

ADHERENCE TO HEMODIALYSIS TREATMENT: THE PERCEPTION OF CHRONIC RENAL PATIENTS*

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ABSTRACT: This descriptive exploratory study, with a qualitative approach, aimed to identify factors which influence adherence to hemodialysis treatment in the perception of chronic renal patients. A total of 35 patients participated, who were assisted by a public hemodialysis service in a state capital in the Northeast of Brazil, with data collection taking place between May and August 2014. The information was collected through a semistructured questionnaire and was analyzed using the ALCESTE software. The main factors that influence adherence were: transport difficulties, deficit of knowledge regarding the illness, limitations of the treatment, problems experienced in the hemodialysis sessions, control of the rates through laboratory examinations, religious faith, the hemodialysis machine, and social support. It is considered, therefore, that the factors influencing adherence are complex, making it necessary to undertake multi-professional activity in order to understand this phenomenon, and to develop educational strategies with a view to raising individuals' awareness regarding the importance of adherence to the treatment and possible improvement in quality of life.

DESCRIPTORS: Chronic renal failure; Renal dialysis; Patient cooperation.

ADESÃO AO TRATAMENTO HEMODIALÍTICO: PERCEÇÃO DOS PACIENTES RENAI CRÔNICOS

RESUMO: Estudo descritivo, exploratório, de abordagem qualitativa que objetivou identificar fatores que interferem na adesão ao tratamento hemodialítico na percepção dos pacientes renais crônicos. Participaram 35 pacientes assistidos por um serviço público de hemodiálise em uma capital do Nordeste do Brasil, com coleta das informações entre maio e agosto de 2014. As informações foram coletadas por meio de questionário semiestruturado e analisadas pelo software ALCESTE. Os principais fatores que influenciaram na adesão foram: dificuldade de transporte, déficit de conhecimento sobre a doença, limitações do tratamento, transtornos vivenciados nas sessões de hemodiálise, controle das taxas pelos exames laboratoriais, fé, máquina de hemodiálise e suporte social. Considera-se, portanto, que os fatores que interferem na adesão são complexos, tornando-se necessária atuação multidisciplinar para a compreensão desse fenômeno e o desenvolvimento de estratégias educativas com vistas à conscientização dos indivíduos sobre a importância da adesão ao tratamento e possível melhoria da qualidade de vida.

DESCRIPTORIOS: Insuficiência renal crônica; Diálise renal; Cooperação do paciente.

ADHESIÓN AL TRATAMIENTO HEMODIALÍTICO: PERCEPCIÓN DE LOS PACIENTES RENALES CRÓNICOS

RESUMEN: Estudio descriptivo, exploratorio, de abordaje cualitativo cuyo objetivo fue identificar factores que influyen en la adhesión al tratamiento hemodialítico en la percepción de los pacientes renales crónicos. Participaron 35 pacientes asistidos por un servicio público de hemodiálisis en una capital de Nordeste de Brasil. La obtención de las informaciones ocurrió entre mayo y agosto de 2014. Las informaciones fueron recogidas por medio de cuestionario semiestruturado y analizadas por el software ALCESTE. Los principales factores que influenciaron en la adhesión fueron: dificultad de transporte, déficit de conocimiento sobre la enfermedad, limitaciones del tratamiento, trastornos en las sesiones de hemodiálisis, control de las tasas por los exámenes de laboratorio, fe, máquina de hemodiálisis y apoyo social. Se considera, por lo tanto, que los factores que influyen en la adhesión son complejos, siendo necesaria actuación multidisciplinar para la comprensión de ese fenómeno y el desarrollo de estrategias educativas para concienciar los individuos acerca de la importancia de la adhesión al tratamiento y posible mejoría de la calidad de vida.

DESCRIPTORIOS: Insuficiencia Renal Crónica; Diálisis Renal; Cooperación del Paciente.

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INTRODUCTION

Chronic Kidney Disease (CKD) is considered to be a worldwide epidemic due to its alarming prevalence and raised rates of morbidity and mortality, with emphasis being placed on the socioeconomic, physical and psychological transformations which it triggers in the individual's life⁽¹⁾.

