

# Teenagers with type 2 diabetes mellitus as a hidden population: A qualitative study of the representations and experiences related to the disease in Mazatlán, Mexico

Nathaly Llanes-Díaz<sup>1</sup>, Dewi Hernández-Montoya<sup>2</sup>

*Affiliations:*

<sup>1</sup> PhD, Consejo Nacional de Ciencia y Tecnología-Instituto Nacional de Pediatría, Departamento de Investigación en Epidemiología, Ciudad de México, México

<sup>2</sup> PhD, Instituto Nacional de Pediatría, Departamento de Investigación en Epidemiología, Ciudad de México, México.

*Corresponding author:*

Dr Dewi Hernández-Montoya, PhD

Instituto Nacional de Pediatría, Departamento de Investigación en Epidemiología. Avenida del Iman #1, Col. Insurgentes Cuicuilco, Coyocán, Ciudad de México. C.P. 04530. Torre de Investigación 1er piso. Ciudad de México, México.

E-mail dherandezm@pediatria.gob.mx; dewishm@hotmail.com.

## Abstract

**Objective:** To analyze the representations that adolescents with type 2 diabetes mellitus living in Mazatlán, Mexico have of the disease.

**Methods:** The study design was qualitative and based on an analytical approach of narrative research. In-depth interviews and participant observation were conducted with eight adolescents (four females and four males). The sample was theoretical-intentional according to age (10-19 years), diagnosis of type 2 diabetes mellitus, and residence in Mazatlán.

**Results and Discussion:** Adolescent experiences and representations regarding the disease were associated with six themes: 1) knowledge of the disease; 2) self-care practices; 3) identity construction; 4) significance of the disease; 5) family support; and 6) gender as a transversal category. Social stigma that is associated with diabetes and its management leading to self-management barriers, the abandonment of treatment and hiding the disease make adolescents with diabetes to be a hidden population. Identity construction is strongly affected by the disease; indeed, diabetes implied a reconstruction of male identity, while for females the disease was associated with overweight that affects their self-esteem. All of the adolescents lived in a constant dichotomy between present and future, with the fear of dying or getting worse. The absence of intergenerational communication and family support within the adolescents' families limited adolescent care practices, exacerbating their emotional distress and living the disease with the feeling of loneliness.

**Conclusions:** Our study showed that adolescents affected by type 2 diabetes mellitus, did not experience nor they did face the disease homogeneously but accordingly to the gender and level of family support, which, therefore, should be specifically considered by care programs and health professionals to encourage adherence to treatment, taking into account the emotional well-being and psychological needs of adolescents.

**KEY WORDS:** Adolescent; Diabetes Mellitus, Type 2; Health Beliefs; Self-care; Self-Efficacy.

## Riassunto

**Obiettivo:** Analizzare le rappresentazioni che gli adolescenti di Mazatlán, in Messico, affetti da diabete mellito tipo 2 hanno della loro patologia.

**Metodi:** Lo studio di tipo qualitativo si è basato sull'approccio analitico della ricerca narrativa. Interviste approfondite e l'osservazione dei partecipanti sono state condotte con otto adolescenti (4 di sesso maschile e 4 di sesso femminile). Il campionamento è stato intenzionale teorico secondo l'età (10-19 anni), la diagnosi di diabete mellito di tipo 2 e la residenza nella città di Mazatlán.

**Risultati e Discussione:** Le esperienze e le rappresentazioni degli adolescenti riguardanti la patologia sono state associate a 6 temi: 1) la conoscenza della patologia; 2) le pratiche di auto-cura; 3) la costruzione dell'identità; 4) il significato della patologia; 5) il supporto familiare e 6) il genere come categoria trasversale. Lo stigma sociale associato al diabete ed alla sua gestione che comporta barriere nell'autogestione, l'abbandono del trattamento ed il nascondimento della malattia rendono gli adolescenti affetti da diabete mellito una popolazione sconosciuta. La costruzione dell'identità è fortemente influenzata dalla patologia; infatti, il diabete mellito ha implicato una ricostruzione dell'identità nei maschi, mentre per le femmine la patologia è risultata essere associata al sovrappeso con ripercussioni sui livelli di autostima. Tutti gli adolescenti vivevano in una costante dicotomia tra presente e futuro, con la paura di morire o di peggiorare la propria condizione di salute. L'assenza di comunicazione intergenerazionale e di supporto familiare hanno limitato le pratiche di cura tra gli adolescenti, esacerbando il loro distress emotivo ed il vissuto della malattia provato con un sentimento di solitudine.

**Conclusioni:** Il nostro studio ha evidenziato che gli adolescenti affetti da diabete mellito tipo 2 non vivono né affrontano la malattia in modo omogeneo ma diversamente in base al sesso ed al livello di supporto familiare che, pertanto, sono componenti che dovrebbero essere specificamente considerate nei programmi terapeutici e dai professionisti della salute per incoraggiare la compliance al trattamento farmacologico, tenendo in considerazione il benessere emotivo e le necessità psicologiche degli adolescenti.

