

**DIABETES AND QUALITY OF LIFE: MEANINGS ASSIGNED FROM THE PERSPECTIVE OF PROFESSIONALS AND USERS****DIABETES E QUALIDADE DE VIDA: SIGNIFICADOS ATRIBUÍDOS NA PERSPECTIVA DE PROFISSIONAIS E DE USUÁRIOS****DIABETES Y CALIDAD DE VIDA: SIGNIFICADOS DESDE LA PERSPECTIVA DE PROFESIONALES Y USUARIOS**

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**How to cite this article:** Moreschi C, Rempel C, Siqueira DF, Pissaia LF, Bedin BB, Chaves MF. Diabetes e qualidade de vida: significados atribuídos na perspectiva de profissionais e usuários. Rev Enferm Atenção Saúde [Internet]. 2021 [acesso em \_\_\_\_];10(2):e202115. doi:10.18554/reas.v10i2.4309

**ABSTRACT**

**Objective:** to understand the meaning of quality of life for a person with diabetes from the perspective of health professionals and users with diabetes. **Method:** qualitative research, carried out with 14 people with diabetes, assisted in the Family Health Strategies of Lajeado / Rio Grande do Sul and with 14 health professionals. Data collected between April and October 2015 through a semi-structured interview with the guiding question: What does it mean to have quality of life for a person with diabetes? **Results:** three categories related to having quality of life: Being healthy - having a controlled disease; Be well with yourself and feel good in your environment. **Conclusions:** quality of life for a diabetic person and health professionals is to be healthy - to control the disease, to be well with oneself and to feel good in their environment, accepting the limitations. Promoting educational actions to improve the quality of life.

**Descriptors:** Quality of Life; Diabetes Mellitus; Family Health Strategy.

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## RESUMO

**Objetivo:** este artigo visa relatar o significado de qualidade de vida para uma pessoa com diabetes na perspectiva de profissionais de saúde e de usuários com diabetes. **Método:** pesquisa qualitativa, realizada com 14 pessoas com diabetes, atendidas nas Estratégias Saúde da Família de Lajeado/Rio Grande do Sul e com 14 profissionais de saúde. Os dados foram coletados entre abril a outubro de 2015 por meio de entrevista semiestruturada com a questão orientadora: O que é ter qualidade de vida para uma pessoa com diabetes? **Resultados:** existem três categorias relacionadas à qualidade de vida para uma pessoa com diabetes: ter saúde - estar com a doença controlada; estar bem consigo mesmo e sentir-se bem em seu meio de convivência. **Conclusões:** possuir diabetes e ter qualidade de vida é ter saúde – portanto, é necessário controlar a doença, estar bem consigo mesmo e sentir-se bem em seu meio de convivência, aceitando as limitações. É importante promover ações educativas para melhorar a qualidade de vida dos usuários diabéticos.

**Descritores:** Qualidade de Vida; Diabetes Mellitus; Estratégia Saúde da Família.

## RESUMEN

**Objetivo:** informar el significado de calidad de vida de una persona con diabetes desde la perspectiva de los profesionales de la salud y de los usuarios con diabetes. **Método:** investigación cualitativa, realizada con 14 personas con diabetes, que reciben atención en las Estrategias de Salud Familiar de Lajeado/Rio Grande do Sul y con 14 profesionales de la salud. Los datos fueron recopilados entre abril y octubre de 2015 mediante una entrevista semiestructurada con la pregunta orientadora: ¿Qué es tener calidad de vida para una persona con diabetes? **Resultados:** hay tres categorías relacionadas con la calidad de vida: estar sano, tener controlada la enfermedad; estar bien consigo mismo y sentirse bien con su entorno. **Conclusiones:** tener diabetes y tener calidad de vida es estar sano, por lo tanto, es necesario controlar la enfermedad, sentirse bien consigo mismo y sentirse bien con su entorno, aceptando las limitaciones. Es importante promover acciones educativas para mejorar la calidad de vida.

