

The perception of illness in people with chronic complications caused by diabetes mellitus

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Abstract: Background: The representations and practices of people who suffer chronic complications of type 2 diabetes mellitus were described and analyzed. The information was analyzed with the constructivist grounded theory, the theories of social representations and experience of the disease, explanatory models of illness, and medical pluralism. The hypothesis of this research was to highlight the presence of diverse representations and practices in people with diabetes mellitus that help to signify the experience of the disease according to their sociocultural context. Objective: To study the experience shared by people suffering from diabetes mellitus and its chronic complications. Material and methods: An observational, retrospective, synchronous and qualitative study was carried out with a sample of five patients. The selection criteria were: having chronic complications of type 2 diabetes mellitus and living in the town of Coatetelco. Likewise, six physicians were included under the following selection criteria: attending to patients at Coatetelco. Eleven interviews were conducted. Results: The interviews demonstrated that the explanatory models of the disease include biomedical, traditional medicine and self-care elements, and are built from collective experience. Culture adopts and resignifies knowledge from different forms of health care. Narratives are a useful tool for the analysis of the perspective and meaning of subjectivities. Conclusions: The knowledge of individuals affected with chronic complications from diabetes is made up of elements resignified from biomedical care, traditional medicine and self-care.

Key words: diabetes complications; diabetes mellitus type 2; medicine traditional; experience of disease; explanatory models

1 Introduction

Advanced chronic diseases, such as type 2 diabetes mellitus, represent a major public health problem, as their prevalence has increased dramatically over the past 200 years [1]; in Mexico, since the year 2000, they have ranked among the leading causes of death, alongside cardiovascular diseases. In 2016, the National Health and Nutrition Survey reported a prevalence of diabetes mellitus of 9.4% [2] in the central region of the country, which includes the state of Morelos, where the prevalence was 9.8% [2].

Chronic degenerative diseases, such as diabetes, are not limited to urban areas [3]; current trends indicate that prevalence has increased in rural populations and that complications are becoming increasingly common. The emergence of a biomedical disease, such as diabetes, in a rural indigenous/mestizo community is part of the health problems within the national context. In Mexico, hundreds of localities face problems similar to those in Coatetelco, a town located in the

municipality of Miacatlán, in the state of Morelos, where the mortality rate from diabetes is above the national average [2].

2 Materials and methods

A retrospective, synchronic, qualitative observational study was conducted with a sample of five patients. The selection criteria were having chronic complications of type 2 diabetes mellitus and living in the town of Coatetelco; additionally, six physicians were selected based on the criterion of providing care to patients in the town of Coatetelco. During the fieldwork, 11 structured interviews and participant observation were conducted.

This study is the result of an ethnographic investigation, defined as a strategy for observing the multiple realities that shape social experience [4]. Prior to conducting the ethnography, the necessary permission was obtained from local authorities, and informed consent was sought from the individuals who participated in the research. The experiences recorded during the study were coded using the Atlas Ti software, version 6.2. In coding the data, grounded theory was employed to incorporate inductive-deductive logic, thereby giving weight to the generation of emerging categories that constituted an important part of the shared information [5]. Furthermore, narratives were used to bring order, coherence, and meaning to the shared life experiences, helping to capture the perspective of people suffering from type 2 diabetes mellitus.

Both the disease and care were approached as a sociocultural process, through which the subjective experiences of people living with diabetes mellitus and its chronic complications were interpreted. All the experiences described were related to the microsocial, mesosocial, and macrosocial dimensions [6].

To describe the microsocial dimension, the concept of "knowledge" was employed, defined as "the set of representations and practices that an individual constructs regarding an illness based on their socialization groups" [7]. This knowledge constitutes a fragment of the affected individuals' experience and serves to designate multiple phenomena observed and studied at various levels of complexity [8,9].

The experience of illness encompasses multiple material and ontological dimensions that endow people's lives with sense, meaning, and coherence. This theoretical concept views illness as a combination of existential dimensions, re-establishing the body as a fundamental part of subjectivity and agency; if the body becomes ill, this represents a new experience that translates into a new network of meanings [10,11].

