RESEARCH

Caregivers experiences about elderly with type 2 diabetes mellitus during the COVID-19 pandemic

Experiencias en cuidadores de adultos mayores con diabetes mellitus tipo 2 durante la pandemia COVID-19

Vivências de cuidadores sobre idosos com diabetes mellitus tipo 2 durante a pandemia de COVID-19

Carlos Alberto Catalán-Gómez
http://orcid.org/0000-0002-9970-4272

Milton Carlos Guevara-Valtier
http://orcid.org/0000-0001-7291-3931

Leticia Reyna-Ávila
http://orcid.org/0000-0001-9862-4062

Velia Margarita Cárdenas-Villareal
http://orcid.org/0000-0001-9315-3193

María de los Ángeles Paz Morales
http://orcid.org/0000-0002-4111-8449


* Correspondence author: carlos_valtier7@hotmail.com

Received: 02/11/2020
Accepted: 15/12/2021
Abstract

Introduction: Currently, the presence of the COVID-19 pandemic has impacted the entire population, affecting patients with chronic diseases such as type 2 diabetes mellitus to a greater extent, which implies a greater burden for their main caregivers. Objective: Identify the experiences in caregivers of older adults with type 2 diabetes mellitus during the COVID-19 pandemic. Methodology: Qualitative descriptive study of a phenomenological type based on the lived experience and perceptions of seven caregivers over 18 years of age of patients with type 2 diabetes mellitus, a structured interview was applied in six dimensions, the data were analyzed with the statistical program Atlas Ti version 7.0, the study adhered to the provisions set forth by General Health Law on Health Research. Results: The caregivers reported being between 18 and 40 years old, mostly men, the length of care ranged from 1 to 20 years; regarding the handling of the information, they stated ignorance with respect to care, and regarding the negative experience in the care during pandemics. In this respect, caregivers perceived situations of stress and generation of strategies for coping with confinement, in the social environment stress and anxiety prevailed; regarding the feeling of satisfaction with care they mentioned being satisfied. Conclusion: A difficult, frustrating, awful, disturbing, scary, and exasperating experience was identified at the time of the COVID-19 pandemic, as well as lack of attention towards caregivers who were prone to suffering from an overload disorder.

Key words: Caregivers; COVID-19; Elderly Diabetes mellitus type 2 (DeCS).

Resumen

Introducción: En la actualidad la presencia de la pandemia por COVID-19 ha impactado en toda la población, afectando con mayor medida a las personas con enfermedades crónicas como la diabetes mellitus tipo 2, lo que implica una mayor carga para sus principales cuidadores. Objetivo: Identificar las experiencias en cuidadores de adultos mayores con diabetes mellitus tipo 2 durante la pandemia COVID-19. Metodología: Estudio cualitativo descriptivo de tipo fenomenológico fundamentado en la experiencia vivida y percepciones de siete cuidadores mayores de 18 años de pacientes con diabetes mellitus tipo 2, se aplicó entrevista estructurada en seis dimensiones, los datos se analizaron con el programa estadístico Atlas Ti versión 7.0, el estudio se apegó a lo establecido en la Ley General de Salud en Materia de Investigación para la Salud. Resultados: Los cuidadores reportaron tener una edad entre 18 y 40 años, en su mayoría hombres, la antigüedad de cuidado osciló entre 1 a 20 años, en cuanto al manejo de la información manifestaron desconocimiento hacia los cuidados, respecto a la experiencia negativa en el cuidado en tiempos de pandemia los cuidadores percibieron situaciones de estrés y generación de estrategias para el afrontamiento ante el confinamiento, en el entorno social prevaleció el estrés y ansiedad, respecto al sentimiento de satisfacción con el cuidado mencionaron estar satisfechos. Conclusión: Se identificó una experiencia difícil, frustrante, horrible, inquietante, terrible y desesperante en época de la pandemia por COVID-19, además existió falta de atención hacia los cuidadores quienes son propensos a sufrir algún trastorno por sobrecarga.

