Original Article

Beliefs about health and illness: a comparison between Ugandan men and women living with Diabetes Mellitus

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Background: The diabetes mellitus (DM) pandemic greatly affects developing countries. Self-care is an important part of management, guided by beliefs about health and illness. Dissimilarities in health-related behaviour in men and women have been described but not comparisons of their beliefs about health and illness.

Aim: To explore beliefs about health and illness that might affect self-care practice and healthcare-seeking behaviour in men and women with DM in Uganda.

Methods: This was an exploratory study with a consecutive sample from an outpatient diabetes clinic at a university hospital. Semi-structured interviews were conducted with 15 women and 10 men aged 21–70 years. Data analysis was conducted by qualitative content analysis.

Findings: Men's and women's beliefs about health and illness indicated limited knowledge about the body and DM. Dissimilar were men's focus on socio-economic factors, particularly affordability of drugs, sexual function and lifestyle, while women valued well-being, support in daily life and household activities and had a higher risk-awareness of DM. Irrespective of gender, limited self-care measures were used, and health professionals were consulted about health problems.

Conclusion: Similarities and dissimilarities were found between men and women in beliefs about health and illness that affect self-care practice and healthcare seeking. Underlying living conditions, with different gender roles, appear to determine the beliefs about health and illness, which are based on individual knowledge. Measures to increase knowledge about DM are urgently needed in Uganda. In diabetes care, it is important to search for individual beliefs and consider gender and living conditions.

Keywords: Care-Seeking Behaviour, Diabetes Mellitus, Gender, Health/Illness Beliefs, Self-Care, Uganda

Introduction

It is estimated that 150 million people have diabetes mellitus (DM) worldwide, expected to double by 2025 (WHO 2004). Much of the increase will be in developing countries and will be due to urbanization and industrialization. Longer life and change in lifestyle from 'traditional' to 'modern', with unhealthy diets, obesity and sedentary activity, conflict with our old hunter-gatherer genes (Hjelm et al. 2003a). This process has been labelled 'coca-colonization' (Zimmet 2000). The regions with the greatest potential for increase of DM in the future are Africa and Asia, where diabetes could become two to three times more common than today (WHO 2005). In Uganda, it is

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estimated that 98 000 people today have DM, increasing to 328 000 by 2025 (WHO 2004).

By 2025, while most people with DM will be over 65 in developed countries, in developing countries the majority will be 45–64 years and in their most productive years. In those with diagnosed diabetes, worldwide, 90–95% have type 2 DM. It occurs most frequently in adults but is also increasingly noted in adolescents. People with DM have a much-reduced life expectancy. Increased mortality and morbidity are due to the risk of developing chronic complications (WHO 2005). Apart from the impact on health, the economic cost of DM and its complications is enormous, in both health care and loss of productivity to society (Hjelm et al. 2003a). Soon DM will be a heavy burden on both the individuals affected and their society (Zimmet & Alberti 2006; Zimmet et al. 2001). Self-care, to promote or restore health, is a cornerstone in the management of DM (Alberti & Zimmet 1998). It depends to a large extent on the individual's beliefs about health and illness (Hjelm et al. 2003b, 2005).

