

The Management of Diabetes among the Rural Poor in South Africa

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Abstract

The objective of this study was to examine the management of diabetes mellitus Type 2 among the rural poor in South Africa. The focus group method was used. Data was elicited from 20 group sessions over a 20-week period on health beliefs and attitudes and rural-dwelling diabetes sufferers' strategies for managing the condition. The study shows poor knowledge of diabetes and poor self-management as delineated in the medical literature. The focus of the rural dwellers' self-management of diabetes was hypoglycaemic control through regular consumption of very-high-calorie food, the type of which have been found to lead to a diet that has very high carbohydrate, high in saturated fatty acids, excess salt and unrefined sugar. The rationale for this is the misconception that hypoglycaemia is a product of low food intake, which would seem to suggest their perception of illness and health belief than the understanding of chronic illness. It was concluded that the government and health care professionals have to do more to develop interventions to facilitate good self-management of diabetes among the rural people. Such interventions should address the sufferers' knowledge of diabetes.

Key Words: *Care interventions; Chronic Illness; Diabetes; Focus Groups; Health Belief; Health Monitoring; Health Policy; Rural Health; South Africa*

Résumé

L'objectif de cette étude était d'examiner le traitement du diabète sucré de type 2 chez les ruraux pauvres en Afrique du Sud. La méthode du groupe de discussion a été utilisée. Les données ont été recueillies auprès de 20 séances de groupe sur une période de 20 semaines sur les croyances et les attitudes de santé et les stratégies des ruraux vivant diabète malades du pour la gestion de l'état. L'étude montre une mauvaise connaissance du diabète et une mauvaise estime de gestion que délimité dans la littérature médicale. L'objectif de l'auto-gestion des populations rurales de diabète était le contrôle hypoglycémiant par la consommation régulière d'aliments à très haute teneur en calories, le type qui ont été trouvés à conduire à un régime qui a très riche en glucides, riche en acides gras saturés, l'excès de sel et de sucre non raffiné. La raison à cela est l'idée fausse que l'hypoglycémie est un produit de faible apport alimentaire, ce qui semble

suggérer leur perception de la maladie et de la santé conviction que la compréhension de la maladie chronique. Il a été conclu que le gouvernement et les professionnels de la santé doivent faire plus pour développer des interventions pour faciliter une bonne auto-gestion du diabète chez les populations rurales. Ces interventions devraient porter à la connaissance des personnes souffrant de diabète.

Mots clés: *Soins intervention; Maladie chronique; le diabète; Groupe de discussion; Croyance à la santé; Surveillance de la santé; Politique de la santé; Santé en milieu rural; Afrique du Sud.*

Introduction

Diabetes is a large and growing health problem in South Africa as in other parts of the world. The International Diabetes Federation (IDF) estimated in 2013 that 366 million people had diabetes in 2011 and estimates that by 2030, there would be 552 million. The data covered 216 countries and territories grouped with the federation's seven regions: Africa, Europe, Middle East and North Africa, North America and Caribbean, South and Central America and the Western Pacific. The estimated 550 million diabetics by 2030 is significantly higher than the World Health Organization's (WHO) estimate of 300 million by 2025 cited by Norris et. al. in 2000; yet, there is no doubting the rapid increase of those with diabetes in the past decades. For example, in the predominantly rural Eastern Cape province of South Africa, where the current research was conducted, the province's Department of Health Figures show a 15.83% prevalence in 2001, 16.05% in 2002 and 19.20% in 2003. However, only 1% of adults are reported to be under treatment for diabetes in public clinics in the province.¹ A one-week survey of patients at 5 outpatient clinics in 5 hospitals and 5 health centres in Amatole, one of six district municipalities in the province, reveals that 21% of the patients has been diagnosed with diabetes (Oloyede, 2004). Type 2 diabetes mellitus, a syndrome characterised by insulin deficiency, insulin resistance and increased hepatic glucose, and formerly known as non- insulin dependent diabetes (Kaplan, et al., 1993) accounts for 95% of the diabetes patients, which would seem consistent with figures in many other areas of the world. This would continue to rise given the economic condition of the rural population and life style.

