67 - ASSESSMENT OF QUALITY OF LIFE IN PATIENTS WITH DIABETES MELLITUS TYPE I

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INTRODUCTION

Diabetes is a word of Greek origin which means not retaining fluid intake and melting flesh in urine. According to what has been reported since its discovery, in 1776, sweet taste was found in the urine. The English man Matthew Dobson discovered that blood had high sugar levels and the term mellitus was given the meaning of honey in 1797, by John Rollo. In his historic account, there are records of diabetes mellitus (DM) in 1552 B.C., describing a characteristic symptom such as polyuria, written on papyrus in the gym (GAMA, 2002).

According to Grossi, Cianciarullo, and Manna (2002), DM type I corresponds to 5% of cases worldwide, with higher incidence in children, adolescents, and young adults; it is the second most frequent chronic disease among these age groups.

According to Brasil (2012), quality of life (QOL) greatly affects patents with DM; this is not only due to the effects caused by the pathology and its possible complications, but also to its therapeutic strategies, such as diet, self-monitoring of blood, and high financial costs, which can lead to lifestyle constraints for patients and their relatives. According to Meada (2011), family members may contribute or not; in addition to the fact that they are legally responsible for the patient, making all decisions with regard treatment, they participate in discussions on the way how the patients must be provided with care and on the best way to conduct this care.

Support provided by a multidisciplinary team working along with patients and relatives who undergo the difficulties related to DM has been an useful strategy in the search for quality of life. Given the above, the following question has emerged: “What are the difficulties faced by patients with diabetes mellitus type I in order to have a good quality of life?”. Thus, this study aims to assess the quality of life of patients with DM type I diabetes using the Brazilian version of the diabetes quality of life questionnaire (DQOL).

METHODOLOGY

This is a descriptive study, with a quantitative approach, carried out in the 9th Regional Health Care Management Office, located in the town of Cajazeiras, Paraíba, Brazil. The population consisted of 131 diabetic patients and the inclusion criteria were having a chronic degenerative disease, i.e. DM type I, and voluntarily agreeing to participate in the research by signing the free and informed consent term.

Among the 131 selected patients, 2 died, 1 moved, 12 were unavailable due to the fact they were not home at the visit time; 11 patients refused to participate in the study, 1 interview was interrupted due to emotional issues caused by the questionnaire, and 51 patients from other regional health care management offices were excluded from the study sample. Therefore, a total of 53 patients were included in the sample. Data collection was conducted using a questionnaire developed by the multicenter study Diabetes Control and Complications Trial (DCCT); it was translated and culturally validated for the Brazilian context (JACOBSON; DEGROOT; SAMSON, 1994, apud, BRASIL, 2011).

The Brazilian diabetes quality of life questionnaire (DQOL) was adapted to Portuguese by Correr et al. (2008), according to the original English version of the internationally accepted protocol proposed by Guillemin, Bombardier e Beaton (1993), and adapted by Falcão (2001). Data were collected in March and April 2013 and the research subjects were directly approached, at home and/or in the 9th Regional Health Care Management Office, after approval by the Research Ethics Committee of Faculdade Santa Maria, under the Protocol 208,689.

The research was conducted so that its legitimacy and reliability was not compromised. Quantitative data were obtained by means of statistical analyses; then, they were included into graphs, tables, and boxes; these data underwent an analysis based on sociodemographic profile using simple statistics. For assessing the second stage of the aims, which were divided into 4 items, we calculated Cronbach's α for each individual domain; we regarded as good parameters the values ≥ 0.70 and as bad parameters the values ≤ 0.60 with regard to quality of life.

RESULTS AND DISCUSSION

According to Box 1, when asked about satisfaction, we found a score of 0.80, i.e. a positive result. Thus, talking about satisfaction is something very difficult, because for every individual we can find different views and situations, depending on her/his viewpoint and what the respondent regards as a standard. There is a need for obtaining examples based on patient's knowledge, which was provided by the health care team, and checking whether she/he is satisfied with her/his current treatment, blood sugar levels, and diet.

Treatment aims to promote conditions for normal growth and development associated to the prevention of acute and even chronic complications of this disease, both for children, adolescents, and young adult individuals. In order to achieve these conditions, professionals must work within a multidisciplinary team, focusing on nutritional issues and acceptance of the proper diet, deployment of an intensive insulin therapy, checking of blood glucose to adjust dosage, thus avoiding problems such as hypoglycemia, physical exercise according to the status of each individual, aimed at the prevention of acute and chronic complications, providing the patient with a family support. These practices are simple in theory and complicated in practice, so, minimizing risks is a must for improving a patient's quality of life (MARCELINO; CARVALHO, 2012).

