QUALITY OF LIFE IN PATIENTS WITH DIABETES USING THE DIABETES 39 (D-39) INSTRUMENT

Luana Rosas ZULIAN, Manoel Antônio dos SANTOS, Vivian Saraiva VERAS, Flávia Fernanda Luchetti RODRIGUES, Clarissa Cordeiro Alves ARRELIAS, Maria Lucia ZANETTI

ABSTRACT

The purpose of this study is to investigate the specific quality of life of patients with diabetes mellitus. It is a cross-sectional study, which was conducted from August 2-28, 2012 in two basic health units, in the interior of São Paulo. A convenience sample, made up of 75 patients, 18 years old or older, both sexes, in a group of self-monitoring of blood glucose, was used. The Diabetes 39 (D-39) Instrument Evaluation, containing five dimensions: energy and mobility (15 items), diabetes control (12), anxiety and worry (4) social overload (5) and sexual behavior (3), was used. Quality of life proved to be highly affected in the items related to the social overload dimension: embarrassment for having diabetes, being called diabetic and diabetes interfering with family life. The elucidation of the assessed factors contributes to the planning of educational programs, insofar as they may hinder the achievement of metabolic control in patients with diabetes.


RESUMO


Título: Qualidade de vida de pacientes com diabetes utilizando o instrumento Diabetes 39 (D-39).

a Nurse. Graduated from the School of Nursing of Ribeirão Preto, University of São Paulo. São Paulo, Brazil.
b PhD in Psychology. Associate Professor 3, Department of Psychology. College of Philosophy, Sciences and Literature of Ribeirão Preto, University of São Paulo. São Paulo, Brazil.
c Ph.D in Sciences from the Graduate Program in Fundamental Nursing. School of Nursing of Ribeirão Preto, University of São Paulo. São Paulo, Brazil.
d Master of Science from the Graduate Program in Fundamental Nursing. School of Nursing of Ribeirão Preto, University of São Paulo. São Paulo, Brazil.
e Ph.D in Sciences from the Graduate Program in Fundamental Nursing. School of Nursing of Ribeirão Preto, University of São Paulo. São Paulo, Brazil.
f Ph.D in Nursing. Associate Professor 3, Department of General and Specialized Nursing. School of Nursing of Ribeirão Preto, University of São Paulo. São Paulo, Brazil.
INTRODUCTION

Diabetes mellitus (DM) is a chronic condition in which the patient needs to control the disease, following an eating plan, increase physical activity and use medication to obtain good metabolic control and prevent acute and chronic complications. In addition to these factors, the importance of family support and diabetes education as tools to assist the patient in adopting effective strategies for coping with the disease is recognized.

To achieve good metabolic control, it is important that health professionals supervise adherence to the established treatment plan and also consider the adversities that the patients have in their daily lives to manage the disease, knowing how to respect their boundaries and explore their possibilities. Therefore, access to health education is an essential condition so that the patient may develop the process of the disease, build a space to learn about their disease and find new and better ways to deal with the vicissitudes of treatment.

The difficulties to incorporating changes in lifestyle can trigger bio-psychosocial repercussions manifested in the daily life of the patient. It is recognized that diabetes is a disease, regardless of age and etiology, that causes a negative impact, which compromises quality of life (QOL). QOL is defined as the individual’s perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

A study has shown that patients with DM have lower QOL levels than those that do not have the disease. Among the variables that affect QOL, there are: type of diabetes, use of insulin to control the disease, age, chronic complications, socioeconomic and educational level, psychological factors, ethnicity, knowledge about the disease and type of assistance, as well as others.

A retrospective cohort study conducted in Houston, USA, which established association between QOL specific to DM with glycated hemoglobin levels (HbA1c) before and after the patients’ participation in a DM self-management program, showed that innovations in primary care dedicated to patients’ self-management and improvement in clinical biomarkers, such as HbA1c, is associated with better quality of life.

