


# Suffering Depression: Illness Perception of Informal Primary Caregivers of Medical Students With Major Depressive Disorder

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## Abstract

When a family member has depression at a level that generates disability in various functional spheres, the informal primary caregiver (IPC) is the individual who provides the majority of emotional and basic needs of the patient. This person is usually a relative and is extremely important in the health-disease-care process. This phenomenological qualitative study aimed to analyze the illness perception, in IPCs of undergraduate medical students previously diagnosed with mild depression. It was found that IPCs generate perceptions about depression based on a lack of knowledge of the disorder, which leads to feelings of sorrow, anger, frustration, and fear, that could interfere with the evolution of patients. Psychiatric disorders, such as depression, strongly impact both patients and people around them. For mental health professionals, in order to provide a more complete clinical approach, it is important to understand the illness perceptions not only of patients but of family IPCs as well.

## Keywords

informal primary caregiver, depression, illness perception, university students, qualitative research

## Introduction

Major depressive disorder (MDD) is a multifactorial pathology that presents regardless of age, education level, culture, and socioeconomic level, and it implies high-impact biopsychosocial consequences that influence the optimal development of the human potential. World Health Organization projects that MDD will become the world's second cause of disability, which highlights the importance of the behavior of this disorder in different populations, especially in those where the impact could be greater due to occurring at important moment in their life, as is the case for university students (1,2).

Regarding the epidemiology of MDD in university students, it has been shown that 25% to 49.8% develop this disorder (3–7). Medical students develop depression in 36.4% to 92.9%, and the consequences of this are reflected in poor academic performance, dropping out, and an excessive consumption of psychopharmaceutical drugs during acutely stressful periods, such as during exam periods (8–10). In the face of an extremely vulnerable time, the role of the family becomes crucial.

Studies conducted on university students diagnosed with depression emphasize family dynamic as a precipitating and/or perpetuating factor of MDD (11). However, as in any chronic and incapacitating condition, when mild or severe depression is present in a family, generally only one person

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assumes responsibility for support and care of the patient. In the literature, this person is described as the informal primary caregiver (IPC) (12,13).

The IPC generally is a part of the support system of the patient (often a family member) and, as a layperson, assumes almost complete responsibility for the patient with respect to meeting their basic and psychosocial needs (14–16). The IPC is developed through private relationships, and their domestic nature makes them invisible in public, such that on occasion, their necessities go unnoticed (17–19). The behaviors of this figure can be a determining factor for the reactions and evolution of the patient (20,21) since a series of subjective meanings are generated in the patient–caregiver relationship and they will be reflected in the motivation to carry out the activities of care, which in turn result in better care for the patient (22).

Understanding how caregivers perceive the disease helps to recognize the meanings they ascribe to the illness as well as expectations and needs. For health professionals, this information could help to identify mechanisms for a better patient–caregiver dynamic that favors a greater well-being for the IPC and a positive patient evolution (23).

Some studies have been carried out with IPCs of psychiatric patients, in order to analyze the subjective experience and perceptions of these actors in the mental health illness process (24–27), and it is striking that, particularly when the caregivers are mothers, in addition to the burden of caring for the sick person, the data that stand out the most are both the concern for the future of the patient and the difficulty they themselves have with regard to the sadness and pain of seeing that their children are ill (28). Because of the importance of the involvement of these individuals with the patient, the aim of this research was to study a previously unexplored space of the perception of caregivers of young adult students with MDD, specifically in Mexico City.

## Method

The aim of this study was to understand first-hand the perception that IPCs have about MDD, and for this reason, a qualitative approach was chosen. The design was phenomenological, directed toward a study of the lived experience concerning the protagonist's own circumstances as well as looking to describe the meaning of the phenomenon experienced by the individuals through analysis of their descriptions (29,30). This research is compliant with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) framework (31). All procedures used in the study were reviewed and approved by the institutional review board and ethics committee of the School of Medicine where this study was conducted.

All participant ICs signed the informed consent form prior the interview, and in addition, names and other identifying data were not included in the transcriptions to ensure confidentiality. We used the random codes to identify the

audio material and transcripts and to analyze information in order to respect the anonymity of participants.

