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RESEARCH

Stakeholders' perceptions of dietary and related self-management challenges and education programme preferences for type 2 diabetes adults

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Objective: To inform the adaptation of an intervention from a primary healthcare setting to a tertiary setting, the dietary and related self-management challenges and education programme preferences of adults with type 2 diabetes (T2DM) were explored.
Setting: A study was undertaken in a tertiary teaching hospital in Gauteng Province, South Africa.
Methods: A qualitative approach was employed. Data were collected via focus-group discussions and open-ended self-administered questionnaires from a convenient purposive sample of T2DM patients ($n = 28$; 40–70 years) and health professionals ($n = 10$) respectively. Data were analysed using a thematic framework method.
Results: Participants revealed diabetes-related knowledge deficits and struggle with adhering to diet, exercise, medication and appointment keeping as problems affecting patients. They also perceived multiple barriers to effective self-management (financial constraints, unsupportive social and physical environments and personal factors). Patients perceived the challenges to greatly impact on their quality of life and consequently the motivation to self-care appropriately. Participants desired an education programme in the form of monthly group meetings with approaches to enhance learning (e.g. use of examples from peers and the provision of education materials). Strategies for motivating and sustaining programme participation (e.g. testimonials from successful participants) were perceived as necessary. Involving family was seen as a key support for positive behaviour change.
Conclusion: In adapting the intervention, the participants' preferences for education need to be considered and the unique challenges addressed. In particular, strategies for enhancing the patients' motivation and the self-efficacy to effectively self-manage are essential.

Keywords: challenges, dietary self-care, self-management education, stakeholders, qualitative, South Africa, type 2 diabetes

Introduction

Diabetes mellitus is a public health problem, with increasing prevalence and rising mortality especially in low- and middle-income countries.[1] South Africa is among the top ten African countries in terms of people living with diabetes.[1] Diabetes significantly contributes to the burden of non-communicable diseases in South Africa[2] and was the second most important cause of deaths in 2015.[3]

Treatment of diabetes, a chronic disease, is reliant on self-management, making patient education critical.[4] Diabetes self-management education (DSME) empowers the person with diabetes with the knowledge, skills and motivation needed to perform appropriate self-care.[5] The value of DSME is proven for various outcomes including knowledge, self-care behaviours and metabolic control.[5–7] Diabetes self-management education is also a cost-effective intervention strategy.[8] Despite the important role of DSME, poor diabetes knowledge among people with diabetes is a significant barrier to effective self-management.[9–12] In developing countries, several calls have been made to intensify DSME to improve self-care among people with diabetes.[13,14] However, in developing countries structured DSME programmes are few.[15,16] In South Africa those that do exist are concentrated in primary care settings,[17] despite evidence for poor metabolic control at other levels of care.[18,19] At a tertiary hospital, few (15.5%) people with T2DM achieved glycaemic target despite being on appropriate pharmacotherapy.[19] This scenario may indicate suboptimal lifestyle behaviours including diet and exercise,[20] hence the need for intervention.

Diet plays an important role in the metabolic control of diabetes,[21] but both patients and health professionals consider dietary self-management to be particularly challenging.[22] To test the efficacy of a nutrition education programme (NEP) in a primary healthcare setting, a targeted DSME programme was implemented among poorly controlled T2DM patients using a randomised controlled trial design over 12 months. The NEP led to a clinically significant reduction in HbA1c (~0.6%) and significant improvements in some dietary behaviours beyond six months[23] and is, therefore, considered an effective intervention.[24] For the NEP to achieve positive health outcomes in a new setting, identifying differences in the target population is a critical step towards enhancing its appropriateness to the new setting.[25]

This study therefore explored the dietary and related self-care problems of adults with T2DM in a tertiary healthcare setting, as well as the preferences for a diabetes nutrition education programme to inform the adaptation of the NEP (described above). The specific aims were to (i) explore the general problems related to diabetes self-care and those specific to diet, and (ii) solicit suggestions for a diabetes education programme.