Literature review

Dissimilarities in risk perceptions (Jakobsen 1999; Jakobsen & Karlsson 1993) and health-related behaviour in men and women have been found (Koch et al. 1999, 2000). Women had a higher risk-awareness and were more caring and nurturing, while men were more ego-oriented and focused on technical measures (Jakobsen 1999; Jakobsen & Karlsson 1993). Thus, men described the positive impact of DM on their lifestyle, believing its complications meant taking better care of themselves. They also saw DM as part of life and tried to limit its restrictions (Koch et al. 2000). Women, on the other hand, saw the disease as intrusive. They feared complications, and their daily lives were made stressful, watchful and restricted by DM (Koch et al. 1999). Our previous investigations of men and women separately showed that Arab, ex-Yugoslavian and Swedish men claimed the importance for health to be occupied, economically independent and to retain sexual function (Hjelm et al. 2005). Swedes focused on heredity, lifestyle and management of DM. Non-Swedes stated that supernatural factors, migration experiences and the emotional stress of being an immigrant influenced the development of DM, negatively affecting health. Women of the same origin described health as freedom from disease. Arabs showed an information-seeking health-related behaviour, in contrast to a passive self-care attitude in ex-Yugoslavian women. There was active self-care behaviour in Swedish women (Hjelm et al. 2003b). Both investigations showed limited knowledge about and less perceived seriousness of DM in foreign compared with Swedish-born persons, irrespective of gender (Hjelm et al. 2003b, 2005). In the literature review, no empirical studies have been found comparing beliefs about health and illness in men and women of the same origin. Previous studies have focused on men and women separately and, thus, lack a comparative approach.

The study

The aim was to explore beliefs about health and illness that might affect self-care practice and healthcare-seeking behaviour in Ugandan men and women with DM.

Diabetes care in Uganda is run in the ordinary healthcare system. Currently, some hospital outpatient diabetes clinics have been developed (World Diabetes Foundation 2008). The clinic studied is under the department of internal medicine at a government university hospital, and is based on physicians specialized in diabetology and non-specialized nurses.

Health services in Uganda are provided by a mix of public, private for-profit and private not-for-profit providers (Xu et al. 2006). There is no national health insurance system. The Government is the main provider of health services being free for all its users. However, health services are underfunded and frequently drugs are unavailable and this forces patients to purchase from private pharmacies.

Method

Design

An exploratory study design and a consecutive sampling procedure were used. Individual semi-structured interviews were chosen to give respondents freedom to present their views and reach a deeper understanding of the topic studied (Patton 2004).

Participants

A consecutive sampling procedure was used. The clinic nurse recruited respondents. Inclusion criteria were: diagnosis of type 2 DM, duration of DM >1 year, age >20 years and without known psychiatric disorder. The sample comprised 15 women (aged 30–64 years, Md 49 years; see Table S1) and 10 men (aged 21–70 years, Md 47 years) born and living in south-western Uganda. Most females were treated with oral agents or diet, while males predominantly were treated with insulin or combined with oral agents, possibly related to higher prevalence of type 2 DM in females and type 1 DM in males (Alberti & Zimmet 1998). Most were married, with limited education and had occupations of low socio-economic status. Consecutive sampling gave all visiting the clinic the same opportunity to participate. Demographic characteristics were similar to most people in Uganda (SIDA 2007), and they originated from an area where 75% of the population is living.

Ethical considerations

A university ethics committee approved the study. Written informed consent was obtained from respondents in accordance with the Helsinki Declaration.

Data collection

Data were collected in 2004. The interview started with standardized questions on socio-demographic and medical variables. Then a thematic interview-guide with open-ended questions, including descriptions of common health problems related to DM, was used. Themes investigated were: content of health; factors of importance for health; causes, explanations and perceived consequences of DM; health-restorative activities; care-seeking behaviours. The interview guide was based on findings and experiences from previous investigations (for more details see Hjelm et al. 1999, 2003b) and peer-reviewed by general practitioners and nurses working in diabetes care. A pilot-test was made with four men and four women (not included in the study) resulting in minor changes to the wording.

The interviews were held in secluded rooms outside the clinic, lasted for 1–1.5 h, were audiotaped and transcribed verbatim. Nine interviews were held in English (official language) and 16 in the local language Runyankore, led by a bilingual female nurse not involved in management of the respondents' diabetes. Interviews in Runyankore were translated into English and then back-translated. The results might be limited to people with low education as language use may differ in different social groups. Runyankore is one of 40 indigenous languages in Uganda (SIDA 2007) belonging to the Bantu languages, which occupy most of the southern half of Uganda and are mutually comprehensible. Living conditions are important for people's thoughts irrespective of social position and need to be elicited.