Another U.S. study, which described the relationship between acculturation based on the Spanish language, psychosocial coping with DM and perceived social support in the daily management of the disease, using the D-39, showed that individuals with depleted psychosocial coping skills were more likely to need help in managing the daily routine of DM, with acculturation explaining little about getting help.

In this sense, DM educational groups have been created in spaces for the development of psychosocially coping with the disease, as well as for equipping the patient for self-care actions, aimed at improving their quality of life. However, prior to the planning and implementation of educational groups, health professionals still find it difficult to identify the self-management activities already implemented by patients, as well as assessing QOL, taking into account the specific aspects related to DM.

Examining the accumulated knowledge on the QOL of patients with DM, it was found that the literature is sparse and consists of studies with non-specific and generic instruments. Based on these, the goal of this study was to investigate the specific QOL of patients with DM. It is hoped that
this study will contribute to elucidating the factors involved in the QOL of patients with DM. Evaluating the QOL before participation in an educational program can provide benefits for planning actions focused on the real needs of patients, providing a baseline for future evaluations, which allows for investigation of the impact of the intervention implemented.

METHOD

A cross-sectional study was performed at two Basic Healthcare Units (BHU) in the western district of the City Health Department of Ribeirão Preto, in 2012. These health units were selected because they are located in the Western District and are linked to the University of São Paulo. The study population consisted of 401 people with DM enrolled in the home Self-monitoring of Capillary Blood Glucose Program (SCBG),(11) implemented in November 2005, in accordance with Municipal Law No. 10.299/04, which establishes standards of protection for people with diabetes to guarantee supplies for SCBG at home.

The convenience sample consisted of 75 subjects with DM, who agreed to participate in a DM educational program to enhance self-care in the self-monitoring of capillary blood glucose in the municipality. The study included: users with DM, over 18 years of age, of both sexes, residents of Ribeirão Preto-SP or the region, tracking them in the home self-monitoring of capillary blood glucose program in the two BHU elected; presenting cognitive conditions that enabled participation in the educational group.

To obtain the data we used two instruments: a form and the Diabetes 39 (D-39) Assessment Questionnaire.

The form contained the sociodemographic variables: sex, complete age in years, education, family income, occupation, and clinical variables: time of diagnosis, treatment for control of DM and the presence of comorbidities.

The D-39 instrument was chosen because of the possibility of being used on the whole population of patients with DM, regardless of demographic variables, gender, age, educational level, health status or ethnic group.(9) It is an instrument originally developed in English and specifically designed to determine the quality of life related to health of people with T2DM.(12) The D-39 instrument was adapted and validated for the Brazilian context,(13) showing good internal consistency, with a Cronbach’s alpha of 0.917.

The instrument can be self-administered. It consists of 39 items, covering five dimensions (domains) of the quality of life of people with DM: energy and mobility (15 items), diabetes control (12 items), anxiety and worry (4 items), social impact (5 items), and sexual behavior (3 items). The D-39 instrument also includes an overall evaluation domain of (2 items), which includes self-perceived QOL and severity of diabetes.

The D-39 instrument allows people to respond to how their QOL was affected during the last month by a particular action or activity expressed in each item; placing an X in a point on the scale represented by a continuous line, with spaces occupied by numbers 1-7, 1 being the number where QOL was absolutely unaffected, and the number 7, extremely affected.

For data collection, patients were recruited by telephone, to attend the basic healthcare unit to which they were linked, on a day and time that was previously agreed upon. Patients were informed about the objectives and nature of the study and, after they consented, signed the Free and Informed Consent Form. Data was collected in August 2012 in a private room, upon application of the individual instruments, even at the patient registration phase, before starting the educational program. The average time for filling out the instruments was thirty minutes.

For data analysis, descriptive statistics were used to characterize the distribution of sample responses in the D-39 instrument. We calculated the percentage distribution of patients with DM in accordance with: the responses to the items of the five dimensions of the D-39, the classification of self-perception of QOL and severity of the disease.