Methods

Study setting

This study was conducted at a diabetes outpatient clinic of a public tertiary teaching hospital affiliated with the University of Pretoria (South Africa). Patients are usually referred to this clinic on the basis of either poorly controlled diabetes or the presence of diabetes complications. No structured diabetes education was offered to the patients at the time of the study. Most of the education at the clinic is offered on an individual basis based on the assessed need by the physician. Cases deemed to need lifestyle intervention are referred to the dietitian for further counselling. The study received ethical approval from the Faculty of Health Sciences, Research Ethics Committee, University of Pretoria (no. 4/2016).

Participants and recruitment

Participants included male or female adults with T2DM and the health professionals (HPs) serving them at the diabetes clinic. A convenience purposive sampling method obtained the sample. Eligible patients were between 40 and 70 years old, had lived with diabetes for at least one year and could speak English. Patients were personally recruited at the clinic waiting room before their consultation. Twenty-eight T2DM patients (17 males) participated. Their mean age was 59 years (SD 9 years) with a diabetes duration of 1–37 years. Most of the participants (81.9%) were on insulin (42.9% monotherapy; 39% combined with an oral hypoglycaemic), had at least a high school level of education (82%), were unemployed (71%, including pensioners) and were married (71%). They comprised mainly black (57%) and white races (35.7%).

Health professionals were able to participate if they had worked with the patients for at least six months. Ten health professionals (three doctors, five dietitians, two nurses) participated. Most were females ($n = 7$) and had served the patients for more than one year ($n = 6$). Half were aged below 30 years. All participants gave written informed consent after the study was explained.

Study design and data collection

This was a qualitative exploratory study that employed two data-collection methods, namely focus-group discussions (FGDs) and open-ended self-administered questionnaires. Data were collected between March and May 2016. Five FGDs with four to seven patients were conducted using a semi-structured interview guide. The FGDs were held in a physician's consultation room prior to consultation (most patients arrived more than two hours early). The FDGs lasted 45 minutes to one hour. The first author (JM) acted as the group moderator while a PhD Nutrition student took notes. Both the moderator and note-taker have previous experience with conducting FDGs. Health professionals completed a self-administered open-ended questionnaire at a time that was convenient for them.

Data analysis

All data were transcribed verbatim by the first author (JM). The first author analysed all data. A thematic framework approach was employed for data analysis.[26] This method allows themes to be developed from both the research questions and the accounts of the participants.[26,27] The framework analysis was conducted in five steps, namely familiarisation, thematic framework identification, indexing, charting and mapping, and interpretation.[26,27] (Table 1) Credibility was ensured through regular discussions with the research team during the analysis. Data were also validated through peer debriefing whereby findings were discussed with impartial colleagues,[28] including the FGDs, and note-taker.

Results

The results are presented in two main categories, namely dietary and related self-care challenges and desirable education programme characteristics. Themes were identified within these categories. The participants' quotes are presented as focus group (FG) for patients and health professionals (HP). Tables 2 and 3 present example quotes for themes within the two categories respectively.

Perceptions on diabetes dietary and related self-care challenges

Knowledge deficits and misunderstanding

Knowledge deficits concerning certain aspects of diabetes and its treatment were revealed from both the patients' and the HPs' accounts. Patients revealed they did not know enough about foods regarding portion sizes, composition and glycaemic impact. Their accounts also exposed confusion and uncertainty regarding medication indications, glucose level targets and diabetes complications (Table 2).

Health professionals felt that patients had poor knowledge about diabetes and its treatment. As a result, patients did not understand the rationale for treatment recommendations or the importance of treatment adherence. Health professionals mentioned poor knowledge about food groups and the composition of foods as problems among patients (Table 2). In addition, HPs corroborated the patients' findings regarding poor knowledge of the glycaemic effect of foods: 'They do not know which foods influence blood glucose' (HP7).