As an important condition for health monitoring, its continuous rise in South Africa will have a major impact on both the use of an already stretched health service due to HIV/AIDS. Current health policy concerns in the country and in the continent, which have brought about a research industry on acute communicable diseases (HIV/AIDS in particular) and spurned numerous health education and campaigns aimed at bringing them under control, appear to overlook the rising prevalence of

¹ *Prevalence of Hypertension and Diabetes, Eastern Cape 2001-2003. Eastern Cape Department of Health Annual Report, 2003-2004*

chronic illnesses. An awareness of chronic illnesses like diabetes, hypertension and so on is thus salient. Formal chronic illness care needs to be improved. A valuable key to this is research in this area where the knowledge gathered can be fed into health programmes to improve the knowledge and health behaviour of the chronically ill. Available evidence suggests that the knowledge of both acute and chronic illnesses tend to be poor among those in the rural areas referred here to as areas characterized by small numbers of people, low population density, small communities geographically distant to urban resource centres and physical remoteness. In South Africa, as in most African countries, rural dwellers have meagre holdings or access to land, little or no capital and low opportunities for off-farm employment. They are generally viewed as being in poverty, which is far more than an absence of income and about disempowerment and limited horizons to fulfil and perceived to be 'traditional' in their practices. In their cosmology, illness is perceived as linked to social and supernatural causes and responses have typically been to use different treatment simultaneously – local herbs and biomedicine. The emerging picture of the chronically ill in the rural areas of Africa is thus that they scarcely access biomedical services or adhere to treatment regime to improve clinical outcomes. It becomes important therefore to investigate the ways that those in the rural areas diagnosed with Type 2 diabetes and who are required by health professionals to undertake and sustain a complex array of self-care behaviours manage the disease.

The main guiding questions of the study were: how do the poor in the rural areas diagnosed with Type 2 diabetes manage their diabetes? What is the level of their knowledge of diabetes? What modality of social knowledge underpins the ways that they manage their diabetes? The literature on lay health beliefs suggests that individuals draw on causal theories of illness available to them in their immediate cultural and social context to make sense of the illness and they choose from a range of available options, simultaneously and sequentially, depending on the causal theory, severity and time-frame of the illness to deal with the illness. Ware and Kleinman (1992:547) suggest, for example, that, "health and suffering, like other existential states are patterned by culture realized as local worlds of experience."

The central organising concept of the study was 'manage', which refers to the sort of behaviour to promote health and prevent complications such as taking medications, monitoring blood glucose levels, following a diet, engaging in regular exercise and caring for their feet. In order words, when a person diagnosed with diabetes take steps, consciously, to ameliorate the effects of diabetes. The study was conducted in Nkonkobe (pop. 143,167) and Amahlathi (pop. 137,618) local municipalities of the Amatole District Municipality (pop. 1,657, 373) in the Eastern Cape Province (pop.). The poverty map of South Africa, which was constructed by Statistics South Africa, revealed that the province has about 70% of its population living in the rural areas (Hirschowitz, 2000). Taking account of a number

of indicators,² the map showed that the province is the poorest in terms of average monthly expenditure, has the poorest district council in the country and is the most in need of infrastructural development such as clean water and sanitation in terms of household index. It is the most in need of life circumstances as employment creation. Health problems are large; it has the highest prevalence of HIV/AIDS in the country. Quite clearly, those in the rural areas of South Africa, as indeed most countries in Africa, seem overwhelmingly burdened by functional limitations, higher rates of poverty, limited transportations and a high level of medical conditions. It is against this complex health, socio-economic and environmental problems experienced by the rural dwellers that the study could be cast.

Method

The Focus group

In recent years, a number of reliable and valid self-reported measures describing different facets of the management of diabetes through questionnaires and structured interviews have been developed (Toobert, et al. 2000; Harris et al. 2000). In addition to these are distinctive qualitative approaches such as symbolic interactionism and phenomenology, using methods such as grounded theory (Charmaraz, 1990) that focus entirely on subjective accounts of health-related experiences. One of such is the focus group. In fact the literature reveals that research on a variety of health-related topics continue to be a major area of focus research, which generally involves organizing and running a series of small, focused group discussions and analysing the resultant data using a range of conventional qualitative techniques (there is an extensive methodological literature on the practical details of conducting focus groups. For example Barburr and Kitzinger, (eds.) (1998); Kitzinger, (1995); Krueger, (1994); Morgan, 1996, Morgan and Krueger, 1993; Stewart and Shamdasani, 1990). The method has proved useful in eliciting data on health beliefs and attitudes where the participants' own meanings of health and illness renders it possible to understand, for example, coping behaviour and adaptation to negative life events, as well as offering important insights into people's phenomenological life worlds (Fife, 1995, Radley, 1999, Hoppe et al. 1994). Analysis of these explanations concerns itself with the meaning of what is said.