## Data Collection

To obtain first-hand information that permitted greater understanding of the IPCs' perception of the study subject matter, a semi-structured targeted interview (32) was used. The interview process utilized different support tools including an interview guide which was designed according to the research objectives and following the guidelines suggested by Taylor and Bogdan (33).

## Procedure

Medical students previously diagnosed with mild MDD who were receiving treatment in a specialized service for mental health and psychiatry in a public university in Mexico City were individually referred by their treating psychiatrist to one of the researchers in order to provide information about the study. Thirty-two depressed medical students were invited for an informative meeting about the project, where they were asked to identify their IPC and gave authorization for contact them in order request their participation. Only 7 patients allowed for their IPCs to be contacted. After patients signed the corresponding informed consent form, an appointment was set up with the IPCs, and at this point, only 4 IPCs agreed to participate. The interviews with each IPC were carried out, on the dates that best suited each individual, at the interviewee's home.

Although the total number of participants in the purposeful sampling of this study was due to the IPCs that agreed to participate (and that were previously identified and authorized by the patients), in qualitative research the wealth that each participant contributes to delve into the analysis of the research objective is very important; therefore, it was kept in mind at all times, to reach information saturation (34,35).

Data saturation was observed among the participants after 3 interviews, but the team decided to include the total of four IPCs to corroborate adequate saturation (34). The interviews were conducted by a social worker with a master's degree who was trained by a research psychiatrist with extensive experience in qualitative research to conduct the interview. During the interviews, participants were encouraged to speak freely, and with the support of the interview guide, research topics of interest were covered. Interviews were digitally recorded, and both interviews and field notes were transcribed.

Research was conducted in Spanish. Translation into English for the purpose of writing a manuscript for publication was carried out by a Spanish psychiatrist speaking fluent in English and an epidemiology student English speaker fluent in Spanish and accustomed to the Spanish of Mexico City.

**Table 1.** Characteristics of Participants.<sup>a</sup>

ID	Age	Scholarship	Current occupation	Additional information
Mrs. G	60 years old	Completed middle school	Home printing	Born in the state of Hidalgo, at the time of the interview, married. Aside from being the only person devoted to housework in her home, she worked in the printing shop that her husband began 15 years ago, which allowed her to cover basic needs of her family. She described herself as a “fighter” and committed to the well-being of her children.
Mrs. M	37 years old	Trade school degree in automotive engineering	Home sales	Born in Mexico City, at the start of the study she was married, but soon after she divorced her husband, so she had to move to live in her parents’ house, where other siblings of her also live with their respective families. Even though she finished a technical degree, she never worked, due to forming a family. During the interview, she said that she took care of the house and had a local printing and gift business in a market. Her life objective was to give her family a life different than her own.
Mrs. A	42 years old	Completed middle school	Home sales	Born in the State of Mexico and separated from her partner 3 years before the study. She was the head of her family and sells clothes in markets in Mexico City, an activity which she said allows her to cover the needs of the house, clothing, food, health, and education for her children, and also allowed her to spend time with them. She referred to herself as a brave person who can solve any problem.
Mrs. L	52 years old	Trade school degree for secretarial work	Home	She worked at home since she started her family, although she went to trade school to become a secretary. Born in the state of Veracruz, she described herself as a sensible person dedicated to her family.

<sup>a</sup>All the participants lived in Mexico City and one of them in the State of Mexico. Their houses were located in neighborhoods of medium and low socioeconomic level, where the homes tend to be overcrowded and in which, on many occasions, several families live on the same property.

## Analysis

Once all the material was transcribed, it was organized and analyzed using the technique of “meaning categorization (36),” it means that the information was coded into mutually exclusive categories to facilitate its organization and analysis. This procedure is both deductive and inductive. All researchers (note 1) independently performed the analysis of each category, and then the findings were discussed to reach a consensus. When constructing the interview guide, a priori categories were established based on what was established in the literature on the subject studied. The initial analysis was carried out on the categories established a priori, but during the analysis process, emerging categories were found and others were also modified or eliminated. In this study, the following categories were used in the final analysis: (a) Perception of family dynamic and structure; (b) Perception of depression; and (c) Perception of herself as a caregiver. All the researchers analyzed each transcription independently and then they discussed the categories to reach consensus.

