

Clinical conditions and health care demand behavior of chronic renal patients

Condições clínicas e comportamento de procura de cuidados de saúde pelo paciente renal crônico

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Descritores

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Abstract

Objective: To identify the clinical conditions and health care demand behavior of chronic kidney patients in the therapeutic itinerary for hemodialysis.

Methods: Qualitative, descriptive and exploratory study based on an interview with ten patients at a renal replacement therapy clinic under hemodialysis treatment and analysis resulting from the use of the Collective Subject Discourse technique, by means of the software qualiquantisofty.

Results: The clinical conditions on the therapeutic itinerary evidenced symptoms of unease and the baseline disease profile identified included hypertensive nephrosclerosis, diabetic nephrosclerosis, undetermined cause and diabetic nephrosclerosis associated with arterial hypertension. The behaviors that negatively affected the health control were the delay to receive care in the health network, the non-acceptance of the disease and the treatment.

Conclusion: Few patients received early monitoring without any sign of symptoms. Nevertheless, the majority were hospitalized suddenly.

Resumo

Objetivo: Identificar as condições clínicas e comportamento de procura de cuidados de saúde pelo paciente renal crônico no itinerário terapêutico para a hemodiálise.

Métodos: Estudo qualitativo, descritivo e exploratório a partir de entrevista com dez pacientes de uma clínica de terapia renal substitutiva em tratamento hemodialítico e análise resultante da utilização da técnica do Discurso do Sujeito Coletivo por meio do software qualiquantisofty.

Resultados: As condições clínicas no itinerário terapêutico evidenciaram sintomas de mal-estar e o perfil das doenças de base identificadas foram nefrosclerose hipertensiva, nefrosclerose diabética, causa indeterminada e nefrosclerose diabética associada com hipertensão arterial. Os comportamentos que prejudicaram o controle de saúde foram à demora no atendimento na rede de saúde, a não aceitação da doença e do tratamento.

Conclusão: Poucos tiveram acompanhamento precoce, sem manifestação de sintomas. Todavia, a maioria deles tiveram internação hospitalar de maneira repentina.

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Introduction

The global prevalence of chronic renal disease is estimated at around 8-16% and represents a growing public health problem around the world. In the United States, the incidence and prevalence have doubled in the last 10 years.⁽¹⁾

The number of people diagnosed with the disease who have reached the advanced stages and need to start emergency treatment is increasing and in unfavorable conditions for patients and health professionals, as it significantly compromises the quality of the inclusion in and adaptation to the treatment.

This situation arouses the following reflection:
- What factors are present in the patient's therapeutic itinerary that interfere in the diagnosis and treatment?

Therapeutic itinerary is considered as the route the individuals follow in search of health or therapeutic care. The evolution of chronic renal disease is silent and the course is frequently asymptomatic until the advanced stage is reached. As a result, the patient only seeks medical care when one or more complications of the disease and/or comorbidities are already present,⁽²⁾ which puts up a greater challenge for professional care.

The therapeutic approach is essential for inter/cross-disciplinary actions and also fundamental for communicative practice oriented towards mutual understanding.⁽³⁾ And, when the conduct is early and appropriate to patients with diabetes *mellitus*, arterial hypertension or chronic renal disease, and articulated among the complexity levels of the health network, this permits retarding the start of dialysis therapy.⁽⁴⁾

Chronic renal disease has gained alarming proportions.⁽⁴⁾ Brazil has important prevalence and incidence levels of patients under renal replacement therapy, and hypertensive, diabetic and obese patients are considered risk groups for the development of chronic renal disease.^(5,6)

Although the National Primary Health Care Policy considers that all health professionals are responsible for guaranteeing holistic care delivery, highlighting the prevention of problems, a gap re-

mains between the primary and secondary care levels, as obstacles remain for user access which can compromise the comprehensiveness of care.⁽⁵⁾

At the medium complexity level, specialized diagnostic and therapeutic care is expected, guaranteed based on the referral and counter-referral process of arterial hypertension, diabetes *mellitus* and kidney disease patients. At the high complexity level, the access to and quality of the dialysis process needs to be guaranteed with a view to achieving a positive impact on survival, morbidity and quality of life.⁽⁶⁾

It is considered important to know the factors present on the therapeutic itineraries of patients demanding health care, which influence the form of coping with the disease diagnosis as well as with the prescribed treatment. Knowing the itinerary allows to us apprehend the interference of the scenario and of the team's approach and posture in client care.

Thus, the objectives of this research were to identify the clinical conditions and behaviors of kidney patients on their therapeutic itinerary to take part in hemodialysis and to discuss how these data can support nursing interventions.

Methods

Qualitative research developed between January and March 2013 at a private renal replacement therapy clinic accredited by the Unified Health System in the City of Rio de Janeiro, in the Brazilian Southeast.

