

Adherence to treatment in children with Chronic Renal Failure: inclusion of the psychologist to the interdisciplinary team

Adherencia al tratamiento en infantes con insuficiencia renal crónica: inclusión del psicólogo al equipo interdisciplinario

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Abstract

Chronic Kidney Disease (CKD) is one of the main causes of mortality worldwide. In Mexico there are around 140,000 patients with this condition. The aim of this research was understand the factors that facilitate and inhibit the adherence to treatment of pediatric patients with CKD, with interdisciplinary approach and the inclusion of the psychologist to promote comprehensive patient care. A descriptive qualitative study was carried out by the interview technique with analysis by categories. Four professionals participated: a doctor, a nurse, a nutritionist and a psychologist of the Children's Hospital and of Galeno Hemodialysis Clinic in Morelia, Michoacán, Mexico. The results showed the importance of psychological support to the patient for the acceptance of the diagnosis, emotional management, adherence to treatment and social support, especially with their primary caregiver. Finally, a model of CKD patient care is proposed from an interdisciplinary approach.

Keywords: Adherence; Children; Chronic Renal Failure; Psychology.

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Resumen

La enfermedad renal crónica (ERC) constituye una de las principales causas de mortalidad a nivel mundial. Se calcula que en México existen alrededor de 140.000 pacientes con este padecimiento. El presente trabajo tuvo como objetivo comprender los factores que facilitan e inhiben la adherencia al tratamiento de los pacientes pediátricos con ERC, dando énfasis en el abordaje interdisciplinario y en la inclusión del/la psicólogo/a para favorecer la atención integral de los pacientes. Se realizó un estudio descriptivo de tipo cualitativo, por medio de la técnica de entrevista con análisis por categorías. Participaron cuatro profesionales: un médico, una enfermera, una nutrióloga y una psicóloga del Hospital Infantil y de la Clínica de Hemodiálisis Galeno en Morelia, Michoacán, México. Los resultados mostraron la importancia del acompañamiento psicológico al paciente para la aceptación del diagnóstico, el manejo emocional, la adherencia al tratamiento y apoyo social, en especial con su cuidador/a primario. Finalmente, se propone un modelo de atención al paciente con ERC desde un enfoque interdisciplinario.

Palabras clave: Adherencia; Infantes; Insuficiencia Renal Crónica; Psicología.

Introduction

According to the World Health Organization (WHO, 2017), one in 10 people worldwide has some kind of kidney damage. In Mexico, there are about 140,000 patients with renal failure (Fundrenal, 2017), and in 2015 13,300 deaths were reported due to this cause (Inegi, 2016).

Chronic kidney disease (CKD) progresses in five stages in which the patients generally becomes aware of the condition until they reaches the last stage and requires renal replacement treatments, which must be accompanied by a strict diet and liquid restriction, in addition to taking multiple medications.

However, the absence of symptoms and the complexity of the treatment make it difficult for many patients to follow medical indications, especially when it comes to changing habits and lifestyles (Contreras et al., 2006).

To promote adherence to treatment, the international guidelines for renal patient care point out the importance of an interdisciplinary approach that addresses the medical, psychological and nutritional aspects (KDIGO, 2013).

Interdisciplinary work in the health area

Until a few years ago, patient care was based on the biomedical model. Nowadays, the concept of health has changed to a biopsychosocial model that recognizes biological, psychological and social factors in the health-disease process. Hence the importance of providing comprehensive and interdisciplinary care (Alonso, 2004; Deacon, 2013).

However, psychological and interdisciplinary assistance in CKD in Mexico is difficult to achieve, given that the health system does not provide sufficient funds for its implementation, which is in addition to little or no hiring, especially for psychology professionals in health institutions. (García-Llana et al., 2010; Piña, 2004). Some of the consequences are: (1) the impossibility of integrating interdisciplinary teams with professionals who are sure of their function; (2) lack of knowledge on how to integrate the teams; and (3) salaries lower than their professional performance or hiring as clerks or

administrators when in reality they work as health professionals (Piña, 2004).

Patients with CKD receive psychological assessment until they are in the transplant protocol, in which risk factors, cognitive functioning and emotional state are evaluated to exclude a diagnosis of psychopathology in the transplant candidate patient or in his family. (Alcázar et al., 2001; Naqvi, 2015). In addition, it evaluates the capacity of adherence to treatment in order to achieve an adequate post-surgical evolution (Krauskopf, 2017).