### TAKE-HOME MESSAGE

*Adolescents with type 2 diabetes mellitus in Mazatlán, Mexico constitute a hidden population; new identification strategies of this population should be promoted differentiated by sex and family support; not only for the care of the disease, but to reduce the emotional distress that adolescent with diabetes experiences.*

**Competing interests** - none declared.

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## INTRODUCTION

Type 2 diabetes mellitus (T2DM) is a chronic disease with strong emotional implications for the adolescents affected [1]. From a medical perspective, a healthy lifestyle can improve the life quality of adolescents, which includes a balanced diet, regular exercise, and strict adherence to pharmacological treatment. However, these aspects can generate chronic distress because adolescents may feel constrained to alter their daily practices. Furthermore, the social representations of diabetes, which is considered as a disease affecting only adults, generate conflicts in the identity construction of adolescents and their projections to the future [2].

Indeed, there is evidence showing that the experience of living with diabetes affects the mental health of adolescents with type 1 diabetes, who should have similar daily and long-term repercussions as those with type 2 diabetes [3–5]. Even if the qualitative evidence of T2DM in adolescents is only recently emerging [6, 7], several studies have yet shown that this disease is associated with eating disorders and dissatisfaction with the body image, conditions that may negatively impact on adolescents' self-esteem and psychological well-being [8–10].

Similarly, studies have demonstrated that the stigma associated with diabetes makes it common for young patients to hide T2DM due to the fear of being excluded [11]. School is the main space for socialization among adolescents; however, in this context, the disease tends to be hidden more frequently, particularly by young males. This phenomenon has implications for adolescents' health, particularly when it leads to the treatment failure [12].

Although there are common elements in the perceptions and stigma affecting adolescents with T2DM, research found important differences, which are based on socioeconomic status. Indeed, within the most favored social classes where self-care practices are better, there are more knowledge about the disease and resources to treat it, the level of adolescent satisfaction increases, and uncertainties

about the future development of the disease decreases, compared to young people of lower-income backgrounds [13].

The support of family and friends, both emotional and logistical, is also associated with more positive meanings of the disease and better care practices, such as having a healthy diet and physical activity, being adhering to drug treatment and dealing with distress and other self-destructive coping behaviors [7, 14]. In addition, the interaction among adolescents with diabetes allows them to share their experiences, increase self-care practices and construct more positive perceptions about the disease [15].

### *Evidence in Mexico*

Studies in Mexico have mainly focused on risk factors that are related to the metabolic disorders experienced by adolescents [16, 17]. Some qualitative studies have approached young people's perceptions regarding diet and eating habits [18, 19]; however, the literature on the perceptions of adolescents affected by T2DM is very scarce in our country.

Conversely, some research has been conducted on how adults experience both the T2DM and the subsequent lifestyle associated with the disease, showing that they are at high-risk of decreased psychological well-being because of the strained coping with changed life routine, such as relationships, work-related and financial issues [20]. Even though the evidence indicates that the incurability of the disease has repercussions on the representations of patients [21], family support could represent a decisive factor in the well-being of patients and in the development of positive meanings with regard to the disease [22].

### *Aim of the study*

Aim of our study was to survey how adolescents with T2DM represent and perceive their disease. Specifically, our objective was to analyze the representations that adolescents with T2DM, aged 10–19, have of T2DM during a period of strong physical, psychological and emotional changes, such as adolescence, in certain neighborhoods of Mazatlán, Sina-

loa, in northwest of Mexico.

The present study might be relevant in the Mexican context providing analytical elements from a qualitative perspective for the study of T2DM among adolescents, who could be a hidden population, due to stigma associated with the disease that probably is the most important cause of treatment dropout and hiding the disease.

## METHODS

This research was qualitative, interpretive-descriptive, and based on the theoretical approach of social constructivist theory from which, social practices and behaviors are considered to be culturally constructed. From this perspective, the meanings that individuals give to their action, with which they interpret reality and influence it, acquire centrality; therefore, the interpretation of individuals about their own experiences, in this case diabetes, is fundamental to understand the representations and experiences around the disease [23, 24].

The analytical approach of narrative research was used, which allows to better analyze how individuals perceive, understand and make meaning of life situations or experiences in particular contexts [25, 26]. The objective is not the generalization or search for causality but the description and interpretation of broader social processes and the generation of new research questions and topics [27].

Also, we used the theoretical perspective of social representations, because it constitutes a bridge between the psychological and social dimension considering the way in which the persons apprehend the situations of the daily life, the characteristics of the contexts where the individuals are immersed and the messages and information that circulate in those scenarios. Therefore, social representations involve a mental activity in which persons fix their position in situations, events and experiences of daily life, anchored in concrete social and cultural structures. In this sense, social representations are forms of socially constructed and shared knowledge [28, 29].

We understand social representations as the set of knowledge, affected by socioeconomic

and historical determinants, which individuals have about social reality, which organizes practices and influences how they perceive themselves and others [28].

### *Ethical consideration*

This research was approved by the Ethics Committee of the National Institute of Pediatrics in Mexico. It was carried out under the consent of the adolescents and the approval of their parents. Likewise, the confidentiality of the participants and their anonymity were ensured.