The study being reported here used the Focus group method for the reasons above. It proved a useful method to learn about the vocabulary and thinking patterns of the participants in their rural context. Crucially, it enabled an understanding of the nature of their knowledge of diabetes. Above all, and most importantly, a clinically useful picture of the rural-dwelling diabetes sufferers' strategies of managing diabetes was obtained.

2 These indicators are: a) Formal housing (brick dwellings, flats, townhouses, backyard rooms etc.), b) Electricity for lightning from a public authority or supply company, c) Tap water inside the dwelling, d) A flush or chemical toilet, e) A telephone in the dwelling or a cellular phone, f) refuse removal at least once a week by a local or district authority, g) Level of education of the household, h) Average monthly household expenditure, I) Unemployment rate, j) Average household size and k) the proportion of children in the household under the age of five years. C.f. Hirschowitz, R (2000) *Measuring Poverty, Statistics South Africa*.

Procedure

Participants for the study were recruited over a period of approximately seven months. They were eligible for the study if they were diagnosed with Type 2 diabetes at least 18 months prior to the study. This criterion was established in an attempt to ensure that the participants would be able to describe and discuss their experience of the diabetes and how they manage it. All participants had been seen routinely in the clinics, health centres and outpatient department of the hospitals surveyed for the study over a 12-month period. Most of the study participants ($n=15$) were recruited by word of mouth in the rural settings in the Nkonkobe and Amahlathi local municipalities. Another subset of participants ($n=35$) was recruited (from 58) at the outpatient department of the surveyed hospitals, the clinics and health centres. 10 recruited sufferers of diabetes were unable to participate. 40 diabetic patients eventually participated in the study (30 women and 10 men). Patients were included at the time of the first clinic visit within the 7 months of the recruitment process to avoid patient duplication.

The participants were grouped into 5. Each group had 8 participants. The allocation of participants to group was determined by proximity of residence to the site of group discussion, which affected the gender composition of groups. There were 2 groups that were predominantly female, one group had 4 men and 4 women, and the other 2 groups had 3 men each. There was a total of 20 group sessions over a period of 20 weeks. Four-sessions were held with each group, with a group coming after the other after the end of the four weeks. Sessions were held once a week with each group in what served as community 'hall' consecutively for 4 weeks. Each group session lasted 60 minutes. There were no ethical constraints on any of the participants during or after the group sessions. They were all guaranteed anonymity and confidentiality in the handling of the data and reporting of the research.

The participants received a 15-minute instruction (see Fig. 1) at the beginning of the first session. This was a brief summary of the project, which was read to them in Xhosa language (the local language in the Eastern Cape). It was emphasised to the participants that there was no interest in right or wrong answer; that they were required to just 'talk' to the issue as they arose in the group discussion. At no point was lead provided on any of the discussions except the starting issue of each session of the group discussion, which was determined *a priori* to give frame to the session. An 'assessment' of the participants followed the 15-minute orienting instructions. This was with their consent. This included demographic data, the recording of the prescribed medication, measurement of blood glucose level with ONE TOUCH Ultra Test Strips (Lifescan, Johnson and Johnson, UK) and the measurement of blood pressure with an automatic digital blood pressure monitor (Omron Healthcare, UK) after a 5-10mm rest.

During the recruitment period at the clinic and hospitals, effort was made to obtain the

glycosylated Haemoglobin, or HbA1c test results of the participants from data recorded in the patient notes. HbA1c is a blood test reflecting blood glucose levels over 2-3 months before the test is taken, thus giving an indication of long-term blood glucose control (Gonen et al. 1977). However, obtaining the HbA1c test result proved difficult, as most patients have not had test after initial diagnosis and also because many of the surveyed hospitals, clinics and health centres seldom carry out such tests because of lack of diagnostic instruments.³ It would have been useful to have the results of the HbA1c test. However, since the use of HbA1c as a measure of long-term blood glucose control in research and diabetic clinics has been the subject of debate (Snehalatha, et al., 2000), there was no further attempt to obtain the results. Semi-structured interview was conducted with the participants in the beginning to establish their socio-economic characteristics.

Fig 1 Orienting Instruction

I am interested in how people with diabetes manage their condition. I want us all to talk about diabetes, what you know about it, whether you know of people with similar condition, when you knew about your diabetes, how you got to know about it, what was done when you knew about it, what you have been doing since then, what other people with diabetes that you know do about it, what pains you experience, whether this affects you in any way – going to work, shopping or visiting family, relatives and friends. Obviously when one is ill, one uses medication, what medication do you use, who prescribed it, how regular do you use it, and if you know the cost, how much does it cost? Who pays for the drugs?

