose of the interview. Open questions were asked and other techniques such as reflective listening and clarification used to facilitate the interviews. The interview guide consisted of two main sections. The first section focused on the patient's experience of the educational programme with regards to the communication style, session structure, information on diabetes, use of educational material, group sessions and organizational aspects. The second section explored the patient's response to the programme through change in self care activities especially diet, medication, physical activity and foot care. The interviews were conducted at a time arranged with the patients at their own homes. Interviews were recorded on a digital audio-recorder.

Data analysis

The raw data for analysis was in the form of verbatim transcriptions of the recorded interviews. Transcripts were checked for accuracy prior to the analysis and the researcher was supervised during the process. Atlas.ti qualitative data analysis software was used to assist with organizing, coding and charting of data. Data analysis used the framework approach and involved five steps:

1. Familiarization

This was a process of getting to know the data. Listening to the recorded interviews and reading through the transcripts.

2. Identifying a thematic framework

This was a process of identifying the key emergent themes which addressed the study objectives and any other unanticipated, but relevant issues. The end result of this stage of the process was an index of themes organized in a logical framework that could be used to systematically code the qualitative data. The first section of the framework dealt

with the patients' experiences of the educational programme and the second section dealt with any changes patients had made to their lifestyle or activities at home.

3. Coding

The thematic framework was applied to all the data in the textual form by annotating the transcripts with numerical codes from the index.

4. Charting

This involved a process of reorganizing the coded data from all the transcripts in thematic charts which brought all the data on related topics together.

5. Mapping and interpretation

The charts were then used to make sense of the different themes in terms of the range and strength of viewpoints and experiences as well as how these issues might be associated with each other.

Ethical considerations

The main study was approved by the Health Research Ethics Committee of Stellenbosch University (N09/10/260). This assignment was approved as an addendum to the main study. Patients gave written consent to participate in the main study. Verbal consent to the interviews were obtained prior to commencement of the interviews and recorded.

Results

Patients from 13 health centres were interviewed and four health centres could not be included. This was either because patients could not be contacted or were unable to speak English. One male patient and twelve female patients were interviewed and ages ranged from 41 to 68 years as shown in Table 1.

Table 1: Demographic profile of interviewees

Patient	Gender	Age (years)	Race	Home Language
1	M	53	Coloured	Afrikaans
2	F	50	Coloured	Afrikaans
3	F	58	Coloured	Afrikaans
4	F	62	Coloured	Afrikaans
5	F	59	Coloured	English
6	F	68	Coloured	English
7	F	41	Coloured	Afrikaans
8	F	47	Coloured	Afrikaans
9	F	57	Coloured	English
10	F	68	Coloured	Afrikaans
11	F	67	Coloured	Afrikaans
12	F	53	Coloured	English
13	F	63	Coloured	Afrikaans

The information on diabetes

It was clear from the interviews that patients were satisfied and even excited about the information they received:

“The information was an eye-opener for me.” (ds500159)

“The information that we got was excellent. I feel that it was something really worthwhile sitting in. Everybody who is diabetic [and I mean there is a lot of diabetics around these days] and if everybody who is diabetic can have what we have, I am sure that they will have a better, a wider perspective of what they are going through.” (ds500162)

There was acknowledgment that they had received new information:

“For me, it was something good and I learned a lot and there is a lot of things that you actually didn't know.” (ds500156)

Patients appeared to have trust in the quality of information:

“I felt good about it because the information that they gave to you are good information. They are not going to teach you the wrong things.” (ds500157)

The patients recalled specific information about how to adjust their diet; for example avoiding fats and oils, controlling portion sizes, avoiding sugary cool drinks and diluting fruit juices:

“They told me what food I have to eat and they explained to me in depth.” (ds500157)

“How you should take the skin off your chicken.” (ds500153)

“The vegetables can take your whole hand. You know and your hand ... you can it in large quantities and your meat too, white meat is healthier ... than red meat for example chicken, fish ... and if you eat pork ... cut the fats and like I said I am going on with what I have learned.” (ds500153)

In addition to recalling specific aspects of the dietary information there was also an understanding of the need for a balanced diet:

“We have to eat the right foods and so on. We have to try to follow a balanced diet.” (ds500150)

Patients reported on learning when and how to take their specific medication:

“The training sessions were very good for me, I could learn from it, I could use my pills right now because it didn't work was probably because I didn't use it

correctly and then when I got to the sessions, now I understand what I have to drink.” (ds500151)

Patients expressed that in spite of receiving treatment for diabetes, sometimes for many years, they had not received clear information about their medication before:

“Not even the doctors told me this is how you take your tablets and that is how you take it.” (ds500154)

Patients recalled specific information about foot care; for example to cut the toe nails straight, to keep the skin dry in between the toes, to make sure they wear comfortable shoes, to make sure there are no objects inside the shoes that can hurt or injure their feet before putting shoes on:

“I found it quite interesting, because there is a few things that was explained. that I didn't think about, like, don't rub lotion between your toes like and cut your toe nails straight and things like that ... the way to cut your toe nails..” (ds500154)

There was very little recall of information regarding stress and diabetes. Patients did mention that they were told that stress has an effect on diabetes but were unable to elaborate more:

“Yes, she did talk, she mentioned about stress that has a big impact on the sugar sufferers.” (ds500153)

There was very little reported on information given about smoking and alcohol use. Comments were restricted to the general knowledge that smoking and excessive alcohol use is unhealthy. No specific recall was made about information regarding smoking cessation or reducing alcohol consumption:

“Yes. Smoking is very dangerous.” (ds500153)

Organization of the educational sessions

It was clear from the feedback that some venues were viewed as being suitable for the educational sessions while others were problematic. The reasons for patients regarding venues as unsuitable included the following: room too small for the number of patients, interruptions during the sessions (people using equipment in the same room, other people needing to speak to the health promoter), lack of privacy and confidentiality and no specific room allocated. The inadequacies of the venues made some patients feel as if they were not really wanted at the facilities. Problems with space could therefore be due to the limitations of the physical infrastructure (not enough space) as well as poor planning and prioritization of the space that was available:

“The only thing that I said we didn't have enough place to sit in, we were in a little room.” (ds500158)

“Yes people don’t necessarily, like say you could be talking, suddenly it was like you don’t want everybody to know and yet they can come in and make photocopies and another stand there and the phone is ringing. Phone okay but she didn’t sit like forever on the phone, she’d say I have got this group here and phone back and so I’ll phone you back or whatever and that was inside you know people in the building that is doing that; but it was too small man.” (ds500158)

“I found that the health worker got to the clinic and were scrambling and running around and tried just to get a room to use for her own use, do you understand and it has a problem and I think the head of the clinics, you know, when we were there, often saw it more as a liability.” (ds500149)

Suitable venues were described as having enough space, having a bathroom close by, having appropriate seating and all the equipment needed for the session:

“No, it was good because we had a lot of space to sit in a circle and to look and each other and not sit behind each other. So, the space was good.” (ds500150)

The information about the date and time of sessions were communicated to the patients by means of SMS (short message service on cellular phones) or a phone call from the health promoter. The general experience amongst patients was that there were problems with the system of communication. The challenges the patients encountered included the following: too short notification prior to the sessions, no notification at all, no notification of changes to the arranged sessions resulting in patients arriving to find the session has been moved to another day or time:

“Yes, like I said, the whole communication system is, was clearly not of the best, there was definite breakdown points, all the information didn’t always get to me, I maybe got phone calls, then the whole thing already happened, do you understand and so on. There was definitely communication breakdown. In the sense that I couldn’t, I didn’t get phone calls or that I got it at the wrong times or too short notice.” (ds500149)

There were patients who felt the system worked very well for them and they had adequate notification to enable them to attend the sessions:

“Yes, DS let me know a week in advance. Yes. Then he sent me a message on my phone to say ... to say, patient, we have a meeting on Tuesday at twelve o’clock and so on. DS always let me know a week in advance...I was satisfied yes.” (ds500156)