Palabras clave: Cuidadores; COVID-19; Adulto mayor; Diabetes mellitus tipo 2 (DeCS).
Abstrato

Introdução: Atualmente, a presença da pandemia de COVID-19 tem impactado toda a população, afetando em maior medida os portadores de doenças crônicas como o diabetes mellitus tipo 2, o que implica em maior sobrecarga para seus principais cuidadores. Objetivo: Identificar as experiências de cuidadores de idosos com diabetes mellitus tipo 2 durante a pandemia de COVID-19. Metodologia: Estudo qualitativo descritivo do tipo fenomenológico baseado na vivência e percepções de sete cuidadores maiores de 18 anos de pacientes com diabetes mellitus tipo 2, foi aplicada uma entrevista estruturada em seis dimensões, os dados foram analisados com o programa estatístico Atlas Ti versão 7.0, o estudo atendeu ao disposto na Lei Geral de Saúde de Pesquisa em Saúde. Resultados: Os cuidadores referiram ter entre 18 e 40 anos, em sua maioria homens, o tempo de cuidado variou de 1 a 20 anos, quanto ao manejo das informações, manifestaram desconhecimento sobre o cuidado, quanto à experiência negativa no cuidado. Em momentos de pandemia, os cuidadores percebiam situações de estresse e geração de estratégias de enfrentamento ao confinamento, no meio social prevaleciam o estresse e a ansiedade, no que se refere ao sentimento de satisfação com o cuidado que referiram estar satisfeitos. Conclusões: Foi identificada uma experiência difícil, frustrante, terrível, perturbadora, assustadora e exasperante no momento da pandemia de COVID-19, bem como a falta de atenção aos cuidadores propensos a sofrer de um transtorno de sobrecarga.

Palavras-chave: Cuidadores; COVID-19; Idoso; Diabetes mellitus tipo 2 (DeCS).

Introduction

In 2017, the World Health Organization (WHO) estimated that the proportion of adults over 60 years of age will double from 605 million to 2000 million by 2050 (1). Aging as a result of demographic transformation has become a public health problem. Therefore, older people are more prone to develop functional disorders such as loss of autonomy, adaptability and motor dysfunction, a consequence of multiple health problems that affect them (2,3). Currently, in the presence of the COVID-19 pandemic, health systems face a massive burden of care for people infected by this virus, which puts at risk the follow-up given to people with chronic pathologies. In addition, the health measures imposed by the government to remain in confinement limit the care of people with type 2 diabetes mellitus (T2DM), thus generating conditioning and logistical difficulties to provide care at home. This condition causes the elderly to be dependent on care provided by informal caregivers (4).
The care of a person with T2DM mainly falls on family members, who most of the time do not have the skills required to provide proper care, despite this they assume the responsibility by committing to perform the activities for a long period of time \(^{(5, 6)}\). These activities have an impact on the caregiver’s health, as they assume care of minimal complexity, but on many occasions they also provide care of greater complexity, which requires follow-up or close monitoring, such as the administration of medications, including insulin, which implies dependence or loss of autonomy on the part of the caregiver \(^{(7, 8)}\).

The caregiver fulfills various roles in the family, invests time and resources in carrying out the various actions for the care of the person, becoming an essential element that favors autonomy and satisfies the needs of care \(^{(9, 10)}\). It is currently recognized that caregiving is an important element for caregivers, since they are very prone to manifest disorders in their physical and mental health caused by the overload of activities \(^{(11)}\).

To date, no studies have been found that report the experiences or opinions of this population group during the COVID-19 pandemic, so the results will allow us to acquire relevant information. The aim of the study was to identify the experiences of caregivers of elderly adults with T2DM during the COVID-19 pandemic.

**Methodology**

Qualitative research that allowed understanding the phenomenon being lived in terms of the experience and perceptions of caregivers of people with a chronic disease such as T2DM. The study was supported by Martin Heidegger’s concept of phenomenology since it seeks, without prejudice or theories, to investigate, understand and interpret the being and/or person as a concrete experience and as a conscious subject \(^{(12, 13)}\). The study was carried out with the participation of seven caregivers selected by convenience and contacted through family members and acquaintances referred by them; caregivers over 18 years of age residing in Chilpancingo, Guerrero, Mexico, who reported being in charge of the care of elderly persons with T2DM and who agreed to participate voluntarily, participated in the study. Data collection was carried out by means of a data questionnaire that was collected by the interviewer and a structured interview comprising
six open-ended questions was conducted by telephone due to the confinement, lasting approximately 30 to 40 minutes and with prior informed consent.