Data

The focus group discussion explored participants' thoughts, beliefs and attitudes regarding diabetes and its treatment. The discussions were audio taped, transcribed verbatim and translated from Xhosa to English. Data generated from the transcript can be described as very rich and meaningful. The thematic qualitative analysis (TQA) (Mason, 1987), which draws upon symbolic interactionism, phenomenological and grounded theory frameworks and aspects of discourse analysis for technique, was used. This is typically a two-stage procedure of the identification of themes and a more detailed interpretative conceptual analysis. The translated transcripts were systematically analysed using content analysis. Data were organized into topics by attaching words to segments of texts – symptom perception, perceived consequences (severity and impact of diabetes, vulnerability, to complications), perceived control of diabetes (self-efficacy, locus of control), treatment (benefits/costs) and practical and emotional support from family and friends. This was then thematised as: seeking health care,

³ This was highlighted in the Province's Department of Health Annual Report. See *Prevalence of Hypertension and Diabetes, Eastern Cape 2001-2003. Eastern Cape Department of Health Annual Report, 2003-2004*

pharmaceutical treatment, dietary management, physical activity and social support. Everything else that presented itself as illuminating was noted. The organizing topics were derived from psychology research literature on coping. Much of the research on coping takes its cue from the conceptual work of Lazarus and Folkman (1984) who developed a measure consisting of a series of predicates, each portraying a coping thought or action that people sometimes engage in when under stress.

Embedded in the Ways of Coping scale is a distinction between two general types of coping:

- i) The problem-focused coping and
- ii) the emotion-focused coping. The former is aimed at solving or doing something to alter the source of the stress; the second is aimed at reducing or managing the emotional distress that is associated with the situation. Although most stressors elicit both types of coping, problem-focused coping tends to predominate when people feel that the stressor is something that must be endured (Folkman and Lazarus 1980). These two ways of coping are general because there are so many ways that individuals cope with stress. Indeed, as research (Folkman et al 1986, Scheier, Weintraub and Carver, 1986) show, there are quite different factors that account for the ways people in stressful condition cope with their condition. Carver et al. (1986) suggest that some emotion-focused responses involve denial, others involve positive re-interpretation of events, and still others involve the seeking out of social support. These responses are very different from each other and they may have very different implications for a person's success in coping. Problem-focused coping also involve several activities: playing, taking direct action, seeking assistance and screening out other activities. The analysis of the data drew from this.

Results

Descriptive

Participants' demographic characteristics and health references are presented in Table 1. Other results are presented using extracts from the transcripts as evidence. The mean age of the participants was 50 years as Table 1 shows. The mean age at diagnosis of diabetes was 44 years. The mean systolic blood pressure was 155 mmHg and the mean diastolic blood pressure was 103 mmHg. All the participants were prescribed oral medication. 20% of the participants drank regularly (average of 6 litres of beer per week). 10% had a family history of diabetes.

Table 1: Participants' characteristics

Age	Mean - 50 years Range - 42-61 years
Sex	Male - 10 Female - 20
Marital status	Married - 28 Single/Divorced/Widowed - 12
Mean age at diagnosis of diabetes	44 years
Mean duration of diabetes	6 years
Hypoglycaemic regimen	
Oral medication	All
On Insulin	None
Mean systolic blood pressure (mmHg)	155 mm Hg
Mean diastolic blood pressure (mmHg)	103 mmHg
BMI (kg/[m.sup.2])	34.1
Regular drinker of alcohol	20% (n=40)
Family history of diabetes	10% (n=40)

Participants' knowledge of diabetes

Table 2 below shows the participants' source of knowledge of diabetes and the number of the participants who got such knowledge from each source. All the participants were diagnosed diabetic by the doctor but the disease was not explained to them sufficiently for any reasonable claim to such knowledge. Only a handful were able to claim any form of knowledge of the disease from the sources listed in the Table. 20% claimed some form of diabetes knowledge from one-to-one consultation with the doctor.

"The doctor said I have this thing [diabetes] and he told me it is because I have too much sugar in my body. He said he would give me tablets and that I should use it in the mornings, that it would help"

"After the doctor said my eye problem is caused by diabetes, he said I must take tablets everyday and that I should see the nurse who will talk to me about it and the type of food to eat. I never saw the nurse but I knew it was diabetes then."