### *Procedure*

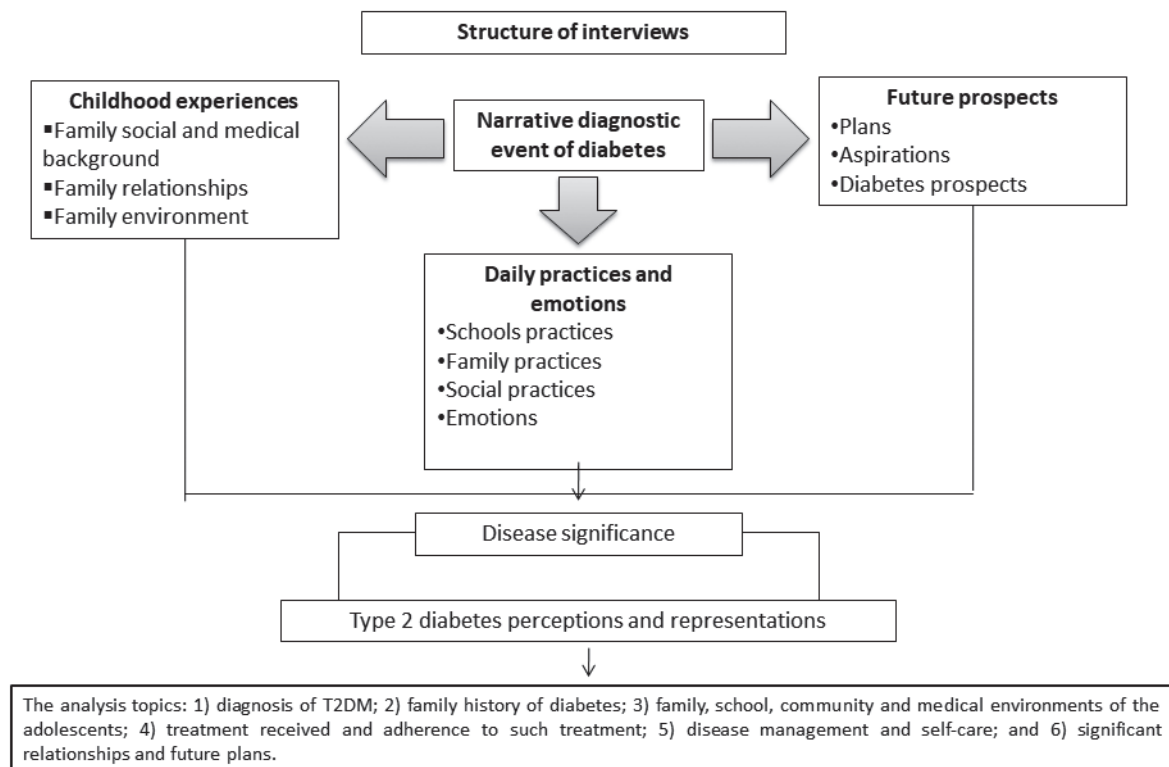
#### *Study Instruments*

In-depth interviews were conducted in the *life-story* mode, which involved re-interviewing each participant with their informed consent and that of their parents. Participant observation was also conducted with the purpose of understanding the family and social contexts in which the participants were socialized, their relations and T2DM representations. The number of interview sessions that were performed with each participant was sufficient to achieve the purpose of this research [30].

Interviews were transcribed to be systematized, coded and analyzed using *Atlas Ti* software. Data analysis was elaborated by the open coding. The starting point in our interviews was the narrative diagnostic event of diabetes, which is considered to be a structure that gives meaning and organizes other events and adolescent experiences in different temporalities [31]. The interviews were organized on six topics as follows:

- 1) diagnosis of T2DM; 2) family history of diabetes; 3) family, school, community and medical environments of the adolescents; 4) treatment received and adherence to such treatment; 5) disease management and self-care; and 6) significant relationships and future plans (see Figure 1).

Prior to the interviews, medical consultation sessions were held with the adolescents to check their health status, to confirm the dia-



**Figure 1.** Narrative structure of interviews and topics considered.

gnosis and treat the disease.