## Results

Participants were 4 IPCs from undergraduate medical students diagnosed with mild MDD. All of the participants were women, mothers of the patients, with ages ranging from 37 to 60 years old at the time of the interview. More details about the participating IPCs can be found in Table 1.

Next, the analysis categories will be described. Some testimonies that exemplify the dimensions of these categories are found in Table 2.

In order to understand the foundation of the IPCs of the medical students who attend clinical care, the first category analyzed the information obtained about the dynamic and structure of the participant families.

### Category 1: My Family Life

The analysis of the family dynamic and structure made possible the visualization of the motherly role of the women, of whom the majority were also the heads of their household.

According to Estrada (37), the families of the interviewees were in the stage of the family life cycle of adolescence, with traits of economic and emotional dependence on the heads of the family. The university school activity of undergraduate medical school requires a full-time commitment, and therefore, the hierarchy was exerted by the paternal subsystem, which established a rigid behavior control due to the process of adaptation to the patient’s age and the presence of the psychiatric diagnosis.

In general, the boundaries of the family structures seemed clearly defined. Alliances and coalitions within the family were exacerbated due to the presence of MDD. This is because the presence of an illness such as depression activates the psychological resources of individuals, and previously dysfunctional family attitudes and behaviors can

**Table 2.** Some Categories of Analysis and The Quotations That Exemplify Them.

Categories and their meaning	Examples of quotations
Category 1: My family life	<p>“At home the rules are very loose, my brothers and nephews do what they want. Some nephews of mine use drugs and nobody tells them anything. Those who set the rules, because they are the ones who pay almost everything here at home, are my parents, but since they are older, many times nobody cares what the grandparents indicate. Now that my son is sick and has abandoned activities at school, I have not told my parents that he is ill because it would be a great disappointment, they have all their hopes for him because he would be the only one in the family to study in University [ . . . ]” Mrs. M</p> <p>“[ . . . ] All my life I wanted to have a family to live, talk and trust, but the reality is very different, especially with teenage children. I admit it yes, we are very strict parents, there are rules and schedules at home because if not everything gets out of control. But sometimes with my daughter my husband and I, we did play or talk or go to the park together, but now I realize that with the depression she has, all of that is gone. Today we do not speak anymore, I do not know how to approach it or how to treat her [ . . . ]” Mrs. G</p>
Category 2: Depression, Illness or disease? <i>Perception of the concept of MDD</i>	<p>“[ . . . ] I kept labeling it as laziness or issues of her age [ . . . ]” Mrs. G</p> <p>“[ . . . ] I called it laziness because she did not want to get up, and when she got up, she did it reluctantly because she did not want to do it, but that’s how young people are! [ . . . ]” Mrs. L</p> <p>“[ . . . ] I know depression is an illness that has to be controlled [ . . . ] that they can hurt themselves, and when they say ‘major depression’, well I understand it as something more severe, more complicated, and it scares me [ . . . ]” Mrs. G</p>
Category 2: Depression, Illness or disease? <i>Subjective definition of depression</i>	<p>“[ . . . ] now I see it as a normal emotion of life, because when that happens it is something that you have to fix, it’s urgent that you make something of your life, that’s how I understand the message [ . . . ]” Mrs. A</p> <p>“[ . . . ] I have listened a lot to a well-known psychiatrist on the radio . . . what can happen [with depressed patients], that they can commit suicide . . . I did think about the suicide of my daughter, and later I thought: What if she does go crazy? . . . and sometimes instead I thought that it would pass [ . . . ]” Mrs. L</p> <p>“[ . . . ] I began to realize that my daughter was depressed because when I heard a program, they said that there were physical changes, and for her, her hair began to fall out and she became very droopy, she always was very tired, and didn’t want to get up, and she lost her appetite [ . . . ]” Mrs. L</p>
Category 2: Depression, Illness or disease? <i>Normalization of MDD manifestations</i>	<p>“[ . . . ] now I see it as a normal emotion of life, because when that happens it is something that you have to fix, it’s urgent that you make something of your life, that’s how I understand the message, and one becomes accustomed [ . . . ]” Mrs. A</p>
Category 2: Depression, Illness or disease? <i>Perceived causes of MDD</i>	<p>“[ . . . ] I think I am the total culprit . . . because of the problems with her dad and because I had another relationship and she found out [ . . . ]” Mrs. M</p> <p>“[ . . . ] my daughter was aware of the problems between her dad and I, well when living here she noticed . . . Also, he [her husband] picked up the idea that whatever thing he wanted to say to me, he did it through her . . . because of that our daughter got sick [ . . . ]” Mrs. L</p> <p>“[ . . . ] when we arrived here to Mexico City . . . it was a complete change for her . . . coming from the State of Mexico to here was the last straw, in order for her to be how she is[.]” Mrs. G</p> <p>“[ . . . ] well I attributed it at first to her growing up, to the changes that children have when they grow up . . . that it was laziness . . . that she was doing badly because of her age, that she didn’t mature [ . . . ]” Mrs. G</p> <p>“[ . . . ] she had a boyfriend, and well, her boyfriend left her and she suffered a lot, and still suffers [ . . . ]” Mrs. M</p> <p>“[ . . . ] she always arrived from school in a bad mood, and she said: ‘my classmates know everything, and I don’t know anything . . . I realize that I’m dumb, taking a place that I don’t deserve, and so many who want to study here, I study and when I’m in school I don’t know anything . . . nothing’ [ . . . ]” Mrs. L</p> <p><i>Fears and concerns with respect to the MDD diagnosed in IPCs’ children:</i></p> <p>“[ . . . ] I’m afraid that she will hurt herself because I have read and hear that a lot of people, especially young people commit suicide, and they can have a crisis and not be able to get out of it [ . . . ] they can have crises and want to cut their veins like other people have done [ . . . ]” Mrs. G</p>

