Redefining diabetes and the concept of self-management from a patient’s perspective: implications for disease risk factor management

T. K. Masupe\textsuperscript{1,2,*}, K. Ndayi\textsuperscript{1}, L. Tsolekile\textsuperscript{1}, P. Delobelle\textsuperscript{1,3} and T. Puoane\textsuperscript{1}

\textsuperscript{1}School of Public Health, University of The Western Cape, Bellville 7535, South Africa, \textsuperscript{2}Department of Family Medicine & Public Health, Faculty of Medicine, University of Botswana, Corner Notwane & Mabuto Road, Gaborone, Botswana and \textsuperscript{3}Chronic Disease Initiative for Africa, Department of Medicine, University of Cape Town, South Africa

*Correspondence to: T. K. Masupe. E-mail: tiny.masupe@mopipi.ub.bw

Abstract

The colliding epidemics of non-communicable diseases including diabetes with chronic infectious diseases in Sub-Saharan Africa requires contextualized innovative disease management strategies. This qualitative study conducted in a peri-urban township near Cape Town, South Africa aimed to identify and gain in-depth understanding of contextual and environmental issues pertinent to the patient that could influence Type 2-diabetes mellitus (T2DM) care and self-management. Participants included purposively sampled diabetics or pre-diabetics from the community, PURE study database, facility health club and health care providers. Data collection employed in-depth interviews, focus group discussions (FGDs) using structured interviews and FGD topic guides. Thematic data analysis was done to identify recurrent themes. Themes identified: knowledge and awareness about T2DM; health-seeking behaviour; weight perceptions; healthy lifestyles; self-management; health education needs and health care provider experiences. Patients defined T2DM as a physically and emotionally dangerous disease caused by socio-cultural factors, influenced by the sufferers’ food and socio-cultural environment with significance placed on physical, social and emotional effects of T2DM diagnosis. Patient-centred definition of T2DM is key to enhancing T2DM self-management. Patients suggested that personally rewarding benefits of physical activity and healthy diet such as anti-ageing, brain boosting, energy boosting which are commonly harnessed by food, tobacco and beauty industry should be considered in T2DM self-management strategies.

Introduction

Chronic non-communicable diseases (NCDs) have been rising over the years, with 68% of global mortality attributed to NCDs in 2012 and estimated to cost seven trillion US$ cumulative economic losses in low- and middle-income countries between 2011 and 2025 if no concrete action is taken to combat the epidemic [1]. The highest burden is estimated to be in developing countries [2]. Cardiovascular diseases and metabolic conditions account for the highest prevalence [1]. In South Africa, a high prevalence of Type 2-diabetes mellitus (T2DM) has been reported across the population, estimated at 8.3% among people aged 20–79 years in 2013 [3] and even higher at 13.1% among urban dwelling black South Africans [4] and at 26.3% in the coloured population [5]. The prevalence of T2DM and hypertension in the setting of this study, a peri-urban predominantly black township in Cape Town is likely to be high. Given the emerging pandemic of NCDs, new innovative approaches to disease prevention and management are critical.
Historically, diabetes has been defined in terms of abnormal glucose metabolism detected by various biochemical tests [6] or, in the case of T2DM, due to abnormal exocrine pancreatic function [7]. T2DM in the patient education literature is also defined in terms of abnormal tests of glucose metabolism [8, 9]. The research question for this study relates to what diabetes really means to the lay person and the patient from a phenomenological and social ontological perspective. Based on our findings, we will define diabetes from a patient’s perspective and argue that lack of this appreciation from a health care professionals’ perspective significantly hampers diabetes control and patient self-management. We also argue that the concept of self-management is more complex than discussed in the literature and does not take into account the understanding and interpretation of the concept, by the very patient for whom it is designed.

The concept of self-management in its ideal form should be patient-centred, encompassing the different facets of patient context, multi-disciplinary health care teams and a responsive health care system [10]. Chronic disease self-management programmes (CDSMP) have been in existence for many years and focus on behaviour change for the major risk factors (physical activity, smoking cessation, alcohol consumption and diet) as well as patient self-efficacy for specific disease management. Guidance on T2DM management in South Africa has been provided by the Society for Endocrine Metabolism and Diabetes of South Africa (SEMDSA), it includes a focus on self-management [7]. According to SEMDSA, self-management is centred on patient education, which should include training on basic diabetes knowledge; glucose self-monitoring; recognition and management of both chronic and acute diabetic complications; risk factor modification behaviours such as smoking cessation, physical activity, diet and alcohol minimization and coping mechanisms such as psychosocial support. As in many other settings in the region, however, comprehensive patient education and assurance of patient adherence remains impossible to achieve [11, 12].

The literature suggests that patients enrolled in CDSMPs have better health outcome measures compared to those receiving the usual standard of care for T2DM [13] and other chronic diseases [14, 15]. Studies describing these programmes, however, tend to be randomized controlled trials with a short follow-up period of 6–12 months. Evidence from a systematic review of interventions tailored for self-management by Radhakrishnan [16] also casts doubt on the true effectiveness of these interventions when reviewed holistically taking into consideration all other resources required to provide such care and suggests that these interventions may not be superior to standard of care interventions. These findings are also supported by others [17].

The current study is nested within the SMART2D project. SMART2D is a multi-site study on T2DM of which the overall objective is to formulate and implement a contextually appropriate T2DM self-management approach through facility and community components for prevention and control of T2DM in three settings: a rural area in a low-income country (Uganda), an urban township in a middle-income country (South Africa) and vulnerable immigrant populations in a high-income country (Sweden). The study aims to evaluate the outcomes of the self-management approach and added benefit of the community component compared to the facility component only; and to translate the findings in dialogue with stakeholders into relevant input for national guidelines and policies, using reciprocal knowledge transfer across the different sites.

