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Ability to manage diabetes – community health workers' knowledge, attitudes and beliefs

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Background. Diabetes constitutes a significant health problem in South Africa. Early detection and good management can prevent or delay complications, with national guidelines for diabetes treatment now available to facilitate this. However, problems are being encountered with their implementation and there is evidence that preventive care is still inadequate in South Africa.

Community health workers (CHWs) are lay personnel employed to serve as a link between professional health care staff and the community. They visit homes and can be a powerful force for diabetes prevention and adherence to treatment regimens, given appropriate knowledge.

Method. We conducted a study to evaluate the knowledge, beliefs and attitudes of a group of CHWs serving a poor urban area, using focus groups and personal interviews.

Results. The CHWs did not have the requisite knowledge, attitudes and beliefs to make a positive impact on prevention and management of diabetes. For example, they cited eating sugar as a cause of diabetes. They advised folk remedies that purportedly diluted the blood sugar. Their patients took prescribed medication irregularly. Obesity was not considered an important risk factor. Poverty, however, was recognised as an obstacle to proper treatment.

Conclusion. Training is clearly needed to empower the CHWs with skills to work within their communities to identify risk factors for diabetes and other non-communicable diseases, with emphasis on diet and physical activity.

Diabetes constitutes a significant health problem in rural and urban areas of South Africa. Cross-sectional population-based epidemiological data gathered using oral glucose tolerance tests show that the age-standardised prevalence of diabetes in rural areas ranged from 4.6% in KwaZulu-Natal[1] to 6% in the Free State.[2] Corresponding figures range from 4.8% in a partly rural population[3] to 8% among urban blacks in Cape Town.[4] The latter figure is a considerable increase from 3.6% found in a similar population in Cape Town in the 1960s.[4,5] It is not surprising that the prevalence of diabetes appears to be rising in South Africa, as it is in other developing countries, given the ongoing urbanisation and economic changes that increasingly expose the population to documented risk factors such as obesity and low levels of physical activity.[4,6]

There is strong evidence that early detection and good management of diabetes, such as good glycaemic and blood pressure control, prevent or delay complications.[7-9] Internationally, much attention has been given to improving the level of diabetes care and consequently outcome, particularly since the St Vincent Declaration in 1990.[10] However, problems exist with health service delivery in South Africa and diabetes care is suboptimal.[11-13] Health care is poorly funded, leading to overcrowded clinics, inadequate numbers of staff, high patient loads, short consultation times and poor records. Health workers have not received appropriate training, are demotivated, may have problems communicating with patients and do not use protocols for patient management.[11-14] The work of Bradley[15] among general practitioners in the black residential areas of Cape Town also pointed to shortcomings in the quality of diabetes care currently provided to patients. In South Africa, health services focus mainly on the curative rather than preventive aspect of non-communicable diseases.

Community health workers (CHWs) are lay personnel employed to serve as a link between professional health care staff and the community. The positive role of CHWs as key agents in improving health has been widely documented. Assuming that they are equipped with accurate information and appropriate skills, they are in a unique position to influence health behaviour in the communities they serve.[16] Their potential role is particularly important given the deficiencies that exist in current clinical diabetes care.

Very little is known about the knowledge, beliefs and attitudes of the CHWs providing advice on prevention and treatment of diabetes. This information is important because health care providers and non-governmental organisations are increasingly recognising the CHWs' potential role in outreach programmes.[17] To address this issue we conducted a study of the diabetes-related knowledge, beliefs and attitudes of CHWs from a black urban township in Cape Town, where diabetes prevalence is high.

Methods

This study was carried out in Khayelitsha, a large predominantly informal settlement located some 30 km from the centre of the Cape Town metropole. The population of the settlement is approximately 329 000.[18] An estimated 43% of adults are unemployed. The majority of employed people have occupations that are typically unskilled and low-paying.[19] Public health problems such as HIV/AIDS, undernourishment, tuberculosis and inadequate health facilities in the area are matters of concern.

The CHWs included in this study were employed by Zanempilo (formerly known as the South African Christian Leadership Assembly, or SACLA), a non-governmental organisation, to render primary health care services in under-resourced areas in and around Khayelitsha. The CHWs were residents of the area and shared the same socio-cultural and demographic profiles as other members of this community. In 2000, at the request of the community, Zanempilo agreed to add a health-promotion component to the CHW activities that addressed primary prevention of non-communicable diseases such as hypertension and diabetes. The Khayelitsha CHW activities therefore included community support and disease prevention at all levels. Of the 43 CHWs who participated in this research, most had worked as CHWs for more than 5 years.