Likewise, improving quality of life is related to greater satisfaction with regard to treatment and the level of physical and psychological impairment of the patient. Thus, the quality of life of a patient depends on wisdom, knowledge, and understanding of her/his current needs, in order to deploy proper management and self-care (LIMA, 2009).

Box 1 – Satisfaction of individuals with regard to DM.

Cronbach's α	Number of items
0.80	**15**

Source: Prepared by the authors.

Given the above, Box 2 shows that the research subjects also regard the impacts of DM as positive, obtaining a score of 0.75. When asked about the impacts, we noticed that these involved their daily life complaints with regard to pain, shame of treating the disease in public, interaction with the family, feeling bad about her/himself, due to food restrictions and inability to perform some tasks, such as writing, driving, among others.

Indeed, assessing QOL involves the general impacts of DM, such as drug therapy and the increasing doses of insulin; the use of modern devices for insulin administration may indicate a beneficial impact on patients' psychological issues and quality of life (LIMA, 2009). There may also be a major event which reduces patients' quality of life.

According to Silva et al. (2003a), the individual may realize that the impacts of DM are not always negative; she/he may think that diabetes increased her/his pleasure of eating, improved her/his fitness, and led her/him to prove she/he is able to achieve goals despite having the disease; besides, she/he regards the increased physical exercise and healthy diet as something which contributes to a healthier lifestyle.

Physical exercise is more than a stage of impact for patients, because the disease interferes with her/his act; it may cause a complication when practiced without proper guidance or even become something unpleasant for a sedentary person. However, according to Lima (2009), physical exercise must be included in the management of individuals with diabetes. Like other elements of the treatment, physical exercise must be individually prescribed, in order to prevent risks and increase the benefits, thus providing well-being.

When asked about it, many respondents say they do not comply with the diet for treating diabetes; this becomes another hard time in their lives, making the onset of complications related to this disease more likely. This fact has been reported in the literature with regard to epidemiology. There is a need for raising awareness of the importance of nutritional balance and physical exercise as a measure to manage blood glucose, preventing risks and problems. However, this adherence is difficult; when DM is diagnosed, it often involves abrupt changes in lifestyle (LIMA, 2009).

The family context of the research subject is of paramount importance in order to face the process of change and fit into the normal pattern (glycemic control); everyone involved in this stage must contribute, since patient's quality of life will positively affect the quality of life of her/his relatives, thus minimizing the impact of DM. Poor glycemic control may be associated to family conflicts..

Box 2 – Impact of DM type I.

Cronbach's α	Number of items
0.75	**18**

Source: Prepared by the authors.

Box 3 shows that the distribution of social/vocational concerns constitutes a good parameter, obtaining a score of 0.75.

For patients with DM, the social context involves a crucial knowledge, since it is essential with regard to the various kinds of control required, especially for treating children and adolescents; in the latter age group, several physiological and psychology changes take place and, besides, even friends and colleagues exert a strong influence on adaptation, thus, the quality of relationships has a particularly significant impact on the well-being of adolescents living with a chronic disease (SILVA et al., 2003b).

A problem reported by some adolescents and/or young adults is the lack of support from teachers in school life with regard to the prejudice of colleagues (FREITAS; SOBÓIA, 2007). This fact points out that learning becomes more difficult, the student often do not wish to continue her/his studies; this psychological implication may lead to distress and fear and, as a consequence, this may trigger occupational problems in the future.

Within the occupational domain, the wish for a better future and professional fulfillment constitutes a key motivation. Freitas and Sobóia (2007) analyzed the number of medical leaves of patients with DM; due to their physical status, often, these patients are not able to meet the attendance requirements in their job, thus, they tend to be afraid that DM reduces their chances to be hired. Therefore, DM may affect patient's psychological status and her/his socialization, compromising her/his professional performance and daily life relationships.

This entire context of social and vocational concerns leads the patient with DM to feel a lack of autonomy in society, interpersonal relationships, and school. She/he wishes for a better living standard, covering emotional, intellectual, and spiritual issues, something which promotes individuals' health status and even the relationship with her/his family.

Box 3 – Social/vocational concerns.

Cronbach's α	Number of items
0.79	**7**

Source: Prepared by the authors.