This is why this study aims to understand the factors for adherence to treatment in pediatric patients with CKD. Emphasis is given to the interdisciplinary approach and the inclusion of the psychologist to favor comprehensive patient care. This will allow us to have the precise knowledge to design a psychological intervention proposal to serve this population.

Method

This is a qualitative descriptive study, using the interview technique, conducted in a hospital setting. For this purpose, four professionals from the “Eva Sámano de López Mateos” Children’s Hospital and from the Galeno Hemodialysis Clinic in Morelia, Michoacán (Mexico) participated in the study: a doctor specialized in pediatric nephrology, a nurse, a nutritionist specialized in renal nutrition and a psychologist, who also treat patients with other chronic pathologies.

As an instrument, an eight-question semi-structured interview was designed to determine the factors that

favor or inhibit adherence to treatment, as well as the perception of the need for interdisciplinary work in which the psychologist participates. The interview addressed the following topics: (1) work performed in the nephrology area; (2) factors that facilitate and hinder adherence to treatment; (3) incorporation of the psychologist into the interdisciplinary team; and (4) recommendations for improving patient treatment.

To conduct the interview, we sought the approval of the Ethics Committee of the Children’s Hospital at Morelia and the Chief of Pediatric Nephrology. After obtaining the data, professionals in charge of providing care to patients with CKD attending outpatients and inpatients were contacted. We had the authorization of each of them to conduct the interviews, after approval by the Ethics Committee of the Children’s Hospital as part of a proposal for psychological intervention in children with a diagnosis of CKD. Subsequently, a schedule was agreed for the interviews, which were analyzed by categories. The interviews were conducted during September 2019, lasting approximately 45 minutes each one and were applied by a health psychologist with experience working in a Pediatric Nephrology service.

Results

Four major categories were constructed from the transcription and analysis of the interviews with different subcategories presented in Table 1.

These categories are presented below along with the testimonies of the participants.

Table 1 – Categories and subcategories of analysis of interviews with health professionals

1. Characteristics of the nephrology area and interaction between health professionals	<ul style="list-style-type: none"> • Reasons for choosing this specialty • Functions and activities of health personnel
2. Factors involved in treatment adherence	<ul style="list-style-type: none"> • Elements that facilitate the adherence to treatment • Elements that hind the adherence to treatment
3. Incorporation of the psychologist in the Nephrology area.	<ul style="list-style-type: none"> • Emotional support in the pediatric patient • Coping strategies for coping with illness
4. Recommendations for a possible intervention	<ul style="list-style-type: none"> • Performing interdisciplinary work including Psychology personnel • Caring for the caregiver • Promoting self-care • Raising public awareness

Characteristics of the Nephrology area and interaction between health professionals.

Reasons for choosing this specialty

I like everything about my work, because there are many areas of opportunity, because there are few pediatric nephrologists. (Nephrologist)

It is a forgotten area within the specialty of nutrition in pediatrics, there are few specialists in this area, and there are patients who are forgotten and, above all, also... so you have to present it as a science. I think the fact that it is a complicated and difficult pathology, presented as a challenge in which you have to make your patient reach results. (Nutritionist)

Functions and activities of health personnel

My work is distributed between medical and assistance activities. There are days when I have a consultation and there are days when I perform assistance activities such as inserting vascular accesses for hemodialysis, inserting catheters for peritoneal dialysis, kidney biopsies and transplant protocols for the children from nephrology. (Nephrologist)

My role is the connection and disconnection of patients to the hemodialysis machine, transdialysis care and I can give them guidance on home care, postdialysis care. (Nurse)

We, nurses, are the direct support of doctors, we basically do most of the work, in terms of treatment follow-up we rely on the doctors, we do not rely on hospitals or anyone else, we rely on ourselves, nurse-doctor, and that is where the chain is cut. (Nurse)

My job is to see the nutritional support of all patients in the hospital, I am mainly dedicated to renal nutrition. (Nutritionist)

A psychologist in the hospital approaches the family and the children to soothe everything that has to

do with all the procedures that will be performed on the child in the hospital ... Once we achieve this, we follow-up the patients' state of mind, how they are adapting to the hospital and, above all, to the situation they are experiencing. (Psychologist)