### *Analytic categories*

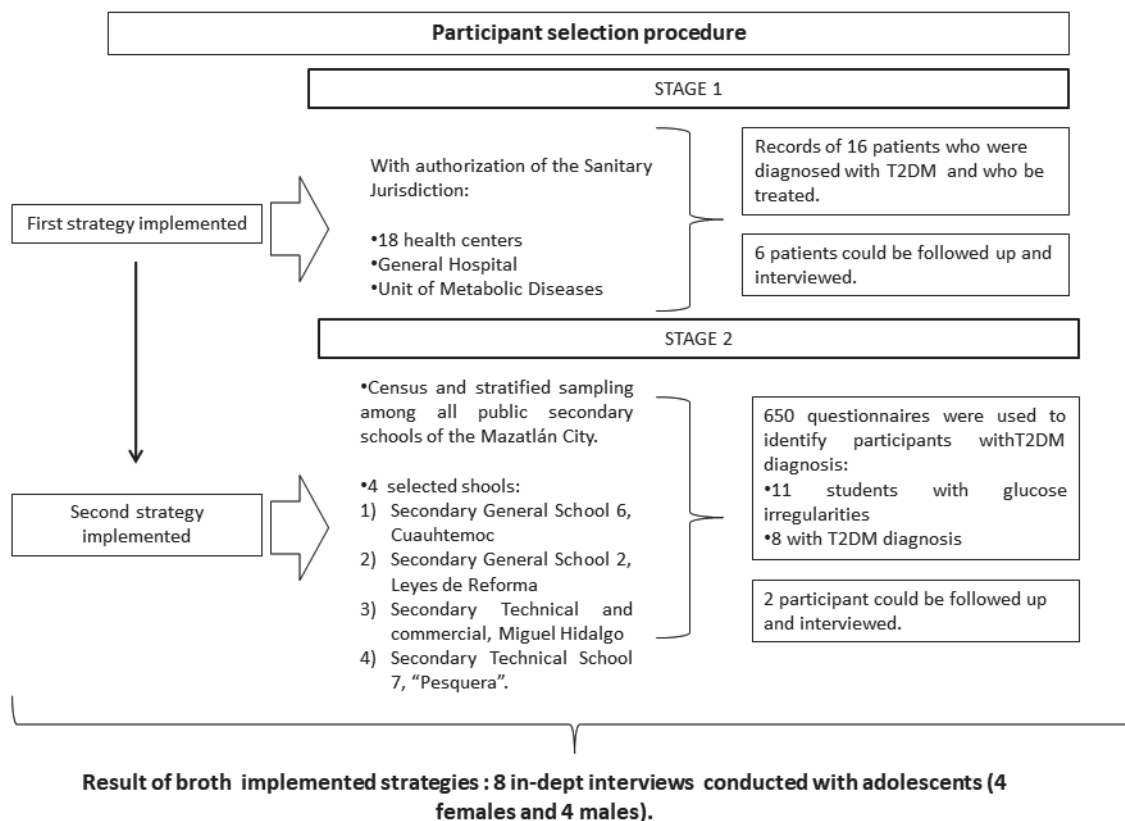
Following the open coding process, six analytic categories of analysis were identified to approach to the T2DM representations: 1) Knowledge about the disease; 2) self-care practices; 3) identity construction; 4) disease significance; 5) family support, and 6) gender, as a transversal category.

### *Participant selection criteria*

The sample was theoretical-intentional according to the following selection criteria: a) age (10–19 years); b) T2DM diagnosis with more than six months of evolution; c) no any other chronic comorbid disease; and 4) residence in Mazatlán. Placing the research in Sinaloa was pertinent because it represents the state with the second highest incidence of T2DM among adolescents in Mexico.

This research is part of a larger research project; however, the fieldwork period from which the interviews were obtained for writing this paper began in April 2015 and ended in April 2016.

The participant selection was conducted in two stages in which different strategies were implemented as the fieldwork was developed. In the first stage, participant recruitment was initiated in 18 health centers, the General Hospital and the Unit of Metabolic Diseases of Mazatlán with the authorization of the Sanitary Jurisdiction. Among all of the patients, only six of them could be followed-up with and interviewed because of problems tracking patient due to treatment withdrawal. This situation involved a second selection procedure in secondary schools where the population was captive. In the second stage, we considered four schools, based on a census and stratified sampling among all public secondary schools in Mazatlán. A total of 650 questionnaires were used to identify adolescents with T2DM. It was difficult to identify cases based on this strategy because adolescents can be unaware of their condition and those who know it do not want to be identified as having the disease. Despite the difficulties with both strategies, 8 adolescents were interviewed. Although the sample obtained is apparently small, it is important to consider some aspects.



**Figure 2.** Participant’s selection process according to the strategies implemented.

First, the participants were in social exclusion conditions which make difficult access to adolescents. Therefore, other strategies were also used to find cases that were not registered in the health system and which showed clinical suspicion of the disease, through the intentional search in the Mazatlán public secondary school environment. In addition, during field work, not all adolescents with this disease could be considered in the study; indeed, due to their social adversity, they did not want to participate and maintained a rejection towards health authorities.

Furthermore, the World Health Organization has reported that type 2 diabetes mellitus has increased its frequency in the pediatric age in low-income countries, but the under-reporting of the disease in this type of population is considerable [32]. According to the national prevalence of type 2 diabetes mellitus in adolescents in Mexico, reported by the National Health and Nutrition Survey 2012 [33], the estimated population size of minors affected by T2DM living in Mazatlán was only thirteen out of 24,000 adolescents, who live in

that municipality [34, 35]. Other qualitative researches on T2DM conducted in Canada and the United States with adolescents have obtained similar samples to our study because of barriers identified [7, 11, 14].

## RESULTS

### *Participant profiles*

Sociodemographic, family history and clinical data of participants are showed in Tables 1 and 2. With regard to family history of diabetes, Table 1 shows that except for one adolescent, all of the participants had a close family member affected by diabetes, most commonly being their mother or maternal-line relatives; this, may be due to the absence of information from the paternal line in several cases in which the father was absent; and there was no a tendency for siblings to develop the disease. There was also heterogeneity in the age at diagnosis, which may explain the different experiences concerning the disease.