**Descritores:** Calidad de Vida; Diabetes mellitus; Estrategia de Salud Familiar.

## INTRODUCTION

Diabetes Mellitus (DM) is an endocrine-metabolic abnormality, characterized by an absolute deficiency of the hormone insulin or by a resistance to its action, which interferes with the entry of glucose into the cell and increases plasma concentration.<sup>1</sup> It is a disease that presents high prevalence and is related to high morbidity and mortality rates, representing an important public health problem.<sup>2</sup>

According to a study carried out with people with DM assisted in the Family Health Strategy (ESF) in a city in Rio Grande do Sul in 2018, it was found that the majority of the population with diabetes is female (72.0%) , in

the age group of 59 to 69 years of age (35.6%).

It was observed that most have another family member with the same disease (51.9%), and most have lived with the diagnosis for more than 6 years.<sup>3</sup>

DM, together with Systemic Arterial Hypertension (SAH), is responsible for the leading cause of mortality and hospitalizations in the Unified Health System (SUS) and also represents more than half of the primary diagnosis in people with chronic renal failure. to dialysis.<sup>4</sup>

Diabetes can compromise QoL, therefore, it is important to consider that QoL is related to subjectivity and multidimensionality, as well as the presence of

positive and negative dimensions of each person. In this logic, according to the concept of the World Health Organization (WHO), QOL is understood as "the individual's perception of their position in life, in the context of their culture and in the value system in which they live and in relation to their expectations, its standards and its concerns". This is considered a broad concept, as it incorporates, in a complex way, physical health, psychological status, level of independence, social relationships, personal beliefs and the relationship with significant aspects of the environment.<sup>5</sup>

From the perspective of the concept of QoL established by the WHO, the theoretical model of QoL of satisfaction stands out. This theoretical model is related to satisfaction with the various domains of life, defined as important by the individual, considering that the condition of satisfaction is a subjective experience and is associated with the level of expectation of each individual. Thus, a person can be satisfied with their QOL having different levels of acquisitions, depending on their expectations.<sup>6</sup>

A relevant contribution to the theoretical model of satisfaction is related to the conditions with which the individual should be satisfied to have a good QOL. In this logic, it is considered that the basic needs of human beings need to be addressed so that they can feel good. These details include, for example, health, mobility, nutrition and housing. Therefore, considering that this theoretical model takes into account the existence of universal basic needs, it supports the idea that

it is possible to develop a QOL instrument from a cross-cultural perspective.<sup>6</sup>

In 2015, the International Diabetes Federation estimated that 8.8% of the world's population aged 20 to 79 years (415 million people) had diabetes. Given this trend, it is estimated that, in 2040, the number of people with diabetes will exceed 642 million. The increased prevalence of diabetes is associated with several factors, such as the epidemiological transition, nutritional transition, rapid urbanization, greater frequency of sedentary lifestyles, obesity, increasing population aging, and even greater survival of people with diabetes.<sup>7</sup>

Furthermore, it is important to mention that DM can remain asymptomatic for a long time, and that its clinical detection is often made not by symptoms, but by its risk factors. It is estimated that part of people who have diabetes are unaware of their own condition. For these reasons, it is important that the teams of the Family Health Strategy (FHS) be aware not only of the symptoms of diabetes, but also of its risk factors (unhealthy eating habits, sedentary lifestyle and obesity). The therapeutic approach to detected cases, monitoring and control of blood glucose, as well as the beginning of the education process are fundamental for the prevention of complications and for the maintenance of their QOL.<sup>4</sup>

Given the above, this study aimed to understand the meaning of quality of life for a person with diabetes from the perspective of health professionals and users with diabetes.

## METHOD

The research is characterized as qualitative, carried out with 14 people with diabetes, registered in the SIAB/e-SUS, assisted by the ESFs of Lajeado/RS and health professionals of these ESFs. 14 health professionals who work with this population also participated in the survey. A professional and a person with DM were randomly chosen in each ESF in the municipality.

This municipality has 71,445 inhabitants, 71,180 residents of the urban area and 265 residents of the rural area, which characterizes the municipality with a high degree of urbanization (99.9%).<sup>8</sup> Primary care in Lajeado/RS has 14 FHSs and these services use the SIAB/e-SUS.

