









RESEARCH ARTICLE

Patient experience in automated peritoneal dialysis with telemedicine monitoring during the COVID-19 pandemic in Mexico: Qualitative study

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Abstract

Aim: The aim of the study was to understand the experiences of patients on automated peritoneal dialysis (APD) during the period of confinement due to the COVID-19 pandemic.

Design: Qualitative exploratory study, phenomenological through semi-structured telephone interview.

Method: A priori sampling was carried out with patients on APD with remote monitoring and telephone follow-up, in 13 hospitals in Mexico.

Results: Twenty-nine informants, mean age 45.41 ± 16.93 ; 15 women and 14 men. The analysis revealed four categories of analysis: *home isolation*, *clinical follow-up*, *socioeconomic challenges* and *infodemic*. The experiences of these patients led them to somatize emotions, presenting symptoms such as anxiety, sadness, loneliness, sleep, eating and digestive disorders, situation that sets the tone for future research on telemedicine care models, coping styles, emotional support strategies and socioeconomic impact on patients with chronic home treatments during the pandemic.

KEYWORDS

CKD, confinement, COVID-19, depression, experiences

found. The sufficiency of the topic was achieved after the analysis of 20 interviews; however, all remaining interviews were checked for saturation.

2.5 | Ethical considerations of the study

Regarding ethical considerations and due to the COVID-19 pandemic, the participant was informed about the research project and informed consent was requested. Each was notified about the confidentiality of the study, in addition to the freedom to leave the interview at any time that he may need it. The anonymity of the participants was maintained, and the alphanumeric method was used for the handling and processing of the information. In addition, doubts generated were clarified, and said consent was authorized verbally. This study was approved by the Ethics and Clinic Investigations committee at "REDACTED".

2.6 | Rigour criteria

The credibility criterion was fulfilled, counteracting the perspective of the central researcher with the support of a qualitative researcher, managing to examine the qualitative nature of the data. In addition, the researchers discussed the responses and their own behaviour. In relation to the experience of the participants, the data were also triangulated by the researchers. With this, it was possible to build the central and subsequent themes, using textual transcriptions. Regarding the criterion of conformity, the interviews were recorded to later be transcribed verbatim. The characteristics of the informants, already mentioned above, were described.

3 | RESULTS

Twenty-nine patients were interviewed, with a mean age of 45.41 ± 16.93 ; 15 women and 14 men, and more than half were married 18 (62%). The main cause of CKD was diabetes (38%), followed by arterial hypertension (34%), and others (28%). In addition, it should be noted that most patients were self-sufficient (86%). The mean time on APD with RM was 696.55 ± 71.24 days (see Table 3).

Derived from the interviews, four categories of analysis were identified on the different experiences of the patients. In addition, it was possible to recognize physical and psychological symptoms that can have an impact on quality of life, as well as the need for care by a mental health specialist. The following categories were found:

3.1 | Home isolation

The patients reported that they distanced themselves from the family to avoid contagion from both sides. In some cases, it was the

TABLE 2 Main themes and subthemes

Theme	Subthemes
Home insolation	Manifestation of insolation Separation from loved ones Contagion from someone known Loss freedom
Clinical follow-up	Modification of routine health sources Afraid to go the hospital Telemedicine in APD with RM
Socioeconomic challenges	
Infodemic	Panic of getting infected Sceptics about the virus

relatives who chose to isolate the patient so as not to contribute to contagion. The isolation, the restriction to carry out many activities, even not wanting to talk to anyone to avoid contagion, led the patients to generate feelings of loneliness.

3.1.1 | Manifestation of isolation

For some participants, the isolation turned into incarceration, where the family decided that they would not go out for any reason. That interrupted daily activities, such as going for a walk or working.

Refraining from the activities they did daily led patients to show some signs of depression, anxiety, feelings of not wanting anything and not feeling useful. Some even reported lack of appetite and insomnia, which could be confused with uremic symptoms. However, throughout the interviews, the patients reported that they perceived these symptoms to be due to worries and fears derived from the risk of contagion, isolation and economic needs.