Data analysis

Collection and analysis of data proceeded simultaneously until theoretical saturation was reached (Patton 2004). Notes were made from the taped interviews as themes emerged. Patterns, contradictions and themes came from comparisons of respondents' statements (Mayring 2000). By reviewing each line of the texts, topics were identified and the material was condensed into content categories (see example in Table S2). The lay theory model of illness causation (Helman 2007) and the model for healthcare-seeking behaviour (Kleinman 1980) were then introduced and used as main analytical categories (Patton 2004), as previously described (Hjelm et al. 1999, 2003b, 2005). Illness can be experienced as caused by factors in the individual, nature, social relations or in the supernatural sphere. Explanations of disease guide strategies for self-care, treatment of diseases and healthcare-seeking behaviour (Helman 2007). Health care can be sought from the popular, professional or folk sector [i.e. family, friends or relatives, professionals, or folk-healers (Kleinman 1980)]. Finally, the findings from the analysis of men and women were compared.

To increase the trustworthiness of the results, the transcripts were analysed independently by two researchers (Patton 2004): a diabetes specialist nurse and a general nurse (first and second author) and showed high agreement.

Results from qualitative studies may have limitations because of the difficulty of generalizing data (Patton 2004), but carefully collected and analysed, they are transferable to similar populations or contexts.

Findings

Beliefs about health

Health was described in terms of individual factors. Men emphasized the ability to perform daily activities and affordability of needs, adding good hygiene and following advice. Women focused on physical, social, mental and spiritual well-being and freedom from worries. They also cited freedom from sickness or pain and being able to perform daily activities:

> . . . doing your daily activities. (Male 7)
>
> Having all you need without any problem and following all you are told regarding diabetes . . . and affordability. (Male 14)
>
> . . . being hygienically fit. (Male 6)
>
> . . . when you have no other form of sickness . . . Feeling well with no problems . . . no pain . . . do your usual activities. (Female 4)

Respondents, irrespective of gender, predominantly talked about individual factors as a 'healthy diet' as important for their health as diabetics. Women also mentioned self-monitoring of blood glucose (SMBG) as significant. The combination of individual and social factors was also discussed but men talked about 'following advice' while women said 'regular visits to the physician'. Men also discussed social factors such as 'access to drugs' and 'sufficient money to buy drugs'. 'Regular intake of drugs' was claimed in both groups.

Respondents acknowledged instrumental tangible support from their family members. First aid and hospital contact were necessary to most respondents. Men focused on economic support, encouragement and advice in contrast to women, who emphasized the need for emotional and material support, with assistance in household activities. Men also talked about the need for assistance in preparing food:

> To act immediately to give first aid . . . with sweet drink in case of hypoglycaemia or take me to hospital . . . (Male 6)

Help with buying drugs. (Male 3)
. . . care for me and appreciate my condition as a diabetic- . . . cooking food, to encourage me . . . friends discuss with me to be strong and they are beside me . . . (Male 12)
They look after me, and children too assist me with my household . . . activities, relatives are supportive. (Female 26)
Friends continue to talk to me and encourage me to be strong. (Female 23)

All respondents considered health professionals were important for improved health, as they gave and prescribed treatment and care, as well as counselling. As factors harmful to health, men mainly cited lifestyle factors (individual factors) such as 'drinking and smoking' and 'sexual dysfunction' and 'since I developed diabetes I became impotent'. Women discussed the influence of access to and affordability of drugs (social factors) and complications related to DM e.g. 'hypertension', 'pain in the legs' and 'back-ache'(individual factors).

By examining bodily signs, respondents became aware of whether health was better or worse:

You know by some signs. If it is getting worse, I pass a lot of urine, my cheeks even start to swell. If it's better I feel well. . . . pass urine . . . drink normally . . . (Male 7)

Women also added 'regular blood glucose checks' and 'regular visits to health care'. In both groups, some talked about 'access to drugs' while women claimed 'affordability of drugs and to follow advice' (social factors) and also 'regular diet and medication' (individual and natural factors).