"The doctor told me that my problem was diabetes. He said old people have it and young people too but that mine is old people's diabetes."

25% of the participants claimed some form of knowledge of diabetes from the nurse. They said the nurse explained their condition to them when they went to hear the result of their blood test, which the doctor had ordered to be taken.

“The doctor said that I needed to do blood test. I went to the hospital after some days to do the test and I went back after many days. The nurse came to me carrying a file and she looked at me and after a while said that I have diabetes. She said that it was not a big problem but I have to look after myself and take tablets that the doctor would give me.”

“It was the nurse that said that I might have diabetes but I must see the doctor. I saw the doctor who, after testing me said I must go to the blood test people. I went there and they said that I come another day for blood test I saw the nurse and she said that I have diabetes.”

10% of the participants got to know about diabetes from other sufferers. They said that those to whom they described their experience told them that the experience, which was similar to theirs, was diabetes.

“My neighbour told me it was the same thing he was suffering from before he went to the doctor who told him it was diabetes. He told me what the doctor said he should do.”

“My children’s friend told me her mother had a similar thing. That it is called diabetes and I must go to see a doctor. I did and had blood test and then was told I had diabetes. I was told to take tablets everyday.”

Table 2. Diabetes Knowledge and source

Diabetes education	None
Dietician visits	None
Doctor consultation	20% (n=40)
Nurse	25% (n=40)
Other	10% (n=40)

Seeking health care: hospital and health centre visits

Formal services care (doctors, nurses, dieticians) is very critical in the management of diabetes even though it is a condition that can be self-managed. Such care, which typically has to be sought by diabetes sufferer, involves formal diabetes education, dietary education and monitoring of blood glucose in health-care settings (hospitals, health centres and clinics) where sufferers do not have the means for self-monitoring. The findings show that 5% (n=40) of the participants reported visiting any health care setting once in the past 12 months for “check-up”. During the same period, there was an average of 5 severe diabetes symptoms experienced by all the participants. The narratives reveal that the participants do not have any knowledge of self-monitoring of blood glucose level, do not monitor their blood glucose levels and has never done so since being diagnosed with diabetes

and has not purposely visited health centres or hospitals to have their blood-glucose level measured. The 5% who reported visiting for “check-up” did so because of a weakening of vision and repeated episodes of fainting. The doctor who saw them linked these to their diabetes. Typical examples of this are:

“I do not know why I suddenly don’t see and then feel weak and weak and so I went to see the doctor. My son said that I have to and he took me.”

“I fell one day and have experienced it about four times before I think that I have to see a doctor. I hesitated for long because I thought it was because I felt hungry when it happened. Everybody kept saying that it could be too serious. So, I went to see the doctor.”

Seeking health care in health care settings is often a difficult decision to make by the participants who find the experience unpleasant. What emerged from their narratives is that getting to these settings mostly involved “waking up early”, difficulty of transportation and hours of waiting (often as a result of long queues and absence of key health personnel).

“I do not have the energy to go through the big trouble of having to wake up early to walk to the road and get transport to the hospital. It is far away and no taxis. So, I have not been there for many years now”

“When I struggle to take taxi and get to the hospital, I have to wait to see the nurse and then cannot see the doctor because when I am finished with the nurse, the doctor is finished for the day.I have not been to hospital for over a year though I have this problem again and again.”

“It takes a whole day to go there (hospital) and then you don’t get anything because the nurse sometimes say there are no doctors and I leave without seeing a doctor. I go again until many times and then get tired of going. So, I have not been there (hospital) for a long time, probably two years.”

Pharmaceutical treatment

The participants expressed the view that pharmaceutical treatment did not seem to be particularly beneficial. They perceived of drugs as failing to “cure” them. Their narratives focused mainly on the efficacy and ‘toxicity’ of hypoglycaemic agents. They saw the prescribed drugs as ineffective in “curing” their diabetes and tended to comment on the power of herbal medicines, which many emphasized cured the underlying causes of their constant tiredness, weakness and eye vision problem. Whilst they viewed the curative properties of herbs more favourably than hypoglycaemic agents, they reported using them when seeking immediate relief of “surface” symptoms.

"I keep taking tablets for sometime but it hasn't stopped my diabetes. I go to the herbalist who gives me drinks that I take and feel better".

"I don't understand this tablet thing. It is good to have them because I know I have been given something but it is not stopping this thing (diabetes) and the tiredness. The medicine from the herbalist is good for my body."