**Methods**

**Type of study and setting**

The study was undertaken in Langa township, a mainly Xhosa speaking part of Cape Town, South Africa. The study site was selected because of complementarity with another study conducted in this area, the Prospective Urban and Rural Epidemiological (PURE) study, which tracks lifestyles, risk factors and chronic diseases among 150 000 people over a period of 15 years across 17 high-to-low-income countries [18]. The township was established prior to the apartheid era for black Africans and in 2011 had a population of around
52,000, of whom nearly half was younger than 25 years old and six in ten did not complete secondary education [19]. The settlement is underdeveloped, lacks infrastructure and civil services, and the population is served by two health facilities of which only one offers chronic care services including T2DM care and management. Factors associated with rising levels of NCDs in this population have been described by Puoane and Tsolekile [20], and one such major contributor was socio-cultural factors driving health behaviours in the townships. For example, eating lean meat was considered ‘stingy’ and preference is given to eating fried foods such as fried chicken skins which are tasty and affordable. Walking as part of physical activity on the other hand was associated with chores that people who have now moved from rural to urban areas do not want to be associated with anymore. These include walking to fetch water, gather firewood and tend animals. When it comes to diet, food is considered as part of showing love, acceptance and humanity and for those living in the townships, eating food items such as meat daily is considered a sign of higher social status [21].

Study design
This was a qualitative study with a phenomenological design using in-depth interviews and focus group discussions (FGDs). The study design was chosen because the main objective was to gain a deeper understanding of what diabetes means to patients living with it and their experiences of engaging in self-management of T2DM.

Study population
The study sample was selected from the population of adult patients having lived with diagnosis of T2DM and receiving services for their T2DM in the selected facilities in Langa Township. A purposive sampling approach was used to include only patients who can provide information that will lead to a deeper understanding of living with T2DM. Participants for this study were sampled from the PURE database and by referral from health facility staff and included males and females aged 35–72 years old; having been diagnosed with T2DM or known to be at risk of T2DM and selected from the health club attached to the facility or from their community. In addition, health care workers involved in the care and management of T2DM patients were purposively selected, including physicians, nurses and community health workers (CHWs) in charge of the health clubs. Health care workers eligible for the study were those actively caring for patients diagnosed with T2DM in Langa Township.

Data collection
Data were collected using in-depth interviews and FGDs. There were seven FGDs with eight participants per group conducted with men and women. In addition, two in-depth interviews were conducted with health care workers. Data were collected using a semi-structured interview guide, that was translated in the local language (isiXhosa) and preliminary analysis conducted to refine these instruments, while further FGDs and in-depth interviews were organized until saturation was achieved. Written consent was sought from all study participants and permission to use a recording device obtained. Interviews and FGDs were conducted in isiXhosa lasting between 45 and 90 min and all recordings were transcribed verbatim. These interviews were done by research assistants trained in conducting qualitative interviews including FGDs and in-depth interviews, they were supervised by researchers in the study who are trained in qualitative research methods. All data collectors were bilingual and fluent in both English and isiXhosa, live in the area and understand the culture and norms. The study area is mainly inhabited by Xhosa South Africans. Data were analysed using thematic analysis with codes to identify recurrent themes, by systematically searching transcripts in line with a set of predefined themes. This approach, known as the framework approach [22] was found to be suitable for analysis of qualitative data in multi-disciplinary health research [23]. Continued data analysis was used alongside data collection to allow further refinement of research questions and avenues of enquiry to be
developed. Reliability of study findings was assessed using consistency checks, by comparing the findings with results from prior/co-existing research, using within-project triangulation, feedback from research participants and feedback from end-users of the study findings (stakeholder checks) [24].

### Results

#### Participant demographics

Seven FGDs were conducted with individuals diagnosed with T2DM. Out of these, five FGDs were conducted with participants enrolled in the PURE-study (Groups 1, 3, 4, 6 and 7). Two FGDs were conducted with female PURE-participants known to be at risk of T2DM, selected according to their body mass index, age and the presence of hypertension. FGD participants were between 30 and 70 years old.

PURE is a global study which seeks to identify the population level factors that drive the development of known risk factors for chronic NCDs, so that their distribution in the entire population can be shifted favourably by appropriate societal interventions (primordial prevention) [18] It includes participants from 23 countries at different levels of development, including South Africa which is a middle income country with two study sites managed by the North West University and University of the Western Cape. The current study was conducted in Langa, the University of the Western Cape study site, where 2058 people were recruited for study participation in 2009–2010.

Group 1: Composed of PURE participants who were all male aged between 45 and 72 years.

Group 2: an all-male group aged between 43 and 69 years. (Non-PURE) two men were also known to be hypertensive in this group.

Group 3: mixed male and female group aged 49–66 all had hypertension (PURE).

Group 4: all male group aged 35–58 diabetic (PURE).

Group 5 all women aged 32–65, all had hypertension while two had diabetes (Non PURE).

Group 6 all women aged 36–60 and diagnosed with diabetes (PURE).

Group 7 All women aged 40–68 all had diabetes (PURE).

Initial codes for the FGDs were developed by the study team from the SMART2D topic guide. Two coders were assigned to analyse the transcripts. One coder used a manual approach while the second coder used Atlas. Ti software version 7.5.0, 1993–2016. Codes identified from meaning units in the texts of the transcripts were grouped into sub-categories and categories. Relationships between different categories were explored in more detail and re-analysed, leading to the emergence of several themes in accordance with the framework of the topic guide, which are summarized in Table I.

#### Health seeking behaviour

As regards health seeking behaviour, study participants accessed care from the local clinic only and therefore were inclined towards seeking medical attention for their diabetes from conventional or modern medical practitioners. Some participants however also sought care from local herbalists while some combined both traditional and modern medicine for their T2DM.

Health seeking behaviour varied depending on the perceived intensity of distress from immediately seeking assistance to delayed access of care and other forms of self-care, such as buying paracetamol and home-made remedies. People delayed to seek help for diabetes symptoms unless they perceived the disease as very serious

She only started going to the hospital when she realised that she was on death bed

Health seeking behaviour was also influenced by the fear of diagnosis as well as potential treatment for the symptoms

I didn’t feel like taking tablets, I kept saying I’m going to fetch my medication but when that day came [laughs] I never went