The new disease [...] makes me feel bad because it changed my life completely, now nor does it let me go out to the store. I feel as if I was in a jail, always doing the same thing, it gives me a lot of nerves and I feel very anxious because I cannot do anything. [...] I feel desperate, imprisoned, very angry, I do not want anyone to talk to me because it bothers me a lot

F6

[...] I am unemployed, I begged my boss not to fire me away, but he told me that he did not want to risk the company for me, that I could get infected, and the company was not going to be responsible. Now I do not know if he will hire me again. Sometimes I don't even sleep because of that anguish, of what is I'm going to do without money or work

Ñ15

TABLE 3 Demographic data of the 19 patients with RM in face COVID-19

Demographics data	Frequency (%)	Mean \pm DS
Age (year)		45.41 \pm 16.93
Gender		
Female	15 (52%)	
Male	14 (48%)	
Educational level		
No academic instruction	2 (7%)	
Primary School	7 (24%)	
Middle school	9 (31%)	
High School	7 (24%)	
Professional	4 (14%)	
Marital Status		
Single	11 (38%)	
Married	18 (62%)	
Primary disease type		
Diabetes Mellitus	11 (38%)	
Hypertension	10 (34%)	
Unknown	7 (24%)	
Renal Hypoplasia	1 (4%)	
Self-sufficiency		
Yes	25 (86%)	
No	4 (14%)	
Tracking time by remote monitoring (days)		696.55 \pm 71.24

3.1.2 | Separation from loved ones

The patients expressed feelings of loneliness, since their relatives preferred to keep their distance so as not to expose them to any risk.

Some patients chose not to seek their relatives to avoid inconvenience and worry. However, losing physical contact and family gatherings generated a feeling of loneliness, even abandonment, in the patients.

For some patients, the driving force to move forward and adhere to treatment is their family. The separation could predispose the symptoms of anxiety and depression.

The truth is that since the pandemic began, I have not seen most of my children because they work, and they always used to come to see me or came on weekends

B1

My family completely separated from me, I only see them on video calls, but it is not the same because when the video call ends, I am alone again. My grandchildren, who are the ones I miss the most, and thanks

to them, they made me want to get ahead, not to fall, but right now I feel alone

H8

Everyone goes to work, and I stay alone, I spend all my day sleeping, I spend it vomiting and with a lot of diarrhea. I feel like my children don't care about me anymore. I feel like they are already annoyed at me, but I try not to nag them

B29

3.1.3 | Contagion from someone known

Among the many feelings that patients face is that of the silence of the void left by those close to them who lost the battle against COVID-19. Inevitably, reflecting on losses is a reminder of the risk that contagion represents.

[...] "I can't get over my brother's death; I couldn't even go say goodbye to him because all my nephews were infected [...]"

L12

"[...] A covid nephew would pass by, and now I am sad because my son was infected with covid and I am afraid that something very ugly will happen to him"

Y26

I get nervous attacks every time I find out that an acquaintance or family member fails because of

Z27

I am very worried because my husband contracted COVID and is sick and I am very afraid that my children, my grandchildren and I will be infected. I have a lot fear that my husband will die because he is a bit delicate and he is the one who always takes care of me, and I want to go help him and take care of him, but my children will not let me.

E05

3.1.4 | Loss of freedom

Living through the pandemic was a challenging experience, changing routines, ways and means of relating and living together as a family. Confinement and social distancing, in every sense, generated a feeling of sadness, hopelessness and loss of freedom.

I feel trapped, caged, as if I were a caged bird [...]

Ñ15

reinforced, taking advantage of the patients' RM. This strategy made it possible to continue with the clinical follow-up of the patients, as well as to detect complications early and, in some cases, start outpatient treatment, without the need to go to the hospital.

[...] they take care of us and have us very closely watched to comply with our treatment correctly.

N14

[...] they check if my treatment is going well, or if I am having some alterations. In the same way, they realize when I have any complications with the machine or if I start to present some failures, and they also realize when I do not perform dialysis.

