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**VIVIENDO CON DIABETES TIPO 2: DESCUBRIENDO LOS SIGNIFICADOS QUE LA FAMILIA CONSTRUYE EN TORNO A LA ENFERMEDAD CRÓNICA**

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**Resumen.** El presente estudio busca descubrir y describir los significados que la familia construye en torno a la experiencia de la diabetes mellitus tipo 2. Para ello, a través del enfoque familiar sistémico y la utilización de preguntas circulares, se entrevistó a tres familias que tienen un integrante que vive con diabetes mellitus tipo 2. Las familias hacen alusión tanto a los significados construidos, y a los en los cambios en la vida familiar que suponen un nuevo estilo de vida impuesto por la llegada de la enfermedad.

En la metodología, se utilizó el diseño de Análisis Fenomenológico Interpretativo y mediante entrevistas en profundidad, se espera haber captado e interpretado la experiencia de las familias participantes. La muestra consideró a la persona que vive con diabetes y a los miembros de la familia que viven con él/ella, que tienen un vínculo cercano y/o que tengan algún nivel de responsabilidad en el tratamiento de la enfermedad. La persona que posee la diabetes presenta adherencia al tratamiento actualmente y se encuentran en un ciclo vital de adultez o adultez mayor, con presencia o ausencia de complicaciones médicas asociadas.

Dentro de los resultados, afloran sentimientos de tristeza, y ambivalencia frente al diagnóstico: hay negación, resignación y a su vez, aceptación con respecto al presente y futuro con la compañía de la enfermedad. El apoyo familiar percibido para la persona que vive con diabetes mellitus tipo 2, es primordial para cumplir con los cuidados que la enfermedad requiere, siendo ellas quienes cumplen la función de cuidadora.

**Palabras claves:** experiencia familiar, diabetes tipo 2, significados, enfoque familiar-sistémico, vínculos

## **LIVING WITH TYPE 2 DIABETES: DISCOVERING THE MEANINGS THAT THE FAMILY BUILD AROUND CHRONIC DISEASE**

**Abstract.** The present study seeks to discover and describe the meanings that the family builds around the experience of type 2 diabetes mellitus. To do this, through the systemic family approach and the use of circular questions, three families who have a family member were interviewed who lives with type 2 diabetes mellitus. The families allude both to the constructed meanings and to the changes in family life that suppose a new lifestyle imposed by the arrival of the disease.

In the methodology, the Interpretive Phenomenological Analysis design was obtained and through in-depth interviews, it is expected to have captured and interpreted the experience of the participating families. The necessary sample to the person living with diabetes and the family members who live with him/her, who have a close bond and/or who will have some level of responsibility in the treatment of the disease. The person with diabetes currently adheres to treatment and is in a life cycle of adulthood or older adulthood, with the presence or absence of associated medical complications.

Among the results, feelings of sadness emerge, and ambivalence towards the diagnosis: there is denial, resignation and, in turn, acceptance regarding the present and future with the company of the disease. The perceived family support for the person living with type 2 diabetes mellitus is essential to comply with the care that the disease requires, being those who fulfill the role of caregiver.

**Keywords:** family experience, diabetes type 2, meanings, systematic family approach, relations

### **Introduction**

The systemic family approach considers chronic illness as a problem that affects the other members of the family, those who dynamically influence the illness experience (Cifuentes, Chauriye, Erazo, Ferreira, & Jara, 2010); that is, the theoretical principle of social systems is based on the cooperation of all those involved to seek the best resolution (López, Pérez, Oropeza, & Roca, 2016; 2020).

In the presence of a chronic disease, the members of the family system fulfill and sustain different roles in which they deploy the necessary resources so that compliance with the treatment is not altered; however, the disease interrupts daily functioning in a variable way. In the first place, it depends on the severity attributed to the disease, and on the place the affected person occupies in the family; simultaneously, the way in which the symptomatology is inserted in the family's system of beliefs and values, interfering in the state in which the organization finds itself. The same disease can have an impact in different ways, evidencing particularities in one family or another, also influencing the moment of life and the life cycle in which the disease may emerge (López, Moncada, Suarez and Suarez, 2020; Figueredo, 2014; Pérez, Mercado and Espinosa, 2011; Armengol and Fuhrmann, 1998).