"I do not have drugs that I am told that I have to take everyday. How can you take drugs everyday if it cannot work? What is the purpose? So, I do not take it. I take the drink that I get from the herbalist."

"I now that drugs are good when you feel ill. For example, I take [panadol] when I have headache and then it stops. But I do not understand this [diabetes] drug, which the doctor says I take everyday of my life. Why? If it cannot help like when I take [panadol] for my headache, why take it?"

"I think what everybody is saying is true..... Why do you take drugs if you have this thing [diabetes] forever? You just have to be careful not to be hungry and weak and then if you are, just try to drink local medicine. It is good because as everybody say, it makes the body heal well."

"Taking drugs every day for life is putting poison in the body. I don't use it anymore for a long time. I drink the local medicine and feel better."

Dietary Management

The participants seemed to agree that food consumption is beneficial to them in managing their diabetes. They seemed to have developed this as a principle with less knowledge of any dietary control which would include limited intakes of carbohydrate, salt, fat and so on. Most of them considered food as necessary to combat hunger and tiredness. What they claimed to eat hardly followed the standard recommended food intake for diabetes sufferers.

"Strong food is the medicine for it [diabetes]. I make sure I eat all the time otherwise I will always feel tired and fainting."

"What helps me is food. I feel tired many times if I do not eat. I have to eat a lot and I make sure I eat before I go anywhere because sometimes, you get tired and people do not know you have to eat."

"I have been having this thing [diabetes] for a long time and I think medicine cannot cure it. When I begin to tire and sometimes feel so weak that I feel like passing out, what always come to my rescue is food. I eat strong food mostly pap (local staple food in powder form made from corn and prepared with boiling water to make a hard paste. This is eaten with vegetable

and beef or lamb. It is very high in carbohydrate).

"I hear that one has to eat little strong food like pap.... But this is not good advice because it is pap that helps me with my tiredness. I just have to eat many times a say."

"I don't like medicine because it doesn't work. If it works, I will not continue having this thing [diabetes]. For me, food is best. I eat a lot because I don't get tired but I am slow sometimes. Maybe too much food.... {Laugh}... but I will not substitute food with drugs."

Physical activity

The participants' narratives revealed that physical activity in any form actually compromises their health. They believed that their tiredness and weakness resulted from "over-work". They did not therefore engage in physical activity as a part of diabetes self-management strategy. Though strenuous physical activity was part of their daily life because of the demands of the rural areas, this was seen as something to avoid. Their physical activities were thus work-related rather than therapeutic.

"I have to do physically demanding work and I sometimes feel a little bit worried because of my condition... which cannot tolerate such activities"

"My body does not like physical activities as I get tired and weak So, I just avoid it"

"It does not make sense to do heavy things (physical activities) because there is no point in creating more trouble when you have this thing [diabetes]. It makes it worse."

"I avoid hard work (physical activity) because it is part of my problem. Sometimes I think that it is not doing me any good if I continue with the long distance walk to the next village. But I have to do it because I go there to sell things."

"I am getting old and need to be careful walking too long a distance. I think it [walk] contributes ... I am careful not to go long distance."

Social support

In the research literature, it has been shown that one of the ways that those under stress cope with it is to seek out social support. Carver et al. (1989) suggest that people seek social support for two reasons, which differ in the degree to which they imply problem focus. They seek social support for instrumental reasons – that is, they seek advice, assistance or information and they seek social support for emotional reasons – that is, getting moral support, sympathy and understanding.

What the present study reveals is the latter support – the participants mostly sought sympathy. The nature of their diabetes condition is that there is hardly any symptom but when they experienced hypoglycaemia, they tend to make it known to all those around them. They did this because:

“When I feel this weakness, I cannot get things done because I can’t lift myself. So, I let people know and I get help.”

“I need people to know to understand that I need help when I find it suddenly not able to do things. They feel for you and help.”

“I need people to take care of me when I suddenly feel fainting. They feel sorry and help. So, I make my condition known to them and I get support.”

“I like the support I get because it makes feel well. Not that the thing [diabetes] stops but I feel relieved with the support. People show understanding and they help.”

“I seek understanding because it is good for my condition especially when I become very weak and feel like fainting. The people around feel for you and help.”