For analysis of the QOL of patients with DM, using the D-39 instrument, as with a Likert type, seven-point scale, one must consider the amplitude of the distribution of responses. Thus, based on previous research,(13) the authors of this study established that the criteria for a QOL analysis would be “unaffected” and “very much affected” as the highest and lowest values achieved at each end of the scale (1 and 7, respectively) and a percentage of subjects above 50%.

The project was approved by the Research Ethics Committee of the School of Nursing of Ribeirão Preto. Protocol No. 418.

RESULTS

In terms of demographic variables, it was noted that most patients were female and aged 50–69 years. Regarding education level, most completed elementary school. Regarding clinical variables, 35 (46.6%) patients had the disease for 10 years. Regarding comorbidities, most had more than one comorbidity, especially hypertension and dyslipidemia. With regards the use of drugs, the majority used insulin treatment. As for the number of doctor’s visits / year, it was found that half of patients had one to four doctor’s visits per year.

Table 1 shows the percentage distribution of patients with DM according to the responses to the items of the five dimensions of the D-39. In columns 1 and 7 the highest and lowest values obtained at each end of the scale can be seen, i.e., QOL “unaffected” and “very much affected,” the values above 50% of subjects being considered significant.

In relation to: the Energy and Mobility dimension of the D-39 (Items 3, 7, 9, 10, 11, 12, 13, 16, 25, 29, 32, 33, 34, 35 and 36), only for items: 29, not being able to do household activities (50.7%) and 34, difficulties in taking care of oneself (64.0%), was it found that the QOL of patients with DM was greatly affected. For item 13 - Not being able to do what you want, there was an even distribution of responses between QOL greatly affected and not affected (29.3% each) (Table 1).

Regarding the Diabetes Control (items 1, 4, 5, 14, 15, 17, 18, 24, 27, 28, 31 and 39), Anxiety and Worry (items 2, 6, 8 and 22) and Sexual Behavior (items 21, 23 and 30) dimensions of the D-39, it was found that in all these dimensions, the QOL reported by patients with DM appeared not be affected (Table 1).

In relation to the Social Burden dimension of the D-39 (items 19, 20, 26, 37 and 38), it was found that items: 20, Embarrassment at having diabetes (64.0%), 37, Being called diabetic (70.7%) and 38, having diabetes interfering with your family life (57.3%), indicate that the QOL of patients with DM was greatly affected (Table 1).

Table 2 shows the median, the mean and standard deviation of the domains and the total score of the D-39 obtained by the study subjects.

The medians obtained in the domains of the D-39 (Table 2) suggest that the dimensions diabetes control, social overload, anxiety and concern were those that produced comparatively better appreciation of the QOL of patients with diabetes. The energy and mobility domain and, principally, sexual behavior, were the ones with the lowest median

Table 1 – Percentage distribution of patients with DM according to the responses to the items of the five dimensions of the D-39. Ribeirão Preto, SP, 2012.

<table>
<thead>
<tr>
<th>Items</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Decrease or lack of energy</td>
<td>25 (33.3)</td>
<td>06 (8.0)</td>
<td>09 (12.0)</td>
<td>08 (10.7)</td>
<td>09 (12.0)</td>
<td>07 (9.3)</td>
<td>11 (14.7)</td>
</tr>
<tr>
<td>7. Other health problems besides diabetes</td>
<td>22 (29.3)</td>
<td>07 (9.3)</td>
<td>09 (12.0)</td>
<td>09 (12.0)</td>
<td>04 (5.3)</td>
<td>10 (13.3)</td>
<td>14 (18.7)</td>
</tr>
<tr>
<td>9. Feeling of weakness</td>
<td>28 (37.3)</td>
<td>06 (8.0)</td>
<td>07 (9.3)</td>
<td>03 (4.0)</td>
<td>07 (9.3)</td>
<td>10 (13.3)</td>
<td>14 (18.7)</td>
</tr>
<tr>
<td>10. How far you can walk</td>
<td>24 (32.0)</td>
<td>07 (9.3)</td>
<td>06 (8.0)</td>
<td>05 (6.7)</td>
<td>07 (9.3)</td>
<td>10 (13.3)</td>
<td>16 (21.3)</td>
</tr>
<tr>
<td>11. Need to perform exercises regularly</td>
<td>15 (20.0)</td>
<td>06 (8.0)</td>
<td>11 (14.7)</td>
<td>06 (8.0)</td>
<td>09 (12.0)</td>
<td>06 (8.0)</td>
<td>22 (29.3)</td>
</tr>
</tbody>
</table>

