

HEALTH STATE AND REPRESENTATIONS ABOUT THE DISEASE FROM THE PERSPECTIVE OF PATIENTS WITH DIABETES MELLITUS

ESTADO DE SAÚDE E REPRESENTAÇÕES SOBRE A DOENÇA NA PERSPECTIVA DE PORTADORES DE DIABETES MELLITUS

EL ESTADO DE LA SALUD Y LAS REPRESENTACIONES ACERCA DE LA ENFERMEDAD DESDE LA PERSPECTIVA DE PACIENTES CON DIABETES MELLITUS

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Objective: evaluating the health status and its dimensions in patients with Diabetes Mellitus treated in a teaching hospital in the light of the Commonsense Model. Method: a descriptive study with qualitative analysis of the data. Participated twenty patients hospitalized and in outpatient care. The data were submitted to content analysis and interpreted according to the concepts of the Commonsense Model. Results: the discourses were categorized according to the identity of the disease and its concepts; duration and time for diagnosis and symptoms; causes of the disease and its explanations; consequences and treatment; control and perceptions about prognosis. Final Considerations: the concepts of health status and its dimensions related to Diabetes Mellitus interpreted in the light of the Commonsense Model described it as a disease with physical signs and potential for complication, even associated with death; however, they also revealed ignorance of the real causes and consequences of the disease.

Descriptors: Conceptions. Diabetes Mellitus. Health-Disease Process.

Objetivo: avaliar o estado de saúde e suas dimensões em pacientes com Diabetes Mellitus, atendidos em um hospital de ensino, à luz do Modelo do Senso Comum. Método: estudo descritivo, com análise qualitativa dos dados. Participaram 20 pacientes hospitalizados e em atendimento ambulatorial. Os dados foram submetidos à análise de conteúdo e interpretados segundo os conceitos do Modelo do Senso Comum. Resultados: os discursos foram categorizados de acordo com a identidade da doença e suas concepções; duração e tempo para o diagnóstico e os sintomas; causas da doença e suas explicações; consequências e tratamento; controle e percepções sobre o prognóstico. Considerações finais: as concepções do estado de saúde e suas dimensões relacionadas ao Diabetes Mellitus, interpretadas à luz

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do Modelo do Senso Comum, descreveram-no como uma doença com sinais físicos e com potencial de complicação, inclusive associada à morte; contudo, também revelaram o desconhecimento das reais causas e consequências da doença.

Descritores: Concepções. Diabetes Mellitus. Processo Saúde-Doença.

Objetivo: evaluar el estado de salud y sus dimensiones en pacientes con Diabetes Mellitus tratados en un hospital docente a la luz del Modelo de Sentido Común. Método: es un estudio descriptivo con análisis cualitativo de los datos. Participaron veinte pacientes hospitalizados y en atención ambulatoria. Los datos fueron sometidos al análisis de contenido e interpretados de acuerdo con los conceptos del Modelo de Sentido Común. Resultados: los discursos fueron categorizados de acuerdo con la identidad de la enfermedad y sus conceptos; duración y tiempo para el diagnóstico y los síntomas; causas de la enfermedad y sus explicaciones; consecuencias y tratamiento; control y percepciones acerca del pronóstico. Consideraciones finales: los conceptos del estado de salud y sus dimensiones relacionadas con la Diabetes Mellitus, interpretadas a la luz del Modelo de Sentido Común, la describieron como una enfermedad con signos físicos y potencial de complicación, incluso asociada con la muerte; sin embargo, también revelaron ignorancia de las causas y consecuencias reales de la enfermedad.

Descriptorios: Conceptos. Diabetes Mellitus. Proceso de Enfermedad-Salud.

Introduction

The impact of chronic non-communicable diseases (NCDs) has overcome the physical dimension and negatively affects the individual, abruptly or chronically. One of the health scenarios that has raised numerous concerns due to physical, emotional and social alterations refers to Diabetes Mellitus (DM)⁽¹⁾.