(continued)

**Table 2.** (continued)

Categories and their meaning	Examples of quotations
Category 2: Depression, Illness or disease? <i>Perceived impact of MDD</i>	<p>“[ . . . ] in illnesses one doesn’t know what is going to happen and that makes me very uncertain, it upsets me, it makes me worried, I don’t know what to say to her, how to talk to her, what to do [ . . . ]” Mrs. G</p> <p>“[ . . . ] right now my daughter is lost! . . . I don’t know what’s wrong, I don’t know what is going to happen to her, she doesn’t want anything, I don’t know what she wants in her life [ . . . ]” Mrs. M</p> <p>“[ . . . ] she stopped doing her activities, she went to play chess and she distracted herself, but now she doesn’t do anything here, she doesn’t even have friends [ . . . ]” Mrs. G</p> <p>“[ . . . ] before we spent time together and we played domino a bit or we went out for ice cream and used that to talk, but now, now, that doesn’t exist anymore [ . . . ]” Mrs. G</p> <p>“[ . . . ] my son has always been intelligent and always interested in studying, he ironed his clothes, organized everything a day before, but since the separation it isn’t like that anymore, he had problems in school, repeated a year and isolated himself [ . . . ]” Mrs. A</p>
Category 2: Depression, Illness or disease? <i>The chosen therapeutic alternatives for MDD</i>	<p>“[ . . . ] We told her to get help, exercise or do some activity, you need to move around and not be here cooped up in the house! [ . . . ]” Mrs. G</p> <p>“[ . . . ] I saw my daughter, her suffering, and I told her that she was going through a difficult situation and she had to find help here, at school, with her teachers because I didn’t know how to help her [ . . . ]” Mrs. G</p> <p>“[ . . . ] I took her to acupuncture, I spent a lot of money on a famous masseuse who is on TV, my daughter felt better but obviously the treatment didn’t resolve it because we are left without money and we never finished the treatment [ . . . ]” Mrs. M</p> <p>“[ . . . ] She hasn’t stopped taking her pills, we buy them, even though sometimes we don’t eat, but also I think that if she does something she likes or keeps herself occupied it would help, I’ve thought about taking her swimming, but the money is so difficult, I will see if she can get a grant [ . . . ]” Mrs. M</p> <p>“[ . . . ] before coming here, first I brought her to the pediatrician that she has seen since she was born, and he gave her vitamins, later she still was doing badly and I mentioned to my gynecologist so that she would check if it wasn’t something physical and when I talked to her she told us it was something with her emotions and she recommended a psychologist who told us that if she didn’t get immediate attention from a psychiatrist, my daughter was going to die, I was very distressed and after listening to this well-known psychiatrist on the radio immediately I told my husband that we needed to make an appointment with him . . . and well we only went once, but it helped my daughter a lot . . . and later we found out that this place existed and so here we are [ . . . ]” Mrs. L</p>