Continues...
12. Loss of vision or blurred vision: 23 (30.7) 05 (6.7) 08 (10.7) 05 (6.7) 10 (13.3) 06 (8.0) 18 (24.0)

13. Not being able to do what you want: 22 (29.3) 03 (4.0) 04 (5.3) 08 (10.7) 09 (12.0) 07 (9.3) 22 (29.3)

16. Diseases other than diabetes: 32 (42.7) 06 (8.0) 07 (9.3) - (-) 09 (12.0) 05 (6.7) 16 (21.3)

25. Complications due to your diabetes: 24 (32.0) 06 (8.0) 06 (8.0) 10 (13.3) 07 (9.3) 09 (12.0) 13 (17.3)

29. Not being able to do housework: 38 (50.7) 06 (6.7) 03 (4.0) 03 (4.0) 10 (13.3) 03 (4.0) 13 (17.3)

32. Need to rest several times a day: 27 (36.0) 03 (4.0) 14 (18.7) 02 (2.7) 14 (18.7) 05 (6.7) 10 (13.3)

33. Difficulty in climbing stairs: 22 (29.3) 03 (4.0) 05 (6.7) 07 (9.3) 11 (14.7) 04 (5.3) 23 (30.7)

34. Difficulties in taking care of yourself: 48 (64.0) 10 (13.3) 02 (2.7) 04 (5.3) 05 (6.7) - (-) 06 (8.0)

35. Restless sleep: 29 (38.7) 06 (8.0) 03 (4.0) 03 (4.0) 07 (9.3) 07 (9.3) 06 (8.0)

36. Walking slower than others*: 25 (33.3) 08 (10.7) 06 (8.0) 06 (8.0) 07 (9.3) 07 (9.3) 14 (18.7)

### Dimension 2: Diabetes Control

1. Daily use of medication: 25 (33.3) 06 (8.0) 09 (12.0) 09 (12.0) 10 (13.3) 03 (4.0) 13 (17.3)

4. Following a prescribed treatment: 27 (36.0) 09 (12.0) 03 (4.0) 06 (8.0) 12 (16.0) 04 (5.3) 14 (18.7)

5. Dietary restrictions: 22 (29.3) 08 (10.7) 07 (9.3) 08 (10.7) 09 (12.0) 07 (9.3) 14 (18.7)

14. Having diabetes: 19 (25.3) 04 (5.3) 06 (8.0) 09 (12.0) 11 (14.7)

15. Losing control over sugar levels: 18 (24.0) 04 (5.3) 09 (12.0) 09 (12.0) 06 (8.0) 20 (26.7)

17. Having to test sugar levels: 25 (33.3) 10 (13.3) 06 (8.0) 02 (2.7) 12 (16.0) 06 (8.0) 14 (18.7)

18. Time required for control: 27 (36.0) 06 (8.0) 06 (8.0) 06 (8.0) 13 (17.3) 06 (8.0) 11 (14.7)

24. Trying to keep diabetes controlled: 20 (26.7) 11 (14.7) 07 (9.3) 06 (8.0) 11 (14.7) 05 (6.7) 15 (20.0)

27. Keeping track sugar levels: 31 (41.3) 11 (14.7) 07 (9.3) 06 (8.0) 01 (1.3) 12 (16.0)

28. Needing to eat at regular intervals: 27 (36.0) 08 (10.7) 04 (5.3) 09 (12.0) 10 (13.3) 05 (6.7) 12 (16.0)

31. Having an organized routine due to diabetes: 27 (36.0) 04 (5.3) 06 (8.0) 09 (12.0) 09 (12.0) 03 (4.0) 17 (22.7)

39. Diabetes in general: 23 (30.7) 03 (4.0) 06 (8.0) 07 (9.3) 11 (14.7) 06 (8.0) 19 (25.3)

Continues...
value, suggesting further depreciation of QOL in these dimensions.

Table 3 shows the distribution of patients with DM according to the responses obtained in relation to their own perception of QOL and the severity of diabetes.

Table 4 shows the measures of central trends regarding self-perception of QOL and severity of diabetes.

By analyzing the classification of self-perceived quality of life and disease severity, for patients with DM (Table 3), it was found that the distribution gradient of responses is more focused on items related to QOL being unaffected. On the other hand, the distribution of answers relating to the perception by the patient of the disease (Table 4) shows that the subjects feel that they have a serious disease. Therefore, patients do not appear to perceive the relationship between QOL and severity of the disease.

DISCUSSION