In order to maintain the confidentiality of the participants, a code was assigned that was used in the transcriptions and in the corresponding results. The interviews were recorded and transcribed verbatim in Word format, added and analyzed in the program Atlas Ti version 7.0. The qualitative analysis of the data was developed by constructing an inductive taxonomy of the findings by reducing the descriptor codes to nominals and these in turn to categories by means of content analysis techniques. The content of the transcripts was presented in the form of clippings in order to respond to the main categories. The main dimensions were identified and the data analysis by categories was executed. The main themes identified were: a) Lack of knowledge and information management, b) Negative experience of caregiving in times of pandemic, c) Concern about confinement in the face of pandemic, d) Lifestyle changes during pandemic, e) Mental disorders in caregivers, and f) Feelings of satisfaction in caregiving.

The study adhered to the provisions set forth by the General Health Law on Health Research, which establishes the guidelines and general principles that all scientific research involving human beings must follow and establishes the ethical guidelines for the development of research in the area of health, in order to guarantee human dignity, the rights and well-being of the individual (14).

**Results**

Seven interviews were conducted with caregivers of persons with T2DM, identifying a higher prevalence in males 57.1% and only 42.9% in females, 57.1% reported ages between 31 and 40 years and 42.9% were between 18 and 30 years old, in relation to schooling 42.9% studied high school and secondary school respectively and only 14.3% studied elementary school. In relation to schooling, 42.9% studied high school and junior high school respectively and only 14.3% studied elementary school, 57.1% of the people had been with T2DM for 1 to 10 years, 57.1% of the caregivers reported having cared for people with T2DM for
1 to 10 years, in relation to the role they had with the sick person, 57.1% reported being a son or daughter (Table 1).

a) Insufficient knowledge and handling of information

Most of the caregivers do not know biomedical information regarding the treatment of T2DM, only two of them have knowledge based on the experience of caring for people with this condition. Likewise, the information management reported for gathering knowledge is based on the use of social networks, Internet, television and friends. They recognize the importance of receiving support for the development of their caregiving activities through statements “How could they take better care of him than I do” and “I feel I should do more than what he does for my relative”, “I do not know the complications, but I do try to inform myself so as not to carry out activities that instead of benefiting harm my mom”, “...I do not know what is happening in the city and everything is as before in care”, ”...I also read information on the internet...”, ”I don't have any, I rely on videos I find on networks or YouTube...”, ”I don't know any information, they just tell me in writing what I have to do...”, ”...I keep an eye on TV and radio to see if they give us information...”, ”A little, I usually do research with family and friends...”, ”...I do keep up to date on the networks, but they don't give information to us as caregivers and it is a bit worrying because I do not know if special care is given or if we continue doing the same things...”.

b) Care experience during confinement

The COVID-19 pandemic has caused caregivers stressful situations, but at the same time has generated strategies for coping with confinement, not only for personal reasons but also because they are responsible for a person who demands their care. All caregivers reported having “difficult, frustrating, awful, disturbing, scary and desperate” experience in this time of the pandemic, with expressions such as: “Disturbing, outside the cases are increasing and in addition to that, being in charge of someone with T2DM...”, “Awful, not knowing what care to give to my dad was already something worrying...”, ”People with T2DM are the most affected by COVID-19, it worries me a lot...”, ”Scary, she is the only one who gives me strength, I am already fed up with
the confinement...”, “Desperate, I am not complaining about the care, but I am desperate about the confinement...”, “Horrible, I would like to be somewhere else for a while, of course with my sister...”, “Frustrating to a great extent since I can't go out...”, and “Difficult, sometimes I want to give up...”.

Table 1. Sociodemographic data of the seven interviewed caregivers, 2020, n=7.

<table>
<thead>
<tr>
<th>Category</th>
<th>f</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>42.9</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30 years</td>
<td>3</td>
<td>42.9</td>
</tr>
<tr>
<td>21-40 years</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>Schooling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>1</td>
<td>14.3</td>
</tr>
<tr>
<td>Middle School</td>
<td>3</td>
<td>42.9</td>
</tr>
<tr>
<td>High School</td>
<td>3</td>
<td>42.9</td>
</tr>
<tr>
<td>Time with T2DM of the user</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-10 years</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>11-20 years</td>
<td>2</td>
<td>28.6</td>
</tr>
<tr>
<td>21-30 years</td>
<td>1</td>
<td>14.3</td>
</tr>
<tr>
<td>Length of time in care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 10 years</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>11 – 20 years</td>
<td>3</td>
<td>42.9</td>
</tr>
<tr>
<td>Caregiver's role</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Son/Daughter</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>Brother/Sister</td>
<td>2</td>
<td>28.6</td>
</tr>
<tr>
<td>Other person</td>
<td>1</td>
<td>14.3</td>
</tr>
</tbody>
</table>