Category 3: Me, a Caregiver? <i>Assuming the role of caregiver</i>	<p>“[ . . . ] sometimes I tell myself I am not going to be so worried because later my husband gets irritated, he goes like ‘It is that you hallucinate . . . it’s your imagination!’ . . . I think I am overprotecting her . . . nagging her [ . . . ]” Mrs. L</p> <p>“[ . . . ] I don’t understand what’s happening to her, but I’m afraid and in order to know what is happening, it’s better that I let her do what she wants [ . . . ]” Mrs. G</p> <p>“[ . . . ] I’m the only person my girl can talk to, because my parents don’t know what’s going on with her and she doesn’t get along with her dad, so if she wants to come here so they can treat her, well I bring her, if she doesn’t want to come, then we don’t come, if she wants money to go out, I give it to her, I look for where it can come from, if she doesn’t want to go out I stay with her . . . if she cries, well I cry with her [ . . . ]” Mrs. M</p>
Category 3: Me, a Caregiver? <i>Perceived impact of being the caregiver</i>	<p>“[ . . . ] I have asked God to give me the strength I need but, well, it’s a little complicated because life, everyone’s activities have changed, now I have to work and support everything and sometimes my head hurts, I want to cry, I get cold, I get hot, I break down and I have to put up with it because I am the mom, I am the core . . . [ . . . ]” Mrs. A</p> <p>“[ . . . ] I can’t find the words to say it, to explain it, seeing all my family, like that . . . it is very difficult, I even have to pretend that nothing is happening in front of everyone else, it’s very taxing for me [ . . . ]” Mrs. A</p> <p>“[ . . . ] I started drinking alcohol, and I felt good because I think it made me less hungry, and above all, it let me not think about my daughter’s illness [ . . . ]” Mrs. L</p>

(continued)

**Table 2.** (continued)

Categories and their meaning	Examples of quotations
Category 3: Me, a Caregiver? <i>Their own perceived needs (as IPC and mother)</i>	“[ . . . ] I love my son a lot and I feel bad for sometimes not knowing what to do. I don't know how to deal with what he lives with, I want to know what to do to help him. I need him to follow his dream and I have every intention in the world to help him, but sometimes I don't know how, and that's why I think that it's important that you guys as professionals create a space where you teach us, and we as mothers commit to becoming better, and above all, support our children with this depression [ . . . ]” Mrs. A “[ . . . ] now that I am sharing how I have felt about my daughter's depression, I realize that I need to know more about how to help her and how to learn to become a better mother and a better human being, therefore you guys as professionals, by doing this type of interview, you help us understand ourselves better and know what we need [ . . . ]” Mrs. L
Category 3: Me, a Caregiver? <i>The lack of information as a factor that increases the negative impact of the caregiver's experience</i>	“[ . . . ] it makes me angry that she shuts herself in and I don't know what to do [ . . . ]” Mrs. G “[ . . . ] Sometimes I feel very lonely, seeing my son like that makes me sad, but understanding that it's an illness encourages me, I want to fight, to keep going, to believe that everything is going to be better and that what I decided about his treatment has been the best I could have. I'm afraid, but . . . but now I say: Okay, here we go, working, here we go to see what can be done because we have to survive [ . . . ]” Mrs. A

Abbreviations: MDD, major depressive disorder; IPC, informal primary caregiver.

become more rigid. From the perspective of the IPCs, the roles exercised by the majority of the family members are accepted and filled, however, are not flexible. Regarding the family dynamic of the interviewed IPCs, it can be concluded that difficulties existed in expressing positive and negative feelings in an adequate and direct manner, due to cultural patterns and their own upbringing.

