Assessment of health-related quality of life in people with diabetes and people without diabetes in Tanzania

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Abstract

Background: In developed countries health-related quality of life questionnaires are frequently used to gauge the measure of quality of life, which should be an important goal in diabetes care.

Aims: The aims of the present study were to assess quality of life in people with diabetes and people without diabetes living in Tanzania.

Method: Sixty-eight adults with diabetes were compared with a control group of 60 adults without diabetes, including student nurses and hospital workers. All respondents completed the Swahili version of the SF-36 quality of life questionnaire and answered two open-ended questions about quality of life.

Results: Those with diabetes reported poorer health than the group without diabetes in all eight SF-36 health domains. This difference was statistically significant for all questions but one. The open-ended questions relating to quality of life showed 'satisfaction with basic needs' and 'economic factors' to be the most dominant factors. People with diabetes perceived poorer health measured by the SF-36 health questionnaire than the group of people without diabetes.

Conclusions: Results showed that the SF-36 health-related quality of life questionnaire needs to be expanded to include issues dealing with basic needs and economy.

Eur Diabetes Nursing 2006; 3(1): 34–39.

Key words

Health-related quality of life; SF-36; diabetes in Tanzania

Introduction

Since the 1990s, studies on issues of quality of life have expanded enormously.[1] However, few studies have reported health-related issues in relation to the quality of life in developing countries. Bowden and Fox-Rushby[2] report that among generic health-related quality of life instruments (HRQL) used in studies published between 1990 and 1999, the SF-36 questionnaire[3] was the most frequently used.

Gill[4] suggested that, although there are many problems managing diabetes care in developing countries, good quality of life should be an important goal in good diabetes care.

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Received: 12 December 2005
Accepted in revised form:
25 January 2006

In an earlier study performed in Tanzania, the SF-36 was used for the first time to investigate self-perceived health of people with diabetes. It was found that patients (n=518) perceived poorer health[5] than did a sample of the general adult population (n=3802) living in the same area.[6,7] A second study (n=150) performed two years later showed the same results.[8] This outcome of poorer perceived health among people with diabetes in Tanzania may be due to the lack of availability of anti-diabetes drugs and limited knowledge of how to manage self-care.[9]

The main focus of this study was to further explore the concept of quality of life of people with diabetes in Tanzania. The SF-36 questionnaire, originally developed in the US, was translated into Swahili[6] but the question arose as to whether it corresponded with Tanzanian peoples' meaning of quality of life and whether people with diabetes and people without diabetes share the same views.

Thus, the overall aim of the current study was to assess health-related quality of life using the SF-36 questionnaire and to explore the meaning of the quality of life concept in a patient population with diabetes compared with a control group without diabetes.

Methods and participants

Patients with diabetes

In a study performed prior to the current one, 209 patients with diabetes routinely attended the

diabetes outpatient clinic at Muhimbili Medical Centre (MMC) over a five-week period. Every hour during these five clinic days, eight patients were randomly approached. This led to 162 patients being asked to participate in the study. However, since three of these patients didn't have time to take part, six were under 18 years of age, and three failed to answer questions correctly, a total of 150 patients were included at the time of the first data collection. Results from that study (n=150) are reported elsewhere.[9]

For the purposes of this follow-up study, attempts were made to contact the same 150 patients for a second investigation but 3 had moved elsewhere and 8 had died. Efforts made to contact the remaining patients (n=139) included advertisements in local newspapers and on local radio stations, and patient lists on notice boards at the various diabetes clinics. However, there were difficulties in tracing them and of the 139 eligible patients with diabetes, 70 (50.4%) turned up on the data collection days. Of these, two failed to complete the questionnaires and so 68 patients were included in the study.

Patients who did not turn up for the current investigation were traced for another year to discover what had happened to them. The nurse educators checked all patient hospital records and found nine patients who had visited the diabetes clinic after the data collection days. The other eligible patients were not traced and no reasons were found for why they did not visit the diabetes clinics.

The control group without diabetes

A convenience sample of hospital workers at Muhimbili National Hospital (MNH), Mwananyamala, Temeke, and Ilala district hospitals and student nurses at Muhimbili School of Nursing (n=60) formed the group without diabetes. These people were asked whether they were willing to participate in a control group as respondents without diabetes. All of those approached agreed to participate in the study. Demographic and diabetes-related data for both groups are presented in Table 1.