The programme attempted to have the patient’s educational sessions correlate with their normal clinic visits in order to prevent additional visits to the health centres and disruption with medication collection. The feedback from patients indicated that the educational sessions did not interfere or cause any inconvenience with regards to their

normal visits and collection of medication. The health promoters made arrangements for the patient's medication to be prepared so they could collect them on the same day without having to wait or queue:

"The thing is, when you arrived for your tablets, she would take your card and have the medication made up for you. There was no problem as they collected the tablets for you. The dates of the sessions corresponded with the dates you had to get medication." (ds500160)

It became apparent that patients had some needs that were important to them and if addressed would improve their experience of the educational sessions. Punctuality was identified as an area that needed to be addressed. Patients felt that more should be done to achieve commitment from the presenters and patients and that sessions should start on time. Patients expressed the wish for more sessions and more people to take part in the sessions highlighting that there are many diabetics. There was also a request to start the sessions with a prayer if other patients were agreeable to it:

"That the people that get chosen pitches regularly, that they come at the right time, one can't come at quarter past ten, I mean quarter past eleven, when it starts at eleven o'clock." (ds500151)

Educational material

The health promoters made use of educational materials (e.g, food cards, flip charts and true/false cards) during the sessions to assist with their teaching. There was an overwhelming positive response to the use of these aids from the patients. Patients reported that it helped them remember better because they could see what the promoters were teaching them. The materials were also reported to assist with patients understanding the message the promoters were trying to get across. The use of educational material also made the sessions more interesting:

"Oh the books she had were posters. I think it was wonderful way to learn because we could see them. I think it was wonderful, all of them. It helps a lot because some people are not serious, and when they see the posters they begin to understand. If they don't see a visual aid, then they don't take it seriously. Then it means nothing. You know what I mean." (ds500159)

"The best part was that one could remember. There was one picture she showed which had a picture of a plate with rice and vegetables. She showed what your plate should look like after dishing up. Yes and when I dish up now, I get the picture in my mind, especially the rice as I am very fond of rice, and I mustn't eat too much rice. Then I remember what she told us about the rice. It's the truth, I mustn't eat a lot of rice, more vegetables." (ds500160)

Communication style

Patients generally experienced the communication style as effective and commented that it helped them to understand the information taught by the health promoter. They found the teaching style to be caring and felt they were treated well. Patients also felt

that the communication style was in such a manner that everyone in the group could understand even though they were different ages and from different backgrounds. There were some who felt that it could have been more lively:

“She made sure that she made you understand what she was trying to get across.” (ds500154)

“I must say that everything that she taught us, she explained it very well...” (ds500153)

“We could understand what she was teaching us very well. It was very good.” (ds500160)

Experience of learning in groups

Patients were very positive about experiencing the training in a group format. It allowed them to open up and share their experiences and questions with other members of the group. In the groups they discovered that they could learn from each other through sharing. The group format gave everyone the opportunity to take part in the discussions:

“It was good because in the group session we could exchange experiences, what we were going through. Some person might say ‘oh I have been this and that and that and that hasn’t been right with me’ then I can come and say ‘well I have been doing this and that and that is fine. Maybe you should try this or whatever the case and we could exchange ideas with one another. And it was good. Once we had gone through the pictures and once she has discussed it with us, then we could just open up to one another.” (ds500162)

“As a group we could have got together and the one could have talked about this and then I maybe I picked up the knowledge, I may not do this and that one has that problem and we learned a lot as a group.” (ds500163)

Session structure

The structure of the sessions was experienced as being organized and simple. This empowered everybody to take part and made the plan for each session clear. The recapping section at the beginning of each session helped patients to remember what they were taught previously:

“It was a good structure, because she made, through that you didn’t forget what you learned the previous time. She gave you a preview back on what you learned the previous time and then she continued with what we going to do today. So it was a good thing that.” (ds500154)

“Oh it was lovely! The session was, it was easy, there wasn’t a time that you like ‘what are we going to go through now today?’. It was, as I said, it was good because it was few people, the groups that were called in and as I said the facilitator she was absolutely at ease and it was a pleasure sitting there. Even if I

still go sometimes there to the day hospital she will still know who I am. You understand that?" (ds500162)