Table 1: Data analysis steps using thematic framework approach[25,26]

Step	Application
Familiarisation	Involved listening to audio recordings and reading through the field notes and transcripts
Thematic framework identification	Involved coding three focus-group (FG) transcripts and five health professionals' (HP) questionnaires separately for each group, starting with the patient group. The rest of the transcripts were coded after the initial themes were discussed with the research team. Further revision and refinement of each framework was done as new issues emerged until no new themes could be generated
Indexing	The final coding framework per each group was systematically applied to the respective group transcripts
Charting	A matrix was created per each theme and code, separately for FG and HP
Mapping and interpretation	The matrices were reviewed while making connections within and between codes and cases, to generate themes and categories. Similar themes from the two groups were grouped together to form one common theme

Table 2: Perceptions on dietary and related self-management challenges

Themes	Participants' quotes
Knowledge deficits:	
Misunderstanding/poor understanding and poor knowledge	Everything you eat (portions) must be within your palm (FG5, P6, F)* To be honest chocolate does not build extra sugar in you … you can have some, even an ice-cream it is not much sugar (FG2, P1, F) When I tell myself it is normal it is 10 or 11, which I think is high … the 10 actually is sometimes before I eat in the morning (FG1, P5, F) Metformin is more for the organ (FG2, P1, F), yes for the kidneys (FG2, P3,M) If the sugar goes high, you get a stroke, am not sure when you get a heart attack (FG1, P3, F) Not understanding what diabetes is in the first place, therefore they have difficulty understanding why they must avoid or limit certain foods (HP4)** They don't know which foods are proteins and which are carbs (HP6) Poor knowledge of high fat foods (HP3) Incorrect information, e.g. brown sugar is better than white (HP 4)
Struggle with treatment adherence:	
Dietary	You have to stick to the diet which I do not, I find it very hard to stick to the diet, I love sweets (FG1, P3, F) But when I eat the wrong foods, it shoots up to 14, 16 etc. (FG3, P4, M) I like to take cold drink [soft drinks], I like it too much (FG5, P7, F) I do have problem with portions, I eat a lot, I do not know why I have a lot of appetite (FG5, P6, F) I know I should eat more vegetables and stuff like that, but things are getting more expensive so you cannot really buy (FG1, P3,F) They are struggling with portions (HP9) Not enough vegetables and fruits and lack of variety (HP5) They should be educated not to skip meals (HP6) If I do not eat at night I get lows (FG1, P3, F) Sometimes I do not eat because I am still full (FG1, P1, M)
Medication	Lack of adherence to their medication (HP2) I have problem with insulin, I feel tired with taking, I can skip 2 days (FG5, P6, F) I did not eat or inject today, but I brought my stuff (FG3, P6, M) Sometimes in the morning instead of taking (insulin) at 6, I take at 11 (FG4, P3, M) Sometimes it is balancing between diet and insulin that is a problem (FG5, P1, M) Sometimes I inject in the evening and I have not eaten enough, and in the night the sugar goes low (FG5, P1, M)
Exercise	Most patients do not understand how important physical activity is (HP6) For me I have cut down on a lot of things … except that I do not do any exercise, but I live in a house that keeps me busy in motion (FG2, P1, F)
Appointments	Not keeping appointments (HP1) They default attendance of visits to the health professionals (HP2)
Barriers to effective self-management:	
Cost barriers	I do not always have the money to buy the right kind of food (FG1, P3, F)* Because of poverty they cannot afford fruits and vegetables (HP2)* The problem is that it is expensive, 85% of us cannot afford, we are used to porridge (maize meal) and meat They teach how we can eat … the type of food they tell you to eat is expensive (FG4, P2, M)
Lack of social support: family and social environment	They depend on family diet which may not always be appropriate (HP6) …. if you live with people without diabetes it is difficult, they add too much salt or oil, they have to cook separately for you (FG4, P5, M) It is difficult to support two different kinds of foods (FG3, P4, M) If you are invited to a party, then they will give you juice or cake (FG1, P1, M)
Personal factors and circumstances	The diet can also be very selective and expensive (FG5, P5, M) You cannot just boil meat without salt or spice, it is not enjoyable (FG4, P2, M) Sometimes you get cravings for sweet things and you indulge (FG1, P5, F) But after a few minutes, if I do not feel full I eat another one, 30 minutes I am hungry I grab what is around (FG5, P6, F) Sometimes I walk, I am too lazy to walk, it is boring you walk a couple of days then I do not walk again (FG5, P4, M) I forget to inject myself at the right time, and then the sugar goes up (FG1, P3, F) When I am not at home then is a problem, because you only eat when they are ready (FG4, P2, M) I cannot inject anywhere, you need to be somewhere to be free (FG4, P3, M) Sometimes I cannot carry it [insulin] (FG4, P5, M)
Physical condition and environmental factors	It is not only diabetes, I have high blood and heart problems. All these stops me participating full scale in exercise (FG3, P3, M) With these painful legs, you cannot exercise (FG1, P3, F) You cannot walk during the day because it is hot, you cannot walk early morning or late evening because of the high crime in our community (FG1, P5, F)
Medication care burden and negative impact	I feel tired with taking medication … sometimes I get very angry and skip for 2 days [insulin] … (FG5, P6, F) The hardest part of diabetes is drug and insulin which is a nuisance, but I am coping (FG5, P5, M) When you take medicine it is supposed to keep your sugar down, but you do not know how the body reacts … you use insulin and instead of the sugar going down to 6, it goes up to 10, then it is a problem (FG5, P2, M) This insulin makes your head feel bad (GP4, P4, F)