DM consists of a metabolic disorder characterized by constant hyperglycemia, due to deficiency in insulin production or its action, or by both mechanisms. Currently, it is estimated that 463 million people have DM worldwide⁽¹⁾. Constant hyperglycemia is associated with chronic micro and macrovascular complications, in addition to increased morbidity, reduced quality of life (QOL) and increased mortality rate⁽²⁾.

DM-related complications include hypoglycemia, diabetic ketoacidosis (DKA), and hyperosmolar hyperglycemic status (HHS). Hyperglycemia contributes to macrovascular complications that cause cerebrovascular disease, coronary artery disease and peripheral vascular disease, while microvascular diseases cause retinopathy, nephropathy and neuropathy, and these are specific to diabetic individuals⁽³⁾.

There is an increase in the prevalence of DM associated with different factors that include the modification of urban centers, epidemiological

transition, nutritional changes, lifestyle, sedentary lifestyle, overweight or obesity, population increase and aging, in addition to the longer survival of the population⁽²⁾.

According to the World Health Organization (WHO), increased glycemia is the third factor associated with early mortality, only losing to the incidence of systemic arterial hypertension (SAH) and smoking, becoming a public health problem, which implies control measures for DM and its complications⁽²⁾.

The American Diabetes Association (ADA) points out that a combination of factors is observed that include the poor performance of health systems, little knowledge of the population about DM in relation to the sudden onset of symptoms or progression of type 2 DM, a condition that can remain undetected for several years, giving opportunity to the development of complications. Data indicate that approximately 50% of cases of DM in adults are not diagnosed and that 84.3% of all undiagnosed diabetes cases occur in developing countries⁽⁴⁾.

Another important aspect related to DM is associated with increased hospitalizations, the incidence of cardiovascular and cerebrovascular diseases, visual, maternal alterations and vascular complications that lead to amputations, especially in the lower limbs, requiring

greater use of health services, which in the future may reflect high costs in the systems of all countries, regardless of their economic development⁽⁴⁾.

A study conducted with diabetic patients considered that quality of life refers to the perception of well-being and the findings may support information for the care of people with DM, allowing a more appropriate planning⁽⁵⁾.

Chronic diseases, such as DM, tend to incorporate characteristics based on the beliefs of their patients, which can compromise the acceptance of the disease and its treatment. Understanding the concepts of individuals about changes in their health status can better contextualize interventions aimed at controlling certain pathologies, such as DM. Thus, for the Model of Self-Regulation of Behavior in Health or Common-Sense Model (CSM), the health status represents the integrity and well-being of the individual when he/she does not feel threatened by the negative events of the disease that affects him⁽⁶⁾.

According to the CSM, the perception of the disease can be understood in five dimensions: identity (expressed by abstract labels, such as the name of the disease and its associated symptoms); causes (factors related to the origin of the disease); duration (course of the disease: acute, chronic or cyclic); consequences (severity of the disease and its impact on physical, psychological and social functioning); and control/cure (possibility of curing or controlling the disease)⁽⁶⁻⁷⁾.

CSM can be applied in studies with different populations, as observed in a study with parents of children and adolescents on cancer on the perception of the disease and the treatment of their children, which allows the basis of better intervention strategies⁽⁸⁾. In this study, the application of CSM predicts that patients with diseases such as DM respond to a particular disease, based on their interactions with the social environment, past experiences and their implicit knowledge about the meanings of the disease. The various sources of information with

which they have contact allow the person to construct his own set of beliefs about the disease and its treatment⁽⁹⁾.

The importance of this study is highlighted as a means of contextualizing the diabetic being, its vulnerabilities and the impact on the patient's life in outpatient and hospital care, thus allowing a multidimensional performance in the care of NCDs effectively, minimizing complications during the disease.

Based on the concepts of the CSM, this study aims to analyze the health status and dimensions related to DM of hospitalized and outpatient patients of a teaching hospital in the light of the Commonsense Model.