To examine the knowledge, beliefs and attitudes of the CHWs on diabetes, both qualitative and quantitative methods were used. Two focus groups, each with 8 purposely selected CHWs (chosen on the basis of their regular contact with diabetes patients), were conducted in Xhosa, the local language. The results were audiotaped and transcribed verbatim, then translated into English. The translation was verified by one of the authors (TP), who is fluent in both languages. Three researchers participated in the analysis independently. Content analysis was guided by the objective of the research. Transcribed interviews were read and word codes were assigned to the text. Material was then categorised into headings that arose from coding. These included perceptions about the disease, urbanisation, and beliefs.

Information collected through focus group discussions was used to develop a semi-structured questionnaire for interviews. The aim was to validate the information provided through group discussions. The questionnaire was developed in English, translated into Xhosa and piloted in 10 CHWs who were not part of the study. A total of 43 CHWs were interviewed in Xhosa, a language spoken by all CHWs. In addition to demographics, questions addressed their knowledge of disease, including causes of diabetes, dietary recommendations, treatment, prevention, and the organs most frequently affected. Data from interviews were analysed using EpiInfo version 2000.

Ethical approval for the study was granted by the University of the Western Cape in Bellville.

Results

The independent analysts identified three themes from the focus group discussions. These are given below, with statements made by the group participants during the discussion.

Perceptions of disease

Most CHWs believed that diabetes was caused or aggravated by intake of too much sweet or starchy food. They noted that 'everybody eats sugar even poor people, even if they do not have food they have sugar in their houses, and they can buy sweets from the shop ... they eat a lot of starch which make them fat then they become sick with diabetes'. This was supported by examples of choices of foods that are not healthful, such as high-calorie, high-fat pastries. The CHWs stated that the patients had moved away from their traditions, including dietary habits, and their bodies were no longer strong. Finally, poverty was cited as a cause of disease. 'People also get diabetes because of the cheap wrong stuff that they eat. It's cheaper to buy food with fats, salt and sugar in townships than in rural areas. People buy cheap food because they are poor, meanwhile the cheap food causes them to become sick with diabetes. When you are poor you eat anything in front of you.' And sadly, 'When some people are sick they are told to eat special food for their diabetes, they do not eat it as they cannot afford it because they must share food with the family. Then they do not take their treatment.'

Urbanisation and civilisation

Harmful food habits were blamed on urbanisation. One example cited was sorghum porridge and *imifino* (greens), which historically 'gave people good health' but are now seldom eaten. The group participants felt that economic development had allowed purchase of unhealthy food. There were interesting examples, such as 'There is meat that I am not supposed to eat but because it is easily available in the city, I eat it anyway. We also drink coke more than water, which is supposed to be healthy. We are changing to the Western culture, we eat everything that is not good for our bodies and now diabetes is common.' The CHWs also mentioned stress, saying it was a cause of diabetes: 'People are stressed because there is no work.'

Beliefs

From a medical perspective 'beliefs' are ideas that constitute obstacles to appropriate behaviour.[20] Understanding patient behaviour during illness requires understanding their beliefs and attitudes about their particular disease. The CHWs described variations in prescribed treatment that were motivated by patient beliefs. 'Some people do not take treatment (tablets) because they think it causes kidney diseases. They think that tablets build up in the body ... Some people do not take treatment but take other mixtures such as aloe and camphor ... [They] prepare mixtures themselves, boiling guava leaves, mixing it with other substances. People believe in mixtures because they grew up drinking them as part of their culture.' Sometimes Western treatment is combined with traditional treatment: 'Other people take a break from using treatment for a week while trying the mixtures that a neighbour or a friend have advised them about, but after some time the body gives a signal to go back to the treatment.'

There was considerable agreement among CHWs that patients suffering from diabetes believe they are bewitched. 'Why do all people start itching? Then when they go to see the doctor they are told that they have diabetes ... If a person has itchiness in the vagina, *I will stress on itchiness,* they do believe that there is a snake that is eating her in the vagina.' Sometimes diabetes was termed *unjanyana* (a small dog) because of the amputations it could entail. Others felt that 'this disease has been known for a long time. The name has just been changed from *unjanyana* to diabetes. By then the disease was not cured. A person would just have an itchy body and after some time of continuous itching they developed sores or even wounds that would not heal; later they would lose a toe or a foot.' CHWs noted that 'When told that they have diabetes some people think it is a death sentence because they must take the medicine for the rest of their lives.'