For people with Diabetes Mellitus, the following inclusion criteria were established: people with Diabetes Mellitus registered in the SIAB/e-SUS in 2014 over 18 years old. Exclusion criteria were people who were not mentally able to answer the questionnaires.

The inclusion criteria for the participating professionals were: being a health professional from the team working in the primary care service and working with people with diabetes during the data collection period; have at least six months of service; higher, technical and medium level training for ACSs. The exclusion criteria for these were those who were on vacation or on a medical certificate during the period of data collection.

Data collection was carried out from April to October 2015 through semi-structured interviews with the guiding question: What is having quality of life for a person with DM? The interviews were carried out by the researcher, individually, recorded on a digital device and later transcribed in full. They were held at a pre-established time, in an ESF room with professionals and people with DM at home.

The interviews were analyzed through the Thematic Analysis of Minayo's Operative Proposal, which is supported by the philosophical current of dialectical materialism that is constituted from sociocultural aspects. This analysis is defined by the discovery of the nuclei of meaning, which establish a communication about the frequency or presence of a certain meaning for the object being analyzed.<sup>9</sup>

This research was approved by the COEP of Centro Universitário UNIVATES, under number: 997,286, and CAAE: 42472215.7.0000.5310.

## RESULTS

The thematic content analysis process showed that there are three main categories and are related to QoL in the perception of people with DM: being healthy - having the disease under control; be good about yourself and feel good in your environment (FIGURE 1).

**FIGURE 1** – Meaning of having quality of life for a person with diabetes, in the perception of health professionals and people with diabetes.



Source: Survey data (2016).

### **Be healthy - have the disease under control.**

Both health professionals and people with DM considered that the QoL of a person with DM involves being healthy, which was perceived by the participants as synonymous with having the disease under control. This control was related to several aspects, such as: changes in habits and lifestyles; people's access to health services; ensuring the necessary guidelines regarding the care of DM by health professionals; family support; performing self-care activities inherent to disease control (food, physical activities, medication and glycemic control). In addition, the practice of self-care must be reconciled with their daily activities, in order to remain active, busy, which, in addition to controlling

the disease, can also improve the individual's QoL.

*Having quality of life for those with diabetes is being healthy, controlling the disease, having access to health monitoring, receiving guidance and medication (PS2).*

*It's taking care of yourself, you can't eat anything, keep the disease under control, I only worry when I forget to take the medicine, do a lot of physical exercise and occupy my mind, do my homework (PD2).*

*You have to take care of your diet, medication, so you don't get sick, keep your blood glucose levels under control, do physical activity and keep your diabetes under control. You have to change habits and lifestyles, be healthy (PS3).*

*It means having health, controlling diabetes, because there is no cure. It's doing what I don't do, physical activity, taking care of food, not smoking and not drinking (PD8).*

*It means being able to continue doing your everyday tasks, at home, at work and others (PS10).*

*It's being healthy, controlling diabetes, taking medication, taking care of your diet (PD10).*

In addition, the participants mention that the QoL of a person with DM is related to the absence of cigarette smoking and alcohol consumption habits.

### **Being okay with yourself.**

Participants also attribute meaning to the QoL of a person with DM when feeling good about themselves. For this, they believe it is necessary to love themselves, do what they like, accept the disease, be at peace, develop pleasurable activities, have economic conditions to meet their needs, remain active in their occupations, work and live in harmony with the family and community.

*Feeling good about yourself, being healthy and able to walk, visit my family (PD1).*

*It's being able to do what you like and be healthy. It's being able to work to have everything you need (PS2).*

*It means accepting everything that happens in life, accepting the disease and living calmly, having money to buy basic needs (PD2).*

*Being well, being healthy, being at peace with the family, with the neighbors (PD 4).*

*Having quality of life is the person feeling good about themselves, for those who have diabetes and those who do not (PS3).*

*It's being able to do the things you like, have leisure and be with your family (PS10).*

*Quality of life is being well, having an occupation that may not be a job, it may be something else that you are involved in with an action that occupies your head and that you like to do, feel good (PS11).*

*If you love, want well, know how to live your life, control the disease (PD11).*

*It's to be well, today I don't have the energy I used to, I can't work anymore (PD12).*

*It means being healthy to do what I like, having money for my needs, being well enough to go out (PD13).*

Participants associated the QoL of people with DM with the individuals' satisfaction in feeling good about themselves and performing pleasurable activities.

