

CLINICAL SCIENCE

Early nephrology care provided by the nephrologist alone is not sufficient to mitigate the social and psychological aspects of chronic kidney disease

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OBJECTIVE: Patients with chronic kidney disease who receive early nephrology care have a better prognosis with maintenance dialysis. We aimed to determine whether early referral to a nephrologist can also improve the psychological burden of having chronic kidney disease.

SUBJECTS AND METHODS: Thirty-nine patients with chronic kidney disease that required hemodialysis were studied: 19 had a ≥ 6 -month history of nephrology care (Group1), and 20 had never received any prior nephrology care (Group2). All patients participated in a semi-structured interview that addressed their perceived knowledge and psychological aspects related to CKD and hemodialysis. Demographic and laboratory data as well as socioeconomic status were evaluated.

RESULTS: In both groups, most of the patients were of low socioeconomic status. Group 1 had significantly better laboratory parameters ($p < 0.05$). The patients' answers to the questions showed no differences between the groups: 63% of Group 1 and 55% of Group 2 reported that they had no prior knowledge about dialysis; 58% and 40%, respectively, reported that they "don't completely understand what the doctor says"; and 74% and 85%, respectively, believed that their "kidneys would work again".

CONCLUSION: Pre-dialysis nephrology care improves the clinical conditions of the patients with chronic kidney disease but is insufficient for minimizing other aspects of having chronic kidney disease.

KEYWORDS: Chronic illness; End-stage renal disease; Dialysis; Late referral; Psychosocial aspects.

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INTRODUCTION

Chronic kidney disease (CKD), more than many other chronic diseases, burdens the patients socially and psychologically.¹ It is well known that early nephrology care made possible by early referral results in better clinical conditions for the CKD patients, allows for the possibility of choosing the dialysis method, having a definitive vascular access or even a pre-emptive renal transplant. Ten years ago, Lameire & Van Biesen for the first time defined early referral as the situation where a CKD stage 5 patient is followed in the renal unit for at least one month and to whom the different modes of dialysis are duly explained; late referral as defined as the situation of a patient that is admitted for emergency dialysis.² Afterwards other definitions have been adopted. Late referral is also a negative factor affecting the quality of

life.³ Late diagnosis and late dialysis initiation lead to hypertension, uremia, hypervolemia, emergency dialysis and even death.^{4,5,6} Early nephrology care allows for an adequate predialysis CKD education which can delay the initiation of dialysis and decrease mortality.^{7,8} However, improving survival via dialysis is not enough.⁹ It is, for instance, unknown whether early nephrology care also improves other aspects of having CKD. As Landsman pointed out the CKD patient is a marginal man/woman drifting between the world of the sick and the world of the healthy.¹⁰ Therefore, we compared, at the initiation of hemodialysis, the burden and the coping of CKD patients who were followed by a nephrologist for ≥ 6 months with those patients who discovered they had CKD only when they underwent an emergency dialysis.

SUBJECTS AND METHODS

The study was conducted at Hospital das Clínicas, a university tertiary hospital in São Paulo, Brazil. Consecutive patients attended by the Nephrology Service from May 2007 to January 2008 with the diagnosis of CKD stage 5

(estimated GFR < 15 mL/min/1.73 m²) and indication for immediate initiation of maintenance hemodialysis were evaluated for inclusion in the study. Inclusion criteria were age ≥ 18 years, GFR < 15 mL/min/1.73 m², and the ability to understand and answer the questions we posed to them. Exclusion criteria were pregnant women, psychiatric treatment, previous renal transplantation or dialysis, acute renal failure or acute-on-chronic renal failure, and terminal neoplasia. Patients were included just before the first hemodialysis and comprised two groups. Group1 comprised 19 patients who had been followed by nephrologists for ≥ 6 months in the Nephrology Service of Hospital das Clínicas. The choice of hemodialysis was decided by the attending nephrologist based on the clinical conditions of the patient and the scarcity of places for other types of dialysis in our city. Group2 consisted of 20 patients who discovered they had CKD only when they were admitted to the Emergency Service in emergent need for hemodialysis. Before starting the study we checked how many patients could meet the inclusion criteria within the proposed timeframe of 9 months. We found out, in the last 6 months of 2006, 105 out patients were sent to chronic dialysis treatment through the Nephrology Clinic, and 8 to 10 patients per month started dialysis coming from Emergency Service. On the other hand, each of our patients would have to undergo up to 3 interview sessions so to provide us all the information we required. Furthermore, giving the time-consuming nature of this study, the maximum number that could be included in the study would be 6 patients per month. Due to this situation, we so managed that Group1 would have a number of patients as close as possible to the limited number of patients included in Group2. Only the patients that met the adopted criteria and who had given written informed consent were included. Ten different nephrologists had their patients included in Group1 (median 1.5 patients per nephrologist). Among the nephrologists, seven were seniors and three were residents in their second or third year of training in nephrology.

