

# Rural-Urban Disparities in Health and Health Care in Africa: Cultural Competence, Lay-beliefs in Narratives of Diabetes among the Rural Poor in the Eastern Cape Province of South Africa

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## Abstract

*Rural-urban disparities in health and health care in Africa have been well described; yet, they remain relatively of less concern among many issues in health and health care in Africa. The disparities have been documented to exist in the utilization of cardiac diagnostic and therapeutic procedures, prescription of analgesia for pains, treatment of diabetes (e.g. gym exercise). Among the fundamental root causes of these disparities, which, can be gathered through studies of the health care systems (biomedical and African health systems) are variations in patients' health beliefs, values, preferences and behaviour. Informed by the need to address the seemingly wide rural-urban disparities in health and health care in Africa, this paper brings to the fore rural patients' recognition of symptoms, threshold for seeking care and the ability to understand disease management strategy, all of which are part of the variations in patients' health beliefs and values. The strategy adopted for foregrounding these disparities is through narratives of diabetes by patients in a rural context in South Africa. The chief aim is to contribute towards improving the quality of health care through incorporating patients' understanding of health. The narrative is subsumed under cultural competence and lay beliefs.*

**Key words:** *healthcare, rural-urban disparities, cultural competence, lay beliefs, diabetes*

## Résumé

*Les disparités urbaines-rurales, de la santé et des soins de santé en Afrique ont été bien décrites ; pourtant, ils restent relativement moins préoccupant parmi les nombreuses questions de la santé et des soins de santé en Afrique. Les disparités ont été documentés pour exister dans l'utilisation de procédures diagnostiques et thérapeutiques, la prescription de l'analgésie pour les douleurs, traitement du diabète (p. ex., exercice de gymnastique). Parmi les causes profondes de ces disparités, qui, peut être recueillie grâce à des études sur les systèmes de soins de santé*

*(recherche biomédicale et les systèmes de santé africains) sont les variations de la santé des malades, croyances, valeurs, préférences et comportement. Informé par la nécessité d'aborder le vaste exode rural des disparités en matière de santé et de soins de santé en Afrique, ce document met en avant les patients ruraux' reconnaissance des symptômes, seuil pour demander des soins et la capacité de comprendre la stratégie de gestion de la maladie, qui font tous partie de la variation de la santé des malades, les croyances et les valeurs. La stratégie adoptée pour la mise en ces disparités est par récits de diabète par les patients dans un contexte rural en Afrique du Sud. L'objectif principal est de contribuer à l'amélioration de la qualité des soins de santé en intégrant les patients à mieux comprendre la santé. Le récit est subsumé sous la compétence culturelle les idées reçues.*

**Mots clés :** *soins de santé, disparités rurales-urbaines, la compétence culturelle, les croyances, le diabète*

## Introduction

This paper is an outgrowth of a three-year study of the management of diabetes among the rural poor in the Eastern Cape province of South Africa. The study was conducted between 2011 and 2012 with a re-visit in 2016. It has one main objective: to show, through narratives, how poor women in the rural areas understand and deal with diabetes mellitus type 2 and the significance thereof in highlighting and addressing rural-urban disparities in health. Among the issues in health and health care in sub-Saharan Africa, which has majority of its population living in the rural areas, rural-urban disparities seem to be less of a concern than it should be in many countries. Yet, the issue is well documented, with data showing that rural dwellers suffer disproportionately from chronic illnesses such as diabetes, arthritis and hypertension among other health conditions, and requiring determined attention. What gives rise to the disparities are multifactorial, nevertheless, the most significant factors seem to fall under socio-determinants of health such as the economic conditions of the rural poor, the literacy level or low levels of education of those in the rural areas and in some cases, environments harsh to rural living. For example, in many rural areas, the proximity of sources of water (streams and rivers, which are often polluted) to villages is quite a distance.

In terms of the quality of care experienced by those who have access to the bio-medical health care system, rural-urban disparities would seem obvious. In this regard, the disparities, as have been shown, exist in the use of cardiac diagnostics and therapeutic procedures, prescription of analgesia for pain control, treatment of pneumonia, arthritis and other chronic conditions. What is evident, in many studies that have explored health conditions and utilization of health care systems, is that rural dwellers tend to rely more on the African health systems than the bio-medical health system and are more likely to combine the two in the treatment of their ailments. The fact of this would seem to suggest variations in patients' health beliefs, values, preferences and behaviour.

Besides, many studies focusing on access to bio-medical health care have shown the extent to which this is greatly difficult in rural Africa than in urban Africa (Obuaku, 2014) resulting in significant reliance and utilization of the African health system. The point about access cautions against simply equating rural dwellers to African health systems in terms of utilization of health care, and urban dwellers with bio-medical health system, which seems prevalent in the literature. However, it does alert us to significant rural-urban disparities in health care and draws attention to the long-known character of health policy and indeed economic development policy in Africa: urban bias, which is essentially the allocation of national resources disproportionately to the urban areas despite the rural areas containing the bulk of the population. It is long known, because, it has a long history, as a product of the desire of the newly independent African nations, to industrialize along the similar line of Western industrialization. Development economists have shown that most of the African countries' development plans, usually, five-year plans, excessively emphasize industrialization and tend to neglect rural development. This still persists and compounded by the changing urban landscape in Africa with increased urbanization, a product of population growth and migration from the rural areas and, as we see in some African countries, South Africa, for example, migration from countries with low-level wars.