Competency of health promoter

The general opinion among the patients was that the health promoters were competent and performed well during the sessions. Health promoters who performed well were described as being able to get their information across and able to help the patients understand the information. They engaged well with all members and were very knowledgeable about the topics discussed. They were even described as being friends to the patients:

"She... and she worries when somebody is not there, and she like everyone to be there and everyone to know what she's, she brings her point across, in other words. She make sure that you understand what she's talking about." (ds500154)

"She was a wonderful teacher, I can say she was a teacher. She cared about us. She told us not to use sugar and explained very well what we need to do. It's for our own benefit, not hers." (ds500159)

"You know that was like, she went the extra mile for her people." (ds500162)

There were a few others who felt that their health promoters were not properly trained and that they did not stick to the session material, but used the platform to air their own opinions:

"Yes, like I said, I feel that the person (I don't know what the sixteen others did) but what ours presented, in my opinion, I would say is not really trained for the task. Understand, I think a person that are more in, a person that is more trained. I just feel that sometimes there was something said about the health worker that didn't really make sense that I maybe think was her own opinion that she threw in." (ds500149)

Changes made to diet

Patients generally reported making changes to their diets based on what they had learnt during the sessions. They reported on making very specific changes such as changing to lower percentage fat milk, removing fat from meat, not frying foods anymore, eating brown bread rather than white bread, cutting down on cool drinks and juice, eating less sweets and treats and eating more vegetables. It was clear that patients were well-informed about a healthy diet, but shared that they had to balance that with the reality of limited financial resources:

"Where we always ate all the cereals, now we only eat Jungle Oats, so that is now the best breakfast and so we keep to that. So, yes, I think to an extent, largely, it may not be the perfect, the process is in progress and we are working on that and there is a change somewhere, you know. What we have done to just live a better lifestyle." (ds500149)

“Before I would just eat a piece of cake ... but there at the course I learned that if you are a diabetic, you can't just eat the way you want to, you have to be careful. So, I actually learned because I loved sweet things and I learned to eat less of that and more of what is healthy.” (ds500156)

“Fats I can't handle at all. I used to be the one that used a lot of. And I don't use water and if I do use oil, it is very little. I measure it. And fats, I cut it off and if I see fat.” (ds500153)

“Like chicken stomachs, chicken livers - I have my diet sheet there. I look at it to see what I can eat and what I can't eat, before I start cooking, and I don't cook with fish oil anymore. If I buy butter I buy the low fat or the heart foundation margarine. I can't always afford everything but I buy what I can.” (ds500159)

It was clear that following a diabetic diet was difficult and even frustrating for some patients even though they had the knowledge from their training. Patients also reported that when they face difficult times or psychosocial stress their diet suffered as a result:

“To be honest right now I haven't managed it very, very well because I have been going through a lot of stress and strain these past few months, which again I suppose is the recovery but at least now I know now why not white bread, why eat brown bread and not white bread and that I have learned that one slice of white bread is equivalent to five teaspoons of sugar which is just! And to tell you the honest truth you know, is that I can't manage very, very sweet things any longer. I made myself used to without salt, without sugar, if I have had a piece of cake or something I will have lots of water to flush it out. I have learnt that a lot and I have learnt that it is about the types of food that you eat and how you eat it. Like red meat it is not a very big must but your chicken and fish it's rather go for that. I sometimes also, what I have done is I also use soya instead of meat in my food, in my soups and things that I make. I have tried just to make changes but sometimes I have got the things that when I go through stress [laughs] I eat a lot and I don't care what I eat. But I have been trying very hard just to come back on track now.” (ds500162)

Changes made to level of physical activity

Patients did report an increase in physical activity. There was a deliberate increase in the effort made to walk, but they did not regard walking specifically as a form of exercise. There were very valid challenges identified that patients had to face with regards to increasing their physical activity. They did not have the financial resources to join a gymnasium or club for exercise and therefore took to walking as their exercise. Patients stated that exercising in their communities was problematic in winter when it was cold or wet and that it was also dangerous to walk in their communities. Some patients reported that they also suffered from other medical conditions such as arthritis, which limited their ability to exercise:

“Yes, I went walking and I never did before.” (ds500151)

“But my experience is that I started walking after I got back from the sessions and they give you ideas about how to keep your sugar under control and then I went walking in the evening but because it is so dangerous.” (ds500151)

“Yes, yes I used to but now I can’t walk so I told them (was it them that I told? Yes) I can’t walk so fast, you know I used to walk fast I used to walk, I love walking but I can’t walk so fast anymore and I get short of breath but that’s the asthma. Well they said I got asthma which I doubt it’s just this thing with my chest, that problem that I got with my chest but man and the arthritis, my knees can’t handle it but I walk.” (ds500158)

Change in managing medication

It was interesting to discover that patients learnt new information about the correct way to take their particular medication, but still admitted to deviating from their prescription. Patients reported that they changed dosages, adjusted timing and even skipped medication without consulting health care workers. There were also patients who felt that making the changes with regards to their medication would help other patients but not themselves. There was also a group of patients who said that they had always taken their medication properly even prior to the training:

“What I learned, I’m doing it the right, I can do it the right way or the wrong way, my sugar stays the same.” (ds500154)

“Yes, the message I brought home with me was that I ninety percent, say eighty nine percent of the time I keep to my medication, you know, I take my medication regularly as I can, I even have a packet in the car. If I am somewhere, where I am not home where my medication is then I take it. And that is what I do.” (ds500149)

“I was taking my medication, the insulin hey, I had to take fifty in the morning and forty at night and I wasn’t happy and the tablets, tablets is mos not a problem. You just pop it in your mouth that’s fine but after that, after everything that I’ve heard and learnt there I decided to follow the rules... So I’m eating everything that type, I try to eat everything that I should. I work, I take my readings every morning and every night and I kept my reading very low. I took it to with me to the day hospital every time I had to see the doctor, whole month’s supply he must read it all, don’t read it but I’m going to let you see and so I suppose I shouldn’t have done it but I took, brought my insulin down and I kept it to five point something, six point something. It was always under, under seven, I kept it nice and low all the time through the day and so it went on. I ate properly, I tried to eat properly and I’m now and when I went to the doctor, she wasn’t very happy about it and I told her what I’m doing and I gave her the readings and I said this is it, if I can’t understand if my sugar is low that I must still be taking so much insulin and I brought my insulin down and then I was doing it only at night, which was wrong. I believe I took it just to thirty five at night and that was it for the whole day and then she phoned another doctor and then they said this doctor

asked what my reading was about and she said it was fine and she said okay, I must spread it through the day. Twenty in the morning, fifteen at night and now I'm on thirty five for the day, that is very positive as far as I'm concerned, that was very good." (ds500158)

"I must use it because it helps. It helps for me. I take it regularly every day, every morning I take my medication. I must take it, it was given to me to make me better." (ds500159)

Changes in foot care

There was a significant change in the way that patients managed their feet and patients recalled specific advice such as ensuring that their feet are dry especially in between the toes, cutting their nails straight across and not into the corners, wearing comfortable and closed shoes and not walking with bare feet:

"Yes. I always washed my feet, but I've learnt how to really look after my feet now. Especially shoes, you mustn't wear shoes which pinch you, you need to wear good comfortable shoes. You must keep your nails clean and short. You must be careful how you cut them to prevent in growing nails. So you must be very careful." (ds500160)

"I always check my feet. I do have ointment that I do when its itchy or something like that but I do make sure that I check my feet that it is clear and all that. Last Thursday when we spoke about it the lady asked why check your shoes make sure that there isn't fine bits of sand, stones in it and check the soles. And I love walking barefoot and I said to them we are not even allowed to walk barefoot and I love walking barefoot. So what I do is I got a pair of thick socks and I put that on and I walk barefoot, so I walk without shoes on. But regarding to the feet no I am always checking my feet and making sure they are fine." (ds500162)

"In terms of the changes that I have made. I get shoes that are comfortable. Shoes that are comfortable to me and where my feet can be free and so on." (ds500156)