The last laboratory data obtained before the first hemodialysis were analyzed. GFR was estimated by the MDRD equation.¹¹

Socioeconomic status (SES) was evaluated by an instrument composed of five closed questions about income, type of home, level of education, type of job of the patient and number of people living in the house. Patients were classified as low-, middle- or high-SES according to the total points obtained in the answers to the questions.¹²

As soon as the patients were included in the study they participated in a semi-structured interview carried out by a trained psychologist (with experience in attending patients on hemodialysis) that explained the questions, if necessary, and transcribed the answers. The interview consisted of 12 questions, covering the perceived knowledge and psychological aspects related to CKD and dialysis. The answers to each question were categorized in a blind way by two independent individuals, a psychologist and a medical doctor, using a content analysis technique.¹³ The few cases where disagreement occurred were discussed between them and a consensus reached.

The study was approved by the Committee for Evaluation of Research Protocols of our institution, and written consent was obtained from each patient before the interview.

Statistics: Continuous data were tested for normality by the Kolmogorov–Smirnov test and analyzed by Student’s t

Table 1 - Demographic data and socioeconomic classification.

	Group1 N = 19	Group2 N = 20	P-value
Age (years)	56.4 ± 11.9	47.7 ± 10.9	0.044
Gender (Male/Female)	12/7	11/9	0.745
Level of school education			0.496
None	0	2	
Incomplete elementary school	11	9	
Incomplete high school	4	4	
Completed high school	3	2	
Completed university	1	3	
Socioeconomic status			0.889
Low	18	19	
Middle	1	1	
High	0	0	

test or Wilcoxon test, as appropriate. Categorical data were analyzed using Fisher’s test or chi-squared test. The adopted significance level was P < 0.05. Data are presented as mean ± SD or percentage. All statistical analyses were performed using GraphPad Prism version 4.00 for Windows (GraphPad Software, San Diego, California USA).

RESULTS

Demographic data are presented in Table 1. Group1 had been followed for 26 ± 20 months before hemodialysis initiation. Most patients in both groups had a sexual partner: 75% in Group1 and 65% in Group2.

As shown in Table 2, Group1 initiated maintenance hemodialysis with better laboratory parameters. Moreover, seven patients in Group2 presented hyponatremia, which probably mirrors the hypervolemia they presented at Emergency Service admission. No patient in Group1 presented hyponatremia.

The contents of the answers obtained in the interview were similar in both groups. In Table 3, the answers to the questions about perceived knowledge of renal function and dialysis are presented.

As shown in Table 3, most patients in both groups could explain how the kidneys work, e.g., “The kidney filters salt and excess substances in the body and sends them away in the

Table 2 - Laboratory parameters of Group1 and Group2 collected before the first hemodialysis.

	Group1	Group2	P-value
Blood urea (mg/dL)	160 ± 53 n = 19	222 ± 83 n = 20	0.009
Serum creatinine (mg/dL)	7.2 ± 2.9	10.5 ± 4.2	0.008
Serum sodium (mEq/L)	140 ± 4	137 ± 4	0.004
Serum potassium (mEq/L)	5.1 ± 0.7	5.7 ± 1.3	0.096
Serum albumin (g/dL)	3.6 ± 0.9 ^a	3.4 ± 0.4 ^b	0.356
Serum calcium (mg/dL)	8.4 ± 1.0 ^c	8.1 ± 0.8 ^d	0.379
Serum phosphate (mg/dL)	5.9 ± 1.4	7.2 ± 1.9	0.020
Calcium-phosphate product (mg/dL)	46 ± 9 ^c	59 ± 16 ^d	0.005
pH	7.3 ± 0.1 ^c	7.3 ± 0.1 ^d	0.200
Blood bicarbonate (mEq/L)	20.4 ± 2.9 ^c	17.6 ± 4.4 ^d	0.036
Hemoglobin (g/dL)	11.4 ± 2.0	9.7 ± 2.3	0.013
Leukocytes (10 ³ /mL)	8.3 ± 2.7	8.2 ± 2.7	0.945
Platelets (10 ³ /mL)	250 ± 74	250 ± 118 ^d	0.995
GFR (mL/min/1.73 m ²)	9.1 ± 4.3	6.0 ± 3.4	0.008

GFR: glomerular filtration rate estimated by MDRD equation
^an = 13; ^b n = 15; ^c n = 17; ^d n = 19

Table 3 - Knowledge about renal function and hemodialysis.