Taking this point further, it is noteworthy to emphasize that contemporary statistics show that more than half the world populations live in urban areas (United Population Fund, 2007) 'including roughly 50,000 settlements of at least 50,000 people. It has been suggested that population growth in the future and beyond will be mainly in the urban areas especially in the 500 or more cities that have well over one million to ten million inhabitants and mainly in poorer countries. In sub-Saharan Africa, it is known that the bulk of the population lives in rural areas; however, as earlier pointed out, the proportion of the population living in the urban areas is rising and fast. With the growing population in the urban areas and the increase in the gap between the rich and the poor in most African countries, it is obvious that there would be risk to health especially where urban water supplies are polluted; as currently the case, badly planned areas have become more susceptible to crowding, experience the spread of infectious diseases, flooding and intermittent electricity. Despite this, it remains the case that urban health is relatively better than rural health. Those who focus on rural health in sub-Saharan Africa provide the general features, which only describe and explain it. One such study, which has received world attention is a study of suspected malaria in the rural areas in Africa and Asia (Bangladesh, Ghana and Tanzania)<sup>(United Population Fund, 2007)</sup>. This study randomized 17,826 patients with suspected malaria in rural areas to rectal artesunate or placebo before referral to a healthy facility. The key point in the study is delayed treatment because of access to health facility in rural areas and the consequence thereof. This is a significant weakness of the health care system in Africa, generally: the failure to deliver effective treatment in time.

This failure evidently contributes to avoidable death. As the study shows, while mortality did not differ between groups, the composite of death and disability was significantly reduced in people who received artesunate, in an analysis that was restricted to those with confirmed malaria. Crucially, the effect was largely limited in participants who were delayed for more than six hours before arriving at a health facility - the risk ratio was 0.4919 (95% confidence interval 0.32 to 0.77). Besides the clinical questions raised by the study, described as an “outstanding logistical feat”, which “clearly highlighted that treatment of severe malaria in remote areas can reduce morbidity and mortality” (United Nation Population Fund, 2007) is the need for information on cultural beliefs about illnesses. This, with factors such as transport, distance, impressions of quality of care, will undoubtedly, contribute to highlighting the rural-urban disparities in health and health care in sub-Saharan Africa. It cannot be ruled out that those in the health sector, governments and policy makers are aware of this need especially because of documented variations in health which, include among others patient recognition of symptoms, thresholds for seeking care, the ability to communicate symptoms to health care professionals who would easily understand them, and the ability to understand prescribed management strategy of chronic illnesses and adherence to preventive measures and treatment regime. These factors are crucial in rural-urban health disparities. Understanding them would seem crucial in addressing the disparities. When the health system incorporates, at all levels, its understanding of health beliefs and behaviours, and, how these interact with disease prevalence and incidence, and treatment, then, surely, such a system becomes generally strengthened in terms of health care delivery to the wider population. This assumption underlies the current study, which focuses on the understanding and managing of diabetes among the rural poor. Of significance, as earlier noted, are cultural competence and lay beliefs.

## **Cultural competence and lay belief**

To be sure, the idea of cultural competence, which arguably is integral in some biomedical health care systems, remains conceptually, an idea that lacks consensus. The literature has been very wide ranging in its utilization: in some cases, it is articulated as cultural sensitivity; in some other cases, it is considered as cultural responsiveness or cultural effectiveness as in the work of many others (Betancourt et al, 2005). Nevertheless, cultural competence can be understood at two levels: at the level of the health care system, in particular, biomedical health care system. Included in this is the knowledge of the “other” - the understanding by the professional health care provider of the patient, in cultural context (Lavizzo-Mourey & Mackenzie, 1996). It can also be understood from the perspective of the patients; here one refers to lay beliefs and values in the understanding and management of diseases and illness. Regarding the former, a

health system can be considered culturally competent when such a system has a high level of awareness of the cultural context of the understanding and treatment (cultural knowledge) of a disease and illness, takes this into account at all levels of therapeutic care, including diagnosis, and, mindful of the dynamics resulting from differences in culture. Whereas, at the level of those receiving care, it refers to their values, the belief held by them, their understanding of disease and illness. This conception of cultural competence is put forward, only, when there is evidence of a certain level of integration and interaction of health beliefs and behaviour in the management of illness and treatment of disease.

This conceptualization of cultural competence enables a better understanding of practices such as lay diagnosis and treatment of illness and disease in the rural arrears. To some extent, there is similarity in this conception and the cultural competence in the well-researched health disparities along racial/ethnic lines. Researchers have shown that cultural competence has the goal of developing a culturally competent workforce and healthcare system for delivering the best quality care possible to patients' irrespective of their race, ethnicity, culture or language ability. The assumption, rightly so, is that there are gaps in healthcare among racial and/or ethnic minorities. Research has shown, also, that the gaps are a factor of a complex web of endemic problems such as poverty, racism and prejudice. Culture complicates this complex problem of healthcare disparities. In general, making cultural competence an integral part of healthcare is thus critical in that it promises the means for reducing the rate at which health disparities occur. It could also increase the likelihood of more positive healthcare delivery outcomes for all patients. This applies not only to racial/ethnic health disparities, which seem to get far more attention of scholars and researchers in the social and political sciences, but also to rural-urban disparities in healthcare. The rural-urban disparities in Africa have a different root: urban bias of national government developing plans, which was earlier highlighted

## **The study: Diabetes and its management**

There is the consensus that diabetes is on the increase in many parts of the world. Researchers in South Africa agree that this is also the case in the country. As early as 2001, it was noted that the number of people with diabetes would increase from 135 million to 300 million by 2025 (Norris et al, 2001). Yet, it received less than the appropriate concern, especially in countries such as South Africa, largely as a result of the dominance of HIV/AIDS disease in public health discourse. HIV/AIDS disease also accounts for a sizeable chunk of the health care costs,<sup>1</sup> which does have a significant bearing on the care costs for other chronic diseases. However, with the concerted effort

of health researchers and activists, there is a growing focus on diabetes and other chronic diseases such as hypertension and arthritis in South Africa. The rural areas remain less served with this new focus. Indeed, current evidence suggests that rural dwellers are less likely to receive appropriate and timely treatment for diabetes. This, as earlier noted, is a function of general systemic problems rooted in the socio-economic realities of the rural dwellers, who are less likely to have access to health care resources and high-quality care and medical insurance coverage.