### **Feeling good in their environment.**

The results showed that having QoL, in the perception of a person with DM, means, in addition to being healthy - which implies having the disease under control and feeling good about oneself - it is important and necessary for these people to feel good in their environment of coexistence. The means of coexistence are related to the family environment, neighbors, people they relate to, health services and the community. Having QoL for people with DM is linked to the development of pleasurable activities in their area of coexistence, such as dancing, participating in a women's group, among others. This is what was exemplified in the following statements:

*It's being able to visit relatives, they help me, give me advice so I can accept the disease and take care of myself (PD2).*

*It's living well, participating in women's groups in the community, crocheting, painting, dancing and other things I like to do (PD5).*

*It's living well, you have to take care of your diabetes. There at the health center, they tell you everything you need to do (PD6).*

*It is necessary to feel good, to know how to live life, to love and want it well, to accept that diabetes cannot be cured and to take care of yourself (PD9).*

*It's being able to do the things you like and stay with the family too (PS10).*

*Having quality of life is the person feeling good in the environment in which they live, doing things they like, within the reality of each one, feeling good in all aspects in general, with the family, with the neighbors, with the health service itself (PS12).*

In order for people to feel good in their environment, it is important that they take the necessary care to control the disease, as it is a chronic disease. Therefore, having QoL for a person with DM is being healthy - controlling the disease, feeling good about oneself and feeling good in their environment according to the limitations resulting from DM.

## **DISCUSSION**

Quality of life is the individual's perception of their position in life, taking into account the context of the culture and value system in which they live, and in analogy to their goals, expectations, standards and concepts. This perception can be influenced in

a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationships with their environment.<sup>10</sup>

Based on the theoretical model of satisfaction proposed by Fleck MPA8, QoL is directly linked to satisfaction with the various domains of life considered important by the subject. Satisfaction is a subjective experience and is related to each individual's level of expectation. Therefore, a person can be satisfied and present a good QoL with different levels of acquisitions.

In this study, the results showed that, for those who have DM, having QoL is being healthy - having the disease under control, feeling good about oneself and feeling good in their environment. In other words, being healthy is directly related to disease control, which was associated with the performance of self-care practices, such as care with food, physical activity, proper use of medication and glycemic control. As can be seen, DM is a pathology that requires care from people affected with regard to nutrition, physical activities and self-control, as a way to prevent injuries. The adherence of people with DM to the practices of self-care activities can reward them with a higher QOL.<sup>11</sup>

It was also found that the QoL of a person with DM is associated with access to health services. The importance of access to health services is recurrent in research carried out with chronic patients and, in the case of people with DM, some health problems such as hypoglycemia and hyperglycemia require present and effective health services in their

areas. Access to health services is also verified in the performance and participation in health promotion groups, offered to the community by teams working in primary health care, becoming important tools to offer QOL to people with DM.<sup>12</sup>

Family support emerged as an important strategy that can influence disease control and contribute to improvements in the QoL of people with DM. When the person with DM receives the necessary support from their family group, this can contribute to the assimilation of a healthy and necessary way of self-care provided by the disease, since family members help in caring for the individual.<sup>13</sup>

Feeling good about oneself was related to satisfying some needs of people with DM, among them, loving oneself, accepting the disease, being at peace, developing pleasurable activities, having economic conditions to meet their needs, staying active in their work occupations and live in harmony with their family and community.