Box 4 shows that the concerns related to DM achieved a good standard, with a score of 0.74. Current concerns are growing with regard to QOL of patients with DM, especially doubts whether they have been properly assisted by health care professionals, relatives, and the society as a whole. These concerns are reflected in complications, because DM may lead to irreversible psychological and physiological problems, such as amputation of limbs, interfering with adherence to treatment and lack of motivation due to the rapid bodily changes, a situation which ranges in terms of acceptance, optimism, hope, and pessimism, fear, and worrying about death.

A chronic disease has implications related to patient's acceptance of her/his illness and treatment, including pain, fear of dying, inconvenience, and discrimination. It also involves high economic costs during treatment and costs posed by society, reducing quality of life (PÉRES et al., 2007).

Box 4 – Concerns related to DM.

Cronbach's α	Number of items
0,72	**4**

Source: Prepared by the authors.

Regarding the total score, shown in Box 5, the instrument revealed that the Cronbach's α achieved an excellent coefficient of 0.89, however, the Cronbach's α of concerns related to diabetes was of 0.72; the latter is also regarded as a good score, within the acceptable parameters, even being a lower value when compared to the other data obtained in the survey. As a whole, we found out that the patients are very concerned about DM.

The act of living with quality provides everyday life with balance, making lifestyle healthier and increasing patient's harmony to the environment. Therefore, a good health status depends on managing the emotional, physical, vocational, and spiritual issues, contributing to metabolic control (GUISELINI, 2004).

Box 5 – Total score of the questionnaire on DM.

Cronbach's α	Number of items
0,89	**44**

Source: Prepared by the authors.

FINAL REMARKS

The QOL was regarded as positive among respondents with regard to all aspects assessed in this research, with an emphasis on "satisfaction", which had the highest score (0.80) in the individual items under study, according to Cronbach's α.

This study addresses the positive and negative aspects related to the quality of life of patients with diabetes mellitus type I and it may be applied to action programs of the Brazilian health care system aimed at the care and well-being of users and the well-being of their caregivers and relatives, who live with a chronic condition.

It is worth mentioning that there is a limitation in this research, because, even knowing the problems caused by the disease, which interferes with the life of patients, the positive results indicated by the scores highlight the need to carry out further studies on the theme, in order to obtain more consistent data with regard to the issues involved. We stress the importance of conducting longitudinal studies, which certainly will contribute to increase knowledge on the impact of DM on patient's quality of life.

We hoped that our findings provide professionals with additional means to care for patients with DM type I, taking into account the factors which influence the quality of life of these patients, allowing the implementation of a treatment addressing not only the individual's physiological aspects, but also the psychosocial and cultural ones.

Diabetes mellitus requires daily monitoring and patient's awareness with regard to the diagnosis; she/he needs to understand the role played during the treatment, in order to prevent hospitalization and the emergence of complications. When properly managed, DM type I is a disease which allows the subject to enjoy a normal and painless life.

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ASSESSMENT OF QUALITY OF LIFE IN PATIENTS WITH DIABETES MELLITUS TYPE I

ABSTRACT

Objective: Evaluate the quality of life in patients with diabetes mellitus type I using the Brazilian version of the diabetes quality of life questionnaire (DQOL). Methodology: Descriptive study, with a quantitative approach, carried out in March and April 2013, in the 9th Regional Health Care Management Office. The sample consisted of 53 patients with diabetes mellitus type I, who answered to a questionnaire validated for the Brazilian context. Data collection took place after approval by the Research Ethics

Committee of Faculdade Santa Maria, under the Protocol 208,689. Results and discussion: According to Cronbach's α scores, it was found out that the satisfaction of patients with diabetes mellitus type I with regard to the disease is 0.80, the impact that the disease causes is 075, social and vocational concerns correspond to 0.79, the concerns related to diabetes correspond to 0.72, and the total score of the 44 questions is 0.89. Conclusion: This study addresses the positive and negative aspects related to the quality of life of patients with diabetes mellitus type I and it may be applied to action programs of the Brazilian health care system aimed at the care and well-being of users and their caregivers and relatives, who live with a chronic condition.

KEYWORDS: Quality of life. Diabetes mellitus. Diabetes quality of life questionnaire.