W24

[...] a great benefit that I have, is that if I have any problem regarding my dialysis, I no longer have to take the machine, nor go to the hospital is too far away for me or involves an expense. With the simple fact of notifying my nephrologist or the nurse, they come up with a solution for me.

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The doctor, when she detects a problem, always calls me and explains the situation or makes an appointment with me, so that she can assess me properly

O16

3.3 | "Socioeconomic challenges"

The concern about not having money generated feelings of guilt, anxiety and depression for considering themselves a burden for their relatives. It even led to poor adherence to the nutritional plan because they could not afford the cost of the diet. In more dramatic cases, some informants were left without a place to live, due to the inability to pay the rent and the landlord's misunderstanding.

[...] the pandemic hurt me a lot because I am a merchant and I don't sell much, sales dropped, sometimes I don't sell, and it makes me sad to see that my business went down, apart from the fact that I don't have the money for my food and my care [...]

C03

[...] they fired me from my job, I am unemployed, I begged my boss not to fire me, but he told me that he did not want to risk the company for me, that he could infect me and the company was not going to be responsible [...]

Ñ15

For example, the receipts for basic services arrive and there are some that we are not even able to pay because if we pay them, we no longer eat

R19

3.4 | Infodemic

One of the most harmful effects of the COVID-19 pandemic was undoubtedly the harmful spread of fake news through various sources such as social networks. Disinformation spread alarmingly around the world, generating excessive panic or systematically misinforming the population, which produced two extremes in the face of the pandemic. On the one hand, those patients who had excessive control and lived in panic. On the contrary, the population that argued that the pandemic was just an invention of the government.

3.4.1 | Panic of getting infected

Although we live in times when science and technology have been allied to address and stop the damage, the priceless and painful human losses were inevitable. In this context, panic has permeated, particularly among the communities of peritoneal dialysis patients, which are more vulnerable to contagion, due to the fragility of their immune system, as well as the need to go to the hospital for check-ups.

[...] I am so afraid of getting infected, it gives me such a panic that I don't even want to look out on the street [...]

U22

Day by day we get upset because there are always deaths and I am afraid that the virus will reach my house [...] in the news there are many cases of infections and deaths, that makes us very nervous, my daughter forbade me to watch television because always I was very nervous and worried about everyone

M13

3.4.2 | Sceptics about the virus

In some cases, patients preferred not to believe in SARS-CoV-2. They argued that it is a government lie. Or else that within hospitals, it was invented to end the life of a certain range of the population. These beliefs directly affected the prevention strategies to avoid getting infected. A few patients even stopped taking care of themselves, avoiding the use of face masks to demonstrate the absence of the virus.

The pandemic did not affect me much, because that is a lie, COVID does not exist, the government and you

invent it. You inject us with the virus to end our lives.
You kill them when they enter the hospital

I09

This does not exist and if it existed, I would have already been infected. I do not even use face mask, and nothing has happened to me [...] Apart, everything that they say in the news is totally false

P18

[...] apart from you entering the hospital with a headache, leg-ache or stomachache, and for everything they say that it is COVID, and they even leave the hospital dead [...] the government wants to disappear many because there are already millions of people in Mexico and they want to eliminate the poorest, and make the poverty disappear

T21

4 | DISCUSSION

The present study addresses a delicate topic, little explored and that provides new information, about the experience of patients on APD with RM, during confinement due to the COVID-19 pandemic.

Changes in patient behaviour were identified throughout the COVID-19 pandemic. It should be noted that the characteristics of the interviewed patients are very similar to those reported in the Mexican population on PD, as well as those reported by other scientific articles. Initially, patients reported feeling lucky to be on APD, because it allowed them to continue their activities of daily living. In addition, they could keep themselves safe, respecting with greater adherence the confinement measures to prevent contagion by COVID-19. Similarly, patients who required support from a caregiver reported feeling more comfortable on APD, since the demand for care is less.