The National Kidney Foundation (NKF) defines CKD, in its document titled 'Kidney Disease Outcomes Quality Initiative' (K/DOQI), as a lesion of the renal parenchyma for a period equal to or superior to three months, evidenced by proteinuria and/or hematuria and/or Glomerular Filtration Rate (GFR) below 60 ml/min/1.73m²⁽²⁾.

According to the 2013 Brazilian Dialysis Census, it is calculated that 100,397 patients are included in the dialysis program, with 90.8% undergoing treatment through Hemodialysis (HD) and 9.2% through Peritoneal Dialysis (PD)⁽³⁾.

HD aims to remove from the blood the nitrogenous excreta and the excess of liquid through a semipermeable membrane termed a dialyzer. This process, however, gives rise to a series of distressing factors for the person with CKD, such as metabolic and endocrine alterations, changes in perception of self-image, and changes in lifestyle, these being considered to be obstacles for adherence to the hemodialysis treatment⁽⁴⁾.

Adherence is considered to be a process in which the subject meets the expectations of the treatment proposed, through following guidance and prescriptions recommended by the multi-professional team. It is seen as a tool to be used for the improvement of the service users' clinical situation⁽⁵⁾.

As a result, knowledge of the factors involving adherence to hemodialysis treatment is essential. The acceptance of the disease, and the recognition of the importance of the treatment proposed, lead the client to follow the recommendations provided by the health professionals and, in this way, to reduce the complications of CKD and improve clinical conditions. In addition to this, it confers greater autonomy for the individual looking for alternatives for overcoming the difficulties, and the possibility of adapting oneself to the new health condition⁽⁶⁾.

Considering the difficulties found by chronic renal patients in adhering to the hemodialysis treatment, and the complexity of factors involved

in this issue, this study aimed to identify the factors which influence adherence to hemodialysis treatment in the perception of chronic renal patients.

METHOD

This is a descriptive, exploratory study, with a qualitative approach, undertaken in the HD service of a public hospital which is a state referral center in nephrology, located in the city of Recife, in the Brazilian state of Pernambuco. The participants were individuals with CKD undergoing hemodialysis treatment, who had been registered in the unit for a minimum of 12 months. The following were excluded: persons with compromised communication or cognition, patients who were in transit (service users registered in other clinics, undertaking HD treatment temporarily in the service in question) and those who were inpatients in the Intensive Care Unit (ICU) during the data collection period. The sample was made up of 35 chronic renal patients of the service.

Data collection took place in the period May – August 2014 through a semistructured interview held in a private area prior to beginning hemodialysis treatment. The collection instrument was made up of sociodemographic data and data regarding the clinical situation, such as sex, age range, marital status, educational level, occupation, underlying disease, time in HD treatment, and the type of vascular access. In addition to these, two guiding questions were included: What do you know about your illness? What are the factors which positively and negatively influence your adherence to the hemodialysis treatment?

The recorded interviews were transcribed and analyzed using the *Analyse Lexicale par Contexte d'un Ensemble de Segments de Texte (ALCESTE)* program, version 2010. This software presents an organization of the data through statistical and mathematical analyses, through providing the number of classes, the relations existing between them, the divisions undertaken with the material up to the formation of the classes, and the radical forms and words associated with their respective Chi-squared values, as well as the semantic context of each class⁽⁷⁾.

The study was submitted to, and approved by, the Research Ethics Committee of the Foundation for Higher Education of Olinda, under CAAE 28328914.5.0000.5194. The ethical precepts established for studies involving human beings

were respected, in accordance with Resolution 466/12⁽⁸⁾.

RESULTS

Of the 35 patients who participated in the study, the majority were male (66%), aged over 60 years old (40%) and from 46 to 60 years old (40%), married or in a stable relationship (51.43%), had not finished Basic Education (40%) and were illiterate (29%). Emphasis is placed on the major presence of patients who received sickness benefits resulting from the disease (86%) when compared with those who undertook some form of paid activity (11%).

Regarding the underlying disease, the majority of the participants had no defined etiology for CKD (29%). The association of Systemic Arterial Hypertension (SAH) and Diabetes Mellitus (DM) was the main cause (23%), followed by SAH (20%), other causes such as renal lithiasis, obstructive uropathy, neurogenic bladder, and

nephrocalcinosis (14%), DM (11%) and chronic glomerulonephritis (3%). It was ascertained that 63% of the patients had been in HD programs for a period of 1 to 3 years, 86% presented arteriovenous fistula (AVF) as access for undertaking HD, and 11% underwent dialysis with a catheter.