(*Continued*)

Table 2: Continued.

Themes	Participants' quotes
Strategies for coping with challenges:	
Overeating inactivity	Sometimes I eat more than I should because you fear the sugar will go down (FG5, P4,M) I eat small at a time, but after a few minutes If I do not feel full, I eat another one (FG5, P6; F) You get easily tired, you need to rest more (GP4, P1, F)
Challenges affecting quality of life:	
Stress and worry	I also join them … you must take your medicine, check your blood etc. that is one part. The diet is a big problem, also your diet and emotions work together. Every day you are under pressure with the disease (FG5, P1, M) When you wake up it goes to 13, then you start worrying, the up and down is a concern (FG5, P5, M)
Exhaustion and lack of energy	You have no energy, you are tired and feel miserable (FG2, P1, F) Tired all the time, we do not sleep enough, going to the toilet the whole night (FG1; P3/P4, F) Apart from being tired, you are weak not as strong … it is like something is sucking life out of you (FG1, P2, F)
Pain/discomfort	My legs get very hot and painful at night (FG5, P5, F)
Restriction, isolation and lack of enjoyment	With diabetes it is a sin to eat too much (FG4, P6, M) Everything you do you have to control. If you are in a ceremony you cannot enjoy like everybody else. You see you can be in your corner there (FG4, P2, M)

*FG5, P6, F: Focus group 5, participant number 6, female.
*HP4: Health professional number 4.

Struggle with treatment adherence

Both patients and HPs felt that adherence to lifestyle (including diet and physical activity) and medication were a problem. Patients voiced their concerns with strong language and emotions and felt that effective self-management was difficult and illusive. As one patient put it: 'Treating diabetes is like chasing a bird without a gun' (FG4, P6, M).

Although patients acknowledged knowing the dietary recommendations and the need for adherence, they repeatedly voiced the struggles with diet. In particular, patients felt it was difficult to forgo favourite foods considered inappropriate despite being aware of the detrimental effects on glycaemic control. Health professionals were aware that patients consumed inappropriate foods: 'They still eat junk foods' (HP1). Both patients and HPs emphasised that food portion control, especially of starchy foods, and incorporating adequate vegetables and fruits were dietary problems. In addition, skipping of meals was reported by both groups. In some patients, skipping of meals appeared to be linked with overeating in the previous meal(s).

Undertaking exercise was not given due attention as revealed by accounts of both stakeholder groups. Similarly, both groups reported medication self-care as a challenge. Patients reported they skipped insulin doses or failed to adhere to the schedule. Some patients recounted that balancing diet and insulin was also challenging. As a result they reported frequent incidences of poorly controlled diabetes. Additionally, HPs reported that patients were not adhering to appointments.

Overall, participants' accounts gave some evidence of patients' poor treatment adherence:

> 'Mine is uncontrolled, very rare I have 9 downwards …. Sometimes it is 18 or even 20' (FG5, P7, F)

> 'I get lows, and lots of them. It first goes high sometimes to 28, and then it goes down like a stone.' (FG1, P3, F)

> 'Morbid obesity is often present' (HP6).

Barriers to effective self-management

Both patients and HPs indicated that financial constraints and the cost of healthful foods were the important barriers to dietary adherence. Patients felt that healthful foods are very expensive and therefore not achievable. This perception consequently hindered their willingness to change established eating habits. They also felt that some of the advice they received from dietitians was not compatible with their financial circumstances.