However, patients reported that over time they began to experience higher levels of stress, anxiety, depression, confusion, frustration, helplessness and anger. They referred also to a perception of feeling imprisoned, alone and even abandoned, from home isolation. Similar results were reported in at least 15 studies, analysed in a systematic review and meta-analysis, focused on health personnel and the general population, mainly from China (Xiong et al., 2022). The significant psychological impact, characterized by poor sleep quality, stress, psychological discomfort, insomnia, post-traumatic stress symptoms, anxiety and depression, coincides despite the cultural, social and economic context of each country (Krishnamoorthy et al., 2020).

The origin of these feelings in patients is multifactorial. On the one hand, clinical factors such as the modification of clinical follow-up, the possibility of presenting complications of kidney disease or dialysis at home, and the risk of contagion that requires hospital care, in addition to the consequences when suffering from COVID-19, including death.

On the other hand, socioeconomic factors such as confinement, family separation, job loss and the infodemic entered. (Brooke & Clark, 2020; Department of Psychiatry NIMHANS, 2020; Madani et al., 2020; Mousing & Sørensen, 2021).

During the pandemic, patients have not only lost their freedom and company due to the risk of becoming infected, as they are more vulnerable than the general population. Also, they have had to experience the fear of losing a family member or acquaintance. Therefore, it is a constant reminder of the risk of contracting the virus.

These results agree with those found by Arantes De Oliveira Cardoso et al. (2020), where the real problem appears when they have disproportionate fear and anxiety, feeling in danger of contracting the disease. These emotions can manifest through insomnia, loss of attention, difficulty reasoning, tightness in the chest, etc.

In another order of ideas, the uncertainty due to the reorganization of clinical follow-up, the cancellation of face-to-face appointments and the fear of having to go to the hospital, contributed to generating a feeling of stress and anxiety. However, RM facilitated clinical follow-up through telemedicine. This situation meant a relief for the patients, because they were able to stay safe, with remote surveillance that allowed any complications to be detected in a timely manner, even to start an outpatient treatment without having to go to the dialysis centre.

In particular, the use of this technology stands out because in addition to the clinical advantages, it has shown regarding therapeutic adherence, early detection and outpatient management of complications, advantages have also been found in the timely recognition of psycho-emotional and social conditions, by serving as a two-way communication channel and support strategy during confinement. In this sense, our results are consistent with Walker et al. (2020), who point out that RM empowers patients and caregivers by increasing their knowledge and understanding of kidney disease and dialysis in Australia. Likewise, with Talbot et al. (2022), who show numerous potential benefits of RM, including greater patient confidence and safety and better supervision of treatment.

Most of the patients had the opportunity to express feelings of anxiety and uncertainty about the future of their disease through this tool. This is how RM of APD patients was useful to recognize feelings that can put the patient's health or adherence to treatment at risk. In addition, it can represent an opportunity, both for timely referral to a psychologist and to intervene with health education (El Shamy et al., 2020).

The results do not differ from other research, both quantitative and qualitative, given that the confinement generally affected the entire population, especially people with chronic diseases, since they are more vulnerable (Chan et al., 2021; Xiong et al., 2022).

Therefore, telemedicine and RM open up the possibility of reinforcing home therapy and reducing the risk of contagion, while maintaining confinement, in addition to influencing the mental health of these patients.

Undoubtedly, the socioeconomic challenges that have been faced during the pandemic have been decisive in the mood and mental health of people, particularly patients. These findings are

consistent with those shown by Khodabakhshi-Koolae (2020), who points out that the decrease in financial resources and household income affects the mental health of the population, especially self-employed workers. In addition, there is a converging economic concern with the data reported by Jamili et al. (2022), where patients showed emotions such as anxiety and nervousness about losing their jobs due to quarantine. This is because confinement paralysed the world economy. In Mexico, the government initially prohibited non-essential commercial activities, in order to maintain isolation. People could not leave the house, so they did not consume products or services. Therefore, those who offered services and products had no income to consume. This situation had a negative impact on sales and jobs were lost.

Although APD, being a home therapy and usually at night, allows the patient to maintain their activities of daily living, the risk of leaving the house deprived many of the patients of the possibility of continuing with their jobs or maintaining their business.

Over time, many people were forced to break home isolation, due to the need to generate income that would cover their basic needs.