The research participants were ten patients with chronic kidney disease, corresponding to 70% of the adults from the daytime hemodialysis service, over 18 years of age, male and female, in the first year of hemodialysis treatment, in order to allow them to remind their therapeutic trajectory. Adults without clinical conditions to participate at the moment of the interview were excluded.

Information on the participants' personal and clinical characteristics was obtained from their patient histories. Next, during the hemodialysis session, an individual interview was held, using semi-structured questions, with a mean length of one

hour, addressing the therapeutic trajectory, including aspects of professional care at different health institutions until that moment.

In the data analysis and discussion, the Collective Subject Discourse technique was used, by means of the software *qualiquantisofty*. Based on the methodological figures Key Expressions, Core Ideas and CSD, the essence and meaning of each testimonial could be revealed in one sole collective synthesis discourse.⁽⁷⁾

The reading and rereading of the testimonials and the use of the program devices for data analysis permitted unveiling the meanings the participants attributed, arranged as CSD, as a first approach of the clinical conditions and individual behaviors on the therapeutic itinerary until their inclusion in the hemodialysis.

The study development complied with the Brazilian and international ethical standards for research involving human beings.

Results

The sample consisted of three (30%) male and seven (70%) female patients, with a mean age of 51 years. The baseline diseases identified in the histories indicated 50% hypertensive nephrosclerosis, 20% diabetic nephrosclerosis, 10% undetermined cause and 20% diabetic nephrosclerosis associated with arterial hypertension.

In the testimonials of the recorded interview, it was evidenced that they discovered the kidney disease when they felt bad, starting their care trajectory through the primary care service 30%, hospital 30%, private consultations through the health insurance 20%, adding up 80% of individuals who suddenly started the hemodialysis in an intra-hospital context. The other 20% did not manifest any symptoms, despite periodical monitoring of the baseline diseases at the primary care service, followed by conservative treatment and the start of hospital dialysis. Nevertheless, the kidney problem was detected in a late phase.

As regards the behaviors for care in the health network, two core ideas prevailed as harmful fac-

tors for health control. In this respect, 50% were related to the delay in health care, as indicated in the following key expressions: [...] to schedule the first appointment at the primary care service I had to arrive at four a.m. to catch a queue that went already around the block! I had to sleep in the queue to get a number! [...] That's a massacre for who's ill! [...] But that's what we see every day [...]. I kept on waiting all day, I was only attended at night [...].

Another idea 60% of the participants indicated was related to the non-acceptance of the disease and treatment, as evidenced in the key expressions: [...] the main complication was that I did not want to go there to do it! Not have the courage [...], difficulty to accept it [...]. It is horrible to sleep thinking that you have to wake up the next day [...] to go for dialysis, [...] to leave in order to try and survive, [...] go to a machine and depend on it to live, that's very difficult [...].

Discussion

The results cannot be generalized to the experience of the chronic kidney clients undergoing hemodialysis. Although the method promotes the combination and synthesis of the testimonials in a collective discourse, each of them presents the individual wealth of each participant's clinical and behavioral conditions on the therapeutic trajectory. These, in turn, constitute singular experiences that contain peculiar and individual characteristics, although they can come up as core ideas in a collective discourse.

The understanding of the patients' life dynamics contributes to the reflection on nursing care, as it implies considering behaviors related to the coping and adaptation difficulties, besides existing frailties in the professional approach, indicating that the intervention needs to be more precise. And that the act of welcoming, which is so important for these individuals, lies within reach.

To prevent the kidney disease, all patients in the risk group, even if asymptomatic, need an annual assessment. Simple and cheap tests, such as blood, serum creatinine and urine tests to detect protein,

as these are kidney function markers that can be controlled at the primary care level.⁽²⁾

The care flow demonstrated that the disease was discovered late, so that the patient needed emergency care. More detailed professional care during the diagnosis avoids coming and going to the health sector and the galloping progression of the disease.⁽⁸⁾ The late diagnosis and late visit to the nephrologist indicates that 25.8% of the primary care physicians do not forward patients with characteristic cases of advanced reduction of the kidney function rate to the specialized nephrology service. This signals the risk this situation causes with regard to the morbidity and mortality and the costs related to the complications deriving from inappropriate conducts.⁽⁴⁻⁶⁾

Due to the absence of symptoms in the initial stages of the disease, the health professionals always need to maintain suspicious, mainly in patients with risk factors. This early diagnostic difficulty hampers the opportunity to implement prevention measures, partially due to the lack of knowledge about the definition and classification of the disease stages and the non-use of simple tests for its diagnosis and functional assessment.^(9,10)

Studies indicate that, when patients are attended in the pre-dialysis phase and by an interdisciplinary team, compared to patients who only received traditional medical care, their survival increased by eight months after they started dialysis.⁽¹¹⁾

And the care this team delivers grants the patients satisfactory clinical results when in therapy and reduces the frequency of emergency dialysis, the occurrence of hospitalizations and the mortality rate.^(12,13) For that purpose, the health service team, within its own care logic, in order to attend to the patients' needs to a certain extent and in a certain way, should stimulate their autonomy in view of their new health condition.⁽¹⁴⁾

The diagnosis was evidenced as a difficult phase of coping with the disease and the constraints the treatment imposes. Nevertheless, the support, respect and attention the health professionals granted to these patients were highlighted as a professional competence and a factor that makes things easier.