The perceived skills of health care providers and traditional knowledge and beliefs of the patients also played a significant role in whether a patient
Table 1. Themes, categories and subcategories of the thematic analysis

| Themes                          | Categories                  | Sub-categories                        | Quotation                                                                 |
|---------------------------------|-----------------------------|----------------------------------------|---------------------------------------------------------------------------|
| Factors influencing Health      | Nature of and available     | Distance from people                   | - What makes people lazy to take their treatment is that the facilities are  |
| seeking behaviour               | health services             | Symptoms of disease present            | very far so it would be better if clinics were brought closer for us the    |
|                                 | Specific triggers to health | Symptoms perceived as serious          | elderly even if it here where the kids play . . .                          |
|                                 | seeking behaviour           |                                        | - I was not feeling well, I was bleeding with my nose and it was         |
| Beliefs about the causes of     | Conventional causation      | Genetics                               | discovered that it was high blood pressure.                                |
| T2DM                            | Unconventional causation    | Diet                                   | - She only started going to the hospital when she realised that she was on  |
|                                 |                             | Alcohol                                | death bed                                                                  |
|                                 |                             | Stress                                 | - When I read to enhance my own knowledge I discovered that diabetes is    |
|                                 |                             | Traditional beliefs                    | caused by genes, if your grandmother had diabetes it is likely that can    |
|                                 |                             | Unusual eating patterns                | develop it through inheritance                                             |
|                                 |                             |                                        | - I was going to say, it has something to do with food. You see McDonalds |
|                                 |                             |                                        | and restaurants; those are dangerous foods                               |
|                                 |                             |                                        | - Sometimes in males it is caused by alcohol                               |
| Awareness of T2DM and its       | High prevalence             | A common disease                        | You see sometimes in females it is caused by stress                       |
| severity                        | Multi-system complications  | Cause of mortality                      | - There she kicked a spider, the following day when she was going to work, |
|                                 | Significant severity        | Cause of morbidity                      | she felt that there was something wrong and she went to the doctor. She   |
|                                 |                             | Emotional complications                 | was then diagnosed with diabetes.                                         |
|                                 |                             | General complications                   | - One other thing is liking cold stuff, do you understand because things   |
| Diabetes self-management        | Health professional         |                                        | from the fridge are dangerous                                              |
|                                 | supported                   |                                        | - Yes, they do, I can say it is 70% of them have knowledge about diabetes   |
|                                 | Personal choices            |                                        | - It is common in Vanguard because when I visit there I see people with   |
|                                 | Religious beliefs           |                                        | loads of tablets, and I assume that they are the victims of diabetes.      |
|                                 |                             |                                        | - Diabetes is the most dangerous one.                                     |
|                                 |                             |                                        | - Because if you have a sore it ends up . . . Some end up with their legs   |
|                                 |                             |                                        | removed. There is someone that I know that had both of their legs removed  |
|                                 |                             |                                        | - Something that it kills as well, it’s manhood, yeah. (M: okay)Even with     |
|                                 |                             |                                        | women that happens, it kills her feelings towards another person,          |
|                                 |                             |                                        | - Mhm . . . and then there is another thing that is killed by diabetes, you |
|                                 |                             |                                        | see, eyesight, it kills eyesight                                           |
|                                 |                             |                                        | - Maybe a person eats according to her/his preferences but according to the  |
|                                 |                             |                                        | doctor you are supposed to have a healthy diet, change your eating habits  |
|                                 |                             |                                        | like avoiding fatty foods such as fat meat, and eat fish instead.          |
### Table I. Continued

| Themes | Categories                                                                 | Sub-categories                                                                 | Quotation                                                                                                                                                                                                 |
|--------|---------------------------------------------------------------------------|---------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|        | Traditional practices                                                      | Traditional food controlling T2DM                                                | • When you do not discipline yourself in terms of food. There are people who eat everything under the sun, you can give them a bucket full of food, they eat, and you give them fish they eat. |
|        | Mixed traditional and modern practices                                     | Spiritual intervention                                                          | • They said this person died because he was not taking his treatment. When they went to search his house, they found sealed packets of tablets, he never touched any tablet ever since. |
|        | Lack of self-acceptance                                                    | Mixed interventions                                                             | • We do not know for sure if it is true when they say sorghum and stout controls diabetes.                                                                                                                                                                    |
|        |                                                                            | Peer pressure                                                                   | • I would suggest that they should go to church, in my church some people get cured of the diseases that they were suffering from.                                                                                                                             |
|        |                                                                            | Self-acceptance or denial                                                       | • I would say maybe s/he takes Xhosa mixtures                                                                                                                                                                                                                  |
|        |                                                                            | Stigma                                                                          | • Most of the time people become obese because they are lazy.                                                                                                                                                                                                   |
| Factors influencing physical activity | Barriers to exercise                                                        | Why people do not exercise                                                      | • Most of the time people become obese because they are lazy.                                                                                                                                                                                                   |
|        | Meaning of exercise                                                        | Meaning or types of physical activity                                           | • I am exercising by cleaning my house, moving my beds, wardrobes and cupboards. Also I do my laundry with my hands, I band my waist when I am doing my laundry, and they do not do anything, except that jogging. |
|        | Benefits of exercise                                                       | Early childhood activities related to exercise                                  | • The reason for not engaging in physical activity is laziness, having oppressed mind and unavailability of tracksuits.                                                                                                                                            |
|        |                                                                            | How people exercise                                                             | • If we were granted the opportunity to play sport when we were growing up in our time as black people we were never brought close to sport and then we grew up lazy we complain about muscle stiffness. |
| Benefits of physical activity       | Spiritual benefits                                                          | From the creator                                                                | • Because that is what gives you life this is written in the book. Jesus in the first place didn’t not create man to just laze around, he created man to work but people do not know this |
|        | General health benefits                                                    | Circulation benefits                                                           | • The benefits are that your health is good                                                                                                                                                                                                                   |
|        | Cardiovascular benefits                                                   | Gets rid of unwanted toxins in the body                                          | • The other things with exercising is that it health with blood circulation helping your heart as an exercising person, you heart beats well compared to a person that sits down                                                                 |
|        | Anti-ageing                                                                | Alert and energized                                                             | • In addition to that when you exercise the more you sweat they more things you burn in your body, exercising burns                                                                                                                                           |
|        | Energizing                                                                 | Happy fit and strong                                                            | • You always energetic, you always want to work. You will never feel like sleeping all the time.                                                                                                                                                                  |
|        | Brain power                                                                |                                                                                 | • your brain stays alert and diseases cannot easily attack you because your body cells are active as bhuti mentioned that body cells fights with foreign bodies                                                                                       |
|        | Happiness & strength                                                      |                                                                                 |                                                                                               |
Table I. Continued