Both patients and HPs felt that patients did not receive enough support from family with regard to meal arrangements. Patients recounted that they had to eat differently from other family members or that they had to eat non-appropriate foods prepared for the whole family. Patients also reported that the social environment promoted non-adherence to dietary guidelines because of being offered inappropriate foods.

Patients mentioned a number of personal factors and circumstances as barriers to diabetes self-care. They felt the recommended diet was restrictive, monotonous and tasteless and hence deterred enjoyment. Similarly, cravings, temptations and hunger were reported as obstacles to dietary adherence. Some patients voiced that laziness, boredom and lack of discipline hindered them from undertaking exercises while forgetfulness deterred adherence to medication. Patients perceived medication self-care as a burden and therefore a barrier to adherence. Insulin taking was also associated with side effects or not producing the expected results. In addition, patients viewed breaks in their usual routine as detrimental to adherence. For example, being away from home was reported to impede adherence to medication and diet.

Most patients felt that their physical condition (e.g. co-morbidities and pains), and environmental factors (e.g. hot weather and unsafe neighbourhoods) prevented physical activity (Table 2).

Strategies for coping with challenges

Patients indicated that they tried to deal with self-care challenges, albeit with negative strategies. They overate for fear of hypoglycaemia, ate frequently due to hunger and lack of energy, and rested more often due to tiredness.

Challenges affecting the quality of life

Patients felt that diabetes reduced their quality of life and hence their motivation for self-care activities. They reported feeling stressed due to the daily demand for diabetes care as well as worry about diabetes control. In addition, constant tiredness,

Table 3: Perceptions on desirable diabetes education programme

Themes	Participants' quotes
Content of the programme:	
Diet and exercise	Food groups and their influence on blood glucose (HP7)* Food group knowledge, e.g. what foods are carbs, proteins or low fat (HP6) Portion control and carbohydrate distribution, and general healthy eating (HP4) Emphasise not skipping of meals and healthy snacks (HP6) More information on the benefits of exercise in controlling blood glucose (HP9) General discipline in eating and exercise and taking care of own body (FG2, P1, F)**
Medication self-care	Importance of adhering to medication even when blood glucose seems to be normal (HP10) They should be educated not to skip insulin (HP6) Insulin adjustment (HP7)
Other self-care	Glucose monitoring importance and when to do it (HP8) What to do when they get hypos (HP6) How to take care of the feet and wounds (FG2, P4, M) Something that helps to manage your stress, I have a lot of stress (FG1, P3, F)
Diabetes basics	The basic principles of diabetes (FG3, P4, M) About diabetes and where it is coming from (FG5, P2, M) I have different type of side effects, people must know (FG4, P2, M) Explaining to them in simple terms what diabetes is (HP4)
Programme delivery structure:	
Meeting frequency, times and session duration	Monthly during medicine collection due to financial constraints (HP6) I stay very far, I can only come once a month (FG4, P2, M) I have four clinics to attend, unless it is during the clinic or medicine day (FG5, P2, M) You must link the lessons with the days of collecting medicine (FG1, P1, M) Week days, not Saturday (GP2, All) Early hours in the morning when people are still fresh (FG4, P6, M) Maximum two hours, otherwise people will not concentrate (FG1, P5, F)
Group delivery format	If they see us they should see us as a group, keep it in a group (FG1, P2, M) You meet with other people, you know you are not alone, a group discussion is very good (FG4, P1, F) They learn from others and identify with others with similar condition (HP10)
Delivery to enhance learning:	
Participatory, experiential and skills guided Visuals and culturally appropriate examples Learning from others Provision of easy education materials	Involve the group in some tasks and give practical guidelines … show examples that are culturally appropriate (HP4) Demonstrations on foodstuffs, cooking demonstration, they also should taste (FG2, P3, F2) Show a sort of film-picture like they will understand quicker (FG1, P1, M) Show examples of people who are struggling with diabetes and those who are doing well to explain how they do discipline (FG2, P1, F) If there is a pamphlet explaining what is diabetes, where it is coming from in this way people can learn, even those without diabetes (FG5, P2, M) Provide easy booklets on basics of diabetes and dietary guidelines such as portions to refer to (HP3)
Support for behaviour change:	
Involving family	The family must be involved to help with the diet, when I do not cook my daughter cooks (FG5, P7, F) If my wife is available I will bring her along, she can remember and help because she is always around me (FG4, P6, M) Family support, e.g. family cooking together or reminder to take medicine (HP4)
Enhancing and sustaining motivation for participation and behaviour change:	
Good speaker Use of visuals and reminders Testimonials Group activities and creating anticipation	Make it interesting, have a person who is a good speaker (FG2, P4, M) Something to show people, what can attract attention (FG5, P5, M) A reminder is always needed, we are adults, we forget easily (G4, P6, M) After 3 or 4 lessons, if you see the regulars, ask them to give a sort of testimony to others (G1, P2, M) Yes, they say what they have changed, so that others hear and get motivated (G1, P1, M) Create activities in the group, give them something to look forward to, keep them motivated (FG2, P1, F)
Educator characteristics:	
Positive personal attributes	You need to be very friendly, you must not have an attitude, people here are very sensitive (FG1, P1, M) Being judgmental can discourage participation (HP6) … do not give the lessons to someone who does not know, if it is the doctor then yes (FG1, P1, M)