Based on the interviewees' discourses, 35 interviews were held and transcribed, giving rise to the Elementary Context Units (ECU), which correspond to the classes of words found with the greatest frequency in the raw text (corpus) and higher Chi-square value for the association of these words with the classes⁽⁹⁾. From the participants' accounts, 187 ECUs were generated, which after analysis through Descending Hierarchical Classification Analysis; 62% (116) of these units were used. These ECUs were regrouped according to their lexical similarities, forming 5 thematic classes, ordered according to their statistical association and numerical representativity (percentage of ECUs used) (Figure 1).

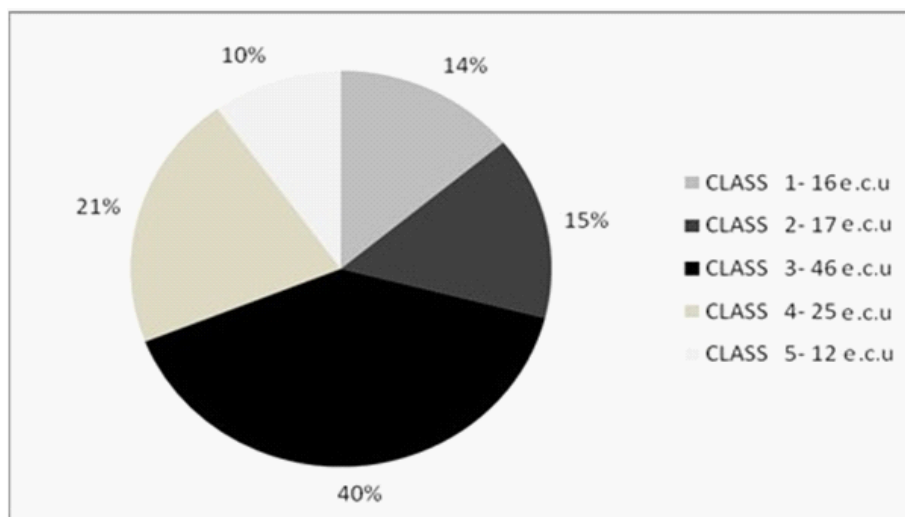


Figure 1- Distribution of ECUs, classified according to the discourse of patients undergoing hemodialysis treatment. Recife, 2015

Class 1: Difficulties with transport to the dialysis service

The patients reported difficulty accessing transport to the HD center. This difficulty is caused by the financial cost with traveling and the Prefecture's lack of commitment regarding availability of the vehicle, as observed in the accounts below:

What is a nuisance most for me is the car for bringing me here, I was paying a lot of money for the car. Now, my son-in-law brings me [...]. (Subject 8)

The first negative point is the Prefecture's transport which brings us here, it is terrible. There are days when it can bring us here, and there are days when it does not. Because of this, we make the effort because some people come by bus, others rent a car, and this is stressful. One can see that everybody arrives here changed, and with their pressure altered. (Subject 28)

I have difficulties with the transport, I used to come in the Prefecture's car, but now I come by bus, by my own choice. (Subject 32)

Class 2: Factors which facilitate the process of adhering to and maintaining the treatment

The factors listed by the participants as facilitating promotion of adherence to the treatment cover both aspects linked to the therapy and spiritual aspects. Among the components related to the therapy, patients highlight the laboratory tests for monitoring the disease and undertaking HD, in which the machine is seen as a means of survival and for relieving the symptoms resulting from the illness, as shown in the discourses below:

I am very ill, what helps is doing the tests for monitoring this disease [...]. (Subject 6)

I began to fall ill, I began to become weak and I went to the doctor who did tests, when the results came back it turned out that I had this [...]. (Subject 13)

It is good for me here, I haven't passed urine, and when I do the hemodialysis I become well and I sleep well. (Subject 16)

Ah, the treatment now has many good things, since this doctor requested tests for me, she reduced my days, that is, I used to come to use the hemodialysis machine three times a week, but now I only come twice. (Subject 20)

Another element which emerged from the analysis was the role of spirituality in encouraging people to undertake the therapeutic plan. "Faith in God" can be identified in the discourse below as a motivating element for continuing with the treatment and accepting the recommendations.