Source: Own Development

The content analysis of the data acquired through the structured interview led to the identification of 6 categories.

c) Concern during Pandemic Confinement

COVID-19 is considered a new psychological illness because it triggers worries, fear and anxiety, and even generates a sense of overwhelm in caregivers: “Yes...I think that being locked up is something we have to adapt to and we did not foresee it, but we have to get used to it, let's see if we do not go crazy”, "Yes...I follow the instructions, sometimes I get desperate for being locked up.... ", "...I don't like having my little sister locked
up and she also gets desperate”, “Yes...they keep me locked up for fear that I might catch it and infect the family...”,”Yes...the uncertainty of knowing that at some point we might catch it...”, “...we have to be locked up, my sister and I have to stay locked up...”, “we have to be locked up, my sister gets desperate and worries me...”, “Yes...it makes us a little anxious to go out and “...Yes...I worry that it will affect her because of her condition”.

d) Care adaptation during the pandemic

All respondents stated that the time in confinement has affected them both in the social environment and in their lifestyle. The problems stated by caregivers are multiple, expressing that before the pandemic they invested much time in the care they provided and it was difficult for them to maintain proper lifestyles because they did not have the time. However, with the arrival of COVID-19 the lifestyle had to be changed generating in them an attitude of resignation to their new way of living and socializing. This was evidenced by the statement that: “Yes... because I have decided since before to modify the food in the house so that we adapt to the food that my mother can consume, at the beginning it was a little complicated, but now with the confinement we adapt to the food and to live together”, “Yes... a little because before I did not focus much on her....”, “Before I didn’t feel so heavy because I used to go out with her and we were distracted, now it is a little bit because she is one of those people who doesn’t like to be locked up...” and “Yes... I used to be free and live alone, before the confinement I was with the lady, but I had my sneaks, now we have to be in the same house and at the moment of interacting it gets a little complicated...”.

e) Effect of confinement on caregivers.

Public health measures, such as social distancing, cause people to feel isolated and lonely, increasing the risk of stress and anxiety. In the present study, most of the caregivers interviewed showed stress and concern about confinement, as the caregivers stated: “...The fact of not being able to go out is already a factor that affects me a lot mentally and well it is not easy to take care of a person with T2DM...”, “...I think that later they will have to attend to us because of so much stress...”, “...It is something that stresses me out, I think that after
this I will have to attend therapies...", "...She is one of those people who does not like to be locked up and it makes me stressed...".

f) Sentiments voiced towards the confinement

Despite the demands of caregiving and the time involved, caregivers reported feeling satisfied, as evidenced by the following expressions: "Satisfaction, because by giving care I personally know that I am ensuring that it is as complete as possible...", "Rejoicing, incredible since my mom has always inspired me to be better and by being the one giving care to her and that through care I can prolong her health... "A lot of emotion, since my sister is for me someone very special and to know that so many years with the disease and to see her so well gives me a lot of emotion and satisfaction to know that I am taking good care of her", "Joy, just seeing her smile makes me full of life and that is why I keep myself updated to always try to give her the best care so she will be healthy and by my side", "Well, I feel happy since she has been so many years with the disease and to know that she is still healthy says that I am taking good care of her.... "I feel satisfied to know that despite not knowing so much about this disease I make an effort to take good care of her...", "I am pleased, what else I can say, she is my everything and knowing that I can support her and that we are together in everything...".

Assessing the responses it was identified that there is a difference between the groups of caregivers with respect to the time they had provided the care, the more experienced caregivers had "certain knowledge" regarding the care provided; however, with the increase of cases by COVID-19 they were concerned as were the less experienced caregivers, these resorted to people to acquire information, others opted to look for on the Internet to find answers to their doubts, which could be worrying because it is not known what they could have considered appropriate to apply to the person with T2DM.