Factors involved in treatment adherence

Elements that facilitate the adherence to treatment

They mainly have a stable family environment, constant and committed parental involvement. This is the patient whose mother is in charge of the diet, the application of medications, the procedures performed and the laboratory studies required, medical appointments, and physical activity. Obviously the cultural level, the educational level of the people also has an influence. Of course this provides some facilities, but it is not a "sine qua non" condition, that is, there are patients who have a very low level and it does not mean they will not have a good adherence, the commitment is not necessarily related to the educational level of the people. It's very clear to me in nephrology patients. (Nephrologist)

There is one factor that is fundamental: that you have the supplies for the complete, timely and efficient care, that is, that you have the medication that the patient needs at the right time, in the right dosage and that the application is correct, and it is timely, in this case, that the indication is the right one. (Nephrologist)

Home care facilitates adherence, and it is noticeable because they arrive with very little water gain, so they are doing it very well, they tolerate their three to three and a half hour session without any problem, without any complication, without any pain. The second is the state of mind, a patients who is doing well in the sessions may come to me demonstrating they are taking care of themselves; so they are happy, they are smiling, making jokes, we share talks of positivism. Those who are doing badly are always negative, they say "I can't! Why is it happening to me? Why am I taking care of myself if I am already going to die?"

I am already dying!", so mentally this is how their state of mind is affected. (Nurse)

Parents are aware of the disease, they know perfectly well what they should and should not consume, but the protection and support they provide to patients is extremely important. (Nurse)

For a child to adhere to the treatment it is necessary that the family members are with them and also explain to them, giving them what they need... If the family members do not give them the treatment as it should be, nothing works. (Nutritionist)

Elements that hind the adherence to treatment

The place where they live, because obviously connectivity in the state of Michoacán continues to be a problem in some parts, for example the Sierra Costa, the Meseta Purépecha region, the Tierra Caliente region, areas that are remote and marginalized. (Nephrologist)

It is mainly economics and state of mind that facilitates and hinders both treatment and home care. Those who don't take care of themselves at home are doing very, very badly. (Nurse)

The money factor, the economic issue, has a great influence. It is very different to deal with a patient, perhaps, with cancer or with a patient with diabetes, even a renal patient, because sometimes they come from distant communities and we know that, for example, a dialysis bag is expensive, very expensive, and so far there is no a free program as in the case of cancer. There is none, and it influence in the family's discouragement at times... for example, bringing the patient to a hemodialysis center is complicated even because of the distance; people who perhaps have the economic resources would do it at the beginning, but then exhaustion begins to set in, and not physical exhaustion, but emotional exhaustion, because patients also suffer demanding a lot of care and sometimes people no longer know what to do or how to do it. (Psychologist)

To place ourselves in the context of the family and of the child, because maybe the doctors forgot that they are with a person who lives in a remote community or in the Meseta Purépecha, and so they do not explain the things well, or they explain it in very medical terms, or they do not even understand Spanish well, and so this is a very important element for adherence (or not). (Psychologist)

Some doctors may see the families as very calm or accepting the treatment at the moment, however, the grief caused by the loss of the child's health must be managed. It is clear to the parents that they have to apply medications at specific times, but they forget to take care of the nutritional or emotional aspect and then suddenly they are children who are very spoiled, who have already acquired many secondary gains because of the disease and it generates a risk factor for greater complications or for lack of adherence. (Psychologist)

What hinders it is the family members themselves, who look for alternative treatments that have a big impact on the disease because they are looking for a solution. (Nutritionist)

Incorporation of the psychologist in the Nephrology area.

Emotional support in the pediatric

The emotional part is important and it is not a situation based on my own words, it is even contemplated in international clinical practice guidelines such as KDIGO. There is a section of psychological care, emotional care where one of the most important points is the acceptance of the problem because it cannot be solved definitively, renal failure cannot be cured, it is controlled and renal replacement therapies are a treatment, a control, they are the prelude to kidney transplantation. So, the emotional work consists of helping the patient to understand what each of these therapies is and that transplantation is not a cure, but only a therapy that will require treatment for the rest of the patient's life, with immunosuppressive drugs that will have side

effects on the patient, with visits to the doctor and monitoring of risk factors such as viral or other situations. (Nephrologist)

I think it is very important to provide psychological support to the patients; they have many repressed feelings, since their own relatives sometimes do not listen to them or feel a certain rejection. (Nurse)

It is very important to focus on the patient's emotional side. I believe that everything must work harmoniously together and when a patient feels well, eats well and follows the medical treatment, this guarantees that the patient will do well. If any of these three things is missing, the patient becomes more depressed and does not want to follow anything. (Nutritionist)