Measures claimed to improve health when diagnosed with DM were mainly prayers, herbs and attending a diabetes class (supernatural, natural and social factors) by most respondents:

. . . pray because it makes me feel well . . . is effective . . . Moringa powder, herbs, white flowering plant . . . advised that it reduces sugar . . . (Female 15)
Diabetic class . . . they teach me and we discuss how to control DM . . . health educate us on how to look after ourselves. (Female 11).

Only one man had used nature cure remedies to improve health. He claimed use of herbs, in terms of 'moringa', which is a green leaf.

To maintain health and prevent complications related to DM, most respondents reported combinations of individual and social factors such as following advice, regular medication, exercise, healthy diet and regular SMBGs. Women emphasized a healthy diet to control weight.

Beliefs about illness

Most respondents, irrespective of gender, had experienced several symptoms when they fell ill with DM such as passing a lot of urine, feeling thirsty and drinking a lot of water but had not suspected DM. Reactions to the symptoms included feelings of dying, having acquired HIV or AIDS, or suspected malaria. One woman added witchcraft and a couple said 'I didn't take it serious'. Most went to see a physician in hospital after consulting friends and family members in the popular sector:

R: Fever, coldness, thirsty, passing a lot of urine, feeling hungry all the time, though I had no appetite . . . I knew I was going to die . . . I just waited for my death . . . (Male 21)
Interviewer: Where did you search for help?
Respondent: My friend first, then a doctor (in) the second instance.
I thought I was going to die . . . I got scared, got worried, because I didn't know how I was going to look after myself. I begged doctor to tell me what I was suffering from, for I didn't believe it was DM. I thought I had HIV/AIDS. After ruling out HIV, I had a positive attitude and accepted the disease like any other disease. (Female 18)

In both groups, the majority claimed they did not know or were unsure of the cause of DM (see Table S2). For a few, there were individual factors such as heredity, increased weight and incorrect food. When a list of potential causes of DM was presented, most talked about obesity, wrong diet and diseases of the pancreas (individual factors). Women added stress (social factor) and focused more on supernatural thoughts, e.g. punishment by God, gods and witchcraft than did men.

In general, limited knowledge was demonstrated when discussing what happens to the body with DM, the effects of insulin, the pancreatic function and action of drugs. Most women were unsure of the function of insulin and pancreatic function, in contrast to men, who talked about its ability to regulate blood sugar vs. digestion of food. Respondents talked about feeling unwell and women especially claimed weakness and described many different symptoms of DM. Women perceived DM to be lifelong while men were uncertain how long it would last. Most men were treated with insulin, in contrast to women, who were mainly treated by oral agents or diet. However, respondents in general saw the main effect of treatment as subjectively perceived well-being. Men also talked about getting better and living longer.

Men found sexual dysfunction, lack of income and high costs of drugs and food were the main problems resulting from DM, while women emphasized reduced activities in the household:

My private parts are weak . . . I no longer function sexually . . . (and) I am unable to meet the needs of financial problems. (Male 9)

I have failed to carry on my household activities as before, being tired, lost interest in sex . . . better that men are taught this. We shall be thrown out of marriage in old age. (Female 13)

All respondents discussed the dangers of DM and fear of the expensiveness and shortage of drugs, leading to early death. Women also added failure to perform daily activities.

Self-care and care-seeking pattern

Respondents spoke of being informed about regular check-ups and acute visits to a physician or nurse when needed as determined by their condition.

Most men reported:

I was not given advice on foot care. (Male 17)

About half of the women had been told:

To put on shoes which are soft and avoid walking barefoot, and check my feet daily and make sure they are kept clean at all times and avoid any form of injury as healing is very slow. (F26).