*HP7: Health professional number 7.
**FG2, P1, F: Focus group 2, participant number 1, female.

weakness, lack of energy and lack of sleep related to nocturia were reported to be common. Patients also felt restricted and unable to enjoy food like other people, resulting to additional feelings of isolation.

Due to the above-mentioned issues, patients perceived diabetes to be worse than other chronic conditions. As one patient put it: 'even HIV is better, but you have to accept' (FG4, P2, M), and another: 'Sugar diabetes is worse than HIV, people with HIV at least can eat anything they want' (FG5, P7, F).

Desirable characteristics of a diabetes education programme

Interest in the education programme

Both patients and HPs indicated that patients would participate in the potential education programme, revealing support for an NEP. As one health professional indicated, 'Most will come to learn more about their condition' (HP1), and a patient said, 'See how to help us, we need the knowledge, we need the information' (FG4, P6, M). Patients felt that participating in an

education programme was an opportunity to promote self-discipline for appropriate lifestyle self-care, and to learn new information from a credible source:

> 'Yes, I will come to be disciplined in eating and exercise.' (FG2, P1, F)

> 'This will help, there is a lot of information out there, we need to get the facts.' (FG5, P4, M)

One patient initially voiced that such a programme was only necessary for those with problems: 'This thing, you do not need people like us, you need people who have problems, but may be yes, I can come because things are changing' (FG1, P1, M). Health professionals acknowledged that non-participation could arise due to patients perceiving themselves as knowledgeable and not needing education: 'They may fail to participate as they may think they know enough' (HP7).

Content of the programme

Patients did not specify the topics or content of the education programme related to diet. They appeared to perceive the problem as not being information per se, but the discipline to apply the information appropriately and consistently in their dietary self-care. As one patient said, 'General information, for diet, actually we have been told before, it is just that we do not apply it all the time' (FG1, P3, F); and another, 'General discipline in eating and exercise and taking care of own body' (FG2, P1, F). Patients appeared more interested in learning about diabetes as a condition regarding causes, symptoms and complications. They were also interested in foot care and stress management (Table 3).

Health professionals felt that aspects that challenged their patients should be included as topics in the education programme. Diet-related topics to be included were portion control, meal regularity, foods/food groups that affect blood glucose, carbohydrate distribution, snacks and general healthy eating. In addition, they felt that patients should also be educated on other self-care areas including exercise and its benefits, glucose monitoring and management of hypoglycaemia. Health professionals concurred with the patients regarding learning the basics of diabetes mellitus as a topic.

Programme delivery structure: frequency, session duration and delivery format

Most patients and HPs felt that education meetings should be held monthly. The frequency of meeting was mainly rationalised to the financial implications related to transport. Patients also felt that more frequent meetings would overload their outpatient visit schedules as some had multiple clinics to attend. Patients suggested the education sessions be aligned with their monthly medicine collection days to reduce the burden. Patients also felt that the education sessions should last one to two hours to avoid diminishing concentration. They would also prefer sessions on weekdays and during the mornings.