The QoL of people with DM is related to the need for subjects to keep busy in their daily activities, reconciling self-care practices with their daily activities, which can keep them active. The need to remain socially active is present in all population groups, as it guarantees the individual's space in the community framework to which he/she was inserted. The same happens with people with DM. Thus, the importance of staying active is related to the increase in QoL, and their occupations provide moments of socializing with other people, in addition to preventing

very frequent depressive episodes after the diagnosis of DM.<sup>14</sup>

Negative feelings can be present due to the limitations required to maintain the disease, as well as positive feelings can also bring out responsibility and generate a certain attitude of respect for the disease. It is assumed that individuals with DM are always in search of meanings for their condition. In addition, depending on the meanings he may come to construct and his attitude towards the disease, the closer he will be to the feeling of acceptance in front of the DM.<sup>15</sup>

Another aspect to be observed in the mutual understanding of QOL refers to the financial conditions of people with DM, and in some cases, after the diagnosis of the pathology, there are increases in expenses with consultations and medication.<sup>16</sup> The income of a family group demonstrates their ability to acquire or not certain goods and, in the case of people with DM, financial difficulties act strongly on adherence to treatment and self-care of individuals.<sup>17</sup>

The self-acceptance of people with DM can offer a higher QoL in their context, as the individual perceives himself as an integral part of a community, and from this point of view, he feels motivated to carry out the proposed treatment and adapt it to your needs.<sup>18</sup>

The results also showed that, for a person with DM to have QoL, it is necessary to feel good in their environment. This environment is related to the family environment, neighbors, people with whom they are related, health services and the community.



In fact, being part of a social group in your community, whether friends or family members, the latter in particular, is essential, as it helps encourage people with DM to understand their own health status.<sup>13</sup>

The family environment in which the person is found is relevant to help in the process of changing lifestyle habits and glycemic control, and for this, it is necessary and essential to have the understanding and collaboration of everyone involved. The mutual and continuous involvement of the whole family can have a positive impact on QoL, not only for the person who has DM, but for the other members, reducing the impact related to the disease.<sup>19</sup>

It is worth reflecting on the importance of a person with DM living well in their environment, according to the limitations of the disease. In this sense, it is essential that care for people affected by this chronic condition is planned and implemented, considering health determinants and conditions, as well as individual needs and possibilities and the family context.<sup>20</sup>

Thus, based on the perspective of the theoretical model of satisfaction, the results showed that, for a person with DM to have QoL, it must be related to the satisfaction of three expectations based on the subjectivity of the participants: being healthy - controlling the disease, feeling good about yourself same and feel good in their environment.

## CONCLUSION

By understanding the meaning of quality of life for a person with diabetes from the

perspective of health professionals and users with diabetes, this study showed that having QoL for a person with DM is being healthy - controlling the disease, feeling good about oneself and feel good in their environment, accepting the limitations resulting from the DM.

It was evident that, in order to be healthy, it is necessary to have the disease under control and to be satisfied with several aspects, including access to health services; ensuring the necessary guidelines regarding the care of DM by health professionals; family support; changes in habits and lifestyles; and carrying out the necessary self-care activities inherent to the control of the disease (food, physical activities, medication and glycemic control).

It was found that and to feel good about yourself is to love yourself, be healthy, do what you like, accept the disease, be at peace, have the economic conditions to meet your needs, keep active in your occupations, work and live in harmony with the family and community. Feeling good in their environment was related to the satisfaction of feeling good in different social environments, such as the family environment, neighbors, people they relate to, health services and the community. Such understanding can enhance the promotion of educational actions that seek to improve the QoL of people with DM assisted in the FHS.

The limitation of this study is based on the fact that the data collection scenario was delimited in a city in the state of RS, however, it is suggested that multicenter studies be carried out. It should be noted that this study

presents relevant data on the meaning of quality of life for a person with diabetes from the perspective of health professionals and users with diabetes, which enable the planning of health promotion actions and the prevention of complications for individuals with DM attended in Primary Care. These data are relevant scientific subsidies for reflecting and, if necessary, rethinking health intervention strategies, as well as delineating public policies that meet the health conditions, both at the individual and collective levels of users with diabetes.

#### ACKNOWLEDGMENT

We thank the Foundation for Research Support of the State of Rio Grande do Sul (FAPERGS), for granting a doctoral scholarship to the first author of this study.

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RECEIVED: 02/26/2020  
APPROVED: 12/04/2020  
PUBLISHED: 09/2021