This crisis had an impact on the health of patients, on the one hand the stress of not being able to meet their needs, on the other hand the difficult decision to go out and run the risk of getting infected.

Finally, the lack of knowledge about the new disease, the high mortality rate, as well as the spread of false and alarmist information, mainly through social networks, led patients to experience extreme situations.

On the one hand, we found patients who really lived in fear of becoming infected, even taking extreme prevention measures, such as exhaustive cleaning of the areas several times a day, constant disinfection of hands and body with antiseptic agents and alcohol gel, use of protection within the home or isolation from the rest of the family. This situation kept the patients feeling anxious, which manifested in the form of sleep disorders, eating disorders, digestion disorders, to name a few.

And on the other hand, there were the sceptical patients about the existence of the virus, who argued that the virus is an invention of the government, where even health personnel were involved in the deaths that were recorded in the COVID-19 care centres. An extremely alarming situation, because based on this belief, these patients commented that they did not carry out any security or contagion prevention protocol. They even argued that despite being vulnerable, absolutely nothing has happened to them, so they concluded that the virus does not exist.

Certainly, both situations are relevant for the health system. Therefore, it is necessary that when communicating with these patients, a comprehensive position must be adopted, without prejudice, based on empathy so that they accept reliable information. This, with the aim of reducing anxiety and panic about contagion and adopt the necessary and sufficient protection measures against COVID-19.

Thus, it is possible that interventions through home renal replacement therapy, with telemedicine and RM, not only reduce the

risk of complications inherent to peritoneal dialysis. Rather, they favour the prevention of contagion by COVID-19, while allowing the detection and intervention of mental health problems in patients, particularly in times of crisis, like this pandemic.

4.1 | Implications for health policy

This care model began to take strength in the digital era, but it was not until the start of the pandemic that it was adapted and refined massively and became a source for health centres.

Under this premise, it is necessary to integrate adaptation processes for new technologies, which merits a joint collaborative effort among the health sector, as well as the industry, for developing, perfecting and successfully implementing devices and platforms that allow the integration of novel users, who can benefit from the new alternatives being implemented.

However, accepting this transition depends in good measure on the cultural context and familiarity that exists with technological alternatives in society; in these cases, telemedicine is a tool that acts as a catalyzer in the process of care by optimizing processes, and results, as is the case in the present study for preventing COVID-19.

4.2 | Findings and limitations of the study

This study reflects the experiences of patients undergoing treatment with APD and RM, during the period of preventive confinement due to the COVID-19 pandemic. The situation sets the tone for future research on telemedicine care models, coping styles, emotional support strategies and socioeconomic impact on patients with chronic home treatments during the pandemic.

However, this study is limited by the fact that the interviews were conducted by telephone, a situation that allowed the interviewer to recover only the oral discourse. In addition, it is possible that the informants were exposed to some distraction.

5 | CONCLUSION

During the COVID-19 lockdown, patients' physical and psychological well-being were affected. Isolation, fear of contracting COVID-19, modification of routine care, as well as socioeconomic needs, led to feelings of anxiety, depression or irritability, which generated various physical manifestations, mainly sleep, eating and mood disorders.

However, the use of telemedicine was identified, not only as a clinical follow-up tool in patients with APD but also as an aid in the strategy of preventing the spread of COVID-19. By favouring confinement, the transfer to the hospital for control consultations is avoided. In addition, being a two-way communication channel, it allows the timely identification of psycho-emotional manifestations, which if not addressed, could compromise the success of the therapy.

AUTHOR CONTRIBUTIONS

MCB, MCR: Study design. IXC, MTV: Data collection. MCB, DPM, MTV: Data analysis. ARS, MRZ: Study supervision. MCB, DPM, MGP: Manuscript writing. RPS: Critical revisions for important intellectual content.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest regarding the research, authorship, or publication of this article.

ETHICAL STATEMENT

The study was presented and received approval from the National Committee for Scientific Research with Serial number: F-CNIC-2020-240 of the Mexican Social Security Institute (IMSS), which ruled it favorable as it did not involve risk to the participants after its review. The registration number is granted: R-2020-785-161.

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