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## **Diabetes self-management: A post-intervention evaluation of challenges experienced in a low socio-economic community**

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### **Abstract**

The global diabetes epidemic continues to grow and countries are struggling to keep pace with the health care demands that the disease creates. The prevalence of diabetes mellitus in South Africa has increased drastically over the last two decades and ranks third in terms of mortality and morbidity for the general population; with an estimated 2.28 million people in South Africa living with diabetes in 2014. The effectiveness of diabetes management ultimately depends on people's compliance with recommendations and treatment. Clients with diabetes may experience several challenges in their daily self-management practices. This study explored the challenges individuals with diabetes mellitus from a low socio-economic community experienced with self-management after they participated in an intervention. Focus group discussions were conducted with 15 individuals with diabetes mellitus from one randomly selected community health care centre in the Cape Metropolitan Region, Western Cape. The discussions yielded six main themes: challenges with a healthy eating plan; challenges with physical activity; financial constraints; other people's understanding of the disease; service received at the Community Health Centre and lack of appropriate expertise/information. Diabetics in a low socio-economic urban community experience several personal and health care system-related challenges that could negatively impact on the self-management practices of the disease. Therefore, a multidisciplinary team should provide person-centred care and implement community-based health promotion programmes to enhance self-management skills of diabetic patients.

**Keywords:** Diabetes mellitus, self-management, challenges.

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### **Introduction**

Diabetes mellitus is a growing public health concern worldwide and its prevalence is escalating exponentially with a high frequency of morbidity, premature mortality, disability, loss of productivity (Steyn, 2007) and socio-economic challenges (Mbanya, Motala, Sobngwi, Assah & Enoru, 2010). Diabetes is recognised as an important cause of premature death and disability (Steyn, 2007). It is one of four priority, non-communicable diseases (NCDs) targeted by world leaders in the 2011 Political Declaration on the Prevention and Control of NCDs (United Nations, 2011). The declaration recognises that the incidence and impact of diabetes and other NCDs can be largely prevented or

reduced by an approach that incorporates evidence-based, affordable, cost-effective, population-wide and multi-sectorial interventions. Improvement in diabetes management will reduce rates of complications, ease pressure on health systems and improve quality of life for people living with diabetes (World Health Organisation, 2016).

Globally an estimated 422 million adults, a prevalence of 8.5%, were living with diabetes in 2014, compared to 108 million in 1980. The global prevalence (age-standardised) of diabetes has nearly doubled since 1980, rising from 4.7% to 8.5% in the adult population (WHO, 2016). Although separate global estimates of diabetes prevalence for type 1 and type 2 do not exist, the majority of people with diabetes are affected by type 2 diabetes. Of great concern is the prediction of the International Diabetes Federation (IDF) (IDF, 2014) that the global number of diabetes sufferers will increase to 592 million (10% adults) by 2035. The alarming emergent rate of the disease in developing countries is disquieting, as it is projected that by the year 2025 about 80% of all new cases of diabetes will occur in developing countries (Jamison, Feacham & Makgoba et al., 2006; IDF, 2009). It is also estimated that 77% of patients with diabetes are living in middle and low income countries (IDF, 2014).

The prevalence of type 2 diabetes mellitus in South Africa has increased drastically over the years due to population growth, ageing populations, dietary changes and sedentary lifestyles, all of which are associated with westernisation and urbanization (Levitt & Bradshaw, 2006; Idemyor, 2010). In 2014, 2.28 million people in South Africa were living with diabetes; a prevalence of 7.0% in the adult population (IDF, 2014). This is startling if it is kept in mind that researchers cautioned us that undiagnosed diabetes is not a benign condition (Jamison et al., 2006).

The risk of type 2 diabetes is determined by an interplay of genetic and metabolic factors. Ethnicity, family history of diabetes and previous gestational diabetes combine with older age, overweight and obesity, unhealthy diet, physical inactivity and smoking thus contributing to increase risk (WHO, 2016). Overweight and obesity, together with physical inactivity, are estimated to cause a large proportion of the global diabetes burden (Global Burden of Disease, 2015). Several dietary practices are linked to unhealthy body weight and/or type 2 diabetes risk, including high intake of saturated fatty acids, high total fat intake and inadequate consumption of dietary fibre (United Nations, 2010; Ley, Hamdy, Mohan & Hu, 2014). In addition, a general trend towards a more sedentary lifestyle due to the advent of modern electronic equipment and computers, as well as more sedentary leisure time, may be causative components in this increased trend (Hu, Leitzmann, Stampfer, Colditz, Willett & Rimm, 2001).