In response to whether a group approach would be an appropriate mode of delivery of the diabetes NEP, both patients and HPs highly endorsed the approach. Group sessions would promote social support and learning. A patient and an HP indicated individual education sessions could benefit some patients: 'Some people may not want to talk in a group, especially if they have problems' (FG1, P1, M), and 'Some few may prefer individual counselling' (HP5).

Delivery approach to enhance learning

Both patients and HPs suggested delivery approaches that enhance learning such as food tasting sessions, demonstrations, use of visuals and use of examples. Health professionals emphasized cultural appropriateness of the examples while patients felt using peer examples would be useful. In addition, both groups felt that education materials presented in simple language should be given to patients to enhance learning. Patients also felt the education materials would promote family support: 'Education materials will be good, our families will be involved and will be informed' (FG5, P5, M).

Incorporating support for behaviour change

Both groups of participants suggested that mechanisms to support behaviour change be included. Involving family members was considered integral to providing support for positive dietary behaviour and medication adherence.

Delivery to enhance and sustain motivation for participation and behaviour change

Patients mentioned that lack of motivation could hinder participation: 'Lack of motivation can make people not to come' (FG2, P1, F). They also suggested approaches to keep participants motivated in the programme. These include making the sessions interesting by using demonstrations, visuals and good speakers, using reminders, testimonials from those with success stories, providing group activities and creating and maintaining anticipation of new things.

Educator characteristics

Patients and HPs mentioned that positive educator characteristics such as friendliness and being non-judgmental would contribute to the success of the education programme. Additionally, patients felt that instructors should be knowledgeable.

Discussion

This study explored the dietary and related self-care challenges among people with T2DM from the perspectives of patients and HPs in a tertiary care setting. From the participants, the desirable characteristics for a diabetes nutrition education programme were gauged. This was done to obtain insight for adapting an NEP from a primary care setting to a tertiary care setting so as to enhance the 'programme fit'.[25]

This study revealed five striking challenges experienced by the patients, namely diabetes-related knowledge gaps, treatment adherence problems, barriers impeding the adherence to treatment, negative strategies used to cope and the negative impact of challenges on patients' quality of life. Our findings corroborate the findings of other studies concerning diabetes knowledge deficits in people with T2DM,[9,10,29,30] even in tertiary settings.[31] Notable diabetes-related nutrition knowledge problems among patients in this study concerned food groups/composition of foods and the metabolic impact thereof on glucose control. This finding has previously been reported in a secondary care setting of a developed country.[32] These knowledge deficits could hinder patients' ability to make appropriate dietary choices because knowledge is a predictor of dietary self-care.[33]

This study also confirmed the challenge of adhering to the treatment recommendations by people with T2DM for lifestyle and medication,[22,30,34,35] as well as keeping appointments.[22] Compared with patients in the primary care setting, patients in this study seemed to experience greater challenges in keeping

appointments, medication adherence and problems with transport related to distance and costs. Additionally, they struggled to balance insulin and diet. The latter may be expected since patients in the primary care setting were not on insulin therapy.[36] To overcome some of the challenges, patients in this study employed negative strategies such as overeating for fear of hypoglycaemia. This finding reveals the magnitude of the struggle to adhere to treatment recommendations in this population group. Similar findings have been reported for patients on insulin therapy in primary and tertiary care settings.[37]

Barriers to appropriate self-care observed in our study have been reported in previous studies around the world.[38–43] Dietary adherence was impeded by the cost of healthful foods and personal factors such as taste and inability to resist temptations and hunger. The social environment and lack of family support were also mentioned to negatively affect dietary adherence, similar to other studies,[9,40–43,44] even in the primary care setting[36] Unlike their primary care setting counterparts, patients in this study did not raise physical access to healthful foods as an issue. This may be related to the geographical location as the primary care participants were located in a rural setting with less access to food outlets. Barriers to physical activity included personal factors such as laziness, lack of motivation, physical conditions such as pains and co-morbidities and the physical environment such as the weather in consistence with other studies.[44]