It could be observed that the patients were central to the life of the IPCs. They defined their children, the patients, as their “precious treasure,” which is correlated with the function of the psychological protection expected from the mother when children still are emotionally dependent.

The obtained information provided elements which can be used to diagnose that the code of conduct, which prevailed in the parents, occasionally became difficult because of the adaptation process related to the patient's stage of their life cycle as well as the features of MDD. Thus, the primary impact of the presence of this pathology in the family dynamic occurs in daily coexistence. Every day, patients and family members cope with feelings of unrest such as fear, frustration, and anger in the face of a psychiatric disorder such depression. The next category aimed an understanding of how the IPCs experience the MDD in their children.

### **Category 2: Depression, Illness, or Disease?**

The appearance of a disease is an event that impacts the life and function of patients and their surrounding world, in the face of this each individual constructs different meanings.

One form of addressing perceptions about the process of an illness is through the explanatory model of illness (EMI) (38), which defines a person's conceptions about their illness, the attributed causes, and their symptoms, which are interpreted as practical decisions in order to attend to or cure the illness. In this sense, the IPC, as the family member who is available to meet the needs of the patient and is responsible for making decisions in the diagnosis and treatment of the illness, deserves a separate examination of the meaning of depression in their family member.

During the investigation into the EMIs, the perception of symptoms, the concept of depression, the illness origins, the fears around the illness, and the impact attributed to the illness were explored.

The initial depressive symptoms that the IPCs detected in their children were in regard to changes in their behavior (irritability, social isolation, lack of motivation) and modifications in their daily activities (abandonment of their hobbies or failure to fulfill obligations), aspects that were not considered out of the expected. In the words of the participants, their perception of the patients' manifestations was it was laziness, and that they were related to their stage of the life cycle. And although, during the interview, they were able to recognize indicators (somatic discomfort, lack of energy, disturbances in attention and concentration, disturbances in sleep, school failure) that could have suggested a problem beyond everyday discomfort, the interviewees acknowledge that, at the time, they failed to recognize that they were part of a mental illness. Informal primary caregivers normalized the manifestations of the patients, instead of considering them part of a disease.

Although in defining the medical diagnosis of depression, the participants said that MDD is a disease that can be serious and that people who have it can harm themselves, they also recognized that this image did not resemble what was observed in their own children. This disparity was a reflection of their knowledge of MDD (obtained largely through mass media) and of their sociocultural context. In Mexican society, as it happens in many others, mental illnesses tend to be considered as the product of a weak character, so they are not thought to be a disease in itself but a manifestation of the way of being. Furthermore, the media show that psychiatric conditions are only present if there are psychotic symptoms, suicide attempts or violence (39,40).

Regarding the perceived causes, as related by the IPCs, they can be grouped into 2 major divisions, specifically: *Personal Experiences* that include attributions of the stage of life cycle of the patient, academic failures, and emotional breakups, and *Family experiences*, including marital conflicts between the parents of the patient and changes in the family dynamic. It is worth mentioning that this second attribution generated feelings of guilt in the interviewees, who felt responsible for the consequences of witnessed family problems.

The fears and concerns that the IPCs have with respect to the MDD diagnosed in their children, they were predominated by the unease regarding the possibility that their children could be harming themselves. The participants emphasized their uncertainty about the evolution of MDD and appropriate actions around the patient. Interviewed mothers were also concerned that their children could not complete projects in their personal and professional life.

The therapeutic alternatives that patients and their families opted for were as diverse as the pathologies themselves and reflected the form in which both patient and family perceived depression. Most centered around self-care practices, since going to some type of specialized mental health treatment is considered somewhat shameful because it indicates that "you are crazy."

Due to the importance of the IPC as a key element in the diagnosis, treatment, and evolution of MDD, the third category was titled: *Me, a Caregiver?*, looking to understand from the interviewee's own voice their needs and experience as both IPCs and mothers of medical students diagnosed with depression.