Although type 2 diabetes mellitus affects all age groups, evidence shows it to be more prevalent in those individuals between the ages of 45 and 64, a group most economically productive in developing countries (IDF, 2009). This tendency has significant economic implications for developing countries (IDF, 2009; IDF, 2014). When diabetes is uncontrolled, it has dire consequences for the health and well-being of the patient. Diabetes and its complications bring about substantial economic loss to people with diabetes, their families and to health systems and national economies through direct medical costs and loss of work and income (WHO, 2016).

The rate at which new cases of diabetes mellitus emerge poses an additional burden on South Africa, which is already plagued by life-threatening infections such as tuberculosis (TB) and HIV/AIDS. Furthermore, diabetes management costs have to compete with other health demands, such as antiretroviral drugs for HIV/AIDS and tuberculosis treatment (Idemyor, 2010). This may contribute to delays and/or poor diagnosis of diabetes and/or its management. South Africa should not lose sight of the impact and importance of diabetes in the face of the HIV/AIDS epidemic.

In most developing countries inadequate resources, such as finance and specialised health professionals, have been reported to be major barriers to addressing chronic diseases like diabetes (IDF, 2009; IDF, 2014). Unfortunately the lack of effective policies to create supportive environments for healthy lifestyles and the lack of access to quality health care means that the prevention and treatment of diabetes, particularly for people of modest means, are not being pursued (WHO, 2016). Another confounding factor is the orientation of health systems toward acute care. Effective management of chronic diseases like diabetes calls for an integrated approach with the patient, family and the community taking an active supportive role (Levitt & Bradshaw, 2006; WHO, 2016). In addition, the efficacy of treatment is highly dependent on the individual's compliance with recommendations and treatment as well as their ability to manage the disease. Diabetes education is the cornerstone of successful diabetes management. It provides information about the disease and its complications, and teaches the patient the skills required for injecting insulin as well as the self-monitoring of blood glucose levels. Most importantly, it empowers patients with knowledge which will enable them to adjust their treatment safely (Moodley & Rambiritch, 2007). However, knowledge does not always result in behavioural change and needs to be reinforced (McManus, Stitt & Bough, 2006). It is therefore of the utmost importance to have proper health promotion programmes in place that will assist people with the adoption and maintenance of healthier lifestyles that could delay the onset of complications.

Apart from the patient with diabetes, research proposes that a range of health care professionals, including medical doctors, nurses, dieticians and specialists

such as ophthalmologists, vascular surgeons and physiotherapists, should be considered integral and significantly important in the treatment and management of diabetes (American Diabetes Association, 2015). If diabetes care is to reach the “grassroots” level, then care needs to be focused at the Primary Health Care (PHC) level. However, in most health facilities in sub-Saharan Africa, access to even the most basic health professionals with appropriate training in diabetes management is not available, thus compromising the quality of care for patients (Beran & Yudkin, 2006; Peyrot, Rubin, Lauritzen, Snoek, Matthews & Skovlund, 2006). Little information is available regarding the individual and social factors underlying the self-management practices of clients with diabetes. This study therefore explored the challenges experienced by individuals with diabetes mellitus from a low socio-economic community in regard to self-management after they had participated in a six-week health promotion intervention one year ago.

## **Methodology**

### *Research setting*

The study was conducted in the Cape Metropolitan District of the Western Cape, one of the five district municipalities of the City of Cape Town, South Africa. The Cape Metropolitan District covers an area of 2 460km<sup>2</sup>, has a population of 3 740 026 million people and is divided into four substructures on which 22 Community Health Centres (CHCs) are situated. Of the individuals diagnosed with type 2 diabetes mellitus in the Western Cape, 55% are from the Cape Metropolitan District. The same CHC where the health promotion intervention was piloted a year ago was therefore selected as the current study is a follow-up of the participants that participated in the implementation phase of the health promotion intervention.