Discussion

The data reveals poor ignorance of diabetes mellitus and poor self-management of the condition among rural dwellers in the Eastern Cape province of South Africa. The participants’ practices of diabetes management were at odds with what has been delineated in the literature as appropriate strategy to self-manage diabetes – an integrated strategy consisting of drugs, physical activity and diet control in daily life. Drugs were perceived as ineffective and toxic, physical activity was regarded, as activity to avoid and cut down where total avoidance was not possible because of the demands of the rural areas. Dietary control did not feature in their strategy for diabetes management. The analyses indicated that participants’ perceptions of drugs, their view of physical activity and the absence of diet control in their management of diabetes were interrelated: hypoglycaemic agents were believed to be ineffective and toxic and to avoid hypoglycaemia, they increased their food intake (their cuisine is characteristically carbohydrate and fat) and took more efforts to cut down on physical activities.

The findings show an *absence* of formal care; in other words formal health care services seemed to play no role in the participants’ management of diabetes. This would seem to have contributed in no small measure to the poor management of the condition as the study shows.

Essential formal service interventions enable improving quality of life and self care which entails the range of illness behaviour undertaken by diabetes sufferers in relation to their diabetes. This would include providing appropriate information and anticipatory guidance: body weight maintenance, blood glucose control, and the treatment of hypercholesterolemia (American Diabetes Association, 2003). There was no evidence for this.

The focus of their self-management was hypoglycaemic control (as evidenced in their concern about “tiredness”, “weakness” and “fainting”), which appears to be in line with formal diabetes care; yet, the strategy was incompatible with medical knowledge. According to current medical knowledge, hypoglycaemic control through dietary is important in diabetes management. An increase in fibre intake and very-low-calorie diet and restricted sucrose-containing food are clearly important. In the participants’ perceptions, regular food intake was considered a legitimate therapeutic modality; however, this was because of the belief that their hypoglycaemia was usually caused by the lack of adequate food intake. Adequate to them meant consumption of very-high-calorie food, the type of which have been found to lead to a diet that has very high carbohydrate, high in saturated fatty acids, excess salt and unrefined sugar. It is important to point out that in as much as food was consumed in abundance to strengthen their physical constitution, that is, as a form of sustenance, it was considered essential ingredient to their quality of life. Food, in their cultural milieu, is salient in solidifying social relationship. So, for them, the idea of dietary control would seem out of place especially because it conflicts with societal norms of attending to the celebrations of others in the rural community. It is therefore reasonable to suggest that adhering to food restrictions, which good management of diabetes requires, thus present unique challenges to the cultural significance of food among rural dwellers in South Africa.

The participants’ misconceptions about food make them overlook the importance of managing other risk factors, for example, body weight gain. Their diet as earlier indicated was hardly restricted and they seemed to be oblivious to weight gain. There was no evidence in their narratives of the cognition of weight gain as detrimental to their diabetes condition. Quite clearly, body weight maintenance did not feature in their management of diabetes. In fact, weight loss would not be considered a goal or important in diabetes management in South Africa because of the stigma associated to body weight loss, which is generally seen as physical evidence of HIV/AIDS. In as much as there is a global trend to look model-thin, this seems to be more among the non-black South Africans. The young and trendy black South Africans, who are easily predisposed to imbibe global western ideas and practices tend to be exceedingly cautious in “loosing too much” weight just as their elders are, for fear of the stigma of HIV/AIDS.

The misconception about food tends to affect, also, pharmaceutical intake. The focus on very high consumption of high-calorie food to combat hypoglycaemia would seem to have contributed significantly to them overlooking the importance of hypoglycaemic oral agents. The participants hardly took prescribed drugs as revealed in their narratives without the knowledge that oral agents for their condition are strictly to control blood sugar, which significantly reduce risk of microvascular complications including nephropathy (Gonen et al. 1977). Much more importantly though, was that hypoglycaemic agents were hardly seen as helpful partly because they viewed it as artificial chemical compounds that are toxic, while herbal medicine, coming from natural sources, was considered safer and more compatible with their physiological functions. To some extent, this would seem consistent with studies that have examined the reasons for non-adherence with drugs, for example, cholesterol-lowering drugs, have focused on medication or patient characteristics. Drug characteristics related to poor adherence have typically been poor drug efficacy, side effects such as nausea and cramping and inconvenience caused by taking the medication in a non-pill form (Bruckert et al. 1999). Patient characteristic related to poor adherence have principally been demographic (Shrott et al. 1997) and lifestyle, (e.g. lack of exercise and higher body mass index – Schrott et al. 1997).