Type 2 diabetes mellitus is the more common of the two types in South Africa, as in many other parts of the world. It is a chronic condition, which requires constant management if blood glucose levels are to remain stable and good health is to be achieved and maintained. Some people find diabetes a very difficult condition to manage despite a reasonable knowledge of it. This would suggest that knowledge of diabetes in itself is insufficient to explain why some people achieve satisfactory metabolic control, more readily than others. It has been hypothesised that psychological variables such as perceived locus of control (optimistic belief, for example) might have an important impact upon the quality of diabetes management and control. What would seem evident from study of which the current paper is an outgrowth is the importance of illness perception or what is known in the literature as illness representations (Oloyede, 2012). This refers to the beliefs or cognitive models that individuals construct about an illness, and hence is a means to understanding and making sense of the illness experience. The beliefs about an illness are considered to be important for determining an individual's response to an illness. Psychological models such as Leventhal's self-regulation model (Leventhal, Meyer, and Nerenz, 1980; Leventhal, Nerenz, and Steele, 1984) posit that people's cognitive representations of illness play an important role in influencing their strategies for coping with an illness and associated emotional responses.

According to the model, illness representations are directly related to coping and through coping to outcome. Coping is therefore seen as a mediating factor between the two. This has prompted further investigation to identify whether illness representations have a direct bearing on outcome and the extent to which these beliefs have predictive value in determining outcome. The results from such studies suggests a pattern of relationships that demonstrate that the components in the illness representation model (identity, label attributed to the illness and the associated symptoms; time-line, expected duration and course of the illness; consequences, short- and long-effects of the illness and its physical, social, economic and emotional effects; cause, factors considered to have led to the development and onset of the illness and cure/controlability, what the individuals believe that they or the medical professionals can do to control the illness or bring about recovery) are more strongly related to and better predictors of outcome than coping strategies (Orbell et al, 1998; Heijmans, 1998; Scharloo, 1998).

A result of the main study (Oloyede, 2012) shows that how the diabetes sufferers perceived their illness influenced their management of it. Although not always formally

considered in treatment, illness-related cognitions may manifest in varying degrees of illness-related disability, emotional distress and treatment adherence among patients, irrespective of their illness (Hagger and Orbell, 2000). This present study tries to elucidate this. There is a reductionist representation of rural dwellers and these have arguably done little to encourage their actual experiences with challenges of diabetes. In this study, a different approach is taken drawing on individual experience to highlight challenges for rural dwellers with diabetes and how they cope with it. The coping literature suggests two main types of coping strategies: emotion-focused and problem-focused. The former describes processes, primarily cognitive that are directed at lessening emotional distress, which can include the use of avoidance, minimization, distancing, selective attention, positive comparisons, and wresting positive values from negative events. The second of the two types, problem-focused strategies refer to the attempts at defining the problem, generating alternative solutions, weighing the alternatives in terms of the costs and benefits, choosing among them, and, acting.

Both types have been studied using a variety of research methods. However, in order to gain a perspective on the experience of rural dwellers with diabetes, the narrative approach is adopted. Williams (1984) argued that the chronically ill person engages in a 'narrative reconstruction' in trying to establish a functional purpose in relation to his/her body, the illness, society and his/her self. Burry (1991) suggested that chronic illness unfolds in such a way that the trajectory is uncertain and thus the situation is constantly changing, which means that individuals engage in negotiating the meaning of their situation. This would imply in the case of diabetes that the experience of attributing a meaning to the condition by rural dwellers and the way of life in the context of the illness in the rural areas in which they live would be fluid. Diabetes sufferers would be fully engaged in this fluidity both in terms of a person and member of society accordingly. The present study set out to explore how far the narrative approach could elicit data concerning the everyday experience of living with diabetes and how it is managed. The rationale for the utilisation of this approach is set out immediately below.

## Method

For this study, the qualitative anthropological method of inquiry was considered useful especially because the questions surrounding the understanding and treatment/management of an illness or disease involves active listening for meaning in tone, word choice, body language, or spatial and temporal clues. In the wider literature, taking the patients' views into account, is considered important in developing services. This is similar to the issue at hand in this study. There has been a range of methods in identifying patients' views. For example, questionnaires have been used to determine patients' views especially in assessing their preferences. Surveys and consensus methods

such as Delphi and nominal group techniques are used to ask individuals to rate, rank or vote for different types of care or attributes of care. However, this study adopts the narrative approach which is a well-established qualitative method of research. Its advantage becomes clear when contrasted with the quantitative methods and its attempt to quantify components of experience, which does not capture the expressive quality of being ill, the complex and pervasive world of illness (Radley, 1993). Qualitative methods are better able to capture such complexities; however, some approaches still fragment the worlds of those who are studied by abstracting pieces of discourse from their social and temporal context (Murray, 1999). A narrative approach with its emphasis on preserving the contexts in which stories are told, allows the understanding of both the conditions of diabetes and the ordinary day-to-day experiences of coping with the disease by rural dwellers and commonplace interactions, reflected through their experience of diabetes.