According to the aforementioned, families are building meanings in relation to the treatment of their condition, and these are influenced by the socio-cultural context and the historical moment in which they live, that is, both the person who cares and the one who receives care can create new and different meanings regarding their life, their own experience, and from their own context, being themselves the protagonist (Aristizábal, Flores and Guillen, 2016; Díaz, Galvis and Velásquez, 2014).

The caregiving experience in people with type 2 diabetes mellitus in the family context determines patterns of care that impact culturally and are reflected in the home (Giraud and Vietto, 2018; Carreón, Martínez, and Zenteno, 2018; Briñez and Muñoz, 2016; Leventhal and Phillips, 2016). Likewise, it is put in relevance how gender roles influence chronic disease care since men are the ones who achieve higher levels of therapeutic compliance than women. It is they who are more likely to assume the care of other family members, postponing themselves (Galvez and Gallardo, 2013; Cerrutti and Binstock, 2009). Consequently, emotional reactions and feelings of fear hinder the search for help mainly in male adults, who delay initiating treatments associated with the diagnostic surprise, which added to not feeling physical discomfort, do not usually consider medical advice (Domínguez, 2017).

With regard to statistics, in Chile, only 36% of diabetic patients in the primary health care system have good metabolic control. The percentage of compensation is deficient in both the public and private systems and the situation becomes alarming when the affected person is the breadwinner of the family since with his deterioration and/or disability, he considerably reduces the family income (MINSAL, 2010).

Diabetes mellitus type 2 in our country is considered within the Explicit Health Guarantees, ranking sixth among the most frequent in the population. As of 2010, the direct cost of diabetes mellitus for FONASA (National Health Fund) reached 27 billion pesos, and for ISAPREs, in the same year, it almost reached 4 billion pesos; a diabetic patient costs 2.5 times the expense of someone who does not have the disease (FONASA, 2016).

For this reason, type 2 diabetes mellitus goes beyond institutional and health frameworks, encompassing the daily life of the person and his or her family system since once diagnosed, it generates changes at the psychic and corporal level, modifying significant areas of life for the human being (Cárdenas and Molina, 2020; Ledón, 2011).

Therefore, research should be directed towards the family setting since the interactions that occur within play an important role accounting for emotional tension in the family that influences the control of those affected with chronic diseases (Epul, 2012; Rivas et al, 2011).

The above means a permanent stay in the health system and, at the same time, the deterioration that generates in the person that others take over and so vice versa (Urzúa et al, 2015).

### ***Daily life and family adjustment to the disease***

Interpretive sociology has emphasized that the subjective experience of health and disease processes cannot be fully understood unless they are analyzed in the context in which they appear, making it essential to understand everyday life, i.e., those things that are done countless times a day without the need to think about them, such as routines and interactions, the people involved, and the people who model what they do (Arenas, Hernández and Valde, 2001).

Living with type 2 diabetes mellitus in the adult's daily life means acquiring an understanding from common sense, that is, the person constructs his or her social representations and meanings without having an exact knowledge of the disease, often accompanied by negative emotions upon receiving the disease diagnosis and influenced by past experiences (scars, food, courage) associated with stressful situations, allowing him or her to function in the social context and transform his or her daily life to live with the disease (Alfaro, Moreno, Ramos, Rodríguez, and Sadimno, 2020; Amagua and Pazmiño, 2019; Franco and Marmolejo, 2016).

Chronic disease worries both individual family members and the family as a whole. The chronicity of the condition, its routines, the economic burden, the frustration in the face of

treatments with little progress, gradually begin to undermine family life, disrupting several areas of it (Cifuentes, Chauriye, Erazo, Ferreira and Jara, 2010).

Mainly, diabetes causes depression by itself, whose restrictive regimen and physical and sexual limitations predispose the affected person to other comorbidities associated with the mental health field (Cienfuegos, et al., 2018; Heredia and Pinto, 2008).

It is observed how the members of the nuclear family may experience social and emotional isolation but also with the extended family and friends. The complex interactions that are generated between the pre-existing family dynamics and the already chronic disease affect the family's identity, amplifying conflicts and dysfunctional patterns that already existed, thus impoverishing family competencies (Cifuentes, Chauriye, Erazo, Ferreira and Jara, 2010).