### Category 3: *Me, a Caregiver?*

All the IPCs agreed on their acknowledgement as the primary providers of emotional support for the patients. The inability to differentiate between the role of mother and caregiver was evident, leading to overprotection of the patient and preventing them from taking responsibility for their own treatment.

It is important to point out that some IPCs mentioned that not knowing detailed clinical information about depression impacted how they lived with their children's illness and

how they made decisions since they behaved as mothers and not as caregivers of a patient.

Interviewees said that the greatest impact that they perceived in themselves was emotional exhaustion, which diminished their quality of life. A lack of knowledge of the underlying health problem and a reliance on only their observations of their children's mood and behavior added to the IPCs believing the patients could change themselves, generated in the interviewees anger, frustration, despair, helplessness, and mood swings that led to consequences such as increased family dysfunction, alcohol consumption, and financial problems.

## Discussion

Family is the first group to which a human being belongs, and there one learns and comprehends the values and social norms that allows individuals to live in other spaces. Through daily interaction, a person has with their family members, they internally forge the way they understand the world and develop skills to cope with daily experiences. This occurs so that when they encounter difficulty, they try to find a way to explain why it is happening to them, in order to make decisions to confront the adversity. Vargas-Melgarejo (41) defined this individual learning process as perception, which is constantly modified according to time and place in the world.

When an illness creates this adversity, EMIs are constructed, and traditionally, family is the space in which care and attention are provided in order to restore health, with this responsibility falling on the IPC who is responsible for meeting the needs of the patient (17).

A discovery that emerged from the IPC's perceptions of medical students with respect to their family system was their sense of belonging. This was explained by Quintero (42), who showed that the family is a space in which one learns to socialize, build confidence, and show affection, no matter the organization or characteristics of the interpersonal interaction.

Within the family, women continue to be the central figure tasked with meeting fundamental and emotional needs, even when they had joined the professional workforce, making them work a double shift. Historically, the care of an ill family member has been considered the role of the woman because she is the person who takes on a commitment, whether due to moral values, personal circumstances such as the effect on that family member, or simply due to the sociocultural context that has determined that the woman is responsible for the physical and mental health of the family, and in this way creating a feminization of care (43–45).

The collected testimonies of the interviewees coincide with the results of other studies, in that they characterize the IPC as a female who voluntarily decides to assume the care of the ill family member (17,19,28). Nonetheless, based on the results, it is valid to question whether the role of the caregiver that these mothers fulfill is really voluntary or simply they fulfill this role due to social conditions.

Care involves the development of diverse activities and frequently implies multiple caregiving roles, which is to say, being a caregiver as well as a mother, wife, daughter, and/or member of the workforce (46). Based on this “multi-role” experience expressed by the interviewees, one notices that they found themselves in constant stress which eroded their mental and physical state. This erosion created feelings of distress such as frustration due to, from their point of view, not adequately fulfilling the role of mother and caregiver, even when they do not differentiate between one role and the other.

Physical fatigue, crying, sadness, frustration, consumption of alcohol, anxiety, isolation, and economic problems were all detected in participants. Together, these are known in the literature as primary caregiver syndrome because they present a symptom picture that reflects the objective and subjective burden that they face while in this role (17–19).

Based on the above, it is necessary to analyze whether the effects on physical and mental health are caused by the depression of their children or whether they are an effect of their own personal situation. To answer this question, it is important to note that, according to the general system theory (47–53), the family system is made of human beings in constant interaction, in such a way that an action or change in one member, impacts everyone else, and vice versa. Nonetheless, it cannot be looked over that human beings are individuals with biological characteristics and particular psychologies, and therefore, the presence of depression in the children of the interviewees was a turning point in exacerbating the symptoms already present in the IPC (54).

Regarding the EMIs that the interviewees held with respect to MDD, the results suggest they were formed mainly due to information received from informal sources, such as mass media, acquaintances and family, and influences from the surrounding context. These perceptions are expected if we consider the human being as a social entity that is part of a group, so that the primary meanings about events such as disease arise initially as the result of this social interaction (55–57). There are various aspects that have been described as influencing the perception of mental illness in Latin America. Gender, educational level, and social security seem to favor a perception toward biological and medical aspects, but for pathologies such as depression, there is a generalized idea that it is due to the way of being of the affected person or to an emotional reaction product of external stressors but not necessarily to a pathology (58). These predominant EMIs in the social environment, largely determine the attributions that each subject makes toward the disease.