By narratives is meant stories narrated by people about themselves or their lives. Such stories, which are usually about life events, are narrated in a manner that gives meaning to the life events through linking them to other life events, and by providing, according to Hyden (1997), temporal ordering of these events. Clandinin and Connelly (2000) suggest that narratives display the context for human activity – temporal, spatial, interpersonal and societal – because they are situated within a broader sociocultural context. Precisely because of this, narratives reveal structures and processes (including those relevant to race and class), not just personal realities (Murray, 1999). Bell (1999) notes that through the stories that people narrate, they construct identities, revise them and try out alternative configurations of self.

Over the years, health and illness researchers have built up a substantial body of knowledge in understanding illness experience using the narrative approach (see for example, Bell, 1999; Ezzy, 2000; Frank, 1995; Good, 1994; Murray and McMillan, 1988; Williams, 1988). Through narratives of ill people, it is known how illness becomes integrated into people's lives and the various socio-cultural factors that impinge upon the process. However, it is through the structure for the analysis of the narratives that one is able to get a clearer picture. Efforts have been made in this direction by a number of theorists. Nussbaum, 1986, Barnard, 1995 Frank, 1995 and Davies, 1997, for example, identified narrative 'types'. Frank (1995) described three 'types' of narratives: a restitution narrative, wherein the teller minimizes the experience of illness and sees it as a temporary interruption that will be overcome; the chaos narrative, where the ill person loses any sense of order, meaning or purpose and is unable to articulate a coherent path for dealing with illness experience and thirdly, the quest narrative. This type of narrative is when illness becomes a challenge to be met. Quest narratives typically involves the narrator seeing himself/herself on a journey in which heroic acts will be necessary and where good can overcome evil.



In dealing with HIV-infected men, Ezzy (2000) factored in the temporal dimension, highlighting how key time is in people's framing of their lives. He suggested the following 'types' of narratives: *restitutive linear narrativism*, which reflects the assumption that the future can be controlled through people's actions. *Chaotic linear narratives*, Ezzy's second type, anticipate a life that cannot be brought under control, and will result in despair and depression. The third type is the *polyphonic narratives*. This type places emphasis in the present, with the future portrayed as uncertain and ultimately unmanageable. Spiritual experiences are included in the narratives and they tell about increased insights and deepened self-understanding. In the study reported here, the women were given the 'platform' to tell their stories of diabetes type 2. These stories are presented and then analysed.

## Participants

The women in the study were part of a bigger focus-group study mentioned earlier. Participants for the bigger study were recruited over a 7 months period from hospitals and health service centres in the district municipalities of Nkokobe and Amahlathi. Both have a population of 143,167 and 137,618 respectively. There were 40 participants in the bigger study: thirty women and ten men. The average age of the participants was 44 years. The participants were considered eligible for the study if they were diagnosed as diabetic at least twelve months before the study. The average period since being diagnosed with Type 2 diabetes was 7 years. This paper limits its focus to three of the twenty women recruited for the larger study. It was evident in the focus-group study that the management of diabetes Type 2 by the rural women in the study was different from the men, hence this present study to explore this experience further.

## Data collection procedures

The three women for this study were selected from three of the five focus groups in the bigger study. These were the women who were more outspoken in the focus groups. The most outspoken woman in each focus group was approached and asked if willing to spend an extra hour per week for a four-week in-depth, open-ended interviews. Three of the five women approached took part in the narrative reconstruction of their diabetes. These were those who availed themselves for the interviews. The interviews were conducted once weekly to allow for a review of the contents and identify questions that might reveal further information. Upon acceptance, a meeting was held with the four women during, which it was explained to them that there were no differences with the focus group study as such except that each one of them would have to be interviewed individually. The interview would be researcher-driven but they would be given room

to speak freely, just as in the focus-group study, on any issue relating to their experience of diabetes.

The interviews started in the fourth week of the focus-group study. The first set of interviews was mainly the description and discussion of the women's type 2 diabetes experience. They were asked to detail their experiences of being diagnosed diabetic, the relationship with health professionals, how they manage their diabetes, their family, spouses and family members' involvement with their management of their condition. Further questions were asked in subsequent meetings about the women's life before their diagnosis including what they do to sustain themselves in their rural setting. The last meeting focused on the women reflecting on life before and after diagnosis. The interviews were audio-taped and transcribed verbatim before being translated from Xhosa, the language of the participating women, to English. During the interviews, field notes of what was observed were kept which were used in the interpretation of the interview data.

## **Data analysis and reporting**

The transcribed and interpreted data were read carefully to tease out core aspects, especially those that were connected to the socio-cultural context of the women participants. There was focus on health belief, coping style and social support. The identification of socio-cultural factors that moderate the effects of chronic illness is important for those who wish to understand the mechanisms of coping with it. For example, social support, which is broadly defined by Cohen and Syme (1985:4) as "the resources provided by other persons" has been shown to moderate the adverse effects of chronic illnesses and stress (Cairney et al., 2003). In actual sense, social support may take many forms such as received support (actual support) or perceived support (potential support), but conceptually two types have been distinguished. These are functional and structural support. The structural type of support refers to the quantitative aspects of support such as network size. Functional support refers to the qualitative aspects of interpersonal relationships, that is, the degree to which one believes help is available.

## **Results**

The results of the study are presented through three descriptive narratives. Part of the ethical guidelines for conducting the study requires that the names of the study participants are not revealed. This was contained in the confidentiality agreement with the women. What this therefore means in the presentation of the narratives is that names will be altered. The ages are left, so also is the setting of the study.