If I stop doing hemodialysis, I'm dead. It is difficult, but, with the faith I have in God, I go ahead. (Subject 2)

Class 3: Deficit of knowledge as a predictor for the progression of the kidney disease

The study's participants showed themselves to have little knowledge regarding their condition, this being limited only to discernment of the causes underlying the kidney problem, and a superficial understanding regarding the disease. The knowledge was shown to be restricted to the consequences of CKD, and to the limitations imposed by the treatment in relation to diet and ingestion of water.

I don't know anything, I just know that the doctor said that it was because of the pressure. But I have never been interested in knowing anything. That I mustn't eat this, that, something else, a lot of things. I mustn't drink much water, I can't do a lot of things.

(Subject 5)

I know it is because of the diabetes and high pressure, because my pressure was very high, and my diabetes. (Subject 8)

It is a disease which means that I can't pass urine, and that's all it is. (Subject 9)

My disease was not caused by diabetes, it was caused by the pressure. It was something that I didn't even know what it was, and I used to drink a lot of water. (Subject 25)

Class 4: Hemodialysis room: a scenario where experiences are exchanged

The interaction of the chronic renal patients with other patients, family members and the multiprofessional team allows an exchanging of experiences and knowledges which constitutes a genuine instrument for exchanging knowledges regarding the disease and treatment. The clients state in the communications that the HD room is an environment of solidarity, which allows the sharing of experiences acquired, and of suggestions for improving the therapeutic monitoring, which contributes to assisting in the process of coping with the disease and treatment.

What contributes is the awareness of all those people helping me, the support of the family members so that I may follow the diet, the coexistence with the other patients who have the same problem as me, and the attention as well, on the part of the staff in the treatment [...]. (Subject 1)

The people who work here talk, they talk about a lot of things and we have to accept what they say. They help a lot. They give advice, they tell you what to do; all that. (Subject 5)

What I know is a few things which we learn from each other and which I learned from friends. (Subject 15)

Class 5: Routines of a session of hemodialysis as limitations of satisfaction with the treatment

The HD, in spite of its many benefits, is considered a painful treatment by the service users. The routine of the sessions, and the change in lifestyle, are seen as negative points in the therapy as they limit the satisfaction with the treatment. The reports of the study participants reveal the existence of various stressing factors involved in their routine, as may be seen in the accounts below:

I can't eat everything that I used to. Everything is controlled, and that is bad. (Subject 22)

I just think it is bad because I can't drink water, I drink very little water. (Subject 23)

What is bad in the treatment is this position, that we stay here for four hours without being able to move, it is not good. (Subject 24)

Sometimes we get agitated, but we have to bear spending four hours there. I'll tell you something, what makes it hardest for me is being punctured with the needles, I can't stand that, it burns rather. (Subject 25)

DISCUSSION

The male population, older adults and adults in transition (46 to 60 years old) were predominant groups in this study, this being in accordance with the 2013 Brazilian Dialysis Census⁽³⁾. The majority of the participants in the study were in a conjugal relationship, had a low level of education, and were receiving sickness benefits. A similar study undertaken in eight dialysis centers in Maranhão, with 330 patients with CKD receiving HD, corroborates these data; 59.6% were married, 56.7% had a low educational level, and 49.1% were receiving sickness benefits as a result of the disease⁽¹⁰⁾.

The Brazilian Dialysis Survey, published by the Brazilian Society of Nephrology (SBN) states the main causes of CKD to be SAH, DM and glomerulonephritis, respectively⁽³⁾. In this study, the majority of the service users did not have a specified cause for the renal condition, this being explained by the presence of diverse comorbidities, thus hindering the defining of the diagnosis. The mutual participation of SAH and DM was also emphasized, as these are the underlying diseases with the greatest impact on the renal physiopathology.

In spite of the growing number of individuals undergoing HD, there is also a migration from this mode of treatment to PD and kidney transplant⁽¹¹⁾, this perhaps explaining the reduction in the number of patients undergoing HD for a greater period of time in this investigation. The prevalence of AVF as the vascular access is owed to the fact that the study was made up of chronic renal patients undergoing HD for a minimum of one year, which is sufficient time for the creation and maturation of this form of access.