Most of the participants used daily insulin, and they manifested symptoms related to

T2DM. In particular, females showed a history of obesity or overweight that, in 2 cases, had been maintained from childhood to adolescence. Only 4 of participants were being treated at a health institution.

Table 2 shows an approach to the participants' dynamics and family structure. Their family socialization was characterized by the physical absence (economic and emotional) of one parent, profile that coincides with that of adolescents with diabetes type 2 in other cultural contexts [7]. Family breakdowns represented events that triggered feelings of abandonment and stress in the participants, which overlap with the diabetes diagnosis in some of them and generate additional emotional distress.

**Diabetes representation**

Our findings showed that representations of diabetes among the adolescents were mainly associated with six themes, of which, gender is a transversal topic, that integrate a body of knowledge that is sometimes contradictory, which allows them to face the disease, interpret their illness and build an identity.

**Knowledge about the disease**

The narratives of the participants showed that knowledge about the disease, from which the adolescents organize their practices and build an identity, is acquired in three ways: health professionals, family history and social context.

Diagnosis is the moment at which the adolescents begin to be directly exposed to medical

**Table 1.** Sociodemographic and clinical profile of participants.

SOCIODEMOGRAPHIC AND MEDICAL PROFILES OF PARTICIPANTS									
Participant*	Current Age	Schooling achieved	Current occupation	Age at diagnosis	Treatment received**	Insulin use	Overweight in childhood	Current body mass index	Family history of diabetes
Women									
Luisa	18	High School	College student	14		Yes	Yes	28.2	Mother/grandmother
Karla	15	Elementary School	Junior high school student	11	Yes	Yes	Yes	42.5	Mother/grandmother/uncles
Diana	16	Junior high school	Technical student	15			Yes	45.1	Uncle
Daniela	14	Elementary School	Junior high school student	14	Yes	Yes		20.3	Mother/grandmother/sister
Men									
Camilo	15	Elementary School	Employee	13		Yes		20.3	Grandmother
Alfonso	18	High School	College student	11	Yes	Yes		24.3	
Oscar	11	Elementary School	Junior high school student	7				20.4	Mother/grandmother
Ernesto	19	High School	Employee	13	No	Sometimes	Yes	28.9	Mother/father

\*The names of the participants were changed by pseudonymous to protect the participant's anonymity.

\*\*Medical treatment institution received before beginning the fieldwork

Source: Own elaboration with in-depth interviews data

**Table 2.** Dynamics and family structures of participants.

DYNAMICS AND FAMILY STRUCTURES OF PARTICIPANTS						
Participant	Current Family structure	Family structure in childhood	Parental absence*	Parental breakdowns after diagnosis**	Siblings	Siblings with diabetes
Women						
Luisa	Live Independent	Nuclear family				2
Karla	Singleparent family (M/S)	Nuclear family	Father		Yes	1
Diana	Singleparent family (M/S)	Singleparent family (M/S)	Father		Yes	1
Daniela	Singleparent family (F/S)	Extended family	Mother			4 Yes
Men						
Camilo	Singleparent family (M/S)	Nuclear family	Father		Yes	3
Alfonso	Nuclear family	Singleparent family (M)			Yes	2
Oscar	Singleparent family (M/S)	Extended family	Both parents		Yes	1
Ernesto	Independent nuclear family	Singleparent family (M/S)				3 Gestational

\*Physical absence or poor contact with one of the parents during prolonged periods.

\*\*Divorce and separations. In some cases the separations are caused by events such as migration or stays in jail by one of the parents.

M=Mother and S=Siblings

Source: Own elaboration with information taken from interviews

knowledge. However, the received orientation is mostly related to the treatment, which is insufficient, and often it is not in accordance with the cognitive and emotional maturity of the patients to allow them to understand the diagnosis. In addition, the adolescents perceive that the information provided by health professionals focuses on the negative consequences associated with diabetes in the long term. This explanation is not accompanied by a description of their condition and how to modify habits and lifestyles, particularly dietary behaviors. Oscar suggests:

*“He [doctor] told me that I had to take care of myself because I had an illness; I do not know what [diabetes] is, and he [doctor] told me that I must be constantly going to [Medical Center], not getting fat, not do this, not do the other, but I did not know why [...]”.*

The female participants mentioned the strong control exercised by health professionals regarding the physical aspect, specifically, overweight and obesity. For them, the medical discourse focused on the need to lose weight, which caused them emotional discomfort for not being able to understand how to achieve it. Among the women, losing weight becomes a principal cause for concern rather than the disease itself. Some of them were referred to nutritionists for weight loss; however, regaining weight caused anxiety, frustration, and ambivalence towards T2DM's treatment, as Karla states:

*“It bothers me to be told: you have to lose weight [crying] because I have to. I don't like being told that because I already know it. I just want to be told how. I don't like being told that I can weigh up to 500 kilos because I don't imagine myself like that [...]. I feel as if they [health professionals] told me to lose weight fast, because you can die and that makes me feel bad”.*