The quality of life of people with diabetes constitute a daily challenge that divides everyday life into a before and after diagnosis, inciting changes in lifestyle habits, which are not always negotiable by other family members (Cardoso, Da Silva, Fagundes, & Noguiera, 2018).

In some cases, what Pauline Boss in 2001 described as "ambiguous loss" tends to occur in which opposing feelings and emotions appear, generating intense anger and sometimes guilt. The response to the diagnosis of a chronic disease has complex psychological and social implications as family members are mobilized in the face of this, showing anguish when the issue of death, limitation, and disability is imposed. This process that the person and his family go through sometimes fails to be elaborated in the best way, being able to develop several conflicts that invade the integral health of the person and often the family system (Angle, 2015; Baldovino, Gomez, Madrid, Ordoñez and Villareal, 2013).

The entire family group undergoes a transformation facing life with the disease, the person, and his family seek their balance and coexistence; that is, in these circumstances they have the possibility of adapting to old age with the disease (Ofman, Taverna and Stefani, 2019). All of the above makes the family experience non-normative events and situations and uncertainty about this member that require an adaptive effort that complexifies the family dynamics (Barbosa, Vanegas and Zamora, 2020; Adfalla and Novis, 2014).

From the narrative perspective, people have different ways of constructing their experiences around diabetes, for example, "living without pleasures" or "living as if they did not have diabetes" that reflect shared ways of meaning and consequently, living with the disease, as well as who assumes the care (Aguilar, Camacho, Orozco, & Vieyra, 2021; González, Machado, & Valderrama, 2020; Heitmann, 2018).

Therefore, and by virtue of the theoretical and empirical background raised with respect to families living with a diabetic member, the following research question is formulated: What are the meanings that families construct around the experience of living with a member who has type 2 diabetes mellitus? From this, the general objective is to describe the experience of families with a member with type 2 diabetes mellitus. And to respond to the general objective, we intend to describe the meanings that the families construct around the experience of the disease and also to reveal the changes that occur in the family organization in the face of diabetes.

## **Method**

### ***Design***

Interpretative Phenomenological Analysis (IPA) was considered as the most appropriate research design, which seeks to answer the way in which people give meaning to their lived experience in a particular context. Its purpose is to describe the meaning of that experience in

relation to the phenomena of interest, to make visible the features of that experience and its common characteristics, based on the understanding and the way in which meaning is constructed through perceptual content (Smith and Osborn, 2007).

Interest in phenomenological design in health sciences has arisen from the need to understand the lived experience, in particular the process of health and illness (Canto, Celis, Negrón, & Sosa, 2018; Mendieta, Fuerte, & Ramírez, 2015). In addition, IPA offers researchers the opportunity to explore how families construct an intersubjective perspective of lived phenomena (Allan & Eatough, 2016).

***Participants***

The participating families are enrolled in a family health center in the city of Osorno. The families were selected through convenience sampling, that is, by the access and administrative facilities provided by the head of the center. Participants were selected based on the following characteristics, choosing one family per age range in the adult life cycle (see Table 1). The inclusion and exclusion criteria were made explicit (see Table 2).

Table 1.  
*Characteristics of participating families*

<b>Participants</b>	<b>Family 1</b>	<b>Family 2</b>	<b>Family 3</b>
<b>The person presenting the diagnosis, plus the primary caregiver and/or person with whom he/she maintains a close relationship.</b>	<b>Family with a diabetic member (20 to 43 years old)</b> <b>Family 1:</b> Composed by Alexis and his wife Lorena, both 34 years old. They live with their three children aged 18 years old, 11 years old, and 1 year 4 months old.	<b>Family with a diabetic member (44 to 64 years old)</b> <b>Family 2:</b> Juan, 58 years old, and his sister Maria, 68 years old, live together.	<b>Family with a diabetic member over 65 years old</b> <b>Family 3:</b> Lety, 70 years old, and her daughter Iris, 50 years old, who visits her approximately 5 times a year due to the physical distance. They communicate by telephone constantly.
<b>Therapeutic compliance (adherence to treatment)</b>	Alexis has had DM2 for 5 years, with therapeutic compliance.	Juan has had DM2 for 8 years and has been compliant with treatment for two months.	Lety presents diabetes diagnosed 11 months ago, with therapeutic compliance.