The CHWs stated that some people believe traditional doctors can cure diabetes, especially if one is bewitched. 'If you go to traditional doctors they give you bitter medicine which helps to dilute the sugar in the blood ... When people who take medicine given by traditional healers go for a check-up they are told that their blood sugar level is low.' Overall, the CHWs stated that 'We do have that belief that there is something evil about diabetes.'

It is therefore not surprising that many participants felt that Western medicine alone could not cure diabetes. In addition to the bitter mixtures, Tim Yan (which contains alcohol) was also used as medicine because patients believed it made them sleep well. 'Families used to keep a bottle of brandy filled with herbal mixture; we were told to drink from it to keep our bodies strong so that we would not get sick.' The CHWs reported the belief that traditional medicine should not to be combined with Western medicine. 'Other people are not supposed to go to the doctor; the ancestors (*amadlozi*) don't want to be mixed with white people because they weaken the effect'. Some CHWs realised that diabetes cannot be cured but that it can be treated with food, medicine and exercise. In general, however, the CHWs believed that traditional healers could cure diabetes, and traditional medicine was perceived as the best medicine.

The structured interviews echoed some of these same themes. Tables I - IV show the responses of the 43 CHWs to the interview questions. Again, almost all respondents felt that too much sweet food was a cause of diabetes, with too much fat mentioned by over half. Approximately one-third mentioned genetic endowment (37%) or witchcraft (30%). When asked about the organs affected in diabetes, more than half the CHWs cited the heart and only 3 mentioned the pancreas. When asked what advice they gave to diabetic patients, the CHWs said patients should eat less sugar and take bitter substances to dilute the blood sugar. At most, 5 of the 43 CHWs mentioned each of the usual preventive recommendations, viz. exercise, proper eating habits, and regular treatment. Measures taken in the community to control diabetes mirrored previous answers; viz. cut down on sugar and fat, and use the traditional bitter mixtures. Surprisingly, medical treatment was mentioned by 40 of the 43 CHWs.

Table I. Perceived causes (risk factors) for diabetes (*N* = 43 CHWs)

	Mentioned		Not mentioned	
	N	%	*N*	%
Lots of sweet foods	37	86	6	14
Too much fat in the diet	24	56	19	44
Inheritance	16	37	27	63
Witchcraft	13	30	30	70
Overweight	5	12	38	88

Table II. Organs perceived as affected in patients with diabetes (*N* = 43 CHWs)

	Mentioned		Not mentioned	
	N	%	*N*	%
Heart	22	51	21	49
Blood vessels	6	14	37	86
Pancreas	3	7	40	93
Kidney	2	5	41	95
Lungs	1	2	40	93

Table III. Advice (lifestyle modification) given to diabetic patients (*N* = 43 CHWs)

	Mentioned		Not mentioned	
	N	%	*N*	%
Eat less sugar	28	65	15	35
Take bitter substance to dilute sugar	30	70	13	30
Do exercises	4	9	39	91
Eat lots of vegetables	2	5	41	95
Take treatment regularly	5	12	38	88
Have time to relax	3	7	40	93

Table IV. Measures taken in the community to control diabetes (*N* = 43 CHWs)

	Mentioned		Not mentioned	
	N	%	*N*	%
Do not use sugar	18	42	25	58
Remove fat from meat	16	37	27	63
Use bitter mixtures	14	33	29	67
Eat lots of vegetables	9	21	34	79
Traditional medicine	5	12	38	88
No alcohol	3	7	40	93
Control weight	2	5	41	95
Medical treatment	40	93	3	7

Discussion

Diabetes is characterised by acute metabolic abnormalities, chronic microvascular and macrovascular complications, and premature mortality. However, early identification and proper management of complications can prevent their progression. National guidelines for diabetes treatment[21] have been developed to facilitate this, but problems are still being encountered with their implementation and there is evidence that preventive care is still inadequate in South Africa. Both the patient and the health care personnel may be responsible. Patients may lack knowledge and/or default on their treatment, while the health care system may lack adequate drugs and/or staff to provide proper care. Studies conducted in Cape Town and Gauteng have previously demonstrated major deficiencies in the quality of care of people with diabetes who attend primary health care clinics.[4,12] In Gauteng, for example, only 33% of all patients were considered to have properly managed care, while all of the individual facilities had at most 40% of patients with satisfactory blood glucose levels.[12]