By adopting the perspective of the patient or the healer and conducting an inquiry, it is possible to recognize how explanatory models (EMs) of various forms of care are constructed. EMs represent knowledge about the episode of illness/suffering/discomfort and the treatment employed, and take into account all those involved in the clinical process [12]. Upon entering the realm of EMs, illness is conceived as part of a cultural system where the categories of disease (objective illness), illness (subjective illness), and sickness (the social meaning of illness) come into play [12,13,14]. The theory of EMs allowed for the construction of a narrative that included mesosocial aspects, integrated and distinguished common sense (popular) narratives from hegemonic ones, and recognized that illness is immersed within power relations [14,15].

Finally, medical pluralism was revisited, which constructs a vision of the coexistence of realities that relate to one another in a conflictive or cooperative manner. Thus, biomedicine—characterized by holding hegemony, establishing an asymmetrical and commercial relationship, and compartmentalizing the body—was acknowledged. Medical pluralism incorporates traditional medicine and complementary alternative medicines, which in their practice represent subalternity, establish an asymmetrical patient-healer relationship, and imprint a commercial relationship on therapeutic practice [16,17,18]. Finally, self-care represents "care provided by the individual themselves or by immediate members of their family or community" [11]. This represents the first real level of care and is characterized by viewing health as a good and

for use [16,19].

The research question arose from constant reflection on the lives of those affected and an exploration of their strategies for improving their health. Thus, from an anthropological perspective, the following question was posed: what knowledge do individuals with chronic complications from type 2 diabetes mellitus possess, and how do they construct it? The hypothesis was to highlight the presence of diverse representations and practices among people with diabetes mellitus that shape their experience of the disease according to their sociocultural context.

3 Results

This study revisited the knowledge of individuals with chronic complications from diabetes mellitus who participated in the research, as presented in Table 1 [20]. During interactions with two men and three women, oral narratives were constructed that allowed for the interpretation of the knowledge of those affected. The act of revisiting the narratives was of great help, as they bring together the perspective and meaning of subjectivities and form part of an active-constructive process that relies on personal and cultural resources to give a chronological order to the experience [21].

In this research study, it was important to understand the meanings behind the experience of "being ill with diabetes and having chronic complications"; thus, the narratives provided a deep connection to that experience, with the aim of understanding the relationship between knowledge and the sociocultural context.

4 From cause to symptom

In their accounts, the participants acknowledged that diabetes is a new disease that cannot be cured, only managed. When they use the term "new", they are referring to the fact that diabetes was not previously a common diagnosis and that people sought treatment for their health problems from traditional healers. Depending on their worldview, their life experiences, and their contact with biomedicine, those affected discriminate the information around them and develop their own classifications of diabetes. For this study, the participants accepted the biomedical classifications; however, there are other popular classifications of the disease based on cultural categorization, such as "hot diabetes," which is related to emotionality and certain conditions derived from traditional medicine, such as fright, shock, and anger; as well as another categorization based on the perception of symptoms and a third categorization that defines it as a moral classification (good and bad diabetes).

There are many different views on the causes of diabetes. For practical purposes, we used the distinction between biomedical and popular perspectives, which allowed us to draw a structural distinction between common-sense culture and the knowledge of positive science. Participants incorporated biomedical elements into their EMs, such as "genetics," "heredity," and "organic affliction," as well as "diets" and "excess carbohydrates."

The accounts encompassed the popular knowledge that defines social actors within their culture, linking diabetes with causality recognized in traditional medicine and with emotional states. As an example of these representations, diabetes is linked to drinking water after emotional events, since water gives strength to the disease or causes the blood itself to turn into water, weaken, or become bad. The representation of the blood cooling when drinking water was also observed; residents of Coatetelco propose this as an action that causes the disease, drawing on a hot/cold conception as a causal relationship. Other shared popular representations include diabetes caused by bad air, bad hour, and witchcraft. There is a typology with a strong psychological, such as "diabetes caused by overthinking or worries." Others originate from "craving," "excessive eating," "excessive work," and "alcohol consumption."