<b>Complications associated with type 2 diabetes</b>	There are no complications associated with the disease.	He presents renal disease, a consequence of complications of DM2.	He has no complications associated with DM2 but has comorbidity with hypertension, osteoarthritis, and arthritis.
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Source: Own elaboration based on data collected in Ministry of Health (2010).

***Inclusion and Exclusion Criteria***

The inclusion and exclusion criteria that account for the choice of participating families are presented below:

Table 2.

***Inclusion and Exclusion Criteria.***

	<b>Inclusion</b>	<b>Exclusion</b>
<b>Criteria</b>	1) Families that present a member with type 2 diabetes with at least 6 months of treatment since its diagnosis. 2) Family members are recognized by the same person with diabetes, living under the same household, and/or there is a close bond and/or they carry some level of responsibility for the care of the disease.	1) Families that have a member who is bedridden, either the person living with diabetes or another member. 2) Families that have a member living with type 2 diabetes and coexist with problematic alcohol and/or drug use or other severe mental health problems, such as schizophrenia, mental retardation, or developmental disorders in that member or any other member of the family.

Source: Own elaboration based on data collected in Ministry of Health (2010).

***Data collection techniques***

As a data collection technique, the in-depth interview was used, which from the systemic approach was composed of circular questions, which allow the participants to construct meanings from their experiences, and in turn, the researchers can interpret the meanings, understanding that the results of this research are the product of a dialogue in a unique and particular moment with the families interviewed. That is why the result is a unique process of self-discovery and understanding for the family, and role of the psychologists, who carried out this technique, is to be a facilitator and ally in the dialogue (Heitmann, 2018).

Family interviews were conducted with the participation of the person presenting the diagnosis of type 2 diabetes, together with the selected family members, which made it possible to capture the circularity of the study phenomena.

It should be noted that the researchers are psychologists by profession, with at least four years of clinical experience in the primary health care system in Chile.

## ***Procedure***

### ***Access to the exhibition***

The first contact of the researchers to gain access to the sample and the study site was with the Director of the Municipal Health Department of the commune of Osorno. As a regular channel and by means of a formal request, a letter was presented to her, with a copy to the director of the specific family health center of investigation, followed by the research project to allow her authorization.

The key informants were the health professionals, who make up the direct care in the treatment, who could be nurses, physicians, or other related professionals. Their role was to inform which families could participate in this study, considering the inclusion and exclusion criteria. Subsequently, direct contact was made with the families who freely opted to participate through informed consent.

### ***Principle of informed consent***

For this purpose, as mentioned above, an informed consent form was used to ensure confidentiality of the data provided by the participants and the right to have subsequent knowledge of the results and permanent contact with the researchers during and after the study, in case further information and/or any reason related to the research was required.

### ***Privacy and Confidentiality***

In order to protect confidentiality, the names of the participants were replaced by a pseudonym and the place they occupy in the family system, declaring the commitment of the researchers to keep their identities confidential.

### ***Analysis plan***

To carry out the analysis, all the interviews were transcribed. Subsequently, a global reading of the interviews was carried out, that is, reading the text several times, in order to have multiple readings and annotations. This initial phase involved close reading of the transcription and, likewise, the audio recordings were listened to several times. This made it easier for the researchers to delve into the data and recall the environment in which the interviews were conducted. Notes were taken about observations and/or reflections on the interview experience and/or comments of importance. Distinctive phrases and emotional responses were made (Pietkiewicz and Smith, 2012).

In a second stage, the researchers worked with their notes (exhaustive details) rather than with the transcript itself, with the aim of transforming them into emergent themes, trying to formulate a concise sentence presenting a slightly higher level of abstraction, i.e., referring to a more psychological conceptualization (Pietkiewicz and Smith, 2012).

Subsequently, the third stage sought connections between the emerging themes, grouping them into interrelationships, conceptual analogies, and providing each group with a descriptive label. Finally, it leads to writing a narrative account of the study, which generally involves taking the themes identified in a list. The final paper contains the interpretive reflection of the researchers, as well as the narrative of the participant and their experience in their own words (Pietkiewicz and Smith, 2012).

### **Computer resources for data analysis**

A tape recorder was used to transcribe the most important elements. For this transcription, the OFFICE program, Microsoft Word, was used. Then, using the same program, tables were generated to systematize the information obtained and, thus, the analysis by theme and sub-theme was carried out.