# Pinkie

## Background

Pinkie is in her mid-50s and seasonally employed in an agricultural setting. She has been in this form of employment for almost 15 years; her earlier jobs were in a white-owned retail store as a shop cleaner and after 5 years as a shop assistant with stacking responsibilities. She was married briefly in her early twenties until she became separated from her husband in her late twenties when her husband left her for “other women” in Johannesburg. She has two children from the marriage and another from a male lover; all three are aged 32, 29 and 22 years. She grew up in a family of 7, three females and two males. Her mother worked as a domestic worker in a “rich white home”; her father was in the mines and came home once in a year which was not regular after sometime. All the children in the family had at least four years of primary school education with the support of their mother but were mostly self-sponsored after that. In her case, she stopped after 5 years of schooling when her mother became diagnosed with arthritis, which she later died of many years after. Within the family, she was the most economically active entering into paid part-time employment as a bagger for a grocery store in her teens before securing full time employment as a cleaner in a retail store. She looks after four of her grandchildren in a low-cost house; their parents are in East London, Port Elizabeth and Umtata and are all co-habiting.

## Illness story

Pinkie was diagnosed, as diabetic at the age of 43 but before that has been experiencing what she never knew was diabetes type 2. This was almost 4 years before she was clinically diagnosed. She was hypoglycaemic most of the time and never paid attention to it. “I just was always tired and hungry. I didn’t know why I keep becoming hungry because I ate *Pap* almost all the time. In the beginning, I thought I wasn’t eating enough. I increased my intake and I must say it helped. I still do because it is now like medicine to me. One day ... after I think a year or so of this *tiring problem*, I collapsed as I was coming back from town. I was lucky to have people around who rallied round and took me to the chemist.... You see, we use the small chemist for any type of ailment. ...So, it was normal to take me there first. Hospital is far away and we have to take transport which is not easily available especially at the time I collapsed”. After this experience, Pinkie became much more concerned with her condition. “I started to think about collapsing whenever I have to walk the distance to where I was working. Though nothing happened for some time but I think about it all the time. I made sure I ate. .... But it is not just the hunger thing

alone but my eyes were becoming weaker. I find that sometimes objects are not clear. At the same time I was having headache but it is the tiredness that was the most worrying.” This constant worry precipitated anxiety, which manifested in regular passing of fluid – urination and sweating. “I then became sweaty and have to use the toilets every time.” It was this experience that led to the first visit to the clinic. There, she was advised to see the Doctor, which she did on a second visit. “The Doctor told me to go for a blood test. I went and then went back for the result but the nurse that I saw said that I should come back because the Doctor was away on an emergency. .... When I eventually saw the Doctor, he told me that I seem to be diabetic and said I needed to do sugar test.... I was asked to go and weigh myself... Oooooo [exclamation]... I must have weighed heavy because I really was heavy. After this, I was then told that I needed to be taking some tablets everyday because I have too much sugar and that my weight was too much. They also said that I needed to do some exercise and eat certain food. ... Hmmm. The food issue .... I can not understand because it was small quantity and I said to myself ..... In fact I asked the nurse, how can I eat so little when I feel hungry all the time. Don't you eat not to feel hungry? Don't you eat enough to have strength? I never quite understood the diet regime. .... I must say I have not taken to their advice on food intake”.

In the years following the diagnosis, Pinkie has had to be slow down in her regular everyday task. She did not because of any particularly serious diabetic-related health problem but that she felt she needed to because she believed she was too active. “I just took it easy but as you know, you do not get yourself off activities in the rural areas. There is always what demands your physical energy and I did this but not much of it because I was too scared of collapsing... You see, I became a bit scared because of the children... Who do I leave them to? They needed me at that time because they were still struggling to get themselves together and I felt that I have to be there for them. They had no father as far as I was concerned. In a way, I was scarred of the future and have to place myself in the hands of God. I must say that it was not as I thought it to be. When I was told it is diabetic but can be controlled, I never for once completely believe because Doctors say that all the time and those they say that to suddenly die. Hmmm. .... Doctors. They are clever. Aren't they? They tell you nicely that things are under control but you discover that it is just to make you feel fine”.

Pinkie has never had to take the drugs she was prescribed because “it is too much to put *poison* in your body”. The fact that Pinkie has not been taken the relevant oral medication as prescribed, does not necessarily mean the end of life but the potential is there if the self-management of her condition does not include other component critical to the management of diabetes and the prevention of complications. Medical literature suggests that diabetes is the leading cause of blindness, kidney failure and foot amputation. The fact that Pinkie seems not to adhere to medication, which she viewed as “poison”, reflects, to a degree, a major culturally related belief because she added “I have heard that this type of medicine, the ones you just take everyday, damage the [kidney]

and it is not lie if I have to go the traditional medicine route which has curative power. I have not done that but I am saying in our culture, it is believed that traditional medicine cures and it does. .... It does.” Pinkie’s management of her diabetic condition has, also, a strong spiritual dimension, which tends to provide her the hope, which she expressed in her story. “I have become convinced that that I shall overcome it although it is a long time now since I have taken prescribed drugs. I know people who are ill for a long time and they become well. I have this very strong thing inside me that this tired illness will stop. .... It has not been as serious as when I fainted but maybe because I now eat strong food [carbohydrate rich meal]. My children have been helpful too because they advised me not to eat too much salt. I believe strongly that it is what I have in me that says I’ll overcome it that is more the reason for my hope. ... Yes, I know they say it is long-lasting but body ailment can be cured unless it is time for one to go to one’s maker.”