Method

This is an exploratory, descriptive study with qualitative analysis of the data in the light of CSM concepts⁽⁷⁾. Data collection was performed at the Endocrinology Outpatient Clinic and Clinical Hospitalization Units of a teaching hospital in São Paulo (SP), between November and December 2019. All patients diagnosed with DM hospitalized in the hospitalization units of a medical clinic and patients treated at the institution's endocrinology outpatient clinic were invited to participate in the study. Patients hospitalized in investigation of DM were excluded. The participants participated in the study for convenience and there were five refusals regarding participation, due to lack of time, not being willing or sleepy, in some cases. Data collection was based on a script with questions with sociodemographic and clinical characteristics related to DM and specific questions based on the domains of the CSM and in the specialized literature.

Data collection was interrupted when the data set obtained in the interviews proved redundant and sufficient to respond to the objectives of the study, according to the structured matrix, based on the CSM⁽⁶⁻⁷⁾. The content analysis of the discourses in their deductive modality was adopted, through which researchers can test pre-existing categories, concepts, models or hypotheses, based on previous concepts,

originating from a given theory, for example. Inductive and deductive analyses are divided into three main phases: preparation, organization and reporting of results⁽¹⁰⁾. In the preparation phase, the material from the discourses was carefully read, highlighting words, phrases and expressions related to the objective proposed for the study. Next, a structured matrix was elaborated, guided by the dimensions of the CSM: identity, causes, duration, consequences and control or cure⁽⁶⁻⁷⁾. Following these steps, only the aspects related to the dimensions of the model extracted from the participants' statements and gathered in categories presented in the results were selected.

To preserve the identity of the participants, we chose to use the alphanumeric system, using the code name P, relative to the participant, followed by Arabic numbering, according to the order of occurrence of the interviews (P1, P2, P3... P20).

The study respected the ethical precepts of conducting research with human beings, in accordance with Resolution n. 466/12 of the National Health Council and obtained approval from the Research Ethics Committee (CEP) of the institution involved, according to certificate of presentation of ethical appreciation (CAAE) n. 18488319.6.0000.5479.

Results

Twenty patients hospitalized and under outpatient follow-up participated in the study. Regarding the characteristics of the sample, the mean age was 60.4 years (SD \pm 9.6), with mean Body Mass Index (BMI) of 32.6 kg/m², predominance of males (65.0%), married (40%), white (55%), with complete elementary and complete mean (30% each), liberal professionals (35%) and Catholics (60%).

The content of the statements obtained were grouped into categories, according to the five dimensions of the CSM, namely: identity – expressed by abstract labels, such as the name of the disease and its associated symptoms; causes – factors related to the origin of the disease; duration – course of the disease (acute, chronic

or cyclic); consequences – severity of the disease and its impact on physical, psychological and social functioning and control/cure – possibility of curing or controlling the disease⁽⁶⁻⁷⁾.

Illness identity

What is DM, representations influenced by individual beliefs that can compromise the acceptance of the disease and treatment, behaviors and coping with the situation experienced. Except for two participants, who reported not knowing what diabetes is, the others were able to define the disease, based on their knowledge and beliefs.

For two of the participants, diabetes is an organic problem, related to the functioning of a particular organ, the pancreas:

Diabetes is a problem in the pancreas that interferes with my entire body. (P2).

Diabetes is a blood sugar problem because of the non-production of insulin by the pancreas. (P5).

Three others related the disease directly to eating habits and restrictions. Glucose intolerance was described, referring to it as “sugar”:

Diabetes, sugar intolerance, I can't eat anything with sugar. (P4).

Eating out of time, eating every three hours, can't eat anything sweet, nothing buried. (P8).

You can't eat certain things that get in the way. (P16).

Illness origin

From the perspective of their patients, in general, the participants showed to know some of the causes of their disease. For half of the interviewees (n= 10), diabetes has as main cause the bad lifestyle habits the exaggerated intake of foods rich in simple carbohydrates, as observed in the following statements:

I think life habits, especially food. (P2).

The sugar, the dough. (P3).

I think it's the sugar we eat. (P4).

Wrong food: pizza, pasta, baked potatoes. (P14).