Table 1. Sociodemographic and clinical characteristics of patients with chronic complications of type 2 diabetes mellitus

Patient	Age	Sex	Education	Occupation	Complication
Patient A	58 years old	Female	Illiterate	Home	Retinopathy, nephropathy, diabetic foot
Patient B	54 years old	Female	Completed primary school	Merchant	Diabetic neuropathy
Patient C	54 years old	Male	Illiterate	Farmer	Diabetic neuropathy
Patient D	52 years old	Male	Secondary school	Musician and bricklayer	Neuropathy and dental disease
Patient E	65 years old	Male	High school	Merchant	End-stage chronic kidney disease

Source: Loza-Taylor T. [20]

Due to the habit of living with family members and neighbors, those affected draw on the experiences of others to understand the prevalence and distribution of the disease. According to the participants, several of their relatives had diabetes mellitus; this was evident in the life stories where the participants' family trees were described.

Participants with chronic complications engage in a variety of disease prevention activities related to their lifestyle habits. A moral perspective on diet was identified: poor diet (junk food and soft drinks) versus a healthy diet (vegetable consumption) as a means of preventing diabetes mellitus. Prevention based on folk knowledge encompasses various practices used by the residents of Coatetelco to counteract the disease, such as avoiding drinking water during moments of fear or fright. The participants suggest that it is better to drink "wine" so as not to alter body temperature.

"Well, look, I had a serious problem at that birthday party, so I think that was the cause—it was a very strong anger. And they say that if you get angry or have a big scare, you shouldn't drink water because water affects you. Apparently, it's better to have a strong drink. I don't know, some alcohol, some tequila..." [Patient D, 2013].

Those affected and their families described various symptoms of diabetes mellitus. In this study, patients were asked about the temporal aspects of their symptoms before, during, and after diagnosis, as well as when their condition was uncontrolled. These subcategories emerged from ethnography, which we have summarized in Table 2 [20].

5 Therapeutic integration of diabetes mellitus according to the actors (traditional medicine, biomedicine, and self-care)

From the perspective of traditional medicine, those affected mentioned that they use various therapies such as cleansing rituals and therapeutic prayers. Treatment is determined based on the type of diabetes acquired, whether due to fright, bad air, or witchcraft.

From a biomedical perspective, the participants described various characteristics that were organized according to the type of narrative, namely: 1) control as a therapeutic focus, understood as an act aimed at prolonging life in the face of illness, but also at improving one's condition and following medical instructions, such as those regarding diet; 2) risk, a concept embedded in popular knowledge to bring about change or transformation in those affected and to alter their daily routines; 3) physical activity, described by those affected as something promoted by biomedical practitioners, without a clear understanding of how it is prescribed; 4) pharmacological treatment, involving the prescription of various medications and controversial care techniques, such as insulin therapy, which some actors consider a "hot" medication and believe should not be administered when suffering from "hot diabetes," as mentioned in the following account:

"They say insulin is hot, because, for example, if you get really angry and are taking a lot of medication, they say you turn black—and it's true, because once I got angry and was on medication, and just like that I turned black, black..." [Patient A, 2014].

And, finally, specific therapeutic dynamics and rationales were observed in self-care. There are alternative, folk, biomedical, and traditional medical therapies that encompass the vast majority of treatments and are unknown to biomedical practitioners. It was found that self-care integrates care through practices and knowledge from all forms of care, but also constructs its own knowledge that redefines illness, health, and the body.

Table 2. Symptoms recognized by people with type 2 diabetes mellitus

Types		Symptoms
Before diagnosis	None identified	
During and after diagnosis	Weight loss, drowsiness, insomnia, dizziness, nausea, vomiting, headache, fatigue, weakness, sensation of having a hot body, diarrhea, loss of appetite, embarrassment about having the symptoms, intense thirst, frequent urination, numbness, feeling drunk, fainting spells, fainting, feeling like your eyes are getting smaller, skin becoming dry or rough, hands losing their color (apparently because the blood turns to water)	
Loss of control	Blurred vision, dull eyes, drowsiness, lethargy, loss of strength, and alterations in taste	

Source: Loza-Taylor T [20].

6 Ontological-bodily continuity: chronic complications

Drawing on traditional knowledge, the participants identified the causes of chronic complications of diabetes mellitus based on the affected organ. It was necessary to help them adapt their understanding of the disease as it undergoes a gradual and irreversible progression, a process that alters the EMs. The participants mentioned that the kidneys rust or are damaged by witchcraft; pork, beans, and eggs can cause diabetic foot; anger and heat can cause "nerves" or diabetic neuropathy; and excess salt "affects the eyes," causing diabetic retinopathy. The following were also identified as general causes of chronic complications: "neglect, alcohol consumption, useless blood, blood dryness, watery blood, and melted flesh."