The findings in the present study did not show any active adherence to medication indicating a reflection of the participant's poor knowledge of diabetes more than other valid reasons as those highlighted in the previous paragraph. The fact that they could not distinguish between chronic disease, which diabetes is, and, which is life-long but controllable and acute illness is very salient in understanding the non-adherence to medication of the participants. Prescribed drugs were viewed as curative. In other words they associated drugs to cure; drugs and cure of an illness were seen as synonymous. If one expected to be cured of an illness, drugs were seen as functional to that end. Drugs are thus means to an end. When that presumed end, *cure of an illness*, was therefore not the *real* end, (which is hypoglycaemic control), they therefore, saw no need for adhering to medication and consequently disengaged from taking drugs. This behavioural disengagement came out clearly in the narratives. This can be dysfunctional in the self-management of diabetes because of the proven efficacy of hypoglycaemic agents (United Kingdom Prospective Diabetes Study, 1998). This finding, behavioural disengagement from drugs, is consistent with research on medication adherence which suggests that patients will be least adherent when treatment is preventive rather than curative, when the illness is symptomatic and when the treatment is over a long period (Rand, 1995).

However, it would seem to be important to better understand the disengagement from prescribed medication as an adaptive response. This is because their behavioural disengagement was disengagement from prescribed drugs and not mental

disengagement from their diabetic condition. There was no evidence that they ignored their condition; the evidence is that they did not see any curative profit from adhering to prescribed drugs, which shows, more than anything else, their poor knowledge of diabetes as a chronic illness. The disengagement from prescribed drugs allowed the participants to *retreat* into their cultural milieu to tap into their cultural understanding of their condition and the ways to treat it. They were predisposed to this partly because their cognitive association of the prescribed drugs to cure was challenged. One must stress a point at this juncture. The fact that the participants, who are rural dwellers, were predisposed to seeking permanence to a life-long condition by shunning a medically-proven way of managing the condition would seem to tell us more about illness perception and belief than it tells us about their understanding of chronic illness. This broad statement is underlined by the findings reported in this present paper. Their narratives clearly revealed that where prescribed drugs do not seem to “work”, they would resort to other forms of treatment. Secondly, the participants expect all illnesses to be curable unless, as in their cultural cognitive scheme, driven by a force beyond human control. They hardly described their diabetic condition with a specific frame of reference (chronic or acute). Their discussion was framed in terms of their experience of the illness. For this reason, there is merit in suggesting that the management of diabetes among the rural poor is informed more by their knowledge of the condition.

Conclusion

The research reported in this article was grounded in qualitative data generated from 5 focus groups of 40 participants. The findings suggest that the focus group approach used in the study offered useful means of eliciting and understanding the management of diabetes in rural areas characterized by limited health resources and long distance to such health resource centres. What would seem evident from the study is the importance of illness perception. How diabetes sufferers perceive their condition influence their management of it. The findings show that illness-related cognitions manifest in treatment adherence. Diabetes was hardly perceived as chronic in the sense of life-long and controllable and this formed the basis of the participants’ disengagement behaviour from adhering to prescribed hypoglycaemic oral agents. Partly underpinning the participants’ perception of diabetes is a total lack of diabetes education. The literature shows that patient education in the form of diabetes education, dietetic advice and instructions on self-management of blood glucose is an integral part of diabetes care. The present study provided evidence that there was no such education received by the participants.

What was particularly evident in the focus group discussions is the social support that the participants receive. This is informal support, which involves the support of family (including nuclear, extended family and kin). Unrelated people accepted as family members, supportive neighbours, friends and other community members are part of this informal circle of social support.

One critical point that must be highlighted which would seem highly relevant in health and development policy is that in regard to disease management, the poor in the rural areas are frequently faced with multiple tasks or demands that include accessing health resources and evaluating different treatment options. Many experience what has been referred to as 'access stress' where structural barriers – poor distribution of health services – distance and geography present them from successfully meeting such demands. They find that physically getting to a health resource setting is a Herculean task and tend to give up. Only when they experience very severe symptom of their illness do they push themselves to get to a health resource centre. For a chronic illness like diabetes, this may have adverse effect on the management strategies.

The findings are relevant to clinical practice in rural settings. Several studies of the management of chronic disease have identified the need for clinicians to gain a better understanding of patients' views about their illness and treatment as a basis for clinician- patient partnership. This applies to diabetes care in the rural areas. The findings can be seen as contribution to offering directions for developing interventions to facilitate good management of diabetes in the rural areas. Interventions could therefore address patients' knowledge. Rural sufferers of diabetes should be encouraged to perceive diabetes as life-long conditions that need to be managed even when the symptoms are absent.

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