Others referred to “obesity” (P9), genetic questions (P14) and sedentary lifestyle (P5) as

probable factors that led them to develop the disease. One of the participants mentioned that his illness was a consequence of excessive alcohol consumption:

Pancreatitis and excessive alcohol. (P10).

Duration of the disease and discovery of the diagnosis

Six respondents said they didn't identify symptoms until they felt bad and went to the emergency department. Among the main signs and symptoms described by the others, the following stood out: polyuria, polydipsia and recurrent infections.

I realized when I was working. Too much pee, thirst, leg pain. (P1).

Urine, foamy, stomach infection [Helicobacter pylori] and urinary, very thirsty, peeing a lot, bitter in the mouth and looks like sand. (P4).

Three other participants cited visual changes, dizziness and weight loss:

I started to notice in the views, to watch television, it hindered. (P3).

Thinning, excessive thirst. (P6).

Peak of diabetes, blurred vision, dizziness, thirst and going to the bathroom a lot. (P12).

Consequences and treatment of the disease

As for the representations about the consequences of the disease, it is observed that they were linked to its control. For the participants, the control of glycemic indices was responsible for important changes in the present, which can be determinant to avoid the serious consequences of the disease:

Now diabetes is more controlled even with the foot problem, but in the past it has greatly disturbed me in terms of controlled eating, libido in sexual intercourse, weakness, tiredness, and blurred vision. I hope I never get out of control again because it interferes with everything in life. (P2).

Responsibility to care for, change food and medicines. (P12).

Regarding the present, the participants mentioned the discomfort resulting from the disease and its treatment:

Lack of memory and tiredness. (P9).

Blurry vision. (P8).

Taking injection three times a day. (P10).

The [high] number of drugs, due to the discomfort of hypoglycemia and occasional tiredness. (P5).

Two interviewees mentioned that they already experience, in the present, the consequences of not having taken the necessary precautions to ensure their survival free of the complications of the disease. This finding expressed some hopelessness about the future:

I think the stroke was due to diabetes, my kidney is also not good. I don't expect anything forward. (P1).

Poor quality of life has already appeared, vision, kidneys. (P7).

When discharge makes me irritable, I have kidney complications. (P11).

Two other interviewees mentioned not having noticed any significant repercussion of the disease until the moment they participated in the study; one of them explained that he has lived with the disease for a short time:

There was no [consequence] no, I found out 6 months ago. (P3).

The other mentioned not believing that there will be something serious, because he did not notice signs indicative of potential complications:

I didn't notice anything, and I don't think it will have any consequences. (P13).

Disease control/cure

Regarding the representations about the control/cure of the disease, the respondents expressed concerns about the expected effects or those that may be harmful, according to the following statements:

I think the medication takes effect right away, but then I miss something. Insulin too. It would be nice if it always had an effect. (P1).

I take too much medicine and it is not good to take too much, because it is bad for the body. (P3).

Although the participants evaluate that the disease is under control, thanks to their constant efforts to comply with the prescribed treatment, monitoring the disease, by means of a glucometer,

seemed to bother two participants, due to the pain caused by perforation in the fingers to perform the verification of glycemic indices, as well as the administration of insulin by parenteral route, which implies daily subcutaneous injections:

Great [the treatment], minus the insulin for being an injection. (P12).

I don't like the injections on the finger and the insulin. (P15).

I think it's good, I just don't like the injections all day. (P17).

I don't like insulin, so I preferred the medications. But probably now I have a need to change, that already worries me. (P2).

Discussion

According to the International Diabetes Federation (IDF), it is important to highlight that DM and other chronic diseases have a higher prevalence in people over 50 years of age and have increased significantly, being one of the fastest growing non-communicable chronic diseases, especially in developing countries⁽¹⁾.

The mixed method allows identifying the relationship of the characteristics of the sample and relating them to the CSM, being able to identify points of vulnerability of diabetic patients in relation to the disease, causes, duration, consequences and cure, which highlights the importance of intervention with the group to better adapt treatment and results.