The respondents reported that advice had been given concerning the importance of SMBG but they used bodily signs to assess the blood glucose, rather than expensive equipment:

I do not have the requirements to use, but I use the signs when it is too high and low I know from the signs . . . passing a lot of urine and drinking a lot. When I am sleepy I know it is low. (Female 2)

. . . the machine for testing is very expensive. Can't afford about 60 000 shillings. (≈$30; Female 11)

When discussing dietary recommendations, most women cited the importance of sugar-free food, reduced in carbohydrate and fat, while some talked about regular meals. Men mainly discussed regular meals and avoidance of fat, bodybuilding food and salt. Some discussed a sugar-free diet with plenty of fluids. As regards advice about exercises, most men had been informed of the importance of exercise in terms of walking, in contrast to women, of whom few had received any advice. All respondents, irrespective of gender, had been advised:

To take drugs regularly, avoid overdose, eat the food immediately . . . (Female 26)

Generally, respondents claimed they usually followed advice. The reasons for not following advice were: 'hadn't got advice', 'lack of testing equipment' and men also added 'lack of time'. For men, the advice was meant to improve health, prevent complications and death while women claimed it helped them to live with the disease.

Common health problems in DM included: impaired glycaemic control, hyperglycaemia, repeated episodes of hypoglycaemia, gastrointestinal infection, common cold and pharyngitis, urinary infection, foot problems (crawling, burning, decreased sensitivity, wounds), spasm in the calf, hypertension, and albuminuria. A pattern was evident where most respondents had sought help from physicians or continued with treatment. Men had experienced these problems to a greater extent than women. Their causes were mainly related to DM or sugar. Some women expressed uncertainty by giving a variety of causes. A few described using herbs.

Discussion

This study is unique in exploring beliefs about health and illness in men and women of the same ethnic origin. It has been claimed that gender is a socio-cultural construction (Kulick 1991) and differences have been found in health-related behaviour in males and females (Jakobsen 1999; Jakobsen & Karlsson 1993; Koch et al. 1999, 2000). In this study, health-related behaviour was similar, with limited self-care activities, irrespective of gender, although beliefs about health and illness differed. The focus on socio-economic factors, such as affordability of drugs and sexual function in men, is similar to what has been found in studies of men of different origins (Hjelm et al. 2003c, 2005) and might be explained by the fact that men had a more severe disease pattern treated with insulin, which is more expensive than oral agents in Uganda (in August 2007 e.g. Insulin Mixtard 30/70® 100 IU/10 mL cost ≈ $12, Metformin® 500 mg 100 tablets cost ≈ $3, Glibenclamide® 2.5 mg 100 tablets cost ≈ $4). Throughout the study, socio-economic factors were discussed, for example concerning SMBG, which participants saw as impossible because of the costs, instead relying on bodily signs. The question is how reliable they are, given the limited knowledge of DM demonstrated. The dissimilarities might be explained by different gender roles (Ellis et al. 2006; Whitehead & Lockwood 1999). They correspond to the description of men as assertive and women nurturing (Jakobsen & Karlsson 1993), leading to societies with male dominance, especially in economic life (Hofstede 1984), with continuing patrilineal hierarchy and acceptance of the traditional authority of men (Ellis et al. 2006). Studies in Uganda (Whitehead & Lockwood 1999) have been claimed that women generally do not, and are not expected to, control cash income or economic assets; they remain in the subsistence sector where their economic contribution is not valued. In this study, too,

women discuss socio-economic strains, possibly explained by the pressures on women to expand their income-generating activities as a consequence of the worsening economic crisis (Whitehead & Lockwood 1999). Both men and women have to cope with new economic pressures and women have a key role in sustaining the household.

As previously found, women showed a higher risk-awareness than men (Jakobsen 1999; Jakobsen & Karlsson 1993) by recognizing the lifelong character and negatively complications of DM and discussing the importance of weight control, while men were unsure. It is interesting that women, more than men, claimed to be informed about the importance of foot care, although men seemed to have a more severe disease pattern, with insulin treatment, than women. They should have had more contact with healthcare professionals and received more information about DM (Hjelm et al. 2003c). However, specialist knowledge in diabetology, particularly among nurses, is limited as the area is under development. Another factor influencing risk-awareness is duration of disease, but this did not differ. In general, the results showed limited knowledge about the body and DM, which may explain the limited self-care and the proneness to seek help from health professionals.