Coinciding with other studies, difficulties in the family dynamics of university students with depression can impact the evolution of the disorder (7,59,60). In this specific population, one of the most evident indicators is low academic performance. At this point, it is valid to reflect if the signs and symptoms of depression that manifest in the children of the IPCs were exacerbated particularly by studying medicine or whether these

conditions were already present in their family interaction, and put into context by the experiences of each IPC.

The manifestations of depression of the children of the participants of this study were normalized, which suggests that the students had symptoms that were neither identified nor treated. Likewise, the interviewees did not notice their own risk factors for the presentation of emotional distress, factors coming within the individual (for both patients and caregivers), and social impact that was mentioned during the interviews. Consequently, the perceptions acquired through the experiences of these mothers reflects the need to implement contextualized programs of alphabetization and intervention that provide the necessary tools to face the physical, emotional, and interpersonal consequences involved in fulfilling the role of caregiver. The lack of knowledge about what is happening to their children and the perception generated around the situation caused a delayed search for the patients care. In addition, it caused the IPCs to experience feelings of distress about the disorder, themselves, and even their children.

The wear on the caregiver does not favor a better outcome in the patient either. Other studies have highlighted the need to design convenient and effective strategies to provide support and stability to the IPCs of patients with a psychiatric disorder (13,54).

Stigma may have been one of the factors that influenced the perception and attitudes that these IPCs developed toward their children’s depression. This stigma may have resulted in the reluctance to recognize something more serious than an everyday discomfort in the affected person and the avoidance of a specialized search. In families where a member has been diagnosed with a psychiatric disorder, Muñoz et al (61) says that 2 types of stigma can occur: (a) public stigma, that can be transferred from the patient to their whole family, or alternatively, they can experience the stigma through observation when they see the stigmatization of their family member; and (b) self-stigma, in which the family internalizes the messages (originating from society in general, from professionals, and other members of the family) regarding their responsibility for the illness, which consequently generates feelings of guilt. Both types of stigma result in complicated health care pathways that delayed prompt care. For future research, it would be important to intentionally investigate this component as part of the meanings that are built around depression in key factors such as caregivers.

Although this research provides information on the perception and experiences of depression in a specific actor (patient caregiver), thus contributing to the understanding of this disorder, there are limitations linked to the specificity of the studied population. For example, it is unknown if the perceptions are similar in other family members, if the IPCs of students from other areas are different, or how the perception changes once patients receive treatment and depression is controlled. The health-disease process is interactional, so it would be important to analyze whether perceptions are shared between IPC, patient, and health personnel.



The lack of a larger number of interviewees could be considered by some readers as a limitation; however, it is worth noting that, unlike random sampling, the invitation to participate in qualitative research follows very different principles where participants have specific characteristics for which they are selected since they can offer in-depth and detailed information on the topic of interest for research. Therefore, even a single individual could be the subject of a complete study; hence, the size of the sample is not in itself a limitation in this research.

## Conclusion

Findings show that depression, on one hand, is seen as a shocking factor in the life of the patient as well as the life of the IPC, but on the other hand, it is experienced as an opportunity to strengthen their family bond and even to grow personally. It is reinforced that psychiatric disorders, such as MDD, strongly impact the people around patients, particularly figures such as the IPC. This compels health care personnel to explore the illness perception of all the involved actors (including IPCs) of the health illness process in order to have an effective clinical approach which results in the welfare of the patient.

## Authors' Note

Olga Robelo-Zarza and Ingrid Vargas-Huicochea contributed in all parts of the research process and manuscript preparation. Nora Kelsall and Ana Rodríguez-Machain have contributed in the data analysis and manuscript preparation. Ingrid Vargas-Huicochea and Nora Kelsall translated the manuscript into English. All the authors have agreed upon this version of the manuscript. Approval was given by the Ethics and Research committees of Universidad Autónoma de México (UNAM). Approval number: Reg. 147-2011.

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