Patients in this study, unlike their primary care counterparts,[36] portrayed impaired quality of life due to the self-care challenges as demonstrated by the reported presence of distress, tiredness and lack of energy and the perception of inability to enjoy life as other people do. These combined with the perception that diabetes is difficult to treat may hinder the patients' motivation to self-care. appropriately[35] People with T2DM on insulin therapy and those with more complications are reported to experience more diabetes-related emotional distress.[45] The daily demands of living with diabetes and the complications associated with diabetes have been reported to impact negatively on patients' psychological well-being[22] and quality of life.[46]

With regard to a desirable diabetes nutrition education programme, our findings indicate that the two groups of stakeholders considered such a programme beneficial for the patients and patients were positive about participation. This positive finding is important because research has demonstrated low participation in DSME programmes by patients with diabetes who were invited to participate.[47]

The two groups of stakeholders expressed the need for patients to understand diabetes as a condition, similar to participants in the primary care setting.[36] The patients did not specify the diet-related topics or content they wanted included in the NEP, similar to the primary care setting[36] and other settings.[48] In contrast, HPs had a clear idea of the dietary education needs of patients, which were reflected in the challenges and barriers to self-care. Notable topics different from the primary care setting were food groups, meal regularity and carbohydrate distribution. Other key topics suggested by HPs were glucose monitoring, management of hypoglycaemia and the importance of adherence to self-care. Patients felt that self-discipline for diet and physical activity were important topics for an educational programme as they perceived lack of self-discipline to apply the self-care guidelines was a problem. Thus a need exists for the planned intervention to enhance motivation, self-efficacy and self-control such as regulation and monitoring in line with theories of behaviour change such as social cognitive theory.[49]

Patients in this study suggested monthly meetings, contrary to those in a primary care setting who indicated high satisfaction with weekly meetings.[50] The motivation for less frequent meetings is supported by the perceived burden for attending extra clinics related to complications and the distance and associated costs, similar to other patients in a tertiary setting.[51] Participants in this study supported a group delivery format and recommended family involvement and the provision of education materials to enhance learning and promote behaviour change. These results corroborate those found in the primary care setting[36,50] and other regions.[51,52] Patients in this study expressed the need for motivational strategies to enhance programme participation and behaviour change. This expressed need for motivational change is possibly in response to their own perception of a lack of self-discipline for self-care and the HPs' observation that patients did not adhere to appointments.

An important strength of this study is the fact that the experiences of the patients and their healthcare providers were considered, thereby providing triangulation of data sources. The health professionals provided insight into some matters that patients had difficulty in articulating, e.g. the topics/content related to dietary self-management. Only patients able to understand English were included, limiting the generalisability of our results to other patients attending the clinic or other tertiary hospital clinics. Additionally, data on patients' glycaemic control, which might have provided more insight on differences in perceptions between those with good and poor control,[40] were not included.

Conclusion and implications

The findings of this study add to the literature on the numerous challenges faced by patients with diabetes while undertaking daily self-care activities, indicating the need for continuous support to navigate through this process. Overall, patients in this study felt that they had a limited capacity to manage the personal, environmental and economic factors that challenge diabetes control. This lack of self-efficacy needs addressing through an intervention since patients' assessment of their diabetes self-management has been shown to correlate with glycaemic control.[53]

This study revealed participants' interest and support for the potential education programme, providing an opportunity for adapting the NEP. Given the unique challenges that the patients in the tertiary care setting face, the existing NEP needs to be adapted to incorporate strategies to deal with these challenges as well as the provided suggestions for the programme. In particular, strategies are needed to enhance self-efficacy to self-manage, and the ability to self-regulate and address major problems such as balancing diet and insulin. Patients also need to be empowered with knowledge and skills for healthy coping with diabetes (e.g. dealing with stress) as a means to improving self-care, as coping is demonstrated to influence outcomes.[54] Additionally, motivational needs of patients need to be considered. Planners of interventions as well need to be sensitive to patients' circumstances in order to provide practical information/strategies. A next step in this study is the actual adaptation of the intervention and consequent implementation and evaluation.

Authors' contribution

All authors contributed to the conception and design of the study. JWM collected and analysed the data, with inputs from GJG and PR during the analysis. JWM drafted the manuscript. GJG and PR reviewed and critically revised the manuscript. All authors read and approved the final manuscript.

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