### *Information on the intervention*

The health promotion intervention comprised the following: introduction of physical exercise (cardio-respiratory endurance and strength exercises), information on a healthy eating plan, how to deal with stress management and teaching the patients self-management techniques, giving them information on the possible long-term complications and signs and symptoms of hypo-/hyperglycaemia.

### *Sample and Data collection*

Twenty-six clients volunteered to participate in focus group discussions a year after the six-week health promotion intervention. For the current study, 21 of those participants could be reached telephonically, of which 15 agreed to

participate in the follow-up focus group discussion (FGD). Written informed consent was obtained from the clients prior to the FGDs. Three FGDs, with 5 participants per group, were conducted at the CHC by the researcher while a research assistant took field notes. Participants were asked to reflect on their experiences with regard to the challenges they experienced with self-management of the disease. They were encouraged to talk freely and share their experiences in the discussions. Each FGD last approximately 45 minutes.

#### *Ethical considerations*

Ethics clearance to conduct the study was obtained from the University of the Western Cape, South Africa (Ethics approval reference no: 11/4/2). Permission to conduct the study in the selected health centre was granted by the Western Cape Department of Health and the Facility manager. The study was conducted according to ethical practices pertaining to the study of human subjects as specified by the Faculty of Community and Health Sciences Research Ethics Committee of the UWC and the Western Cape Department of Health.

#### *Data analysis*

Data from the audiotape recordings were transcribed verbatim by an independent person with experience in transcribing. A comparison was made between field notes to verify accuracy. Content analysis was done by extracting meaningful ideas of the participants' opinions (coding into themes). Emerging themes were identified by the author after the transcripts were read through several times. To fit small categories together, grouping of the themes into broader categories was done. After the derivation of themes, an independent researcher read through the transcripts and generated themes that were then compared to the themes of the principal author.

Trustworthiness of qualitative data is measured by its credibility, which in qualitative research is determined by the match between the constructed reality of the participants and the reality presented by the researcher (Lincoln & Guba, 1985). Several steps were considered to build credibility: lengthy engagement and persistent observation; checking by participants on the accuracy of the feedback of the data so that they could comment and verify the accuracy of the recordings as well as verbatim transcription of responses. Independent researchers were asked to read through the transcripts and generate the themes.

## **Results**

A total of 15 clients, 10 males and 5 females, who agreed to participate in the study had a mean age of 62.93 years (SD=6.41). All of the participants expressed

that they had some difficulty with regards to self-management of diabetes. The content analysis produced various themes, as outlined below.

#### *Challenges with a healthy eating plan*

The majority of the participants confided that they find it very difficult to follow a healthy eating plan. Living circumstances was one of the reasons mentioned, as can be gleaned from the following statements:

*“I stay on my own and don’t cook for myself. My wife passed away...I just eat bread and whatever is easy to make for myself.”* (Male, 69 years)

*“I stay with my daughter and her family. I eat whatever they cook”.* (Female, 61 years)

*“I stay with my sister and her husband. She cooks all the food he loves. It is usually unhealthy. He likes fried foods. I don’t have a choice; I must eat what I get.”* (Female, 67 years)

However, one of the participants, a resident domestic worker is very grateful for her employer’s assistance in maintaining a healthy eating pattern. She stated the following:

*“They are so good to me. They make sure that I eat healthy and regularly every day.”* (Female, 62 years)

Working conditions also make it very difficult for some of the clients to follow a proper meal plan. For example, two of the participants indicated that:

*“It is not easy to eat regularly and healthy due to my work on a building site. We don’t have regular breaks.”* (Male, 58 years)

*“I work long hours. This makes it very difficult to eat regularly.”* (Female, 54 years)

#### *Challenges with physical exercise*

Although the clients are cognisant of the importance of physical activity, most of them do not engage in physical activity. Safety in their neighbourhoods was of great concern, as the quotations illustrate:

*“I have to leave home very early to get to my work in time. It is also dark when I get home after work. I don’t feel safe to exercise... here is lots of gangster where I stay.”* (Male, 61 years)

Lack of time also hinders physical activity participation, as expressed below:

*“When I get home from working long hours, I still must cook and look after my family. I don’t have time to do exercise.”* (Female, 48 years)

Changing a bad habit was also reported to be a challenge when it comes to exercise.