### **Pinkie’s story-telling style**

Pinkie spoke about her diabetic condition freely. She never deflected the focus away from her experiences. She did not tell it in an abstract sense; she put it the way she understood it. She adopted a ‘story-teller-approach’, in order words, she had an air of confidence; the story was hers. She exuded knowledge of her experience but not necessarily an understanding of diabetes that is consistent with conventional understanding.

## **Lindiwe**

### **Background**

Lindiwe is a 54-year-old grandmother, born in the same village where she still lives. Her husband died a year before the present narrative of her diabetes mellitus type 2. She was brought up together with her six siblings by religious parents who were strict disciplinarians. She grew up being obedient and learned to be obedient to her husband whom, throughout their marriage, she never questioned. She married to a local boy when she was eighteen in a traditional Xhosa wedding. She did not go beyond primary school but considered herself to have education. She could speak English very well because she used to work as a ‘helper’ in the church and in the house of the English parish priest. Her first job was as a ‘helper’. She was paid little but found the job delightful because she was exposed to English literature like the writings of the Bronte sisters and Shakespear’s *Merchant of Venice*, *Macbeth* and *Romeo and Juliet* a story that cropped up in her dreams many times before she got married. She was proud to be married to her husband who was a chorister in the same church.

She could not go beyond primary school because her parents could not afford to have more than two of them in high school at the time. She could have got a sponsorship from the church to go to a teachers college but the parish ran out of funds and her set had to wait for their turn for sponsorship, which never materialised. This did not deter her from immersing herself in books. She continued to 'help' in the church many years after her marriage before she got a job as a 'bookkeeper' taking care of the "daily earnings" in a local white-owned hardware store. She did that for many years contributing to educating their children; two of the children went to university and two others went to a technikon. She is proud of the children and points to her own religious and disciplined home as the source of their success. She eventually stopped working in the hardware store when it was sold to a Xhosa businessman within the municipality but from a bigger rural town. The man had she been in the township of the rural town. She got a job 'helping' in one of the local primary schools three days a week.

### **Lindiwe's illness story**

Lindiwe became diagnosed as a type 2 diabetic when she was 45. She was of the opinion that she had been diabetic at least three years before the diagnosis because she was well aware of the disease. She thought she did not pay attention to it at the initial stage of her suspicion because then she had arthritis which preoccupied her most of the time. She knew of two friends who were diagnosed as diabetic and "this was the source of her knowledge of diabetes. When I was diagnosed by the doctor, it was not a surprise to me. But before then, I mentioned it to my husband and in fact to my siblings on one occasion when they all came home for Christmas. It was not taken serious as such. I think it was because none of them understood what it was. Not that they have never heard of diabetes but not in the sense of having an enlightened discussion about it." Lindiwe concentrated on dealing with her arthritis, which became so serious at one stage that she was detained in hospital for two days. It was during this period that she was diagnosed as diabetic. This followed the "tests, which I did in hospital. ... Apparently, the tests revealed what made the doctors to have me do all the tests that diabetic people do. After this, I found myself being told that I am diabetic and have to be on medication. Well, I did but this has not been regular... I suppose it has to do with not having time to go and get the drugs and also because they are not usually available. I take it occasionally though. But I must say that I pray a lot and this has helped over the years. .... I can as well say it is because I pray that I do not think of medication, as I should. .... No, no, no, prayer is not a substitute for medication. I am not saying that but that it has given me strength and probably as a result, I think less of regularly taking the prescribed drugs".

After the diagnosis, Lindiwe took time to know more about diabetes because “I like to know about things that I do not know or know vaguely. I think it has to do with the person that I am. As I told you earlier, I always like to read and this must have been why I am this curious person. .... I spoke to quite a few church friends who were nurses. It was from them I got to know more about diabetes. One thing that I did was to talk to the people I knew were diabetic especially the type [type 2 mellitus] that I have, which comes with old age. This was good because I understood from their experience what I should do but I was not so sure whether they did the right thing because they always ate all those things I was told to avoid”. Lindiwe’s husband was supportive because he “always was ready to listen whenever I talk about it but after a while, I think he became tired of listening [laughter]. I expected that.” The fact that she had nurses that educated her about diabetes and a husband that listened and spoke to those with the disease obviously helped her in her management of the disease as spelt out in the literature. Though, it was not completely a textbook management of the condition. However, Lindiwe had a reasonable knowledge of diabetes, she did not visit the health centre to monitor herself. “It was too much a bother. You have to go some distance to see a doctor who sometimes might not be there. Besides, I do not experience anything serious but tiredness. I feel exceedingly tired sometimes and when I do, I know it is the diabetes and that I am doing something wrong. I have to tell you the first thing that comes to my mind is food. I have heard from those who are diabetic that you need to eat well.... Most of them that I know ate *pap* regularly, at least twice a day [laughter]. Well, most people here in the rural area eat *pap* everyday. It is just the quantity that makes a difference. I eat a lot of *pap* to keep going and avoid tiredness”.

Lindiwe thinks that despite her reading of diabetes, her understanding of it and what to do comes more from her experience of it and experience of the disease by others who have it. She thinks the idea of daily drugs hardly is questionable. “I know this is medicine but how can you be taking drugs everyday for life? It is clear that this is not an illness that will kill you when you do not take the prescribed daily drugs. No, it won’t! So, why should one take such medication? Why not pray everyday and have strong hope? Yes, you can take the drugs if you have it but not everyday.” Apparent in her story is the acknowledgement of support in her management of her condition. “In my case, I can say that I received lots of support from my husband before he died. I receive support from family, relatives and friends. They know that I am diabetic because I never stop talking about it to people and because I told them how I once collapsed and how I always feel tired and hungry, they never wanted to see me do ant hard work. I think this has helped a lot. .... Because people are always there when you need them or even when you do not need them. My children always say to me to go for a check-up, that they ill pay but going to east London or Port Elizabeth is just too much for me because that is where you get good specialists.”