This the purpose of this study was to investigate the specific QOL of 75 subjects with DM enrolled in a program for self-monitoring of
capillary blood glucose at home. The sociodemographic characteristics of the subjects showed a predominance of females, aged 50-60 years and an educational level equivalent to incomplete elementary education. Regarding clinical variables, 46.6% patients had the disease for 10 years. Comorbidities included arterial hypertension and dyslipidemia. These features are relevant to an understanding of the domains of the D-39.

By analyzing the distribution of responses to items related to the social overload domain, it was found that the factors potentially detracting from QOL were: the embarrassment of having diabetes, being called diabetic and having diabetes interfering with family life. Despite current advances in therapy and dissemination of scientific knowledge, which certifies that diabetes is a disease that can be controlled throughout life, there is the tendency to label this condition as a constraint that stigmatizes the person as someone who has an irreducible disadvantage. This social stigma is often internalized by patients and appears as factor of depreciation of their QOL.

The results in the fields of diabetes control, anxiety and worry, and energy and mobility were similar to those obtained in a study conducted in Houston, USA. The median values in this study were: 43.0, 37.5 and 43.3, respectively.(6)

The medians obtained in the domains of the D-39 indicate that the diabetes control, social overload, anxiety and worry dimensions show that patients perceive a loss of vitality, face mobility difficulties and feel dissatisfied with their sexual function. One

| Table 2 - Descriptive statistics of the D-39 domains and the total score for the sample (n = 75). Ribeirão Preto, SP, 2012. |
|---|---|---|---|
| Domains of the D-39 | Median | Mean | Standard deviation |
| Diabetes Control | 46.6 | 42.8 | 26.6 |
| Anxiety and worry | 42.8 | 43.5 | 28.3 |
| Social overload | 45.6 | 46.2 | 28.4 |
| Sexual behavior | 19.8 | 25.9 | 26.0 |
| Energy and mobility | 35.8 | 42.3 | 38.9 |
| Total score | 43.5 | 41.3 | 22.7 |

| Table 3 - Distribution of patients with DM according to the responses to the items from the General Evaluation of the D-39. Ribeirão Preto, SP, 2012. |
|---|---|---|---|---|---|---|---|
| Items | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) |
| Self-perception of quality of life | 3 (4.0) | 5 (6.7) | 4 (5.3) | 16 (21.3) | 22 (29.3) | 12 (16.0) | 13 (17.3) |
| How severe do you think your diabetes is? | 9 (12.0) | 3 (4.0) | 9 (12.0) | 12 (16.0) | 11 (14.7) | 8 (10.7) | 23 (30.7) |

| Table 4 - Classification of self-perceived QOL and severity of diabetes in the study sample (n = 75). Ribeirão Preto, SP, 2012. |
|---|---|---|---|
| Domains of the D-39 | Median | Mean | Standard deviation |
| Quality of Life | 66.6 | 63.7 | 26.4 |
| Severity of diabetes | 66.0 | 61.9 | 34.2 |
fact that stands out is that the limitations that patients found to their everyday lives are subjectively perceived as more demeaning to QOL than the specific issues that relate to diabetes control or the social burden caused by the condition.