Another way to acquire knowledge about the disease is to live with a family member who suffers from diabetes. This fact promotes the intergenerational transmission of knowledge about T2DM, without necessarily corresponding to that which is obtained from health professionals. However, both types of knowledge are complementary ways of un-

derstanding the disease among adolescents. An example of this is Luisa's story, in which medical and popular knowledge complement each other when she refers to her mother's diabetes trigger:

*“[...] I have known that she had diabetes because of my sister, for scares [worried]. She said that because she always scares [worried], but she did not have a good diet either”.*

The third way to obtain knowledge concerning T2DM refers to community background (neighbors, friends, and teachers) about illness, which builds a collective image of diabetes that is often incomplete and inaccurate and affects the adolescents' perceptions about T2DM, as in the case of Camilo:

*“Well, that can give you a coma; because I've heard a lot of people saying that diabetes gave them 'coma', but I do not know if those people injected [insulin] or not.”*

#### *‘Take care’: self-care practices*

‘Take care’ is a central practice in adolescents' representations of diabetes, appearing frequently in their narratives and promoting ambiguities in how they experience disease. This practice refers to the behaviors that help prevent the consequences of the T2DM in the long term but that are difficult to perform in their day-to-day experiences, which can generate guilt and emotional distress.

‘Take care’ has individual and collective aspects that are mutually affected. Individual aspects involve three elements: dietary restrictions, injecting insulin when necessary, and performing physical activity, particularly among women who are obese and overweight. The collective aspects cover the school, work, family and community spheres, which have the ability to enhance aspects of the individual level or restrict them. Some circumstances in these spheres can promote the abandonment of treatment, particularly; they interfere with healthy eating, as Ernesto suggests:

*“I want to take care of myself, but it's very difficult. In my family, even though they are diabetics, they have never cared of themselves. I arrive at my house and eat the food they make, [...] unhealthy. And at work, I'm the dishwasher, there's food*



*that you want, and I'm hungry, so I eat what I have. There is no way to take care of me!"*

#### *Identity construction*

Identity implies a dual process that involves an individual dimension, namely, how the individual recognizes himself; the other dimension is social, referring to the image that the others, with whom the individual interacts, have of the individual [36]. Therefore, diabetes generates a process of change and adequacies in how adolescents construct an identity, a process that can generate ambivalences and contradictions. The analysis of the interviews suggests that diabetes representation is related to the participants' perception of adolescence as a period of life; hence, their experience with T2DM is ambivalent because it occurs at a moment that is socially associated with health. Diabetes in adolescence represents a disease that is 'out of time', as Luisa mentions: *"If I start to think how everything was, it gives me nostalgia; I feel sad. I begin to cry because I feel that I am too young to have diabetes, to inject insulin and all that"*.

The participants constructed their identity based on strong uncertainties about the future, which varied between men and women. The young people interviewed of both sexes expressed constant apprehension about triggering other long-term ailments and fear of dying, as Oscar suggested:

*"Well, I am afraid that my feet will be cut off [amputated] because I've heard that diabetes gives something bad that I do not know on feet. They get dark, and then you have to cut them off. I'm afraid to die"*.

By contrast, the women's concerns were mostly at the family level, as Karina stated:

*"I am afraid to leave my family alone; I don't want them [relatives] to fight or suffer for me. I do not want them to cry because I can die."*

The inconsistency between being sick and being young and uncertainty about the future led the adolescents to construct their identity using different strategies, among which hiding the disease was the most used. The adolescents did not want some members of their social network to know about their illness;

however, females mostly hid the disease from family, while males mostly hid it from peers. Males with T2DM felt inferior and different from their classmates, but this feeling changed with age. The youngest participants most easily expressed their condition to their peer group. However, as age increases and the high school cycle advances, social pressure on males becomes stronger, particularly in terms of the values that are associated with hegemonic masculinity, such as strength. Then, they start to hide the disease to avoid injecting insulin in public, and they break their diet because they feel that diabetes puts them in a disadvantaged position with regard to meeting the expectations of being a man.

Females participants hide the illness from some members of their family for fear of worrying them, and in some cases, it happens that their parents ask them to hide their condition from their closest relatives, thereby limiting their socialization within the family nucleus, as Luisa declared:

*"No one in my family knows because I've never told anyone. When that happened to me [diabetes], my mother told me: do not tell anyone. So, if it is time to go out with family, for example, they invite me for dinner, I would like to accept it, but what are you going to drink? I cannot take any soda or fresh water. Therefore, sometimes I would prefer not to go"*.

In addition, hiding the illness generates a feeling of loneliness among the participants that affects their self-esteem and complicates the follow-up of treatment and care practices. Ernesto notes:

*"I have felt alone, some days you feel up and some down. One carries many emotions, and you start to cry"*.

#### *Disease significance*

The meaning that is given to diabetes is transformed throughout the adolescents' life pathways. At the time of diagnosis, the significance of the disease is ambiguous in that the adolescent does not have sufficient information about it. However, as time passes, treatment begins, and they must manage the disease daily; consequently, the significance of

T2DM emerges explicitly.