A study conducted with the objective of evaluating knowledge about diabetes, attitude to self-care and associated factors in elderly assisted in primary health care identified that the attitude to self-care in relation to DM decreases with the time of diagnosis and, being a chronic disease, it decreases the motivation of patients to engage with self-care, and may also reflect on many feelings, such as sadness, fear, guilt and revolt, which need to be overcome in order to achieve acceptance of the disease and result in better results⁽¹¹⁾. Another study points out that being a man, living alone and having some complication of diabetes is a factor associated with a negative attitude, related to self-care and complications, which can influence coping with the disease and treatment⁽¹²⁾.

The evolution of the incidence of NCDs, especially DM, is associated with the aging process and the few healthy habits of life, often observed in the Brazilian population. Associated with this, there is the demographic transition and the need for health professionals to seek to develop a strategic planning, with specific care programs to evaluate comorbidities and complications, which added to sociodemographic characteristics can promote better disease control⁽¹³⁻¹⁴⁾.

Regarding the identity of the disease, the statements of two patients describe their ignorance of the disease, different from the other participants who can define DM based on their knowledge and beliefs, including as a physiological problem that compromises the functioning of the pancreas.

According to the Brazilian Diabetes Guideline⁽¹⁵⁾, DM affects 180 million people worldwide. With the increase in obesity and sedentary lifestyle, it is estimated that by 2025, more than 300 million people will have diabetes.

The expected increase in the disease for developing countries is 170% (from 84 million to 228 million people affected). This projection implies an earlier appearance of DM in the population, when compared to other developed countries⁽¹⁶⁾.

The real cause of DM should be clarified, so that the patient has a view of the consequences that the disease can present, as well as the factors that influence the disease and complications of the disease. DM today is considered a public health problem and one of the diseases responsible for one of the major causes of mortality in the world⁽¹⁷⁾.

The cause, from the perspective of its carriers, reflects factors related to bad life habits, genetic issues and lifestyle.

A study highlights that knowledge about DM is insufficient in many patients with confirmed diagnosis of the disease, especially regarding the origin and how it acts in the body⁽⁶⁾.

Inadequate feeding is one of the factors that potentiate the evolution and diseases of the disease, and patients should be well guided about their behavior in the face of this. The Brazilian Diabetes Society (BDS) recommends an adequate diet of foods rich in fiber, vegetables,

legumes and skimmed dairy products, so that it favors the postprandial control of glycemia, thus sensitizing the action of insulin⁽¹⁵⁾.

Regarding the social issue, studies have proven that patients enrolled in social programs, such as the Family Health Strategy (FHS), are more likely to better glycemic control⁽¹⁸⁾.

Regarding the duration of the disease and discovery of the diagnosis, some of the respondents stated that they did not identify symptoms until they suddenly appeared and required emergency care, highlighting classic symptoms of DM, such as polyuria, polydipsia, repeated infections, visual alterations, dizziness and weight loss.

The findings agree with the results of a study that highlights the difficulty of seeking information about the negative aspect that the disease can bring to the patient and his/her family members and previous knowledge about the disease, interfering in treatment adhering⁽⁸⁾.

Because it is a silent and often asymptomatic disease, which corroborates the interviewees' speech, the disease is often not considered important by the population, which makes it difficult to prevent complications of the disease. The WHO, in its report, points out that in 2016 there was an accelerated growth of the disease in developing countries, which led to counseling to raise awareness among the population, with preventive and educational practices, to paralyze its exacerbated growth⁽²⁾.

The literature points to the relationship of complications related to the time of the disease. There is evidence that the greater number of years lived with DM can be affected, not only by the clinical condition, but also by the treatment to which it was submitted throughout life. However, this statement may be distinct in different countries of the world⁽¹⁹⁾.

Based on the participants' statements regarding the representations about the consequences of the disease, it is noted that the perception of the respondents is linked to the control of the disease by measuring blood glucose, and, in their opinion, their inadequacy is related to complications, sensations that

generate discomfort, tiredness, visual alteration and increased consumption of medications, in addition to complications such as hypoglycemia. However, it is noteworthy that some discourses are associated with the fact of negligence in the control of the disease, which generates a feeling of hopelessness in relation to the evolution and outcome of DM.