## **Lindiwe's story- telling style**

Lindiwe spoke in a matter-of-fact educated manner and was seemingly knowledgeable in her description of her experiences. She was evocative about her background and spiritual belief.

## **Zoleka**

### **Background**

Zoleka is a woman of 60 who does not have formal education beyond primary school. She has four boys and a girl aged between 20 and 42 years. Three of them are in Queenstown, one in Umtata and the girl in Cape Town. She does not have any job and relies on state benefit and what she gets from her children two of whom have three of their children with her. She lives in a four room hut which she never stops decorating because she built it herself as “many other women” in her village. She likes to walk around the village because very many of the young ones are coming home with HIV/AIDS and they needed support of “we the old ones”. She has two sisters and a brother. They are all in the sixties and live in the same village.

### **Zoleka's illness story**

Zoleka has been diabetic for well over 13 years. She is the second in the family to be diagnosed as diabetic. She also suffers from hypertension and has arthritis. She suffers intense pain in her joints regularly and seeks help from the local herbalists for her diabetes, hypertension and arthritis. The severity of her condition comes out clearly in her illness story. “I have experienced fainting four times this year alone. I do not know whether this going to stop but since the fainting began almost three years ago, what I do is to make sure that I am always around people or have people around me. I know that I give support to others especially the young ones but I also get support. It is the support that has kept me going because the pain on my knees is intense sometimes. It is the tiring disease that has concerned me most for sometime because I was told it is the cause of the fainting. When I experience hunger, it comes to my mind that I have to eat and I must say that has become my solution. I make sure of food especially starch. People say starch is good and I can tell you it is but I remember when I first went to the doctor and I was told I am diabetic, one of the things he told me which the nurse in the clinic also repeated was not to eat starch. .. I mean that he said I should eat little food and little starch. But this has not helped. I stuck to eating starch and my family makes



sure that I do get it regularly even when I can't cook because of tiredness".

There is ambivalence about prescribed drugs in her account. She accepts that doctors "know what they are doing and are very helpful curing people but sometimes the medicine they give is not strong to cure the person. Look at HIV/AIDS. .... No cure; people die. Look at me; I have this tiring illness they say will never be cured but can be looked after. Does that mean that doctors don't have the medicine for it? You see, the local herbalist has medicine for these ailments and it works. .... Well, it is true that I still continue to faint. If I eat at the right time and eat enough, there is no reason why I should faint. ... I am sixty now and have all these illnesses one of which probably will kill me but I have not given up yet. I still think the fainting illness will be taken care of. It is just that I have pains and high blood [high blood pressure/hypertension]".

### **Zoleka's story telling style**

There was a tinge of fatalism in Zoleka's narrative reconstruction. She also revealed fear and anxiety both of which were as a result of the intensity of her arthritis pain. The fact that she was diabetic and hypertensive did not help. She did not have the energy to narrate her illness and seemed downcast in the interview. She was however hopeful and beamed with vigour when she spoke about the support she gives to the young with HIV/AIDS in the village and the support she gets also for her condition. The fact of this reveals the critical role of social capital in illness management. It seems to be the critical capital in her life because it was when she mentioned it that she seemed "alive"

### **Discussion**

The approach taken in the study being reported here was an in-depth focus but this does not allow for broad generalisation about the experiences of women, in the rural areas, diagnosed with diabetes mellitus type 2. This does not preclude the fact that it yields a deeper understanding of the experiences of these women in the management of the disease. Indeed, the main reason for focusing on individual narratives was to demonstrate the ways in which rural women uniquely negotiate their illness experiences in relation to cultural expectations. The narratives provided by the women do not easily map onto theories of narrative types, which was outlined earlier, in a straightforward manner. Frank's (1995) 'quest narrative' does not fully apply to the narratives. Their narratives were restitutive and were not on quest. Ezzy's polyphonic narrative, with its focus on present experience and spiritual insight, to some extent can give an understanding of all the narratives. Lindiwe did embrace spiritual values and ideas that seem to be consistent with polyphonic narrative, but she did not reflect on her experience of diabetes as such, that is from the perspective of Ezzy's polyphonic narrative. There was hardly any

evidence in her narrative of what has been termed illness epiphanies. The same applied to Zoleka and to a considerable extent, Pinkie. What would seem to be consistent in the narratives is the linear restitutive narrative.

The attempt to fit the narratives of these women into theoretical typologies seemed to be somehow problematic for the simple reason that individual experiences refuse to be ordered in predictable ways. Although, typologies are useful, especially in analytical sense, but they seem to simplify and indeed distort. This raises the methodological question of whether in interpreting narratives of the 'cultural other', so to say, distortions occur. This of course is by now a common methodological question in anthropology.

What is clear from the narratives is that the women did not cultivate the habit of attending health service centres for check-ups and hardly took the prescribed medication. After diagnosis, they did get information from the doctors but it was not what they felt they needed to make appropriate decisions to deal with their 'tiredness' and the feeling of hunger. They all had a positive perspective on food intake even though the type of food they consumed has a high calorie intake, which is not consistent with the medical literature on the management of diabetes. The fact that they use food to control their tiredness and hunger demonstrates a cognitive understanding of their diabetic condition. They spoke articulately about the role of food, describing in great details how this has helped during the interviews.