| Themes                                | Categories                  | Sub-categories                                      | Quotation                                                                                                                                                                                                 |
|---------------------------------------|-----------------------------|------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Factors influencing healthy diet intake | knowledge                  | Meaning of Healthy diet                               | Strength, fitness, happiness, [laughs] and to keep your brain alert.                                                                                                                                       |
|                                       | describing healthy diet     | Cooking methods                                       | - Seafood and chicken, we eat that but you must not fry it you must boil think. Skimmed milk not full cream.                                                                                                 |
|                                       | perceived Barriers to healthy diet | Meaning of Unhealthy diet | - Another thing is to avoid cooked meat and buy a half a sheep’s head. Half a sheep’s head is healthy because it is cooked with water, no oils added.                                                          |
|                                       |                             | Reasons for not eating healthy diet                   | - The most healthy meal I know is samp and beans and samp samp soup and pap and African salad those are our traditional foods but not we now love the new western foods                                            |
|                                       |                             | Cultural perspectives                                 | - When we talk about unhealthy foods we refer to fat cookies. I am referring to fat cookies with chips, Fried meat, fried eggs. They are passing, passing always eating take aways, and they are are ever hungry, they want something quick. |
|                                       |                             |                                                       | - You buy the stews because healthy foods are expensive                                                                                                                                                 |
|                                       |                             |                                                       | - We buy what we can afford                                                                                                                                                                               |
|                                       |                             |                                                       | - No healthy food is really affordable for real the problem is the meat because you find that it is R500 or R800                                                                                         |
|                                       |                             |                                                       | - Healthy food does not taste nice, and it is difficult to eat healthy. It is tasteless.                                                                                                                   |
|                                       |                             |                                                       | - Braai meat, people here are lazy to cook.                                                                                                                                                             |
|                                       |                             |                                                       | - Obesity is not right, when you are obese that means you are suffering from a disease.                                                                                                                   |
|                                       |                             |                                                       | - It’s not okay cause you not active enough, an overweight person might take 10 min to do something whereas an average weight person it will be quicker and they will have the energy |
|                                       |                             |                                                       | - It’s also easy Getting heart disease cause your heart is floating above fats.                                                                                                                          |
|                                       |                             |                                                       | - I do not encourage obesity, because when you are obesity you will think that you are healthy and forget that you are at high risk of getting diseases and the diabetes that we were talking about can make you blind. You will be a laughing stock |
| Views on weight                       | Conventional views          | Health issues                                        |                                                                                                                                                                                                             |
|                                       | Lay beliefs                 | Low energy                                           |                                                                                                                                                                                                             |
|                                       |                             | Physical appearance                                  |                                                                                                                                                                                                             |
|                                       |                             | Employability issues                                 |                                                                                                                                                                                                             |
|                                       |                             | Some stigma                                          |                                                                                                                                                                                                             |
will seek medical help for their symptoms, as shown in this quote:

Sometimes even doctors don’t know the actual cause of a certain thing that he had not encountered before, maybe after some time it will show (Male, 35 years)

Meaning that those who believed that doctors may not be able to diagnose their condition would prefer to wait until such time that they believe the disease process will have reached a state where they can get a correct diagnosis.

Knowledge and awareness about causes and risk factors for T2DM

As regards community awareness of NCDs, hypertension was most frequently reported, but T2DM was also widely acknowledged as a serious condition and perceived to be part of everyday life. Gaps in knowledge were observed with regards to NCD knowledge particularly risk factors for T2DM. Traditional beliefs and beliefs about witchcraft were found to influence knowledge of NCDs, as illustrated by the following:

There kicked a spider, the following day when she was going to work, she felt there was something wrong and she went to (see) the doctor. She was then diagnosed with diabetes. (Female, 49 years)

Age, family history and parental influences in terms of dietary behaviour were identified as contributing to the development of T2DM. Indigenous foods, such as samp and beans, and mealie-meal mixed with pumpkin as well as green leaf vegetables, were considered to be protective and affordable, whereas unhealthy food choices, including fast food, were believed to contribute to the development of T2DM. T2DM was described as a very dangerous disease that left the sufferer with multiple complications including leg amputation and sexual dysfunction as illustrated by the quote below:

Something that it kills as well, it’s manhood, yeah. (M: okay) Even with women that happens, it kills her feelings towards another person (female)

Perceptions on weight

Participants entertained both negative and positive views with regard to overweight, including stigma, increased health problems and effects on personal relationships, but obesity was also perceived as being a sign of happiness and wealth or having a genetic origin, as illustrated by the following:

There are people who are obese, there are people who were born obese, and there are people who are just big. They all need to do exercise, always run so that they can be flexible and not lazy (Male, 35 years)

Healthy lifestyles

Perceived barriers to physical activity included lack of willingness and resources to exercise, and social upbringing where there was no opportunity to exercise. However, some participants contested this and blamed the lack of activity on laziness. Exercise was associated with general health benefits, such as increased capacities, brain booster, detoxification, happiness and general strength. In addition, exercise was thought to confer cardiovascular benefits and have an anti-ageing effect, as illustrated by this quote:

When you are always sitting around you get old quickly, but if you work (out) a lot you do not (Male, 41 years)

Physical activity was also deemed to confer spiritual benefits as illustrated in the quote below:

Because that is what gives you life; this is written in the book. Jesus in the first place didn’t create man to just laze around, he created man to work but people do not know that this is pleasing to the creator.

The definition of a healthy diet seemed difficult to describe succinctly, while the definition of unhealthy diets was diverse and culture dependent. Some defined unhealthy diets as eating fatty local foods such as fat cakes and chips while others defined it as a non-African or Western diet, as illustrated by the following:
But the most healthy meal I know is samp and beans and samp soup and pap and African salad those are our traditional foods but we now love the new unhealthy western foods.

Factors perceived as influencing a healthy diet included inadequate knowledge regarding the difference between healthy and unhealthy foods, the cost of buying healthy food, cultural practices, alcohol abuse and unhealthy cooking methods. Cultural influences on addressing weight seemed difficult to change, although childhood overweight and obesity were thought to be modifiable using lifestyle changes. The taste of food was also considered an important factor in eating a healthy diet as illustrated in the quote below:

Healthy food does not taste nice, and it is difficult to eat healthy. It is tasteless.