I can tell you about my service, I consider that the work we do is good, although honestly sometimes we catch them when they are hospitalized and things are already very bad, because even though we tell them to come, the family member will always pay attention to the doctor's advice, or to what the specialist says, in this case the nephrologist. If the nephrologist does not say "you have to go to psychology and it is part of the treatment", the person does not go. So, from that point on, some cases may be missed, but we try to follow up and make appointments for those we have, and obviously they do very well. (Psychologist)

Coping strategies for coping with illness

Families look for support networks in the face of illness, it is not uncommon they ask me for the summary, the note or the prescription to justify, for example, the transport, because they look for the support network in the municipal presidency to transport or for support with some medication, and they get it. Moreover, if they do not have networks, they try to generate them. It has happened to me that when patients arrived at this hospital they were not engaged in anything and later they are engaged in situations that facilitate the transportation of their

child, for example, they found a way to buy some supplies that are not available in their community and there are some here, and they go and sell them in their community when they return from their child's consultation. They took advantage of the trip and it helps them to generate a resource, then, they do not have the opportunities, but they generate them, and it says a lot about attitude. (Nephrologist)

The greatest help or support that the patients have comes from family members, mainly relatives living in the United States, and the support that the children have from the children's hospital. (Nurse)

I remember a colleague who is not here right now, she had a strategy for a child who brought his dialysis bag and went everywhere with it, when the child had to stay in bed all the time he did not want to go out, so it is also important to teach strategies of things to do despite having a delicate disease. (Psychologist)

Recommendations for a possible intervention

Performing interdisciplinary work including Psychology personnel

At the National Institute of Pediatrics, at the Federico Gómez Children's Hospital of Mexico, and in general at the national institutes, there is a Nephrology Committee and a Renal Transplant Committee in which the psychologist plays a fundamental role. The psychologist's opinion and the psychological diagnosis are considered a fundamental part of the approval or not for the transplant, to know who is a suitable patient or a problem patient, the psychologist helps decide who is the most suitable, for example, he tells you who is very unstable, if he has a psychiatric diagnosis or a condition that gives us a bad prognosis for adherence to the treatment that makes us back out of a transplant, because you are not going to put a donor at risk, then you will have to work until you achieve conditions of adherence. (Nephrologist)

Physically, nutrition is the basis of a successful treatment. When there is a water decontrol of minerals you need in your body, we start from this point. Socially and psychologically, I think they need people who listen to them...I think it is important mental health and its implementation in all age groups that we have in the clinic and in society. (Nurse)

I believe that with us, with the personnel here at the hospital, we need communication and interdisciplinary and valued work, because the relatives will say "the doctor tells me", but if the doctor forgot that psychology has an important part to give support in this adherence, he will send the patient, if not, he will not, that is, he will send him to us when he is already in a very serious condition. (Psychologist)

Caring for the caregiver

Many times family members comment that it is a nuisance, that it is heavy, that it is annoying to have a sick person at home. (Nurse)

There is no awareness that mental health is important and that when we have to take care of a person who is ill, we also have to take care of the caregiver, because we can have our little patient in very good condition, but the person who takes care of him, is exhausted, worn out. That is why sometimes "oh, I want a coke", "well, ok", the caregiver concedes, "I am thirsty and I want more water", "well, ok". So I believe that it also has to do with this question of the bonds and attachments that one has with the patient. (Psychologist)

Promoting self-care

Achieving self-care in the patient is a key element; it is important for the patient to be clear about

his disease and the treatment; this is almost a shell that maintains adherence to treatment. Self-care empowers the patient and makes him the decision-maker of his own life, so he identifies it and tells you: "doctor, I feel that I have high blood pressure". (Nephrologist)

Talking about a pediatric patient, we have to make parents aware that they should not hide anything from their children. They have to talk to them about the process of the disease so that the child can also become aware of self-care when growing up, because there are kidney patients who may reach a point where they can be transplanted, but then it's like "Wait, wait! Yes, you will be transplanted, but the process before and after will not be easy". (Psychologist)