Of the classes which emerged, difficulty with transport to the dialysis service was one of the factors identified as an obstacle to adherence to the treatment. The socioeconomic impact

resulting from the CKD affects the family, as the physical limitation resulting from the illness becomes an obstacle for travel and work. As a result, a considerable number of people with kidney disease cease working and live on income from sickness benefits⁽¹²⁾.

Transport is an important cause of absences and delays in HD, as the renal clients complain of the financial difficulty in meeting the cost of traveling to the hemodialysis center⁽⁵⁾. A study undertaken in a HD center in the municipality of Petrópolis, in the state of Rio de Janeiro, attests that the distance between the place of treatment and the service users' residence, and shortcomings in the transport services network, are stressing factors for the individual and family members, culminating in failure to comply with the therapeutic regime⁽¹³⁾.

It is known that the State has the responsibility to offer public transport which is free, good quality and safe, to people with special needs, as a means of ensuring the comprehensiveness of the care for this vulnerable group⁽¹⁴⁾. Although the municipalities made this service available, a considerable number of subjects did not benefit from this right, when one takes into consideration that some patients used other modes of transport such as bicycles, taxis and rented cars. This shows the gap existing in the provision of public services, in that the service user is harmed by the questionable quality of means of public transport.

The component of the laboratory test was shown to be a resource which helped in the therapy, serving as a parameter for guiding the doctor regarding reducing the number of hours spent in dialysis and in the sessions when indicated; as a result, the patients are incentivized to undertake the treatment with the aim of improving the situation. One can also observe the fundamental role of the tests in the discovery and control of the illness, making the implementation of the necessary treatment possible.

A study undertaken in the Teaching Hospital of Rio Grande do Sul emphasizes the importance of the laboratory tests for identifying clinical changes such as metabolic acidosis, hyperkalemia and hyperphosphatemia, among others, showing that these parameters can influence adherence to the therapy through identifying the basic cause of various problems and allowing intervention for relieving symptoms and optimizing the clinical situation⁽⁶⁾.

Laboratory monitoring in renal pathology is

essential for monitoring the progression of the disease, and identifying secondary complications at an early stage, given the variety of metabolic changes caused by deteriorated renal function⁽¹⁵⁾.

The HD machine was seen as a crucial point of the treatment, a source of well-being, and an unmatched resource for attenuation of the clinical manifestations of the disease. On the other hand, in spite of the recognition of its importance, the patients considered themselves to be hostages to a machine linked to obligatory and painful treatment which brought sudden changes and limitations to their lives.

One qualitative study on the perception and quality of life of patients receiving HD, undertaken in a nephrology center in Rio Grande do Sul, with nine patients, found similar results in that it identified HD as hope for survival with autonomy and quality, while the undertaking of a possible transplant was awaited. However, it was emphasized that the treatment gave rise to various opposing feelings, fragmenting the individuals' perception regarding the therapy, as at the same time that the machine was perceived as an essential item for preserving their lives, it also meant dependency, fear of death, suffering, and a feeling of imprisonment⁽¹⁶⁾.

In relation to the presence of elements related to the therapy, religious faith was seen as incentivizing continuation of therapy. This is a bulwark in coping with critical times, such as discovering that one has a disease, providing comfort and support, as well as bringing important health benefits, with improvement in the psychosocial, physical and spiritual ambits for incentivizing the undertaking of the treatment⁽¹⁷⁾.

One study on spirituality undertaken in two nephrology services in João Pessoa, in the state of Paraíba, with 100 patients with CKD receiving HD, revealed that religious faith modified the subject's understanding positively, with regard to their disease and their life, as well as their way of acting, contributing to adherence and rehabilitation⁽¹⁸⁾. It therefore falls to the health professional to pay special attention to this specific issue, due to the meaning which it represents for the patient, characterized as a basic human need.

The deficit of knowledge as a predictor for the progression of the kidney disease was the class which was numerically most representative of the study. The shortage of information regarding the disease and the treatment may reflect the low socioeconomic and educational level of the

sample in question, as the service users showed difficulty in defining the aspects mentioned.

Another relevant point was ignorance of the importance of controlling SAH and DM in order to prevent the progression of the CKD. The participation of the underlying diseases in the development of this condition is known, there being a lack of preventive work with population groups at risk. This Brazilian context shows the need for greater focus on health education with a view to reducing the incidence of the chronic diseases⁽¹⁹⁾.