T2DM self-management

Factors reported by participants to influence T2DM self-management included personal discipline (e.g. overeating, not being selective in food choices), traditional beliefs and religious practices, as suggested by the quote below:

I would suggest that they go to church, in my church some people get cured of the diseases that they were suffering from (Female, 35 years)

Other behavioural factors that contribute to poor self-management included peer pressure, attributes of the health care professional, fear of diagnosis and treatment as well as convenient ignorance as shown in the quote below:

The homemade sorghum, I drank the beer on Sunday and Monday I was going for checkup. When they checked my blood pressure, it was fine. It was not really fine but the beer helped me

Information sources related to T2DM included personal experience or living with a relative with T2DM, but depended on availability of information and self-assessed levels of knowledge. There was a strong demand for more information about T2DM prevention and management, such as symptom management (e.g. managing hyperglycaemia) and treatment adherence, as illustrated by the following quote:

If you arrived in a scene where the person has already collapsed, how would you know that the person collapsed because of diabetes or because of epilepsy? Maybe if you have knowledge about diabetes you can be able to tell if the person collapsed because of diabetes (Female, 49 years)

Health education needs

Participants reported a need for more community based education regarding T2DM self-management and treatment, with peer group education considered a preferred method of education, as well as use of trained facilitators (e.g. retired nurses). Methods of delivery and types of information sources varied; however, ranging from media-billboards and pamphlets to text based mobile health messaging. Participants also advised to start teaching children about T2DM risk factors to have a positive impact on their lives:

I would like to suggest that diabetes should be incorporated in the school’s curriculum, because children learn fast as they are still young and maybe the nurses should go to school just to give children guidance about diabetes and high blood pressure; now they are focusing on HIV/AIDS and do not give much attention to diabetes – but it is a silent killer (Female diabetic, 45 years)

Provider experiences on caring for T2DM patients

Nurses in the facility reported that clients, when screened for T2DM receive health education, followed by a series of follow-up visits before referring to the facility health club when the patient is considered stable. They reported issues with defaulter tracing due to lack of a defaulter tracking system and
reported ignorance among patients as regards T2DM complications. They advocated for community-based support and follow-up. They, however, did not favour using CHWs as this could be perceived as breach of confidentiality and opined that training the CHWs would add more workload for them. With regards to pathways of T2DM care, patients reported dissatisfaction due to long waiting times and the waste of time spent at facility clubs. In their experience, health professionals also lacked the time to offer patients adequate support regarding their condition.

Discussion

In the current study nested within the SMART2D project, we sought to identify and understand contextual and environmental issues pertinent to the patient that could potentially influence T2DM care and self-management. Findings from our study identified a new understanding of the dialogue health care professionals should have with their patients regarding their health seeking behaviour, physical activity and weight management, which led us to conclude that a patient-centred definition of T2DM should be considered as a starting point for enhancing diabetes self-management. Based on these findings, we also argue that new innovative approaches are required to motivate patients to engage in meaningful, sustainable self-management for early detection, prevention and management of T2DM. Self-management is interpreted as a self-control exercise which is heavily influenced by complex interaction between sufferers’ traditional and religious beliefs, social norms and peer pressure, and something that requires individual capability. Health seeking behaviour, self-acceptance, peer pressure and self-discipline are critical for its success. Approaches to self-management should therefore entail thinking outside of the norm and using health promotion strategies that recognize this complexity. The mainstay of self-management strategies that health care workers direct at patients to undertake at home in managing their T2DM include: increasing physical activity, healthy eating to control the blood sugar and weight management. Patients have heard all this before and in fact believe this is business as usual. Strategies that will better motivate patients to engage in healthy behaviour required for controlling their diabetes should be considered and could include marketing the soft benefits of physical activity, healthy eating and weight management that appeal to patients’ psychological reward systems similar to those used by other industries, such as the fast food, tobacco and the beauty industries, but guided by professional medical ethics. Robinson [25] describes a set of ‘stealth interventions’ whereby behaviour change does not have to ‘look, feel and taste like health education’, but instead interventions should be motivating in themselves and target identity, values, beliefs and emotions at individual, community or societal level.

In this study, T2DM was defined as a physically and emotionally dangerous disease caused by socio-cultural factors and heavily influenced by the sufferers’ food culture and traditional beliefs. Patients did not define diabetes biomedically in terms of blood sugar or glucose metabolism, but as something that one would rather prevent because it changes you as a person, both physically (amputations) and emotionally (sexual dysfunction and loss of libido), and as a disease with a complex aetiology, including witchcraft and unusual eating habits. Similar findings were reported by Awah [26] in Cameroon where culture was a strong influence in patients definition of diabetes and suggested ‘culturally impelling’ and ‘culturally inclusive’ interventions for chronic conditions such as diabetes which are strategies recognized in the WHO innovative care for chronic conditions framework [27]. While the main aim of prescribing increased physical activity, healthy diet and weight management as mainstay towards self-management of T2DM is to control blood sugars, this is not the major goal for T2DM patients compared to healthcare workers’ goal. Therefore, to patients, this is a secondary gain while the primary gain is their prevention of changes in their physical appearance and emotional well-being as a result of diabetes.

The definition of T2DM, when viewed from a social ontology perspective, shows that T2DM is
perceived as a reality by patients based on the morphological and emotional and psychological changes it causes. The definition varies between individuals, suggesting multiple social realities for defining the disease. The prevailing view appears to be inclined to objectivist and constructivist views rather than a pragmatist view. For example, some quotations lean towards a constructivist view that diagnosis of T2DM may not be perceived as a social fact but rather as constructed depending on social factors such as what the parents of a diabetic child may have done to cause the disease. Others focus on an objectivist view that eating junk food and drinking very cold drinks will result in one becoming diabetic. The case can hence be made towards adopting a social ontological perspective in the CDSMPs to enhance diabetes self-management and control.

A recurring theme on barriers toward physical activity was noted to be laziness. Laziness as a barrier to physical exercise has been reported among patients attending a diabetic clinic in a teaching hospital in South Africa [28] and in other studies on diabetic patients elsewhere [29]. Work on motivational issues is therefore needed to get the community to engage in physical exercise.