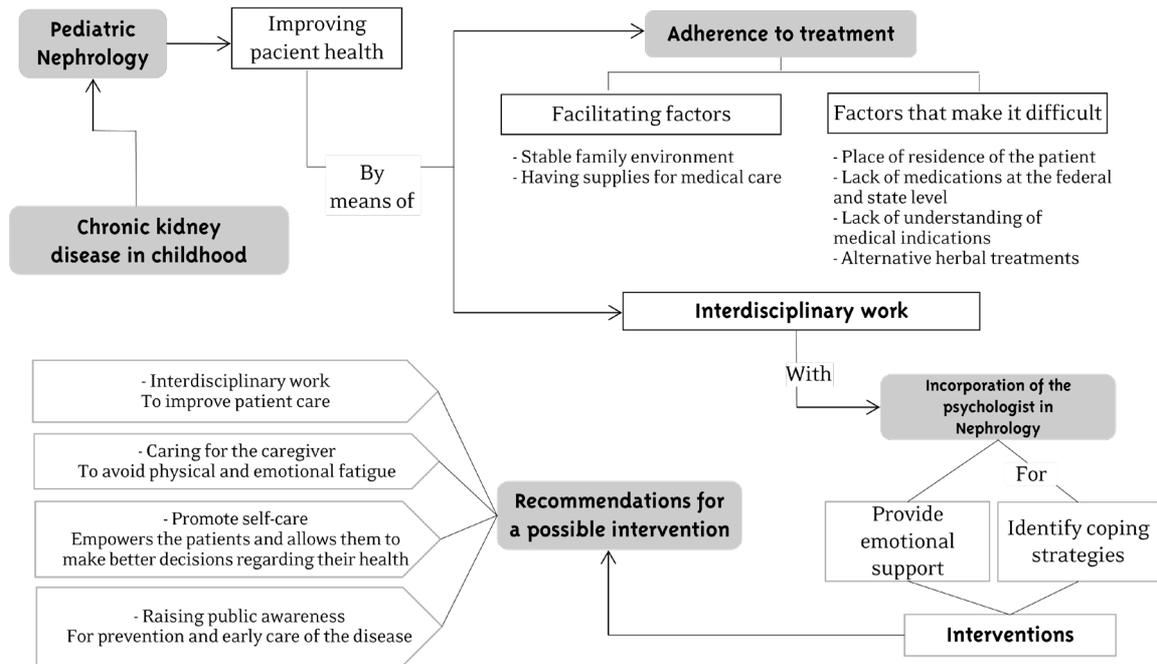
Raising public awareness

From my experience, raising awareness among family members and the population in general about what kidney disease is, what we can do to avoid it, for example, there are pediatric patients who have it due to hereditary issues or since the birth. It is important starting to know about the function and importance of our kidneys, I believe that we would avoid many things. (Nutritionist)

I sometimes tell patients "there are diseases that you can't see on the outside, but inside something is wrong", so we have to pay attention and through some studies we will find out how you are. (Psychologist)

Based on the interviews, an analysis of the interaction between the different categories identified is proposed, which are represented in Figure 1 and which were organized to highlight the role that the psychologist can have in the children's nephrology service.

Figure 1 – Outline of qualitative results of the interviews with health care professionals



Discussion

The approach to a patient with CKD represents great challenges for health institutions and professionals, firstly because there is a limited number of nephrology personnel, and secondly because health systems are not sufficiently prepared to provide interdisciplinary care.

According to the experience of professionals, the complexity of CKD treatment means that many patients have serious difficulties in complying with medical and nutritional indications, as it requires complex behavioral restrictions. Hence the importance of adherence to treatment, which can be influenced by factors that may or may not facilitate compliance (Contreras et al., 2006; Splinter et al., 2018).

Among the factors that facilitate adherence are: having a stable family environment and the necessary inputs to cover the costs of treatment and medications, which coincides with the results of previous research (Guzmán-Carrillo, 2017; Ramay et al., 2017; Zelikovsky et al., 2008).

The factors that hinder adherence are: the patient's place of residence and the low level of

education of the caregiver, which can make it difficult to understand the medical indications, which is also influenced by the abstract language used by the doctors. These factors have also been pointed out in other studies (El-Gamasy; Eldeeb, 2017; Ramay et al., 2017; Sáenz, 2017).

For this reason, both the patients and their families should consider the grief caused by the loss of health and, above all, the acceptance of the diagnosis in order to make changes in their daily activities, developing adjustment and adaptation strategies.

In this regard, it was found that in the face of CKD, families develop coping strategies such as seeking support networks in order to obtain transportation to the medical unit, or they sell products they obtain in the city, which allows them to obtain economic resources for the purchase of medicines and other items. These actions show how families mobilize their psychological resources to get ahead despite adversities (Guzmán-Carrillo; González-Verduzco; Rivera-Heredia, 2015; Rivera-Heredia; Andrade-Palos, 2010).