## **Results**

Three central themes were found that provide insight into how families give meaning to their experience when there is a family member with type 2 diabetes mellitus. The first topic is "*The pain of life with diabetes*," the second topic is "*Shared food brings us together and separates us*," and the last topic is "*My role as a caregiver*."

### **Topic 1: "*The pain of life with diabetes*"**

This topic encompasses those feelings, emotions, and beliefs that appear in the face of the diagnosis and the condition of chronicity that the disease entails. It highlights the feelings of guilt, sadness, and hopelessness that appear and the consequences that would generate in personal and family life. The above is broken down into the following sub-themes:

1.1 "*The world fell apart*." This sub-theme shows that at the moment of receiving the diagnosis, an impact is generated in the person with diabetes, as well as in his/her significant links, threatening the life expectations of the person who suffers from diabetes. There are feelings of sadness and low spirits, accompanied by concern and fear when visualizing a possible future linked to physical and emotional limitation and, consequently, dependence on other family members.

"*I got down, everything fell apart, I had the support of her and my family... yes, at the beginning I got down... I thought that if I controlled it, I could be fine. I was afraid...* (Interview 1, page 1-2, lines 21-24, 34-year-old adult with the diagnosis)." We try to deduce that the person presents feelings of sadness, associated with a low mood due to the diagnostic surprise generated by receiving the news and the fear that accompanies it. Here it can be seen how the diagnosis influences the vital proposition and also the implications that diabetes will have on daily life are visualized. There is uncertainty as to how this disease will influence his life and whether or not he will be able to follow the guidelines to be healthy. Although he recognizes the family support, there is a fear associated with not being able to control himself and the consequences of this on his health.

"*(...) Sometimes I did not feel like living...for a long time. I was listless. I felt like sleeping... Diabetes makes you sleepy, it is like a cancer. It hurts you...*" (Interview 2, page 7, lines 19-21, 58-year-old adult with the diagnosis). The interviewee reports a sense of sadness and hopelessness associated with both psychic and bodily pain. Here the circularity and influence between both ailments can be appreciated. The metaphor of cancer could be associated with the fact that it is a disease, from his perspective, that ends his life. A death that can be real or a symbolic death of what her life implies.

1.2 "*Getting used to what will follow us all our lives*." This sub-theme reports that during the treatment process, family members are involved in negative emotions, initiating a process of

accommodation and ambivalence. A process between mourning and acceptance of the condition is set in motion. This situation may induce adaptive responses such as denial of the disease or resignation to lifelong diabetes.

(...) *"Sometimes he forgets that he is diabetic. He feels bad and goes to the emergency room (alluding to the emergency department) and I ask him, and you said you were diabetic? and there he says, I am diabetic."* (Interview 1, page 4, lines 23-24, 34-year-old adult and wife of a person with the diagnosis). The feelings of denial and the difficulty to assimilate the diagnosis are evident, translating into the affected person's narrative even in critical situations, such as a decompensation. Although the person forgot it, his wife has it incorporated, which could be associated with the identity of her husband due to the impact of the disease that is constituted around diabetes.

(...) *"Get used to it, nothing can be done. I think that if Juan takes care of himself, he can lead a good life"* (Interview 2, page 7, lines 9-10, 68-year-old sister). Feelings of resignation are perceived, which could be adaptive to face the disease and the changes it implies in the life of a person and his family. In addition, there is also an attribution to the member of the family who has the disease of its prognosis, ignoring that in some way the harmful eating habits are not necessarily related only to him but to the whole family system. The latter could lead to difficulties in family relationships.

1.3 *"Worry that something will happen to him/her."* This subtheme refers to the feelings of fear and anxiety that the caregiver feels for the person with diabetes. Families report constantly feeling feelings of uneasiness and fear about the future with the disease and its consequences, which can influence the perception of the diabetes caregiver by intensifying feelings of fear.

*"We all know that it ends in catastrophic things... I don't know... the bad pancreas, the bad liver, the bad heart, because it is deteriorating inside or a poorly cared for wound... it is worrying... I feel concern because it is her health and since one is in charge of her it is also one's responsibility"* (Interview 3, page 3 line 15-18, 50-year-old daughter). The family realizes that the concern for the care of others is driving the practices associated with caring. It also shows the commitment that is acquired, fearing that something will happen to her, with a catastrophic vision of the disease despite the fact that the affected person is currently following her treatment. The meaning of diabetes as a disease is tinged as a fatal disease.