A study that used the CSM with children and adolescents oncologic points to results like that of this study, even in different pathophysiological conditions. The lack of causal link effectively in relation to the disease is highlighted, and the failure to think about this cause-effect relationship can be attributed to the condition of the diagnosis that already causes stress and suffering to the patient and his/her family members⁽⁸⁾.

Another feeling of perception of the consequences of DM points to a very worrying situation, which is the underestimation of the complications of the disease, especially by those with recent diagnosis, or simply for not believing them.

Complications related to DM are hypoglycemia, CAD and HHS. Hyperglycemia contributes to macrovascular complications that cause cerebrovascular disease, coronary artery disease (CAD) and peripheral vascular disease (PVD), while microvascular diseases cause nephropathies, neuropathies, and retinopathy. Treatment of diabetes should be initiated immediately after diagnosis to prevent complications. In relation to retinopathy, it is important to monitor it through periodic ophthalmological treatment, because diabetic patients are 30 times more likely to be blind compared to non-diabetic patients⁽¹⁵⁾.

Visual loss occurs in a manner secondary to diabetic retinopathy and is associated with a significant decrease in the quality of life of diabetic patients, changing their daily life dynamics, most of the time⁽²⁰⁾.

A study shows that the difference between the ignorance of the disease and the level of education of patients are a tendency not to value preventive actions, underestimating the severity of the disease and postponing the search for

medical care, which hinders treatment adhering and increases complications⁽²¹⁾.

Regarding the control of representations about the control/cure of the disease, the respondents describe concern about the form of treatment.

Ad treatment regimen requires frequent lifestyle changes in different areas, such as diet, medication and physical activity, with direct implications for your daily routine. Non-adhering to the therapeutic regimen contributes to the uncontrol of the disease, being a constant challenge for the patient and the health team⁽²²⁾.

It is a fact that the prevention of the disease implies a significant reorganization in health care. In the case of DM, it involves prevention of the onset of symptoms (primary prevention), prevention of its acute and chronic complications (secondary prevention) and control of disabilities produced by its complications (tertiary prevention)⁽²³⁻²⁴⁾.

An educational intervention strategy focused on prevention is based on self-care measures for individuals with DM. It is noteworthy that this is fundamental, however, not everyone has access to or assimilate the information provided. The literature highlights that many health professionals do not do so adequately, because of the deficiency of health services⁽²⁵⁾. The orientations come mainly from the nurse, who, based on anamnesis and physical examination, establishes an individualized planning, being able to implement control measures and minimization of complications resulting from DM.

The guidelines for patients with DM, regardless of the disease time, are effective to support the knowledge of the representations of the disease and its impact on daily life, the importance of treatment and especially identify complications early.

Final Considerations

The concepts of health status and its dimensions related to DM of patients hospitalized or in outpatient care, interpreted in the light of CSM, describe the perception of a disease with physical signs and potential for complication, even associated with death. The reports point

to an ignorance of the real causes and the consequences that the disease can bring. It is a fact that having the diagnosis of DM reflects in the QOL of patients, directly or indirectly, even if patients do not notice it at the beginning of the disease and neglect signs of complication.

Thus, the importance of the role of health professionals in the individualized approach, according to the particularities of the disease, is highlighted as a means of implementing control measures, health education and monitoring of the individual needs of each patient, hospitalized or in outpatient care.

Collaborations:

1 – conception, design, analysis and interpretation of data: Luciana Soares Costa Santos and Alessandra Thomaz de Andrade;

2 – writing of the article and relevant critical review of the intellectual content: Luciana Soares Costa Santos, Fernanda Machado Silva Rodrigues and Lívia Keismanas de Ávila;

3 – final approval of the version to be published: Luciana Soares Costa Santos, Fernanda Machado Silva Rodrigues and Lívia Keismanas de Ávila.

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