ÉVALUATION DE LA QUALITÉ DE VIE CHEZ LES PATIENTS ATTEINTS DE DIABÈTE SUCRÉ TYPE I

RÉSUMÉ

Objectif: Evaluer la qualité de vie des patients atteints de diabète sucré type I en utilisant la version brésilienne du questionnaire sur la qualité de vie dans le diabète (DQOL). Méthodologie: Étude descriptive, avec une approche quantitative, réalisée en Mars et Avril 2013, dans la 9ème Gestion Régional de Santé. L'échantillon était composé de 53 patients atteints de diabète sucré type I, qui ont répondu à un questionnaire validé pour le contexte brésilien. La collecte des données a eu lieu après l'approbation par le Comité d'Éthique de la Recherche de la Faculdade Santa Maria, en vertu du Protocole 208.689. Résultats et discussion: Selon les scores α de Cronbach, il a été constaté que la satisfaction des patients atteints de diabète sucré type I à l'égard de la maladie est de 0,80, l'impact que la maladie provoque est de 0,75, les préoccupations sociales et professionnelles correspondent à 0,79, les préoccupations reliées au diabète correspond à 0,72, et le score total des 44 questions est de 0,89. Conclusion: Cette étude porte sur les aspects positifs et négatifs reliés à la qualité de vie des patients atteints de diabète sucré type I et il peut être appliqué à des programmes d'action du système de santé Brésilien visant au traitement et le bien-être des usagers et de leurs aidants et les parents, qui vivent avec une maladie chronique.

MOTS CLÉS: Qualité de vie. Diabète sucré. Questionnaire sur la qualité de vie dans le diabète.

EVALUACIÓN DE LA CALIDAD DE VIDA DE PACIENTES CON DIABETES MELLITUS TIPO I

RESUMEN

Objetivo: Evaluar la calidad de vida de pacientes con diabetes mellitus tipo I utilizando la versión brasileña del cuestionario de calidad de vida en diabetes (DQOL). Metodología: Estudio descriptivo, con abordaje cuantitativo, llevado a cabo en marzo y abril de 2013, en la 9ª Gerencia Regional de Salud. La muestra consistió en 53 pacientes con diabetes mellitus tipo I, que respondieron a un cuestionario validado para el contexto brasileño. La recogida de datos se llevó a cabo después de la aprobación por el Comité de Ética en Investigación de la Faculdade Santa Maria, bajo el Protocolo 208.689. Resultados y discusión: Según la puntuación del α de Cronbach, se constató que la satisfacción de los pacientes con diabetes mellitus tipo I con la enfermedad es de 0,80, el impacto que la enfermedad causa es de 0,75, las preocupaciones sociales y vocacionales corresponden a 0,79, las preocupaciones relacionadas con la diabetes corresponden a 0,72 y la puntuación total de las 44 preguntas es de 0,89. Conclusión: Este estudio aborda los aspectos positivos y negativos relacionados con la calidad de vida de los pacientes con diabetes mellitus tipo I y puede ser aplicado a los programas de acción del sistema de salud brasileño dirigidos a la atención y el bienestar de usuarios y sus cuidadores y familiares, que conviven con una enfermedad crónica.

PALABRAS CLAVE: Calidad de vida. Diabetes mellitus. Cuestionario de calidad de vida en diabetes.

AVALIAÇÃO DA QUALIDADE DE VIDA DE PACIENTES PORTADORES DE DIABETES MELLITUS TIPO I

RESUMO

Objetivo: Avaliar a qualidade de vida de pacientes portadores de diabetes mellitus tipo I utilizando a versão brasileira do questionário de qualidade de vida em diabetes (DQOL). Metodologia: Estudo descritivo, com abordagem quantitativa, realizado em março e abril de 2013, na 9º Gerência Regional de Saúde. A amostra foi composta por 53 portadores de diabetes mellitus tipo I, que responderam um questionário validado para o contexto brasileiro. A coleta de dados ocorreu após aprovação do Comitê de Ética em Pesquisa da Faculdade Santa Maria, sob o Protocolo n. 208.689. Resultados e discussão: Segundo os escores de α de Cronbach, constatou-se que a satisfação dos portadores do diabetes mellitus tipo I com a doença é de 0,80, o impacto que a doença acarreta é de 075, as preocupações sociais e vocacionais correspondem a 0,79, as preocupações relacionadas à diabetes correspondem a 0,72 e o escore total das 44 perguntas é de 0,89. Conclusão: Este estudo aborda os aspectos positivos e negativos relacionados à qualidade de vida dos portadores de diabetes mellitus tipo I e pode ser aplicado aos programas de ação do sistema de saúde brasileiro voltados ao atendimento e bem-estar de usuários e de seus cuidadores e familiares, que convivem com uma condição crônica.

PALAVRAS-CHAVE: Qualidade de vida. Diabetes mellitus. Questionário da qualidade de vida em diabetes.