(...) *"I know that sugar spikes are suddenly very strong. It scares me because I am the one who tells her what to do in case her blood sugar rises. I worry that something will happen to her"* (Interview 1, page 3, lines 27-30, wife, 34 years old). Likewise, the wife is adopting a new role, loaded with responsibility that goes hand in hand with the fear and concern that complications may occur, feelings that indicate a not very encouraging future. She sees herself involved in the care, perceiving that she has the necessary skills to help the diabetic in case of emergency.

## ***Topic 2: "Shared food brings us together and separates us"***

Families report that, in order to face the treatment of diabetes, they must implement different changes, including relational dynamics, being able to talk about food and habits among all members of the family. To this end, the following sub-themes emerge:

2.1 *"Nutrition that requires supervision."* This sub-theme alludes to the fact that during the process of coming to terms with the changes associated with the food element, the caregiver tends to set limits with respect to food. The person with diabetes feels that he or she is losing power in making decisions about food, as it was an element that was not questioned before the diagnosis. These decisions are influenced by the determinations of the caregiver. Food is evidenced as the means for making one's own decisions.

*"I challenge her about food, but as she is driven by her ideas... She had a sweet tooth, she ate whatever came and if there was a drink, sweets, everything, nobody was careful..."* (Interview 3, Page 10, lines 17-18, 50-year-old adult, daughter of the person presenting the diagnosis). It is suggested that it would be difficult to change habits that were ingrained in daily life. It can be seen that it is difficult for the adult person living with diabetes to assume that others are involved and acquire power in decisions that were previously of an individual nature, showing certain resistance. It is also observed that there may be a feeling of exhaustion and constant worry on the part of the caregiver, which may generate difficulties in the relationship.

*"When he doesn't listen to me about meals or remedies, I get angry. We don't get into more conflict"* (Interview 1, page 5, lines 5-6, 34-year-old adult and wife of a person presenting with the diagnosis). It is inferred that the caregiver also makes an emotional effort to meet the objectives and carry out the necessary strategies to accommodate the diagnosis. Inflexible attitudes are perceived from the member with diabetes, who must adapt to changes that are imposed. However, he or she may receive it as a manifestation of love by collaborating to effect such changes.

2.2 *"Giving each other affection through food."* This sub-theme refers to the meanings behind the element of food, which are associated with the expression of union and affection towards the significant other who visits or lives in the home. Consequently, the family must incorporate new foods to the family diet and others that usually starred in family gatherings are eliminated, for example: soft drinks, barbecues, roasts, pastries, among others. There would be a change in the affective relationship with food, which continues to be an element of affection, maintaining its function but with other elements that ensure the patient's quality of life.

*"We can no longer eat anything tasty...Before, everything was shared, now we are careful, because one cannot eat salt, another cannot eat sugar"* (Interview 3, page 12, lines 39-41, 70-year-old woman). It is interesting to interpret that it is possible to assume the change in spite of the fact that for the family it is usually a pleasure to share certain flavors associated with the experience of being all together. There is a before and an after in family gatherings, where members report that they have knowledge about each other's food and a mutual interest in respecting it, showing a sacrifice in pursuit of caring for the health of others.

*"She makes demands on me at meals. Sometimes I ask her for noodles with sauce and meat, and she doesn't make them for me. If she wasn't there, I would have already cut myself (alluding to death)"* (Interview 2, page 4, lines 11-13, 58-year-old adult presenting the diagnosis). It is possible to perceive that family support is usually essential when it comes to accepting the changes, that is, in this section the person recognizes that in order to maintain an adequate diet it is essential that the other person is present accompanying him/her in his/her care. The affected person appreciates, values, and recognizes their work.

### **Topic 3: "My role as a caregiver"**

This theme alludes to the place adopted by the caregiver, who, through the link with the diabetic, directs his or her efforts to become the main support network for this person. It is also evident that female figures are the ones who take charge of the care: the wife, the sister, and the daughter. Sometimes, changes in hierarchies and family roles are visualized.