"Well, I am very careful with now rubbing any lotion, I had thought that they, when she said that about don't rub lotions between the toes. I use to do it. And didn't tell her that anyway. But I stopped doing that. And, about the way the toe nails has to be cut, I was fond about going into the corners, I don't go so deep into the corners anymore." (ds500154)

Additional changes made

In addition to changes in diet, physical activity, foot care and adherence to medication, patients also reported making changes in other areas such as smoking, drinking and dealing with stressors. Some of the patients had stopped smoking prior to the programme while others had cut down the number of cigarettes they smoked daily in their attempt to stop smoking completely. There was no real change reported with

regards to the use of alcohol as patients reported that they either never used alcohol or used it very sparingly at social events. Some patients did admit they had challenges in their lives which they experienced as stressful. These mostly revolved around family problems, work and diabetes itself. It was interesting to note that patients were made aware of the role of stress in managing their diabetes and they had embarked on different methods of dealing with stress. It is unclear whether these changes were due to the programme or patients' own initiative since patients did not recall any specific information given about managing stress. Their coping strategies included prayer, going for walks, listening to music, watching television and sharing their problems with someone else:

"No, I told them that I am a smoker and I smoke about four cigarettes a day. I smoked less. I smoke less now." (ds500157)

"Then I will also not take more than one or two. And if I do, it is small or half glasses. (ds500153)

"Yes, diabetes is my stress." (ds500154)

"I am a very stressful. My marriage, to be honest with you, over the last few months. That's why I am a very stressful person. My husband is not an honest person, five October, we were married twenty six years. But I just give it to God and He has his time. I feel that my husband is not honest with me, do you understand? That is why I am stressful and that is why my sugar is sometimes not playing along." (ds500157)

"I speak with the Lord, you can't tell your problems to everyone. If we turn to the Lord, He hears you, His phone is never engaged. So, I turn to prayer." (ds500160)

"Or if I feel a bit stressed, I take a walk for the stress." (ds500156)

Paying it forward

There was also an unforeseen but positive response following the educational sessions. Patients reported that they decided to put to use what they have learned by sharing it with other diabetics in the community who did not have the opportunity to attend the sessions:

"It was worth it because what they gave me there, I could say to myself that I have learnt something. So, I can teach it to my children and my husband too." (ds500156)

"So it was really excellent. I really enjoyed every moment and not that alone is that you know when people come 'oh I am diabetic' [cell phone pings] I can tell them I know you are diabetic, I am diabetic too but I am on this programme that is run through the University of Stellenbosch and you know what they have been telling us and teaching us! Now they don't understand, nobody believes it so I show them my certificate. I tell them this is what you need to know and this is

what you need to do and amazingly some of the people have actually listened you know. They were taking also heed of what they should do.” (ds500162)

Discussion

Key findings

This educational programme was useful and effective from the perspective of these patients. It was evident from the feedback that patients gained and retained valuable knowledge. The programme addressed the patients' need for information on managing diabetes. Patients were able to recall specific details about managing various aspects of diabetes especially diet, physical activity, medication and foot care. A significant group of patients regarded the knowledge gained as the single biggest positive experience of the programme.

There were clearly organizational and infrastructural challenges that had an impact on the patients' experience of the programme. The biggest issues were with regards to the suitability of the venues for small group activities. These limitations combined with inadequate planning and utilization of the existing resources led to the problems with space. Patients also reported a breakdown in communication, which in some instances resulted in patients being unable to attend sessions.

In the research study these specific patients were required to attend the sessions. In normal service delivery a different attendance protocol could allow patients to attend the sessions when it is convenient to them. Patients did not experience the programme as interfering with their normal clinic visits and collection of medication. Some patients expressed the need for more commitment from participants and organizers. Poor attendance and sessions starting late were some of the negative experiences patients recalled.

There was very positive feedback on the use of educational materials and the communication style. Patients enjoyed the interaction facilitated by the use of educational material and reported that these methods assisted with their recall and understanding of information. There was an overwhelming response testifying to the competency of the health promoters.