The relationship between physical activity and ageing is not only anecdotal but has been documented in the literature and explained in terms of the effect of physical activity on the growth hormone/insulin like growth factor axis known to regulate age related changes [30]; promoting healthy mitochondrial biogenesis [31] and benefits to the age-related dysfunctional changes in cardiovascular endothelium [32]. This is the science behind recommendations for physical exercise for disease prevention. The population in our study, however, comprising of diabetic or pre-diabetic patients, are unlikely to internalize this kind of knowledge even if simplified in the plain English or translated to their local language. Therefore, a different approach to making this scientific information more appealing and user-friendly, starting from a basic human need for reward, gratification and self-esteem is needed.

People like to look good because it makes them feel good. We propose packaging the message on risk factor management (physical activity, healthy diet, smoking cessation and alcohol in moderation) to appeal to this very simple principle, which can be explained by various psychology theories such as the social cognitive theory [33].

An argument can be made for leveraging on existing social structures and using some of the marketing strategies used by the food and drink industry, tobacco industry or the pharmaceutical industry to appeal to the soft benefits of T2DM risk factor management. Coca cola have launched a new campaign called ‘taste the feeling’ which aims to ‘bring to life the idea that drinking a Coca-Cola—any Coca-Cola—is a simple pleasure that makes everyday moments more special’ and reflect both the ‘functional and emotional aspects of the Coca-Cola experience’ [34]. Given the negative health effects of tobacco, the tobacco industry adverts target features that the consumer can identify with such as age as evidenced by reported doubling of teen smoking uptake within 6 years of Phillip Morris Virginia launching the slims cigarette targeting young women with the slogan: ‘You Have Come A long Way Baby’ [35]. The pharmaceutical industry uses similar approaches to market their products. It is estimated to command a staggering $131 billion by 2019 and trends show that it has grown exponentially since 2009 from $12.9 billion to $15.3 billion despite global economic challenges prevailing during this period [36]. The beauty industry reaches out to consumers using targeted specific measurable effects that appeal to the soft side of the consumer such as looking young, vibrant, age defying characteristics of their products [37], which could also be used for advocating healthy lifestyle changes among people living with T2DM or people known to be at risk of T2DM.

Using physical activity and diet as examples, let us look at some of the methods that can be used in advertising physical activity and healthy eating to prevent diabetes.

**Physical activity message packaging**

Would this kind of marketing health for chronic disease risk factor management be deemed
controversial for the health sector or are health care professionals missing an opportunity to reach the inner core of our patients through the use of tried and tested methods? Would this be deemed unethical, where will the harm be? If this would be deemed to cause harm, one can argue that perhaps by not adopting these strategies that have been shown to work, we are indeed causing harm to our patients and therefore already violating the principle of non-maleficence.

Could healthcare professionals use branded media such as a video showing free, fun ways of exercising other than gym—participants walking with friends for a fun-filled purpose? A randomized controlled study published in the journal *Paediatrics* 2016 done in the USA, showing a vinyl banner attached to the base of the salad trolley displaying vegetable characters; a short television segment next to the trolley with health education delivered by vegetable characters and a combination of the vinyl banner and television segments showed that intake of vegetables increased by 90.5% among children shown the vinyl banner only and 239% among those shown both the banner and the video [38]. Using the ‘metshelo’ meetings (local support groups for social events such as weddings and funerals that meet regularly as happens in South Africa and Botswana) for aerobics sessions for example to promote physical exercise the fun way could be a localized consideration. These sessions could be similar to Zumba fitness but using music that is produced locally and chosen by the patients themselves. Some of the participants in our study for example suggested shared funeral plans or burial societies as a way of supporting each other and promoting healthy lifestyles among people living with T2DM. The idea being that they use these as support groups where they learn and share experiences about living with T2DM, use the meetings as opportunities to discuss lifestyle modifications supportive of controlled diabetes management, given that such meetings and schemes are popular and tend to be well attended. In addition, the health sector could also team up with religious leaders or organizations to promote the message of keeping fit (‘pleasing to the creator’) to appeal to the spiritual side of patients.

Likewise, physical activity was also described as a brain and energy booster by study participants. The health care sector could be promoting physical activity as a natural fun filled treatment that slows down forgetfulness and increases happiness by learning for example from the coke advert ‘open happiness’ [39]. High levels of drinking have also been associated with marketing through digital media, and especially the use of approaches that encouraged interactivity with young people were deemed attractive [40], resulting in the authors suggesting restriction of such marketing strategies. Could an argument be made that rather than restriction measures which have been shown to be ineffective against the transnational food, alcohol and tobacco industries [41] the same strategies could be used to promote healthy behaviours?

**Weight management message packaging**

Consumers have reported finding health messages on food rather confusing especially where health claims are based on one component out of several other unhealthy ones within the same food item [42]. Mechanisms by which marketing of food influences eating habits have been identified in the literature and fall into four categories which are: pricing, marketing communications such as health claims, branding, advertising, promotions and nutritional value; nature of the food product including sensory properties, packaging and composition; the food environment, including availability; and socio-cultural perspectives [43, 21]. Out of these categories, the food environment has been identified as the least studied but the most influential when it comes to driving actions of consumers through its effect on consumer automatic and volitional control [43].

In our study, affordability, availability and taste were some of the important factors contributing to choice of food. Marketing strategies which target these factors can therefore be considered for this population. Such a marketing strategy could include rebranding of healthy foods on non-health related positive benefits that people can relate to [25]. The physiology of food taste, olfaction and reward processes in the brain are well described in the literature.
Food that smells good tends to taste good and this is due to the convergence of olfactory-taste receptors in the fronto-orbital cortex of the brain [44, 45]. Our study findings showed that healthy food is perceived to lack taste and appeal. Some ideas to explore would therefore be to harness the science behind the olfactory-taste convergence theory and have ‘MasterChef-like’ cooking classes for T2DM, which enhance food taste and appeal while preserving essential nutrition, and which persons with T2DM would be encouraged to attend each month when they collect their medications.

Other factors such as portion size which has been shown to lead to increased food intake and potential weight gain [46], and stress mentioned as one of the causes of weight gain in this study and the literature [47], will need to be taken into consideration as part of an overall health promotion package. Another intervention to consider in our study setting would be to engage with street vendors who sell convenience foods. It has been shown that most people will eat convenience food because of proximity to where they are [48]. Street vendors act as convenience food take-aways for local people and bring food to where the consumer is. They could be trained on serving healthy appetizing convenience food. Making healthy food easier to get on the go has been found to increase consumption of healthy food [49].