The higher risk-awareness of women found here is in accordance with previous studies of women (Koch et al. 1999), demonstrating the intrusiveness of the disease and how they try to adapt to the situation. In contrast to an investigation of men by Koch et al. (2000), this was not found in men in this study. Nor did they describe a positive impact of DM on their life. This is possibly explained by their lack of knowledge about DM.

Beliefs about health and illness were mainly related to individual and social factors. Factors in nature and the supernatural sphere were also mentioned occasionally, and help was sought from the professional sector only after advice from family and friends in the popular sector. Thus, the respondents did not show a similar behaviour to what has previously been described in non-westerners (Helman 2007; Kleinman 1980). Models have suggested non-westerners to be more likely to focus on the social or supernatural spheres, first contacting the popular sector (family, friends, relatives) and then traditional healers in the folk sector. This contrasts with westerners, who emphasize individual or nature factors and consult the professional sector when problems arise. As in previous studies (Hjelm et al. 2003b, 2005), the results do not correspond completely with the theoretical models used (Helman 2007; Kleinman 1980) and the implication is that beliefs need to be recognized as individual.

Findings from open-ended questions showed limited knowledge about causes of DM. When probing for it, diseases of the pancreas and, in women, stress and punishment of God or witchcraft appeared. Women thus have a fatalistic view of the disease similar to that shown in studies of North Africans living in France (Dechamp-Le-Roux et al. 1990). In general, the results supported the findings of limited knowledge about DM in migrants from former Yugoslavia and the Middle East in Sweden (Hjelm et al. 2003b, 2005). In discussions on the advice given, most respondents claimed they were willing to comply but they showed they had insufficient knowledge and problems with affordability.

Implications for nursing practice

Knowledge about the body, DM and its management in Uganda needs to be improved through education. Higher risk-awareness might facilitate dissemination of knowledge about DM even in non-diabetic subjects and so encourage prevention. The cornerstones of DM management are dietary adjustment, physical activity, SMBG, drugs and education on how to integrate these components. Nurses worldwide play an important role in this work and need training in diabetes care. In Uganda, specialist training is not economically feasible but at the very least 'in-service' education should be provided. Self-care based on knowledge of good glycaemic control can prevent or delay the onset of micro- and macro-vascular complications (DCCT 1993, UKPDS 1999). Proper management of DM, based on well-developed individual beliefs about health and illness related to gender and living conditions, may reduce drug dependency. The socio-economic burden of DM can also be reduced in a changing and vulnerable society like Uganda (Hjelm et al. 2003a; WHO 2004).

Conclusion

Similarities and dissimilarities were revealed between female and male Ugandans with DM in beliefs about health and illness affecting reported self-care and healthcare seeking. The respondents had limited knowledge about DM and the body and thus seldom practised self-care. When problems arouse, health professionals were consulted. Women demonstrated a higher risk-awareness of DM and focused on well-being and support in managing daily life, while men focused on socio-economic circumstances, for example, affordability of drugs, sexual function and lifestyle. Underlying living conditions with different gender roles appear to determine beliefs about health and illness, based on individual knowledge. Measures to improve knowledge and management of DM are urgently needed, not only for those with DM but also for the Ugandan people in general. Increased knowledge about DM is one way of diminishing the medical and socio-economic consequences of this global pandemic, most

rapidly and severely affecting people in developing countries. In diabetes care worldwide, it is important to search for individual beliefs, cultural context and to consider dissimilarities related to gender and living conditions.

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Author contributions

Both the authors were involved in the study design, data analysis, manuscript preparation and critical revisions. G. Nambozi was also responsible for data collection, and K. Hjelm provided supervision as well as technical and material support.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Table S1 Characteristics of the study population.

Table S2 Causes of DM.

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