To this end, the following sub-themes are derived:

3.1 *"Getting involved in their care."* This sub-theme allows us to interpret that the caregiver is getting involved in the care of the other person, showing commitment and adopting this role with responsibility, allowing to face certain difficulties related to the disease from daily knowledge in order to overcome the complications that emerge.

*"I cured him. I cured him with natural medicine"* (Interview 2, page 4, lines 27-28, 68-year-old adult and sister of a person presenting with the diagnosis). A positive perception of personal competencies and sense of self-efficacy emerges along with the ability to use everyday resources and knowledge to provide optimal care. This knowledge subscribes to a context outside of traditional medicine, which is meaningful to the caregiver and the one being cared for.

*"Sometimes he forgets the pills, but I take care of fetching them and reminding him"* (Interview 1, page 3, line 21, 34-year-old adult and wife of a person presenting with the diagnosis). Here it is perceived how the caregiver adopts a responsibility in the care of her husband, allowing the interpretation that involvement in caregiving mobilizes and transforms the family system, managing to find a balance in the experience of illness. However, this may influence the way in which the affected person acquires commitment in the treatment.

3.2 *"We in care"*. This subtheme points to women as caregiving figures, who welcome and accept this role and are also recognized by the person presenting the diagnosis.

*"She is my sister, if she were not there, I don't know how I would have been..."* (Interview 2, page 4, line 11, 58-year-old adult presenting the diagnosis). Here he points to the recognition of the figure of the sister as the main caregiver, alluding to an unfavorable future if he were to be detached from her support, which is why he values her care. There is a questioning of life in the case of not perceiving anyone in the care.

*"I have her support more than anything else... because she takes care of me as she does of her children... she has put in a great deal..."* (Interview 3, page 6, line 11, older adult, 70 years old, presenting the diagnosis). In the same way, it is perceived that female support is the only support for this person, which implies that if she were not there, there would be no other figure safeguarding his care, perceiving feelings of fear. This would translate as a limiting factor both at the individual and family level since it increases the fears of the affected person and the caregiver, who would feel as the only one responsible for this process, which could become an overload in the future.

## **Discussion and conclusions**

From the interviews conducted with the three families and their subsequent analysis, it is revealed the emotion of surprise and shock at the news of the diagnosis since it is unexpected, initiating a process of adaptation which is accompanied by feelings of fear of limitation due to possible sequelae of the disease and, therefore, with hopelessness about the future. During this adjustment, it is possible to perceive that the family members with whom the person with the diagnosis has a close relationship are becoming involved in the care required by the disease, providing support and assuming decisions that allow an adequate adjustment. They also express various emotions tinged with concern, mainly about the possible consequences associated with diabetes, which leads to a change in the affective bond, emerging an invisible system in the family: "the caregiver and the affected" highlighting the role of the caregiver who protects and is committed to the care of the other.

Consequently, in order to respond to the specific objectives of the research, three major themes are presented in order to describe the meanings that families construct around the experience of illness and also to highlight the changes that occur in the family organization:

1. "The pain of life with diabetes"
2. "Shared food brings us together and separates us"
3. "My role as a caregiver"

The participating families mentioned that the close relationships among them are those that allow them to adequately cope with life with this condition, which is consistent with studies conducted in Mexico (López, Pérez, Oropeza and Roca, 2016; Riquelme, 2015), which report that the family is the main affective and practical support to provide the care that the disease requires. Families that have built a reciprocal support among its members are those that manage to maintain a good quality of life, despite emergency situations and/or consequences of diabetes.

Likewise, it is revealed that the participants are moving towards a process of mourning between denial and acceptance of the changes. Those affected report that they are losing power in decisions that were not previously questioned by the family. Such a loss is not only exposed by the person suffering from diabetes but also by the other members of the family. A study conducted in Bolivia (Angle, 2015) describes this process in diabetes and compares it with ambiguous loss (concept coined by Pauline Boss in 2001), indicating that the affected person and his family go through such loss presenting confusing feelings that sometimes fail to be adequately elaborated, reaching to generate various conflicts disrupting the integral health of the entire family system. It is reflected in the literature (Heredia and Pinto, 2008) that the condition of diabetes can generate other comorbidities in the affected person and his family in the experience of the disease.