The professionals should know and identify them based on the behaviors, so as to help them cope with their current condition and relieve their tensions and fears. In addition, it permits a more focused intervention that can impede/prevent future complications.⁽¹⁵⁾

Despite the thoughtful care and, sometimes, lack of welcoming in hospital care, overcrowded emergencies, which are constant in Rio de Janeiro and cause a low level of problem-solving ability of primary care and a precarious hospital network, leading to uncertainties and/or fears with regard to the accomplishment of the treatment.^(16,17)

The characteristics of the emergency service, as the patient's main entry door to the services, make it difficult to maintain individual privacy in view of the many patients attended and procedures. Sharing actions can be an additional stressor for the patient, already aggravated by the diagnosis and the unstable clinical condition. This influences and hampers patients' coping with the chronic kidney disease and their adaptation to the renal replacement therapy.⁽¹⁸⁾

Effective communication is the first step towards good welcoming and, in a way, when well used, it can mitigate the infrastructure problems they describe. This approach has been documented as a key point in care, with great potential to damage or benefit the patient. Approximately 63% of the sentinel events are directly linked to communication errors.⁽¹⁹⁾

The second limitation, of the personal type, was the difficulty to accept the disease and the treatment. The factors that influence the compliance with treatment are trust in the team, support networks, acceptance of the disease; while the hindering factors are non-acceptance of the disease/treatment and insecurity.⁽²⁰⁾

Denial can be related to insecurity and all other factors identified as limiting. At the start of the treatment, the prevalence of anguishing and depressive symptoms is significant, hampering the adaptation. Therefore, more extensive and active psychological care needs to be considered still during the pre-dialysis phase.⁽¹⁷⁾

This limitation can be closely related with the short time between the diagnosis and the start of the treatment. When the start of the dialysis is not an unexpected event, 85% have time to get to grips with the disease, imagine what it would be like to live with dialysis and prepare well to start the treatment, through monitoring in nephrology consults for six months before the dialysis.⁽²¹⁾

On the other hand, a downward trend was observed in the negative feeling over time, indicating that the patients felt less concerned and less inclined to cry at the end of the first year after starting the treatment.⁽²¹⁾

As the treatment negatively affects the patients' social and family relations and physical-psychological condition; and the stress, anguish and depression many of them go through stem from the lack of information about the disease, their treatment and life expectancy, there is an urgent need for changes in the elaboration of approach strategies.

The health team working in dialysis therapies and mainly in conservative treatment needs to get structured to cope with the problems that emerge among the clients in their respective activity areas, in order to start changing this reality.⁽¹³⁾

The nurses are responsible for monitoring and helping the patients in the process of coping with the disease, surveillance and monitoring of therapeutic targets and strengthening of the health care systems.⁽²²⁾

In addition, they need to heed all aspects surrounding these patients with a view to respecting the limits of each individual, as their know-how needs to be integrated, in which the care is based on a committed, responsible and sincere relationship of trust between professionals and users.⁽²³⁾

As the third limiting factor on the trajectory, the delay to get care demonstrated that the organization of this system is permitting a larger demand than supply at the nephrology service. This hampers the access to the treatment and contributes to the late start; affects the choice of the therapy that best attends to them; and results in a lag in the orientations received, insecurity and non-acceptance of the disease and the health condition.

A better access to health care has been associated with a better treatment and control of hypertension and diabetes, a potential mechanism through which the incidence of chronic kidney disease could be avoided.⁽²⁴⁾

This therapeutic retrospective of successes and errors, fear, facilities and difficulties permitted attributing a new meaning to postures and conducts in coping with the disease and treatment and the steps and mismatches common to patients in the health network. These support professional actions that make the therapy more effective.

Conclusion

Most participants started their care trajectory through the public health network. The clinical conditions during the therapeutic itinerary evidenced symptoms of feeling ill and the advanced clinical profile of the baseline diseases.

The behaviors negatively affected the health control because of the delay to get care in the health network, the non-acceptance of the disease and the treatment. Few participants were periodically monitored for the baseline diseases at a primary care service and did not manifest symptoms. Nevertheless, most of them were hospitalized in emergency situations.

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Collaborations

Torchi TS contributed to the project conception, execution of the research and writing of the paper. Araújo STC contributed to the project conception, writing of the paper and relevant critical review of intellectual content. Moreira AGM, Koeppe GBO and Santos BTU cooperated with

the writing of the article and final approval of the version for publication.

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