The causes identified by the participants following their exposure to biomedicine are understood and reinterpreted in accordance with how they experience their culture and understand their bodies. Infections can arise from burns and wounds; however, the "disposition of the disease" also plays a role— that is, the disease determines in whom it will lead to complications, since it manifests at a different pace than the subjects' bodily rhythms, as there is a separation between disease and body.

According to the participants, chronic complications are very common in the population; they are recognized both by those who suffer from them and by those who share in their suffering. There is a sense that neighbors, acquaintances, and family members are affected, and stories about the illness are not foreign to them. As people recognize themselves in others and share an existential experience, the social meaning of the illness begins to take shape. The participants also mentioned that chronic complications are more prevalent among people with limited financial resources, as well as among those who do not maintain adequate control over their condition and those who do not follow their doctors' instructions.

Participants mentioned various biomedical representations of prevention, such as: adherence to guidelines that can delay the onset of chronic complications, following medication schedules, maintaining a proper diet, undergoing early screening, and managing the condition from the perspective of those affected. Popular conceptions of prevention were exemplified by avoiding certain foods, such as eggs, beans, and pork, which may cause greater complications, or by increasing consumption of other foods like chili peppers, which may prevent infections. Beer consumption was also associated with causing neuropathy, as it increases foot pain.

This chain of meanings extends to various dimensions, such as the cultural and social, shaping the participants' subjectivity. When a chronic condition arises, the participants' perception and interpretation of the world change

substantially; there is no way to escape or avoid perceiving the contrast that the disease marks on their bodies. A wide variety of general symptoms were identified, such as sleep and taste disturbances, which are linked to feelings and emotions. Each participant's symptomatology serves as an analytical tool that allows us to navigate within these subjectivities to identify elements representative of the collective existence of those affected.

7 Therapeutic integration in chronic complications

From a biomedical perspective, patients with chronic kidney disease undergo various treatments that result from social interaction and negotiation within the healthcare system. In a market regulated by the production of a vast network of clinical and therapeutic information, healthcare corporations—both private and public—compete to dominate the market for disease management. With regard to individuals who suffered from renal complications and agreed to begin dialysis therapy, it was found that the treatments administered depended on the family's financial capacity. Often, faced with a precarious economic situation, many affected individuals preferred to manage their symptoms rather than undergo the therapy, as they could not afford it.

Many of the chronic complications of diabetes leave physical marks that result in physical limitations and make those affected dependent on their families. Furthermore, as patients interact with various healers and specialists, their physicality becomes fragmented according to the affected organ or area.

In alternative medicine, practitioners use various types of teas or magnets to improve kidney function. In traditional medicine, cleansing rituals are performed, along with consultations involving crystal balls, eggs (in cases of bewitchment), blessings with holy water and San Ignacio lotion, and rituals such as the Holy Scapular ritual.

Self-care encompasses the beliefs and practices adopted by patients and their immediate families to alleviate their condition. It is important to note that self-care synthesizes all forms of care in its practice; that is, it combines elements of traditional medicine, complementary and alternative medicine, and biomedicine, as well as the use of folk knowledge passed down through families. Those described by the participants are presented in Table 3 [20].

During the research, a large amount of information was gathered about each of the complications mentioned, highlighting that creativity, innovation, and the transmission of knowledge played an important role in the application of new elements that those affected incorporated to shape their social reality. Thus, those affected and their families respond to chronic diseases and their complications, develop their own typologies of the disease, attempt to explain from their own context the causes of diabetes and its complications, and, consequently, propose curative, palliative, and control therapies based on their cultural logic.

8 Discussion

The construction of illness/suffering/discomfort takes shape through a complex interaction, beginning with the act of perception where the body interprets and condenses information from a historical moment, which situates us within a meaningful reality that provides order and coherence to the representations formed by the actors. Being, imagining, and acting summarize the union of the experience of illness and knowledge, which construct EMs with respect to established cultural codes; they form part of cultural time and of the subjective, intersubjective, and social dimensions by complicating the way social relations are understood. Throughout the actors' narratives, it was possible to identify how their subjectivity was separated from illness by biomedicine, as it was valued as a commodity. The reintegration of subjectivity into illness shapes suffering, extending the dimensions of individual existence to the social, defining this as *malaise*.