Different significances of diabetes are identified in the participants' stories. Women, in particular, highlight the positive aspects of T2DM, suggesting that despite the problems, diabetes has strengthened them to face different obstacles in life, as stated by Karina:

*"Well, I feel stronger because I know I can live with the disease. I feel I have more power than before, even though I have more things that I cannot eat [laughs], I feel stronger".*

However, the disease is generally associated with negative issues. Diabetes represents a limitation for socialization, specifically with regards to family. In Mexico, celebrations are commonly centered around the food; therefore, restrictions on eating do not allow the adolescents to fully participate, particularly for those who hide their condition. Simultaneously, the symptoms of the illness and injecting insulin limit interpersonal relationships and everyday practices. Transporting insulin and protecting it from hot temperatures in Mazatlán limits the adolescent's mobility and alters daily activities. Diana provides an example:

*"I used to go to sleep with my grandmother, I enjoyed that, and now I do not go for medicines and all that."*

Similarly, the adolescents perceive that suffering from diabetes stigmatizes and marginalizes them, which is differentiated by sex. Women participants describe the feeling to be excluded because of obesity and the marks that diabetes leaves on their bodies, such as skin spots. At the same time, they feel that the disease can limit their autonomy, generating anxiety when they think that they can be a burden on their families, as Daniela says:

*"I would not want them to think I'm a burden. I want them to continue their life, and I want to continue with mine. I do not like them to feel sorry for me".*

For men, injecting insulin exposes them to discrimination and marginalization; where they live, in their neighborhoods, injections are associated with drug abuse, and they do not want to be stereotyped in that way, as Camilo suggests:

*"[...] my life was not going to be the same, I had to inject myself then! People say something wrong about it, but it is only insulin."*

Likewise, they associate diabetes with limitations to their masculinity in two ways. First, T2DM constrains their participation in the public sphere, particularly in the labor market, which affects activities that have traditionally been adjudicated to males: working and providing for a family. Second, they perceive that diabetes affects their virility, as Ernesto puts it:

*"I met my wife, and that's when the people started to say that I was not going to satisfy her [sexually] and that's when I felt bad about myself again".*

#### *Family support*

Although it has been documented that family support is a central element for adolescents to face the diabetes and have greater adherence to treatment [15], the family dynamics of the participants was characterized by the physical absence of the parents and few channels of communication among the members of the family. Aspects such as the parental migration to the United States, or other cities of the country, as well as the insertion of the parents in precarious works and long working days made it difficult to establish channels of communication between participants and their parents or close relatives. This situation made adolescents feel little emotional support within their families, and live the disease with the feeling of loneliness.

Finally, our findings, as well as participant observation, suggested that adolescents with T2DM are a hidden population [37]. If adolescents are not aware of the disease, the health system cannot catch them; the cases that can be detected, usually by reference to other diseases, have little adherence to treatment; and as already mentioned, these adolescents hide the disease, which makes identification, follow-up and treatment difficult.

## DISCUSSION

### *Adolescents with T2DM: a hidden population*

The fieldwork that was conducted in Sinaloa, Mexico made it possible to identify that adolescents, in spite of the incidence of diabetes among this population, constitute a hidden population [37, 38]. The self-management barriers, the abandonment of treatment and hiding the disease, as a result of prejudices with respect to T2DM, complicated participant identification and recruitment, as other studies have previously shown [11, 39].

Findings of our research are in agreement with past studies that underscore that hiding T2DM is a recurring practice among adolescents; this behavior represents a resilience to face the social stigma that is associated with diabetes and its management [11, 12, 15, 40]. But, at the same time, hiding the disease promotes strong vulnerabilities among the participants, such as the reduced use of health services, limited access to appropriate treatment and impaired mental health.

### *Knowledge about T2DM, family support and self-care practice implications*

In this study, adolescents constructed their diabetes representations from individual and contextual elements. Firstly, the acquired knowledge of T2DM in family, community, medical and school contexts promotes or limits self-care practices, and stimulates certain behaviors, such as hiding the disease. The hiding of diabetes highlights the absence of intergenerational communication within the adolescents' families, considering that there are other members who also suffer from diabetes. In this context, experiences, feelings or fears are not exchanged among family members who have diabetes. This acquires relevance considering the results of some studies that show the importance of family and friend solidarity in diabetes management among adolescents [14, 15].

The parental support that the participants receive cannot be separated from the con-

text where the research was carried out. As mentioned in the section above, adolescents' homes are characterized by the absence of one parent and limited family cohesion, with reduced intergenerational dialogue among their members. At the same time, the families of the participants experience conditions of socioeconomic precariousness and poverty. Family members, including some of the participants, must work long journeys to try to meet basic needs. These conditions promote that care practices towards illness, dietary habits and health care are not priority issues in the daily lives of families; situations that tend to reduce the family support that adolescents with type 2 diabetes can receive in this scenario.