Variables	Patients with diabetes n=68	Control group without diabetes n=60
Sex (M/F)	36/32	13/47
Age years (mean±SD)	45.0±12.2	32±10
BMI (kg/m2) (mean±SD)	24.5±4.6	25.0±5.1
Diabetes duration years (mean±SD)	8.4±5.6	NA
Age at onset of diabetes years (mean±SD)	38.7±11.5	NA
Diabetes treatment		
Insulin-dependent/	30 (44%)	NA
Oral/diet	38 (56%)	NA
Education years (mean±SD)	6.9±3.9	6.8±1.1

NA - not applicable

Table 1. Personal characteristics and diabetes-related data in patients with diabetes and a control group without diabetes

Settings

The data collection took place partly at MNH – which serves as both university and the largest hospital in Tanzania – and partly at three district hospitals – Mwananyamala, Temeke and Ilala – all of which are in the Dar es Salaam area. In all of the hospitals, the diabetes clinics were situated in the outpatient department along with other clinics for patients with medical and surgical conditions. The data collection at MNH took place in the diabetes outpatient clinic. At the three district hospitals, special areas were arranged for the current data collection.

General procedure

Tanzanian student nurses and nurse educators, trained in research methodology, took part in the data collection. The nurse educators translated the written answers of respondents into English where necessary. Although all of the patients with diabetes had previously participated in the first data collection (two years prior to the current one), the diabetes clinic nurse in charge at each clinic formally explained the follow-up study to the patients. The hospital staff received information about the study from the Tanzanian nurse educators. After informed consent was obtained, all participants were assisted by the student nurses and nurse educators in completing the questionnaire.

Measures

Health-related quality of life

The Tanzanian version of the generic standardised questionnaire SF-36 – previously used in the Adult Morbidity and Mortality Project,[10] as well as in a study of patients with diabetes[5] – was used. The questionnaire contains the following eight health domains: physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social

SF-36 health domains	Patients with diabetes n=68	Control group without diabetes n=60	Mean difference	Effect size	p-value
PF	78±23	92±12	-14	0.80##	<0.0001***
RP	61±44	86±28	-25	0.69##	0.0002***
BP	58±30	76±25	-18	0.65##	0.0032***
GH	49±19	66±17	-17	0.47##	<0.0001***
VT	62±19	71±18	-9	0.47##	0.0047**
SF	74±25	80±19	-6	0.27#	0.1299
RE	66±40	83±29	-17	0.49##	0.0140*
MH	69±20	77±15	-8	0.46##	0.0188*

All scales 0–100. A high score indicates better health.
Significance levels: *p<0.05; **p<0.01; ***p<0.001.
Effect size: #=small (≥0.2–<0.4); ##=moderate (≥0.4. <0.8).

Table 2. Mean values (±SD) and effect size for SF-36 health domains in patients with diabetes and the control group without diabetes

functioning (SF), role emotional (RE) and mental health (MH). The questions are Likert-type and some require 'yes/no' responses. For each SF-36 health domain, variable item scores were coded, summed and transferred to a scale ranging from 0 (poorest health status) to the maximum 100 score (best health status). Recommendations included in the SF-36 manual were followed.[3]

Patients' perceptions of the definition and personal meaning of quality of life

This area included two broad open-ended questions, namely 'what is the definition of quality of life?' and 'what does quality of life mean to you?' The respondents were asked to answer these two questions by writing their responses on an A-4 size sheet of paper.

Demographic and diabetes-related variables

Data concerning gender, age, height, weight, and education were recorded. There were also questions about diabetes duration, age at onset and treatment, where appropriate.

Ethical considerations

The medical research ethics committee at MNH – in charge of medical research ethics in the Dar es Salaam area – approved the study design. In the case of the district hospitals, the medical officer at each was informed of the aims of the study and the investigations were approved. The aims of the study and the voluntary nature of participation were explained to all participants and informed consent was obtained from all of them.

Data analysis and statistics

Results are presented as means and ±SDs, and t-tests were used for group comparisons on interval levels. We considered differences significant at $p<0.05$. When calculating the comparisons of the SF-36 scores between patients with diabetes and the control group, the effect size was used. This is the quotation between the difference and the weighted standard deviation.[3]

The two open-ended questions about quality of life were transcribed in order to facilitate an overview of the content. Some respondents answered with very few words, while others wrote longer sentences. None of the respondents wrote more than one page for each question. The transcripts were independently read and scrutinised several times by two nurse educators. The sentences were divided into meaning units which, together with the stated words, were sorted into categories. Thereafter, the two nurse educators discussed the sorting and interpretation of the categories. These discussions led to 100% agreement on how to label the different categories. Thereafter, all respondents' answers were reread once more and clustered into the various categories.