*“I don’t like to walk. I did try, but I just don’t like it.”* (Male, 70 years)

Other participants’ general health and well-being prohibits them from exercising. They stated as follows:

*“My heart problem is getting worse when I walk. I rather not exercise... am too scared...”* (Female, 68 years)

*“I get so tired quickly when I walk with my crutches. You see...my foot was amputated two years ago.”* (Male, 65 years)

#### *Financial constraint*

The overarching challenge in the management of type 2 diabetes mellitus, whether it prevents the clients from buying healthy food or going to the Community Health Centres for regular check-ups, is lack of financial resources. This challenge is exemplified in the following excerpts:

*“Healthy food is very expensive. Bread and jam or pap I can afford.”* (Female, 72 years)

*“I give my grant to my daughter because I stay with them. I have no money of myself.”* (Female, 66 years)

*“The taxi charges me a lot to take me to the clinic for my medicine and check-ups.”* (Female, 63 years)

#### *Other people’s understanding of the disease*

A few of the participants mentioned that not all people, especially at work, understand what the disease entails. This negatively affects appropriate self-management of the disease. Two female participants indicated:

*“My boss is very strict. I have to ‘clock in and out’ if I want to eat when it is not lunch or tea breaks.”* (Female, 48 years)

*“Sometimes I can’t get off work to make my appointment at the clinic. Then I run out of tablets.”* (Female, 54 years)

One male participant, however, praised his wife for all the extra effort she makes to assist him in managing his diabetes.

*“My wife...she is wonderful. She cooks the right food and walks every day with me around the block to make sure I exercise regularly.”* (Male, 61 years)

#### *Service received at the Community Health Centre (CHC)*

The long waiting times to see the doctor or nursing sister at the CHC and to get medication at the pharmacy are major problems. For instance, some of the clients stated:

*“Why do we have to wait so long? Can’t we have a specific time to see the doctor or sister? Or they should get more people to work there.”* (Female, 72 years)

*“To wait for my medication is even worse than a year ago! And I sometimes have to come back if they don’t have the right medication.”* (Female, 54 years)

*“When you get to see the doctor or sister, they are always in a hurry...no time to see you properly. There is too little staff working here.”* (Male, 69 years)

#### *Lack of appropriate expertise/information*

The clients reported that there is no full-time dietician or physiotherapist employed at the CHC. The handouts regarding the management of the disease are also not always relevant to them. The excerpts below exemplify this viewpoint:

*“How can I get a piece of paper with exercises like walking and climbing stairs that I must do every day, but I am in a wheelchair most of the time due to my amputation?”* (Male, 65 years)

*“I don’t understand everything on the pamphlet that they say about the food. And the sister is too busy to explain it to me. Why is there not a dietician here?”* (Female, 72 years)

### **Discussion**

An analysis of the major themes identified during the focus group discussions revealed the challenges experienced by individuals with diabetes mellitus with



self-management of the disease. Even though the study was conducted in a low socio-economic urban setting in the Western Cape, South Africa, some of these challenges are relevant to rural settings. It is also important to note that the challenges can be seen as multifaceted and complex.

The challenges that clients face in their efforts to adhere to the care and management programme for diabetes can be classified into two groups: challenges related to the individual, i.e. cost of transport and cost of prescribed healthy food, while challenges related to the health care delivery system included long waiting times, queues and limited care and management skills of health care professionals. At the individual level, the prime challenge faced by almost all the clients with type 2 diabetes was the lack of finances for transport and the purchase of healthy, prescribed food. The challenge of lack of financial constraint in the present study is consistent with observations made by Kahn, Al-Adbul Lateef, Al Aithan, Bu-Khamseen, Ibrahim and Kahn (2012) in the Al Hasa district of Saudi Arabia and Ganiyu, Mabuza, Malete, Govender and Ogunbanjo (2013) in Botswana, where lack of financial resources was reported to play an important role in the quality of self-management of the disease. A possible solution that should be considered is the use of food coupons as empowerment for those individuals in lower socio-economic communities that could sustainably aid in the maintenance of glycaemic control as well as the patient's weight management.