It is known that the lack of knowledge has a negative influence on the selfcare process, as clients with a low educational level experience difficulty in understanding the recommendations made, and have a higher rate of abandonment of treatment. In addition to this, they present difficulties in preventing their comorbidities, which influences the late discovery of the disease, impeding an early approach and reduction of complications⁽¹⁰⁾.

The social classes which are less favored present weakness in knowledge, thus hindering continuation of the therapy, making it essential for the multi-professional team to act differently with them, using strategies of continuous education with emphasis on the promotion of knowledge. For this, it is essential to provide resources which facilitate understanding, such as the use of simple language, illustrative leaflets, seminars, and conversations⁽¹²⁾.

The existence of support networks for the chronic renal patient is essential in supporting the recognition of the disease, allowing a new understanding regarding the disease and the importance of HD for the patient's new way of living. The coexistence of the person with CKD with their family members as well as the interrelationship established with the other patients and the health professionals, contribute to the patient acquiring positive attitudes concerning her health problem and treatment⁽²⁰⁾.

It is seen that CKD destructures the patient's life because it changes her way of living, triggering physical and psychosocial limitations. As a consequence of this, numerous secondary problems are perceived, such as social isolation, inability to work, depression, pessimism, and desistance from the treatment. At this time, the presence of the family and the health team is fundamental to rebuild the individuals' will to live, self-esteem, and self-control in the course of

the illness⁽²¹⁾.

The multi-professional team shares responsibilities with the service user in order to form a "therapeutic alliance", in which the health professionals have the role of involving the patient and her family members in a process of adaptation, reducing doubts and clarifying the importance of adherence to the therapy for well-being and reduction of mortality⁽²²⁾.

It is important to emphasize that the HD environment affords communication between the patients. This group relationship benefits adherence and coping with the difficulties experienced. The bond formed between the service users allows the construction of knowledge regarding the disease and treatment, as a result of which this relationship allows the continuous learning of some patients from others, thus strengthening the therapeutic adherence⁽²³⁾.

The adversities experienced in HD are a limiting factor for satisfaction with the treatment. As a result, it may be observed that CKD requires rigorous treatment, with the need for radical changes in living habits impacting and restricting peoples' daily life⁽¹¹⁾.

In this way, it may be noticed that chronic renal patients undergoing HD deal with stressful situations resulting from the issue, in following the prescriptions, including the pain and discomfort experienced in the treatment environment. The association of these factors contributes to poor adherence, increase in complications, and negative impact on quality of life⁽²²⁾.

Controlling food and fluid intake is necessary due to the physiological changes entailed by CKD. The patients commonly have restrictions in consuming foods which contain phosphorus, potassium, sodium, proteins and water, compromising their well-being and lifestyle, which triggers resistance to following this control. Another fairly common problem present in the renal pathology is bone and muscular compromise, which leads to intense pain, weakness and malaise, these being exacerbated by the action of the HD. As a result of this, individuals tend to refuse to undertake treatment, fearing the occurrence of intradialytic complications⁽²⁴⁾.

Active listening and effective dialogue, established between the health professional and patient, are the pillars for a relationship of trust and success in the treatment. Trustworthiness allows the individual to explain her fears, doubts and beliefs, and based on this the professional

learns of the difficulties found in order to develop strategies which facilitate the subject's adherence⁽¹⁰⁾.

FINAL CONSIDERATIONS

In the present study, the presence was observed of elements which influenced – both positively and negatively – the patient's response to the treatment. The main obstacles mentioned were difficulty with transport, explained by the low socioeconomic level, the deficit of knowledge regarding the disease, the limitations resulting from the treatment and the disruptions experienced in the HD sessions. The motivating aspects for therapeutic adherence, on the other hand, were coexistence with the HD machine, the undertaking of laboratory tests, religious faith, and the presence of social support.

In the light of the above, it is well-known that one should highlight that adherence constitutes the fundamental point for treatment of CKD, attenuation of complications and of cardiovascular events in the course of the therapeutic plan. For this, it is necessary for health professionals to act in relation to the factors which influence adherence, with the aim of understanding the phenomena which lead to the failure of this process, and to develop educational strategies with the aim of raising individuals' awareness regarding the importance of adhering to the treatment and possible improvement in quality of life.

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