Referring to the primary caregiver, it was also recommended to provide them with psychological

care to prevent physical and emotional fatigue, which coincides with previous recommendations for caregivers of adults with CKD (Romero-Massa; Bohórquez-Moreno; Castro-Muñoz, 2018).

It is important to highlight that some psychologists are inserted in hospital environments temporarily due to their postgraduate projects, attending patients with chronic diseases such as CKD (Guzmán-Carrillo, 2017; Sáenz, 2017). So it would be expected in the future that the number of psychologists involved in the care of this group of patients will increase in order to strengthen the links between the training of human resources with a high level of specialty, such as postgraduate programs and health institutions.

In this sense, the professionals emphasized the importance of the health psychologist as another member of a nephrology service, since their work is fundamental from the preventive stage to coping with the disease, emotional management, adherence to treatment and the transplantation process (Alcázar et al., 2001; García-Llana et al., 2010; García-Flores; López-Chávez; Ojeda-Cervantes, 2014; KDIGO, 2013).

It was also recommended that the population be made aware of the condition in order to identify symptoms in the early stages and thus avoid renal replacement therapies. This is why it is important to call on the health authorities to invest resources and efforts to combat CKD, since it occurs in silence and the patients do not know the risks they face and the consequences they will pay for in the terminal stages of the disease (Lastiri, 2016).

Final considerations

The results of this study helped to highlight the importance of psychological care for patients with CKD as part of an interdisciplinary approach.

Although the Children's Hospital of Morelia has a psychology service, there is no professional in this field in the Nephrology area. This allowed accepting the implementation of a cognitive-behavioral psychological intervention to improve the treatment of patients so that at the end of the research, with the results obtained and the psychoeducational

materials developed, suggestions could be made to other nephrology services at national and international level.

To conclude, we consider it is necessary to follow an interdisciplinary model of care that helps to prevent, stop or slow the progression of CKD and, thus, contribute to a decrease in the incidence and prevalence of the disease.

Focusing on the work of the psychologist from the moment the diagnosis is made, the type of renal replacement therapy and the medium and long term follow-ups are determined, having as main activity the management of emotions, adherence to treatment and social support.

The steps of the model are described below:

1. Step 1: Identification and clinical evaluation of patients

During the medical consultation, it is necessary to identify symptoms and risk factors in patients, which should be accompanied by tests to evaluate renal function and establish a proper diagnosis, such as: estimating the glomerular filtration rate (GFR), quantifying serum creatinine and determining the presence of markers of renal damage such as proteinuria.

2. Step 2: Diagnosis of chronic kidney disease

After establishing the diagnosis of CKD and knowing what stage of the disease the patient is in, it is essential to begin medical treatment and the type of renal replacement therapy (peritoneal dialysis, hemodialysis, transplantation).

3. Step 3: Interdisciplinary work plan

Once the diagnosis of CKD is made, it is important to have an interdisciplinary work team (doctor, nurse, nutritionist, psychologist, and social work) to draw up a work plan according to the needs of each patient. A plan in which each professional makes comments and recommendations for care, with the aim of improving treatment and ensuring constant follow-up of adherence levels by the patient and his primary caregiver.

4. Step 4: Follow-up of work plan

After the patient visits each of the professionals, it is necessary for the interdisciplinary team to hold follow-up sessions to carry out a holistic evaluation of the patient, determine adjustments to the treatment and, thus, prevent possible complications.

Among the contributions of the model is the proposal of an active collaboration between the interdisciplinary team, in which each professional will be able to make contributions independently, but will collaborate to achieve common objectives during the follow-up sessions, which will favor communication between professionals and will strengthen decision making regarding the treatment and evolution of the condition.

We hope for this proposal to be reviewed, analyzed and implemented in the different health systems in order to provide adequate and timely care to patients, because we believe that when professionals work together to achieve a common goal, the use of resources can also be optimized in a more efficient manner.

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Authors' contribution

Guzmán-Carrillo carried out the planning and execution of the study. She analyzed the information and wrote the general structure of the article. González-Betanzos and Rivera-Heredia were in charge of the methodology and category analysis. Salazar-Garza and Montes-Delgado participated in the organization of the information and the general structure of the article. Aguirre-Martínez contributed to the review of the specialized literature. All authors participated in the analysis of the information and in the final writing of the article.

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