The second theme, which points to "Shared food brings us together and separates us," that the person with the diagnosis is difficult for others to get involved and take control of decisions that were previously of an individual nature and that now become part of the family sphere. Our results coincide with studies mentioned in previous paragraphs (Angle, 2015; Riquelme, 2015) in which the family is coupling to the change entering into conflicts and solutions to find a new adjustment. Within the findings, it is possible to evidence that food is usually a central element in family life; when interpreting the meanings, it is revealed that food generates spaces for meeting

and fun. Through food, family identity and a sense of belonging are conceived; therefore, affection is shown when buying, cooking, and sharing food.

And as for the third theme that, alludes to "My role as a caregiver" in which the participating families reflect the birth of a new family structure facing the diagnosis of diabetes, such organization is finding new ways to adapt and that the whole system continues to function invisibly to its members (Adfalla and Novis, 2014), experiencing a transformation.

On the other hand, the empirical and daily life knowledge that the families possess regarding the care of the disease is revealed since the experience of care is influenced by social and cultural patterns. It is evident that the female gender is the one that assumes the predominant role when it comes to assuming care, which is associated with what has been culturally attributed to women; they are the ones who manage certain responsibilities, such as cooking and/or administering medication, optimizing their time between caring for the home, children, grandchildren, and diabetes (Gálvez and Gallardo, 2013).

As relevant background, it is possible to point out that a factor that can have an impact on the experience of diabetes is the moment of life in which it appears and the life cycle in which the family is (Figueredo, 2014; Armengol and Fuhrmann, 1998). However, in the present research, no elements were recognized during the dialogue with the participating families that would account for this. A study conducted in Chile (Alcaño, Bastías, Benavides, Figueroa and Luengo, 2014) supports that people who cope better with the disease are those who have significant family ties regardless of the stage of the life cycle in which diabetes appears.

In conclusion, the relevance of this research is to provide knowledge in an area that is less deepened in our country, regarding the family in the affectation of diabetes mellitus type 2, contributing to the understanding of the experience of diabetes since this is not lived individually but rather in a relational way with those links that are significant and that manage to get emotionally involved in the care.

According to the above, the need arises to conduct a first conversation with families about the experience of diabetes, urging family therapists to perceive the narratives and stories, with the aim of rescuing the resources, skills, and values that could be used to cope with the disease. From this perspective, it is considered that diabetes is diabetes and the person with diabetes is not the problem, leaving behind stigmatizing meanings to the person with the disease, which often intensify the emotions of sadness and hopelessness. In this process, family therapists and health professionals can accompany families to deconstruct their meanings and co-construct new ones in relation to the diagnosis, the treatment, the relationship they have with food, and the new relational structure that emerges. With respect to family psychotherapy, the practice of understanding the meanings that each family member constructs of the process, nurtures, and allows the generation of common stories and alternative stories, establishing understanding among members and strengthening bonds.

It is also possible to consider that these meanings are constructed within a social, cultural, and gender context, allowing to understand the relational experience of the disease, which will

provide elements for health agents to empathize with those family members who take longer to establish changes or have poor adherence to treatments.

Finally, the following questions arise regarding what happens when roles are rigidified in other family systems around type 2 diabetes and, on the other hand, what are the challenges faced by families when there are already problems in the bonding relationship, i.e., it would be interesting to discover how type 2 diabetes impacts on these cases.

On the other hand, it is possible to mention the importance of the development and strengthening of skills of family therapists working in this area around building a circular dialogue that nurtures meanings and facilitates interpretations, that is, to deploy practices that allow the therapeutic conversation to generate experience and how these would impact on the treatment process. It is for this reason that we urge the generation of new national and local studies that investigate the experience of family members in living with type 2 diabetes mellitus.

It should be noted that the methodology used allows us to achieve the objectives initially set out, making it possible to understand and capture the experience of families who have a member with type 2 diabetes mellitus.

Although the sample has been heterogeneous in terms of individual and family life cycle, it is important to mention that this has made it possible to show the core of the experience of a group of families of different ages. As for the limitations of this study, it is possible to mention that no gender distinctions were made, which was not possible due to the scarce male participation in the study, which could have resulted in gender bias.

The bias of the researchers is also recognized since they both work in primary health care, and their resonance may influence the interpretative capacity of the results.

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