The perceived experience of all the caregivers was one of stress, which may be influenced by the time they had been caring for the elderly; the elderly with more time with T2DM had more experienced caregivers and those with less time with the disease had younger caregivers; this last fact could refer to the stress mentioned by the caregivers, since they were young and did not visualize themselves with such a great responsibility
as caring for a sick elderly person. However, in spite of this, they all mentioned that they were happy with the work they performed.

**Discussion**

According to the objective of this study, caregivers mentioned limited or no knowledge about their disease, Scarton, et al. (15) identified that due to the stress generated in family members, the caregiver showed concern and psychological disorders in relation to the care of people with T2DM. In this regard, in a study (16) they identified that the process of adaptation to the disease was perceived as a complication in caregivers due to the care required by the person with T2DM, as well as to achieve health control. In addition, uncontrollable factors such as the pandemic affected this context, placing the caregiver as the main responsible for the health of the person, generating a greater demand on their psychosocial capacities (17).

Although the caregivers showed great psychological demands due to the large amount of time they invested, along with the fact that they did not have defense mechanisms against the stress that confinement generated in them, added to the concern about the fear of infecting themselves or the person with T2DM with the coronavirus, anyhow, they mentioned that living with more family members distracted them a little from the problems. Authors such as Baldwin, et al. (18) reported that when the care of the person with T2DM begins, the lifestyle is modified, adapting the family to the new situation and generating in them the search for solutions to compensate for the affectations in each member. It has been shown that caring for a family member with diabetes surrounded by relatives reduces stress levels in both the caregiver and the person. Navarro, et al. (19) found that living with other family members had positive effects on the medication behavior of people with diabetes, and also reduced stress, generating a change of mood in the caregiver.

In this study it was identified that less experienced caregivers turned to digital resources such as the Internet to resolve their doubts regarding the care they should provide to sick family members, in relation to this there is evidence (20) which shows that caregivers recognize the importance of the development of their activities for the improvement of their family members. They also mentioned that they would like to receive
support for the development of their activities since they did not know the care and did not receive training. In this regard, Cortés, et al. (2) reported that the interactions of caregivers with health professionals and the proportion of strategic resources for the management of a chronic condition can be an opportunity for the emotional support of caregivers, as well as for the search for solutions that could reduce the challenges they faced (21, 22). However, there was evidence that caregivers complained that once the pandemic began, the healthcare system was reconverted, attempting to solve emerging health problems, neglecting people with chronic diseases and their care became the direct responsibility of the caregiver (23). In addition to the above, the caregivers stated that on their own they looked for mechanisms to obtain information, including the Internet, this coincides with what was reported by Cántaro and Mayta-Tristán (24,25) who reported that the Internet can be used as an alternative by caregivers of people with diabetes, and by the sick people themselves in both the dissemination and control of their disease.

The caregivers stated that although at times they felt frustrated, they looked for alternatives to improve their care and the fact of seeing their relatives improve made them forget their frustration, they were certain that no one cared for them better than they did, in accordance with Fajardo, et al, (20) who showed that caregivers considered that their family member depended a lot on them, but they viewed it in a positive way since they considered that they were the people they could trust the most, due to the affection they showed them, which allowed them to provide more and better care than they should (26).

**Conclusions**

Based on the objective established regarding the identification of the experiences of caregivers of elderly adults with T2DM during the COVID-19 pandemic, the results allowed us to identify a difficult experience in the caregivers of the ill persons. However, in the face of adversities such as the confinement generated by the pandemic, they continued to provide care. It is important to point out the need to provide support to this population through workshops or sessions in which they are provided with knowledge and updates on the
care they should provide to patients with T2DM in their family environment. It is recommended to deepen the study phenomenon by considering the popular knowledge of caregivers of people with chronic diseases.

**Conflict of interest**

The authors stated that they have no conflicts of any kind.

**Financing**

This article did not receive any type of funding from any agency.

**Bibliographic References**

1. Organización Mundial de Salud. [Internet]. 2017 [cited 10 Oct 2020]. Available at: http://www.who.int/ageing/about/facts/es/


How to reference this article: Catalán-Gómez C, Guevara-Valtier M, Reyna-Ávila L, Cárdenas-Villarreal V, Paz-Morales M. Experiences in caregivers of elderly adults with type 2 diabetes mellitus during the COVID-19 pandemic. SANUS [Internet]. 2022 [cited dd mm aa];7:e245. Available from: DOI/Link