Among the EMs explored, the participants shared ontological typologies based on their experiences and ethical and moral constructs, which conflict with the morality of the healthcare providers. Constant tensions and interactions between forms of knowledge were observed popular and biomedical, hegemonic and subaltern, shaping multiple meanings of

illness, suffering, and discomfort. This construction of EMs offers a very general overview for understanding the insertion of a disease, recognized by biomedicine, into a fragmented indigenous culture that has altered its worldview and its way of understanding the world.

Table 3. Treatments used in the Coatetelco community for chronic complications of type II diabetes mellitus through self-care

Chronic complication	Treatment used
Cardiac diseases	Oral vitamin serum
Arterial hypertension	Birdseed and tomato peel in room-temperature water
Kidney disease	Ointments with baking soda and lard; dietary modification by the affected individuals (consumption of fruits); use of muicle and rasposa herb to reduce edema; chamomile tea with lemon to improve mood; fermented pineapple peel (for eight days) to promote urination; chlorine to reduce skin discomfort caused by kidney issues
Nerve disease	Warm water for the feet to soothe burning; consumption of alcohol to try to forget or ease nerve pain; black balm applied to the painful areas
Diabetic foot	Gentian violet, cuachalalate, arnica, pegahueso, hierba de golpe, cancerán; actions such as stopping walking or avoiding specific foods (beans, eggs, pork) to prevent further foot damage Biomedical treatment: use of furacin (containing nitrofurazone) for mild wounds and prevention of bacterial infections; use of penicillin powder sprinkled on the wound to close it Traditional medicine: Holy Scapular ritual
Visual alterations	Beetroot and carrot juice

Source: Loza-Taylor T [20].

The vision and interpretation of the body and the course of the disease perceived by those affected are anchored in the symptom, which turns out to be one of the frameworks of the disease/suffering/discomfort, an event that can be studied from biological, cultural, and social dimensions. In this research, participants shared the idea that the disease intrudes subtly or abruptly and, furthermore, is an element that fragments the body. This latter representation constitutes a part of the suffering, where the fracture can be analyzed from the symptom to the exclusion of the disease from the body.

On the other hand, it is important to highlight the knowledge of control/lack of control proposed by biomedicine, which arises from the concept of an experimental control group. In this case, this knowledge is used as a social tool to guide the behavior of those affected and thus distinguish between good and bad behaviors, personalities, or actions, relating them to risk factors, so that physiological indicators or parameters remain within ranges considered normal [22]. Control is part of the therapeutic act that accompanies them in their waking hours and dreams, and it serves not only therapeutic but also political purposes by modifying people's lifestyles; control penetrates subjectivity to modify personalities, judges life actions, and extends its vision to the social and cultural world of the actors; however, it in no way reclaims the subjectivity of those affected [23,24].

Diabetes patients who progress toward some form of chronic complication complicate the way we understand the disease/suffering/illness. At the biological level, organs and systems are affected as a result of an intimate association, which generates new healthcare markets. The progression of the disease gradually increases its added value. The value of the disease increases in accordance with social needs, in this case, with the need to exist [25].

9 Conclusions

This study describes the collective meaning of diabetes mellitus, which should be understood as part of a process with cultural implications that people incorporate into their daily lives. Consequently, these forms of knowledge are a synthesis that offers us a very general overview of what happens at the subjective and social levels, where we also find moral, ontological, mercantilist, and biologicistic constructs that guide those affected.

By assimilating and internalizing this knowledge, the actors reproduce hegemonic and subaltern notions that govern

social relations and lead to the development of cultural care systems. In Coatetelco, those affected expressed different conceptions of diabetes mellitus, such as its relationship to heat, cold, and illnesses derived from traditional medicine—like fright and witchcraft—as well as certain biomedical concepts, such as genetics, heredity, and obesity. Within the core of self-care, the participants employed knowledge that is not solely biomedical or folk-based; the vast majority of this knowledge encompasses the logic, practices, emotions, and behaviors of all forms of care, as it is impossible to separate the cultural elements that permeate their lives. It is important for physicians to recognize this knowledge in order to examine the social, cultural, and biological determinants that influence the development and management of people with type 2 diabetes mellitus.

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Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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