For many years CHWs in Khayelitsha have reported that diabetics in their community were not being seen at clinics to receive medicines and health promotion advice. An examination of records of local residents in one of the Khayelitsha clinic areas showed that indeed 40% of diabetics were not attending clinics regularly and had not received treatment for a period of more than 6 months.[22] This situation underscores the need for the contribution of the CHWs, who visit homes and can be a powerful force for prevention and adherence to treatment regimens.

But do the CHWs have the necessary knowledge, attitudes and beliefs to be such a force? The CHWs in this study did not. For example, eating too much sugar was the item most frequently cited as a cause of diabetes and as a result, eating less sugar was the primary lifestyle modification suggested to diabetic patients. The next most frequently given advice was to take a folk remedy that purportedly diluted the blood sugar, the 'bitter mixtures', and this was also suggested as a community-wide measure to control diabetes. Urbanisation was thought to encourage harmful food habits, minimising patient responsibility in making wise choices. Advising patients to adhere to a medical treatment regimen was mentioned by only 1 in 8 CHWs. Furthermore, although obesity is a risk factor for type 2 diabetes, the CHWs did not mention it as an important issue in controlling the disease. This is probably because of positive beliefs about obesity in this community.[23,24]

The CHWs were very aware of the power of poverty and how it made coping with a serious illness more difficult. Financial hardship is a barrier that should not be ignored because it is a contributory factor to non-compliance. Treatment must wait until food has been taken, after which the treatment may well be forgotten. The problem of how to control diabetes cannot be solved until some progress is made in relieving poverty, and health personnel may need to find ways to assist poor patients with chronic conditions to maintain treatment regimens.

A recurring theme was the combination of medical treatment and traditional remedies, including herbal medicine. This was also reported by Daniels *et al.*,[14] who found that patients discontinued prescribed medication in favour of traditional remedies. This behaviour, which also seems to be common in other cultures, may be caused by patients not realising that treatment is necessary even in the absence of

pain. This is of special concern because most black South Africans do not have medical checkups and seek help only when they experience pain.[25] If the idea of a chronic condition is not clear, patients may expect medicine to effect a cure and not understand why they should continue with the treatment for life. They therefore conclude that Western medicine is not very effective, and resort to traditional remedies. The interface of traditional and Western medicine is an area in which CHWs could be particularly helpful, since their heritage leads them to value and support traditional remedies, while their training can provide an accurate perspective on the importance of Western methods.

The results of this study indicate a need for training the CHWs in the prevention and treatment of diabetes. This training should include the role of diet and physical activity in causation and control of non-communicable diseases including adherence to medication for those who have been diagnosed. Materials already exist at the School of Public Health, University of the Western Cape. A trainers' guide has been specially written with CHWs in mind, focusing on the role of diet and physical activity.[26] The aim of the training is to empower the CHWs with skills to work within their communities in identifying risk factors for non-communicable diseases with emphasis on diet and physical activity. Key messages to be used in the community are also included. A training programme was implemented at two sites (sites B and C) in Khayelitsha during 2002 - 2004.

CHWs can now begin to educate community members on what they have learned from the training. This will enable them to provide an interface with the health care system, and to offer culturally sensitive and medically accurate dietary and lifestyle information on disease to the residents in their community. The ongoing evaluation of CHWs is crucial as more health care providers and non-governmental organisations make use of their unique position in the community for outreach programmes. We hope this model will be replicated in other provinces in South Africa.

One of the limitations of this study is reliance on what CHWs had to say about patients' beliefs (patients were outside the scope of this study). Only two focus group discussions were held because the purpose was to obtain ideas for developing questions, but not to reach saturation (until no new ideas are discussed). The two sets of CHWs are representative of Xhosa-speaking CHWs, so the results could be generalised among the Xhosa-speaking population. Similar studies should be undertaken among other CHWs from different ethnic groups.

Studies are also needed to explore why patients often combine traditional and Western medicine. A mechanism should be developed to encourage a working relationship between medical practitioners and traditional healers. Unless this relationship exists, it will be difficult to control diabetes in the black population.

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