What was also common in the narrative is the little emphasis they all placed on prescribed drugs for their diabetes, which they considered to be toxic [poison]. This can only be understood as evidence of cultural related beliefs because there was reference to the efficacy of the medicine from their local herbalist. Of further interest is social support, which seemed to be an important resource to the women in the way they coped with their diabetes. Social support, in the rural setting as the narratives revealed, involved meaningful interactions between those who suffer from illnesses and those who are around them to provide help in any form that contributes to the sufferer's physical and psychological health. The latter was more the case in the present narratives, which revealed feeling of connectedness as central. In Zoleka's story, one detects reciprocity of support; she gave support for the young with HIV/AIDS and received support from others, in particular, significant others, and, this seemed to have a bearing on her psychological health. Although she was ambivalent about her illnesses – diabetes, hypertension and arthritis – she seemed hopeful that she would overcome them as the other two participants also felt. This sense of hope and transcendence are spiritual resources that the women deployed as part of their coping strategies. As Fryback and Reinert (1999), Landis, (1996) and Relf, (1997) have noted, spirituality is an intrinsic source that has a basis in religion and existentialism. It is described as a sense of hope and self-transcendence, which in turn provides purpose to life. There are researchers who view spirituality as providing a sense of purpose from which feelings of hope and self-transcendence emerge (for example, O'Neill and Kenny, 1998).

When one applies the idea of illness representation to probe the narratives, what would seem revealed, is that the women's cognitive representation of illness plays an important role in influencing their strategies of coping. This is consistent with the findings of the bigger study of which this is a part, and, other findings that apply the illness representation model. In terms of the structure of these representations, there were three cognitive dimensions and not all the five components suggested by Leventhal et al (1980; 1984). The three cognitive components are identity (they attributed tiredness and hunger to diabetes), consequences (in the sense of their tiredness and fainting) and cure/controllability (their belief that if they ate *pap*, then, they could prevent tiredness and fainting)

## Conclusion

The aim of the present study was to show through narratives how poor women in the rural areas cope with diabetes mellitus type 2 as a factor of their cultural competence and lay understanding of the illness. This knowledge is crucial in addressing rural-health disparities in Africa. The disease is a leading cause of blindness, kidney failure and foot amputation. The narratives show that the women held a view of their condition, which hardly can be seen as a chronic view. In other words, in their understanding, diabetes was considered curable. It was however considered to have serious consequences for their lives. They saw it as the source of their fainting, but they seem to see its management as based on consumption of high calorie food. The fact that they perceived regular food intake as critical to their management of their diabetic condition reveals an understanding of that condition; an understanding that derives from experience but not from illness education from health professionals and which is not at all consistent with conventional understanding of diabetes and its management.

What is discernible in the narratives are stories of how and when they had become diabetic and how they have been coping with it. It is evident that they were not just describing a clinical case but talking about their lives. These narrative reconstructions, as Williams (1984) called them, were driven by the women's profoundly performative needs. The women constructed their accounts in such a way that they could make of diabetes in their own way in relation to their lives, as a whole. It included their history, culture and, indeed, the social structure, which has come to be, in them. They placed their knowledge in some wider context for biomedical knowledge, which suggests that the meaning they brought to the understanding of their diabetic is one that can hardly be ignored by health care officials located in urban centres. So, what can be drawn from this study regarding rural-urban disparities?

It is evident that in most African countries, resources are hardly allocated equitably. Socio-economic data reveal, to a degree, a more healthy, vibrant and prosperous urban

Africa than economically impoverished, largely unhealthy rural Africa, with less access to health or social assets. The uneven distribution of health prosperity, poverty and disease burden characterize the rural-urban divide in Africa. In addition, the current profile of health status in African countries reveals variable manifestations of rural-urban health and wellness disparities. With reported changing ecology, the rural population is subjected to increased level of vulnerability and unanticipated exposure to deadly diseases which are likely to exacerbate existing health disparities.

The literature on health and illness reveal, quite clearly, the contribution of research in the social sciences, and indeed, biological sciences, to the debate on the associations between disease and the multiple interactions among economic and environmental factors. Significantly, is how these manifest in the health and illness of rural and populations. In this regard, it would seem evident that the understanding of rural-urban populations' health conditions requires insights from research that examine these conditions in the respective geographical context and disparities between them. These disparities, as a matter of course, have been examined utilizing such concepts as vulnerability, susceptibility and access to health facilities. These concepts are used mostly to examine the health and illness conditions of individuals and groups. However, they have been used to explain variations when geographical disparities are delineated in rural-urban comparisons. In relation to the individual, an individual is said to be vulnerable when such individual is in a position of being hurt or injured or ignored as well as being helped by others (Aday, 1993); vulnerable groups are those that have disproportionate risk or susceptibility to adverse outcomes (Sebastian, 1994). Susceptibility refers to situation of being subject to influences or risk for an adverse outcome. In epidemiological research, risk, a concept popularized in the social sciences by Beck (1992) and Giddens (1990), is widely used in mapping disease and studying health and illness of vulnerable populations'. In rural-urban health disparities, which refer, simply, to differences in health status of rural population as compared to urban population, and, differences in health status that occur among population groups in each context, defined by specific characteristics.

From the highlight above, there has been much progress in studying rural-urban health disparities; nevertheless, serious challenges to our understanding remain. Despite the relative long history of biomedical treatment of illness and disease in Africa, cultural understanding and treatment of such illness still persists. This is even more so where access to biomedical health facilities is less; lay beliefs and cultural understanding would seem to inform treatment of most diseases and illnesses in such cases. Such treatment, however, requires a certain level of understanding and competence for success. This aspect, which applies more to the rural area, needs to be drawn out in the examination of rural-urban health disparities. This is the point of this paper.

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