Another important element to consider is the poor medical-patient dialogue. The participants did not feel understood by health professionals, who in turn transmitted ambiguous knowledge about the disease, without regard for the adolescents' needs. Their narratives showed that the discourse of *healthy eating* predominates medical speech about diabetes; however, dietary habits are culturally and socioeconomically constructed, and changes to those habits are not easy [18]. Therefore, food restrictions were one element that generated great conflict in the participants, and disease control focused exclusively on losing weight, particularly among women.

This situation placed adolescents in a state of constant ambivalence. They had close examples of disease deterioration within their families. They were worried about having the same long-term effects, so they took on strict diets, often led by health professionals, that were impossible to maintain in the medium- and long-term. Lacking examples of self-care practices and healthy habits makes it difficult for them to consistently maintain their regimens over time, which generates emotional guilt and fear to follow the same deteriorations patterns of their relatives.

### *Identity construction*

The process of identity construction seems to be traversed by disease. The repercussions of

the T2DM on daily life seem to significantly affect adolescent's socialization and their perceptions of themselves. The impact of popular beliefs about illness imposes limitations, prohibitions and exclusions on their participation in social encounter activities.

The fear of dying was a central component in the identity construction of the participants. Some studies suggest that young people experience their youthfulness from a perspective that is centered on the present and not as a transition to adulthood to face the future [41]. Nevertheless, the participants in our study lived in a constant dichotomy between present and future, with the fear of dying or getting worse in the short- and long-term, which varies according to the gender norms.

### *Disease significance*

Narratives of participants suggest that meanings attributed to disease vary by sex. For women, major issues seemed to focus on body image and their social desirability for beauty patterns. Most of females had overweight and obese problems strongly associated with T2DM, but their main concern was to lose weight to improve their body image. Furthermore, they did not want to be a burden to their families, as they perceived that diabetes generates limitations in their autonomy. Males, in contrast, perceived that T2DM has been limiting their labor activities and subsequent ability to have and provide for, as other research suggests [21]. In this sense, diabetes is associated with the idea of failure, which is sustained through the traditional gender imaginary that is heavily embedded in Sinaloa society.

## **CONCLUSIONS**

Representations of T2DM constitute a socially constructed body of knowledge regarding a disease that organizes adolescents' practices perceptions and modes of facing the illness. This perspective allows the identification of the social and cultural aspects of health and illness and the different knowledge and behaviors that are present in the day-to-day experience of patients, which is useful for

prevention, care and treatment.

Our research showed that how adolescents experience and face the disease does not occur homogeneously but varies according to sex, which should be considered by care programs and health professionals to encourage adherence to treatment, taking into account the emotional well-being and needs of adolescents. For males, T2DM implies a reconstruction of male identity, in so far as the disease is believed to limit their job prospects and the ability to provide, which is traditionally associated with male roles. However, for women, the association of diabetes with overweight and obesity affects their self-esteem by exposing them to a double vulnerability. On the one hand, diabetes and obesity represent conditions that limit their life expectancy, and on the other hand, it gives them an emotional burden by not complying with the social stereotype of thinness and beauty.

Our study highlighted two substantial findings that have not been pointed out in other qualitative studies and should therefore be analyzed in depth in future research on type 2 diabetes mellitus in adolescents. Firstly, adolescents with this condition constitute a hidden population; that is, a group difficult to identify and follow up. Diabetes representations as an adult condition and social sanctions experienced by people with diabetes in the Mexican context encourage adolescents to hide the disease in their socialization settings, especially in the family and in school, which makes them invisible for health services. Secondly, the absence of intergenerational communication within the adolescents' families about diabetes limits adolescent care practices and exacerbates their emotional distress for fear that their health will deteriorate in the medium term and even for the possibility of dying, as happened with their close relatives. Therefore, the study also highlights the importance of the family nucleus. It is central to continue to investigate the family role and support for the development of healthy practices in adolescents with diabetes through further qualitative research. In addition, our research revealed the relationship between

en emotional distress and diabetes; therefore, it would be important to ask how other family, school and community aspects contribute to decrease or exacerbate the subsequent distress, and to identify the mechanisms that allow them to manage stress from stigma and exclusion in order to promote their emotional well-being.

Thirdly, the research revealed that the participants' identity construction is strongly affected by the disease, and adolescents must find new ways for preparing themselves for becoming an adult, which should be further investigated in the future by qualitative studies related to mental health; especially in precarious socioeconomic contexts, with few job and school opportunities, in which most of the research participants were inserted.

The practice among adolescents with diabetes to hide the disease should be considered by health professionals to encourage adherence to treatment. Our findings showed the

need to incorporate the mental health area at the first time of diagnosis, as an aspect of the comprehensive care strategy in order to provide sufficient psychological resources for adolescents and their families to help prevent the abandonment of treatment.

Importantly, the main limitation of this study is the lack of generalizability of the results among Mexican adolescents with diabetes due to the sample size and the context in which the interviews occurred and the particular context in which participants were recruited. However, our sample was exhaustive for the Mazatlán municipality and our findings generated new important research issues and questions to expand a new line of research. Indeed, the social vulnerability in which young people find themselves, and their family and demographic characteristics makes it difficult to diagnose new cases of this disease and provide them with the necessary treatment.

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