Patients reported implementing change in self care activities following their attendance at the programme. The biggest areas of change were diet, physical activity, medication and foot care. Patients recalled specifics of the changes that they had made in these, but also highlighted that for many of them this was a process which they continue to implement. There were a few attempts to stop smoking and alcohol consumption was reportedly already low. Patients reported different ways of dealing with stress, but it is unclear whether these changes were as a result of attending sessions or on their own initiative.

Some patients reported that they now teach and share their experience with other diabetics in an informal manner.

Comparison to the literature

A meta-analysis that evaluated the effects of group based training on clinical, lifestyle and psychosocial outcomes in people with type 2 diabetes found that group-based self-management training was effective and could result in improved diabetes knowledge, fasting blood glucose levels, glycated haemoglobin, systolic blood pressure levels, body weight and medication requirements.(20) This study found that patients reported an improvement in their diabetes knowledge and changes in self care that could lead to improved biological measurements.

Patients regarded the information learned as the most positive aspect of attending the programme, which echoes the findings of Rygg et al. (21) Another qualitative study reviewed the experiences of people with type 2 diabetes participating in a group education programme versus individual counseling. They found that group education may contribute to strengthening patients' ability to influence and be actively involved in their own care.(22) Our patient feedback on group education was overwhelmingly positive and also reported on the benefits of group interaction that allowed them to assist, share and learn from each other.

Patients reported making changes in the management of their diabetes, especially diet, medication, foot care and physical activity, However, the pragmatic cluster randomized control trial only showed improvement in diastolic blood pressure (personal communication, Prof Bob Mash). This may be because the intention to treat analysis included all patients in the intervention arm, while only 40% of patients attended any educational sessions and only 9% attended all four sessions. This qualitative study was based on the patients who attended 3-4 of the educational sessions.

Strengths and limitations

Interviews were conducted with one member from each of the intervention sites. Members were selected on the basis of willingness to partake, ability to speak English and good attendance of the programme. A weakness could be that patients who attended poorly might have reported on different experiences of the programme and could have shed light on their practical difficulties or reasons for not attending. No Xhosa speaking patients were interviewed and therefore the viewpoint of this part of the study population was not included in the study. Although the majority of the population in the public sector facilities in Cape Town are English and Afrikaans speaking, from the so called coloured community, the Xhosa speaking community are an important sub group. It is possible that they might have had a different experience or perspective on the education.

Another possible limitation could be that the principal researcher conducted and interpreted the interviews alone. This could increase the chance for my assumptions, values and beliefs to influence the interpretation of the data. However, the researcher was assisted by the research supervisor with the data analysis. A strength was that the principal researcher was an independent person and should not have had any influence on patients expressing their true experience of the programme. Another possible strength was that interviews were conducted at the patient's homes in a familiar

environment, facilitating a comfortable and relaxed atmosphere in which the patient felt more in control.

Recommendations and implications

Patients felt strongly that the programme should continue. There are however some recommendations that could improve the patient's experience:

1. Health promoters need to improve communication regarding session venues, dates and times with patients
2. Facility managers need to develop more suitable infrastructure for group education within health centres or group education should only be implemented at facilities with suitable space
3. Facility staff need to appreciate the importance of group patient education and to show greater commitment to assisting with the practical arrangements
4. Health promoters should ensure sessions start on time
5. The team that developed the educational programme should consider developing additional sessions

The results of this study would support the further implementation of the educational programme, although the perspective reported on is only from those who managed to attend most of the sessions. The experience of those who did not attend could be explored in a further study.

Conclusion

The aim of this project was to evaluate the effectiveness of a diabetes group education programme through a qualitative analysis of feedback from the participants. Patients expressed that they gained useful new knowledge about diabetes. The use of educational material was experienced positively and enhanced recall and understanding of information. The general experience was that the health promoters were competent, utilised useful communication skills and the structure of sessions was suitable. Patients reported a change in behaviour especially with diet, physical activity, medication and foot care. There were organizational and infrastructural problems experienced specifically with regards to the suitability of the venue and communication of information regarding the timing and location of the sessions.

Patients experienced the programme as successful and reported that they benefitted from attending and wished that other diabetics could also be granted the opportunity. This study supports the wider implementation of this programme following consideration of some recommendations resulting from patient feedback.

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