Results

Health-related quality of life measured by SF-36

Patients with diabetes reported poorer health and had significantly lower scores than the people without diabetes in seven out of the eight health domains. The patients with diabetes also had lower scores in the eighth domain, social functioning (SF), but the difference was not significant. The highest scores in patients with diabetes were found in the physical functioning (PF) domain, while

Categories	150 answers given by 68 patients with diabetes	201 answers given by 60 control group without diabetes
Satisfaction with basic needs	88 (59%)	89 (44%)
Economy	24 (16%)	19 (9%)
Educational factors	17 (11%)	7 (5 %)
Health factors	10 (7%)	22 (11%)
Participation in social activities	7 (5%)	33 (16%)
Striving for better conditions	4 (2%)	31 (15%)

The percentage is calculated from the total number of answers given in each group.

Table 3. Number and percentage from a total of 351 answers given concerning the definition of the concept 'quality of life' in patients with diabetes and control group without diabetes

the poorest health was reported in the general health (GH) domain. The participants without diabetes showed the same general pattern. The scores of both groups are presented in Table 2.

General definition of quality of life

Both patients with diabetes and those in the group without diabetes provided many examples of what they defined as quality of life. When all the answers were scrutinised, the following six categories emerged: satisfaction with basic needs, economy, educational factors, health factors, participation in social activities and striving for better conditions.

All patients with diabetes gave at least one example that was included in the category 'satisfaction with basic needs.' Many patients highlighted the need to have enough food and good food. Many also mentioned special food for people with diabetes. Also, almost all of the 60 people in the control group gave answers that were included in the 'satisfaction with basic needs' category.

One patient with diabetes defined quality of life in the following way: 'By quality of life I mean when you get your daily basic needs, like clothes, shelter and food without any problems. Also when you get transportation and medical treatment.'

One person without diabetes gave this definition: 'Quality of life in my opinion means living without thinking of any problem, having a good shelter, getting food without any difficulties and living with peace and good interpersonal relationships within the community.' The numbers of answers grouped into the different categories are presented in Table 3.

The meaning of quality of life for each individual

The question relating to what quality of life meant to each individual generated a total of 437 statements. In both groups, economic factors were of great importance. Five categories emerged and are presented in Table 4. Patients with diabetes provided more answers than the participants without diabetes. Furthermore, many people in both groups included statements about satisfaction with basic needs, while the control group provided more answers about health factors.

Category	Examples of respondents' answers
Economy	Get money to buy food, to buy clothes, to have a house, to do something, to earn money, to afford good food, be able to get diabetic diet, be able to feed family good diet, to afford good education, to have good income, to afford daily activities, wealth.
Satisfaction with basic needs	Get food easily, meet daily needs, enough food to eat, meet essential needs, good place to sleep, eat what I want, have a house, daily requirements, free from problems, get drugs for diabetes, clothes and food, good diet, good life, good clothes, good housing/shelter, good environment, good place to live.
Health factors	To be cared for, to be well, to eat diabetic diet, be able to work, live in a good way, free from diseases, being well in health status, healthy life, free from danger, physically fit, proper health care, good facilities in hospital.
Educational factors	Good education, educating children, level of education, health education in the community.
Social factors	Happy with family, missing her husband, unable to move freely, uncomfortable, having a good happy family, healthy family.

Table 4. The perception of the concept 'quality of life' of each individual in the group with diabetes and the group without diabetes

The patients with diabetes expressed how quality of life affected them. One patient with diabetes wrote the following: 'Quality of life for me is not good because I'm still ill. I don't have a house. I don't have enough food to satisfy my family, no transportation. This makes it very difficult to manage with my disease.'

One person without diabetes gave the following example: 'Quality of life for me is not good because my basic salary is not enough and everything in this country is very expensive. So my life has not improved because I don't have enough money to control my life' (see table 5).

Categories	244 answers given by 68 patients with diabetes	193 answers given by 60 control group without diabetes
Economy	108 (44%)	66 (34%)
Satisfaction with basic needs	83 (34%)	58 (30%)
Health factors	33 (14%)	53 (28%)
Educational factors	14 (6%)	16 (8%)
Social factors	6 (2%)	– (0%)

The percentage calculated from the total number of answers given in each group.

Table 5. Number and percentage from a total of 437 responses to the question 'what does quality of life mean to you?'