In the social overload and sexual behavior domains, significant differences were observed: median values of 45.6 and 19.8 in the Brazilian sample and median values of 13.3 and 66.6, respectively, in the U.S. study, suggesting that Brazilians’ QOL is less depreciated because of the social costs entailed by DM. On the other hand, sexual behavior has a greater impact on the QOL of the Brazilian sample. This result deserves special attention in diabetes education programs, to incorporate strategies that facilitate the approach of the aspects relative to the impact of diabetes on sexual life. Already the total score showed similar values in Brazilian studies (median 40.3) and American (43.5).

On the other hand, it was found that the control of diabetes domain was better appreciated by Brazilian patients (median 46.6) compared to a study in Mexico using the D-39 (median 22.6). Also the social overload was more depreciated in the sample of Mexican patients (median 17.0) and American (median 13.3) compared to the Brazilian sample (median 45.6).

In the present study, the results obtained in relation to the classification of self-perceived QOL and disease severity medians were 66.6 and 66.0, respectively. In an investigation performed on a Mexican sample, a median of 50 in both perception of QOL and disease severity was obtained. These results suggest that the Brazilian sample tends to better value its QOL as well as realize their condition as more serious than the Mexican sample. On the other hand, in both cultures, people with diabetes do not perceive the relationship between QOL and severity of the disease, since they perceive that living with a serious illness does not prevent them from seeing themselves as enjoying a quality life.

A study conducted at the national level showed that there was a slight improvement in almost all domains of a generic QOL scale after participation in an educational program. It was also found that participants improved their perception of their general state of health. In contrast, the results of this study show that the observed discrepancy between self-perceived QOL preserved and perceived severity of the disease indicates the need for investment in the educational process in diabetes, in order to modify the patient’s subjective valuation.

The Latin American cultural values that prioritize the provision of assistance to friends and family, are probably related to the psychosocial coping with diabetes. On the other hand, individuals with good psychosocial functioning are more likely to benefit from external social support.

CONCLUSION

The results obtained in this study allow us to conclude that the D-39 items that contributed most to the depreciation of QOL were difficulties in performing household chores and patients being able to take care of themselves, as well as face certain restrictions on their ability to do what they want.

In the social overload dimension of the D-39, it was found that the factors that potentially detract from QOL include embarrassment at having diabetes, being called diabetic and having diabetes interfering with family life. In these respects, the QOL of patients with DM proved to be greatly affected.

Patients showed that their self-perceived QOL was unaffected. However, they consider diabetes to be a serious disease. Thus, they do not perceive the relationship between QOL and the severity of the disease.

The findings discussed in this study may be applied to the design of strategies and monitoring of patients with DM, in order to stimulate the incorporation of issues affecting the QOL of patients and which can impact their self-monitoring, such as probable sexual difficulties. Nurses must add the appreciation of specific dimensions of QOL into clinical practices, to increase the patient’s adherence to treatment of the disease.

The limitations that can be mentioned include the lack of studies, especially national studies, which would enable the comparison of data, expanding the scope of understanding of the issues related to QOL of patients with DM. In this direction it is necessary to invest in new studies for future comparisons.

REFERENCES

2 Francioni FF, Silva DGV. O processo de viver saudável de pessoas com Diabetes Mellitus através de um grupo de convivência. Texto & Contexto Enferm. 2007;16(1):105-11.