Certain challenges with physical exercise were communicated by the participants. The participants in this study are from a socio-economically deprived community; hence the lack of access to safe pathways or parks and the high levels of crime and lack of safety in their neighbourhoods could contribute to their low physical activity levels. These findings replicate that of previous studies that examined exercise preferences and barriers to physical activity in people with type 2 diabetes mellitus in developing countries (Khan et al., 2012; Ganiya et al., 2013). Although addressing issues such as neighbourhood safety and gang violence seem like a daunting task, requiring the collaboration between several national and local government departments and community forums, interim solutions such as tailored physical activity programmes within the community, could be seen as a possible strategy to increase physical activity participation in the respective communities. Research has shown that multidisciplinary community activity programmes that take language use and acculturation into consideration, can be successful in increasing physical activity participation (Evenson, Sarmiento & Ayala, 2004; Abraido-Lanza, Chao & Florez, 2005).

Similar to the problems encountered with physical activity, the majority of the participants reported that they find it very difficult to follow a healthy eating plan. Several reasons were given, i.e. living circumstances, work environment,

financial constraints and other people's understanding of the disease. These results are similar to those reported by Misra and Khurana (2008), Kahn et al. (2012) and Ganiyu et al. (2013) regarding the challenges about a healthy eating plan for diabetics. In the present study it was evident that the participants did not have the knowledge to substitute unhealthy food with healthier options of more or less the same price. They were of the opinion that all healthy foods are expensive. The above findings emphasise the clients' involvement in unhealthy lifestyle behaviour and reflect strong support for health promotion interventions that could facilitate self-management techniques needed for patients to substitute unhealthy food with healthier options. Another possible solution could be to have a dietician at every PHC facility that would advise people on a regular basis regarding their eating plans. In addition, the generic health promotion pamphlets are not effective in conveying all the information needed to adopt and maintain a healthy lifestyle. The health promotion intervention must engage family members of diabetics as well as the community in order to strengthen participation and adherence to management of the disease, thus abating the development of diabetic complications.

Regarding diabetes care, a number of challenges related to the healthcare facilities were mentioned. Aspects in need of attention included: waiting time in the clinic to see a health care professional, difficulty in getting information from clinic staff and clarity of instructions upon leaving. Almost all the participants that responded to suggestions for improvement of services at the community health care centres were concerned about the shortage of staff, especially the availability of medical doctors and nursing staff. Lack of 'personalised' care on the part of health care professionals may have a long-lasting impact on the perceptions of patients about service delivery. Findings from the present study shared the sentiments of Kim and Oh (2003), as the health care professionals reported that, due to the high volume of patients per day, not enough time could be spent with each client, which had a negative impact on the quality of patient care. The long waiting time in the clinic is consistent with the findings of Wong, Tagawa, Hsieh, Shapiro, Boscardin and Ettner (2005) in their study in the United States, where long waiting times at clinics contributed to subsequent missed clinic appointments. To achieve the best results, there must be coordinated activities between the health care facilities and Government's Department of Health to provide sustained quality services to individuals with type 2 diabetes. It is recommended that all primary care facilities should have a specific allocated venue to accommodate health promotion activities (sessions for small groups) by a qualified health care professional, i.e. a nursing sister with special training in diabetes management.

## Conclusion

There are no simple solutions for addressing challenges associated with diabetes self-management but several stakeholders, including government, healthcare providers, people with diabetes, their families and civil society can collectively play a role in reducing the impact of diabetes and improving the lives of those living with the disease. Unfortunately, in many developing countries socio-economic circumstances of clients with diabetes and the lack of access to quality health care hamper effective self-management. From this study it is evident that individuals with diabetes mellitus in a low socio-economic urban community experience several personal as well as health care delivery system challenges in their daily journey with their disease. In order to alleviate the challenges, existing policy guidelines for the management of type 2 diabetes should be reviewed and a multidisciplinary team should implement community-based health promotion programmes to enhance clients' self-management skills.

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