While healthy foods tend to be associated with higher prices and unhealthy foods with cheaper sale prices, there is evidence that lowering price of healthy food items can also increase the uptake and consumption of healthy food [50]. Pricing policies which lower food commodities can however be subject to socio-economic and political considerations, as well as pressure from the food and beverage industries and unlikely to be well enforced. Health promotion strategists should not be deterred but work with local produce that people can access easily such as samp, beans, spinach and other food items which are more likely to work in our study setting. In addition, public health professionals need to start collaborative research work that explores how best the taste-olfaction-reward system already identified to be operating within the human brain can be harnessed to produce food that is tasty, healthy and nutritious in the local context.

Study limitations

Findings are based on interpretations of information provided by people living in a township area of Cape Town where majority fall under the low socio-economic stratum of society. Views reflected may therefore be influenced by their psychosocial environment and not generalizable to the South African population as a whole.

Conclusions

The current status quo needs to be challenged when it comes to promoting healthy eating and physical activity for prevention and self-management of T2DM. This need has been documented in this study using findings from in-depth exploration of factors influencing health seeking behaviours such as the uptake of physical activity, healthy diet and general knowledge about T2DM. T2DM carries a different meaning for the patient compared to the health care professionals, and that meaning places significance on the physical, social and psychological changes that results from the diagnosis. Patient literature on T2DM should incorporate this patient definition of T2DM. Self-management of the disease is also interpreted from a social ontological perspective that health care workers often pay little attention to. Harnessing the important rewards based benefits of physical activity and healthy diet that include defying age, brain boosting, energizing and detoxification should be given due consideration as part of health promotion activities for T2DM patients. Public health professionals need to consider use of so called stealth interventions to promote physical activity and healthy eating among T2DM patients. Further research is recommended using randomized controlled clinical trials and longitudinal studies to evaluate some of the innovative patient centred interventions suggested in this article. This will be in keeping with advances in disease prevention and management suggested in the
WHO report on innovative care for chronic conditions [51].

Supplementary data

Supplementary data are available at HEAL online.

Acknowledgements

The authors wish to acknowledge the following persons for their contribution towards successful implementation of this study: B. Jwili and K. Ndibaza (data collection); the health care workers and staff at Vanguard Community Health Centre for their assistance and support.

Funding

European Commission Horizon2020 Health Coordination Activities (Grant Number 643692) under call ‘HCO-05-2014: Global Alliance for Chronic Diseases: prevention and treatment of type 2 diabetes’. The SMART2D consortium includes Karolinska Institutet and Uppsala University, Sweden; the Institute of Tropical Medicine, Belgium; Collaborative Care Systems, Finland; Makerere University, School of Public Health, Uganda; and University of the Western Cape, School of Public Health, South Africa. The contents of this article are solely the responsibility of the authors and do not reflect the views of the EU.

Conflict of interest statement

None declared.