Discussion

The main finding of the current study was that patients with diabetes perceived their own health to be poorer than did people without diabetes, as measured by the SF-36 questionnaire. The two open-ended questions about quality of life yielded categories different from those of the SF-36.

The self-reported poorer health in patients with diabetes was in congruence with earlier studies,[5] and the current results strengthened this picture. Although the patients with diabetes had completed the SF-36 questionnaire two years prior to the current study,[8] they reported poorer health than did the participants in the control group. One interpretation of these findings could be that patients with diabetes struggled with diabetes management and suffered due to the diabetes.

The SF-36 questionnaire was mainly developed for use in Western countries.[3] The eight health domains concerned issues related to perceived health. For example, respondents were asked to judge whether they felt as healthy as anybody they knew and whether they seemed to get ill more easily than others. Some of the SF-36 questions dealt with how respondents felt: whether they felt full of life, whether they felt so down in the dumps that nothing could cheer them up, whether they felt worn out or whether they were very nervous people. One similarity between the SF-36 issues and the Tanzanians' definitions of perceived health could be seen in the social functioning domain. The SF-36 questionnaire asks whether physical health or emotional problems have interfered with social activities, and many Tanzanians' answers stressed participation in social activities.

The open-ended question about the general definition of quality of life yielded similar results in both the patients with diabetes group and the control group. It appeared that 'satisfaction with basic needs' was a very dominant factor.

The question about what quality of life meant to the individual also showed that satisfaction with basic needs and economy were dominant in both groups. The answers regarding basic needs and economy were sometimes interlaced, but we did try to distinguish between them. One interpretation is that basic needs are more important, and therefore that lower-level needs (such as food and water) should be met before a person can address his or her higher level needs (such as self-actualisation). This seems to apply to all people, no matter whether they have diabetes or not, and is in accordance with Maslow's hierarchy of needs.[11]

One difference between the groups was shown in the factor of participation in social activities, where more people in the control group referred to this factor concerning the general definition of quality of life, while none of the answers regarding what quality of life meant to the individual concerned this factor. One interpretation could be that economy and basic needs were most important when considering the individual situation, while social factors were more crucial to a general definition of the quality of life concept.

In comparing the questions in the SF-36 questionnaire with the definitions given by the Tanzanians, an obvious difference was discovered. This was that none of the SF-36 questions dealt with the issues of 'satisfaction with basic needs' or 'economy'. Most people in poor countries are probably concerned with survival strategies and therefore include these as factors in their definitions of quality of life, while people living in Western countries take such things for granted. The current findings suggest that it is of utmost importance that questions about satisfaction of basic needs and economy be included in investigations into quality of life in developing countries.

Limitations recognised in this study: the control group consisted of people drawn from the hospital environment (student nurses or hospital workers). Results may have been influenced by the fact these people were used to meeting patients continuously and were a homogeneous group not representative of the general population.

Our intention was to trace all patients with diabetes included in the first study. Unfortunately we failed to do this. However, we conclude that this illustrates one of the difficulties associated with conducting longitudinal studies in a developing country.

In conclusion, the current results show that the SF-36 health-related questionnaire needs to be expanded to include issues dealing with basic needs and economy. Furthermore, the very performance of the data collection and the involvement of hospital staff and nurse educators as participants in the current study may hopefully enhance the understanding of patients with diabetes in clinical work.

Acknowledgements:
We are very grateful to the late Professor D McLarty for his advice and guidance and to Professor A B M Swai, who made it possible to perform this study.

Conflict of interest:
None

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A good new Austrian year

John Bowis, MEP

'*Gruss Gott!*', as we are now becoming accustomed to say by way of greeting. The UK recently handed the baton of the EU Presidency to Austria for the first six months of 2006. In particular, we send our warmest greetings to Maria Rauch-Kallatt, Austria's Health Minister, who has promised that one of the Austrian presidential priorities will be to focus on diabetes. Austria aims to intensify the exchange of expertise and to discuss potential steps at EU level and hosted a conference in Vienna in February .

The European Union comes into its own when it shares best practice and sets out recommendations for high standards in diagnosis, treatment, care and prevention. We saw this with the EU's work and recommendations on cancer screening: no Member State now wants to be seen to be left behind in extending screening programmes to those citizens who are most at risk.

The European Parliament is taking the opportunity, provided by Austria's commitment to raising the profile of diabetes on the European health agenda, to call for an EU Diabetes Strategy and a Council Recommendation on diabetes prevention, diagnosis and control. A Written Declaration to this effect was tabled at the January Plenary of the Parliament. It was the first