References

1. World Health Organization. Global Status Report On Noncommunicable Diseases 2014. Geneva: World Health Organization Press, 2014.
2. Mayega RW, Guwatudde D, Makumbi F et al. Diabetes and pre-diabetes among persons aged 35 to 60 years in eastern Uganda: prevalence and associated factors. PLoS One 2013; 8: 1–11.
3. IDF. 2014-11-13-IDF-Diabetes-Atlas-rv. Belgium: International Diabetes Federation, 2014.
4. Peer N, Steyn K, Lombard C et al. Rising diabetes prevalence among urban-dwelling black South Africans. PLoS One 2012; 7: e43336.
5. Erasmus RT, Sota DJ, Hassan MS et al. High prevalence of diabetes mellitus and metabolic syndrome in a South African coloured population: baseline data of a study in Bellville, Cape Town. S Afr Med J 2012; 102: 841–4.
6. Mayega RW, Guwatudde D, Makumbi FE et al. Comparison of fasting plasma glucose and haemoglobin A1c point-of-care tests in screening for diabetes and abnormal glucose regulation in a rural low income setting. Diabetes Res Clin Pract 2014; 104: 112–20.
7. Amod A, Ascott-Evans BH, Berg GI. The 2012 SEMDSA guideline for the management of Type 2 diabetes (revised). JEMDSA 2012; 17: S1–95.
8. Johns Hopkins Medicine. Diabetes Self Management Patient Education Materials. Diabetes Education-Number 2. 2012. Available at: http://www.hopkinsmedicine.org/gim/core_resources/Patient Handouts/Handouts_May_2012/DiabetesMellitus Type 2.pdf. Accessed: 24 July 2016.
9. American Diabetes Association. Diagnosis and classification of diabetes mellitus. Diabetes Care 2009; 32(Suppl. 1): S62–7.
10. Coulter A, Roberts S, Dixon A. Delivering Better Services for People with Long-Term Conditions-Building the House of Care. London: The Kings Fund, 2013, 28.
11. Mollentze W. What the primary healthcare worker needs to know about the management of type 2 diabetes. S Afr Fam Pract 2012; 54: S20–2.
12. Igbojiaku OJ, Harbor OC, Ross A. Compliance with diabetes guidelines at a regional hospital in KwaZulu-Natal, South Africa. Afr J Prim Heal Care Fam Med 2013; 5: 1–5.
13. Distiller LA, Brown MA, Joffe BI, Kramer BD. Striving for the impossible dream: a community-based multi-practice collaborative model of diabetes management. Diabet Med 2010; 27: 197–202.
14. Lorig KR, Sobel DS, Stewart AL et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. Med Care 1999; 37: 5–14.
15. Dongbo F, Hua F, Mgwowan P et al. Implementation and quantitative evaluation of chronic disease self-management programme in Shanghai, China: randomized controlled trial. Bull World Health Organ 2003; 81: 174–82.
16. Radhakrishnan K. The efficacy of tailored interventions for self-management outcomes of type 2 diabetes, hypertension or heart disease: a systematic review. J Adv Nurs 2012; 68: 496–510.
17. Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003; 26: 1–7.
18. Teo K, Chow CK, Vaz M et al. The prospective urban rural epidemiology (PURE) study: examining the impact of societal influences on chronic noncommunicable diseases in low-, middle-, and high-income countries. Am Heart J 2009; 158: 1–7.
19. Nygende A. Statistical Release (Revised) Census 2011. Statistics South Africa 2012.
20. Puoane T, Tsokolile L. Challenges faced by the urban black South Africans in the prevention of non-communicable diseases. *Trbues and Tribals* 2008; 2(Special Volume): 9–14.
21. Puoane T, Bradley HA, Hughes GD. Socio-cultural factors influencing food consumption patterns in the black African population in an urban township in South Africa. *Hum Ecol* 2006; 14: 89–93.
22. Pope C, Ziebland S, Mays N. Qualitative research in health care: analysing qualitative data. *Br Med J* 2000; 320: 114–6.
23. Gale NK, Heath G, Cameron E et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013; 13: 117.
24. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *Am J Eval* 2006; 27: 237–46.
25. Robinson TN. Stealth interventions for obesity prevention and control: motivating behavior change. In: Dube L, Bechara A, et al. (eds). *Obesity Prevention: The Role of Brain and Society on Individual Behavior*, 1st edn. New York: Elsevier, 2010, 319–27.
26. Awah PK. An ethnographic study of diabetes: implications for the application of patient centred care in Cameroon. *J Anthropol* 2014; 2014: 1–12.
27. World Health Organization (WHO). *Innovative Care for Chronic Conditions*, World Health Organization, Geneva, Switzerland, 2001. Geneva: World Health Organization, 2001.
28. Nel C, van Rooijen AJ, van der Westhuizen I et al. Physical activity levels in male and female diabetic patients at the Pretoria Academic Hospital, South Africa. *S Afr J Physiother* 2007; 63: 2–6.
29. White KM, Terry DJ, Troup C et al. Behavioral, normative and control beliefs underlying low-fat dietary and regular physical activity behaviours for adults diagnosed with type 2 diabetes and/or cardiovas-cular disease. *Psychol Heal Med* 2007; 12: 485–94.
30. Lanfranco F, Gianotti L, Giordano R et al. Ageing, growth hormone and physical performance. *J Endocrinol Invest* 2003; 26: 861–72.
31. Joseph AM, Hood D. Diabetes and physical activity. In: Goedecke JH, Ojuka EO (eds). *Relationships between Exercise, Mitochondrial Biogenesis and Type 2 Diabetes*, vol. 60, Cape Town: KARGER, 2014, 48–61.
32. Santos-Parker JR, LaRocca TJ, Seals DR. Aerobic exercise and other healthy lifestyle factors that influence vascular aging. *Adv Physiol Educ* 2014; 38: 296–307.
33. Robinson TN. Save the world, prevent obesity; piggybacking on existing social and ideological movements. *Obesity* 2010; 18: S17–22.
34. Moye J. *One Brand’s Strategy, New Global Campaign Unite Coca-Cola Trademark*. 2017. Available at: http://www.coca-cola.com/usa/stories/taste-the-feeling-launch. Accessed: 14 January 2017.
35. Kluger R. *Ashes to Ashes—America’s Hundred-Year Cigarette War, the Public Health, and the Unabashed Triumph of Philip Morris*. New York: Alfred A. Knopf, 1996, 316–7.
36. Skelly M. *How Consumers Shop: Anti-Aging Skin Care Market Trends 2015* Available at: https://www.linkedin.com/pulse/how-consumers-shop-anti-aging-skin-care-market-trends-michelle-skelly. Accessed: 14 January 2017.
37. Beauty Bulletin. *Anti Ageing Cream Reviews*. Beauty Bulletin, 2016, 1–20. Available at: http://www.beautybulletin.com/face-and-body/anti-ageing-creams/. Accessed: 14 December 2016.
38. Hanks AS, Just DR, Brumberg A. Marketing vegetables in elementary school cafeterias to increase uptake. *Pediatrics* 2016; 138: e20151720.
39. Coca-Cola South A. *Where Will Happiness Strike Next* Coca-Cola. 2011. Available at:https://www.youtube.com/watch?v=OxXUWV8Zazl. Accessed: 14 January 2017.
40. Lobstein T, Landon J, Thornton N et al. *The Commercial Use of Digital Media to Market Alcohol Products: a Narrative Review*. Addiction. 2016; Available at: http://https://dx.doi.org/10.1111/add.13493. Accessed: 14 January 2017.
41. Moodie R, Stuckler D, Monteiro C et al. Profits and pandemics: prevention of harmful effects of tobacco, alcohol, and ultra-processed food and drink industries. *Lancet* 2013; 381: 670–9.
42. Chandon P, Wansink B. The biasing health halos of fast-food restaurant health claims: lower calorie estimates and higher side-dish consumption intentions. *J Consum Res* 2007; 34: 301–14.
43. Chandon P, Wansink B. Does food marketing need to make us fat? *A review and solutions*. 2012; 70: 571–93.
44. McCabe C, Rolls ET. Umami: a delicious flavor formed by convergence of taste and olfactory pathways in the human brain. *Eur J Neurosci* 2007; 25: 1855–64.
45. de Araujo IET, Rolls ET, Kringlebach ML et al. Taste-olfactory convergence, and the representation of the pleasantness of flavour, in the human brain. *Eur J Neurosci* 2003; 18: 2374–90.
46. Kral TV, Rolls BJ. Energy density and portion size: their independent and combined effects on energy intake. *Physiol Behav* 2004; 82: 131–8.
47. Torres SJ, Nowson CA. Relationship between stress, eating behavior, and obesity. *Nutrition* 2007; 23: 887–94.
48. Block JP, Christakis NA, O’Malley AJ et al. Proximity to food establishments and body mass index in the Framingham Heart Study ofispring cohort over 30 years. *Am J Epidemiol* 2011; 174: 1108–14.
49. Shiv BNS. The effect of distractions while tasting a food sample: the interplay of informational and affective components in subsequent choice. *J Consum Res* 2004; 31: 599–608.
50. Chandon P, Wansink B. Does food marketing need to make us fat? A review and solutions. *Nutr Rev* 2012; 70: 571–93.
51. World Health Organisation. *Innovative Care for Chronic Conditions*. World Health. Geneva; 2002.