	Group1	Group2
Do you know how the kidneys work?		
He/she doesn't know	7 (37%)	9 (45%)
Yes, he/she knows	12 (63%)	11 (55%)
Do you know how hemodialysis works?		
He/she doesn't know	3 (16%)	6 (30%)
He/she knows	16 (84%)	14 (70%)
Could you name your disease?		
He/she gives the name or explains some medical characteristics of the disease	13 (68%)	12 (60%)
He/she shows no knowledge about the disease	6 (32%)	8 (40%)
Do you feel informed about hemodialysis?		
Yes	6 (32%)	5 (25%)
No	6 (32%)	12 (60%)
More or less	7 (37%)	3 (15%)
Do you understand the explanations provided by your doctor?		
Yes	11 (58%)	8 (40%)
Sometimes/something	8 (42%)	8 (40%)
They never explain anything	0 (0%)	4 (20%)

urine." (Group1). However, it is noticeable that seven patients of Group1 (37%) were unable to give any information about how the kidneys work.

More than 70% of the patients of both groups could explain how hemodialysis works, e.g., "I know the machine cleans the blood and does what the kidney can't do anymore." (Group1) or "It cleans the blood entering the machine, and after this cleaning (the blood) returns to the body." (Group2).

The question "Do you understand the explanations provided by your doctor?" gave interesting answers, e.g., "Yes, I understand but I don't want to accept them." (Group1). However, 40% of the patients of both groups answered they did not understand well what the doctor said and complained about the language used: "I understand sometimes. They speak in a complicated way." (Group1).

To evaluate whether longer follow-ups could have influenced the perceived knowledge, patients of Group1 were divided into two subgroups: those with follow-up < 24 months and those \geq 24 months, and their answers to the questions presented in Table 3 were compared. To the question: "Do you feel informed about hemodialysis?" all 9 patients with follow-up \geq 24 months answered that they did feel informed, but only 6/10 patients with follow-up < 24 months gave the same answer.

Table 4 presents the results for questions concerning the impact and restrictions that CKD brings about. Although "restrictions" in these questions meant more than only dietary restrictions, most patients took them only as dietary restrictions and complained about them: "Eating cooked fruits is something I still can't get used to. It is very unpleasant." (Group1).

Three patients of each group were so moved by the question about the impact of CKD on their lives that they did not answer and came to tears. All the others showed feelings of hopelessness and suffering: "I feel like an invalid." (Group1) or "I believe that it is only a matter of time because my hour (death) is already settled." (Group2). A feeling of guilt could also be recognized, mainly in Group2, caused by what patients considered carelessness or ignorance: "For me this is God's will. It also means I was careless with my health, with my life. I think I had been overeating fruits and salty foods." (Group2).

Concerning the possibility of finding (or keeping) a job despite CKD, slightly more than half of the patients in both groups showed positive expectations: "Yes, one can work. If one works with one's head (if one is not a manual worker), one can have a normal life." (Group2). However, others felt unable to work: "I don't have the strength to work." (Group2) or, "The

Table 4 - Impact of having chronic renal disease.

	Group1	Group2
Were you given any restrictions after the diagnosis of CKD?		
He/she denies to have been informed of any restrictions	2 (11%)	6 (30%)
Yes: food, drinking, etc.	15 (79%)	14 (70%)
Answer did not fit the question	2 (11%)	0
What is the impact of having CKD on your life?		
Death/sadness	6 (32%)	6 (30%)
It (CKD) is a consequence of ignorance/carelessness with their own health	1 (5%)	6 (30%)
A change for the worse	9 (47%)	5 (25%)
He/she can't explain	3 (16%)	3 (15%)
Do you believe that a patient on hemodialysis is able to work?		
Yes	6 (32%)	8 (40%)
No	5 (26%)	5 (25%)
It depends on the kind of work	5 (26%)	3 (15%)
He/she doesn't know	3 (16%)	4 (20%)
How do your family, friends, and acquaintances consider people with CKD?		
Positive attitudes	7 (37%)	5 (25%)
Negative attitudes	11 (58%)	12 (60%)
He/she can't answer	1 (5%)	3 (15%)

time spent to get to that place to undergo dialysis doesn't allow one to keep working." (Group1).

As shown in Table 4, most patients of both groups felt a negative attitude of their families toward them. This negative attitude was translated by the patients as (1) pity: "They pity me... My parents don't even touch this subject." (Group1); (2) burden: "They think the best is for me to undergo hemodialysis so I won't be a burden to them." (Group2); (3) exaggerated worry: "They feel like I'm a baby. They take care of me as if I were a child." (Group1); (4) fright and death: "The first thought crossing their minds is I will die." (Group2). Positive attitudes were expressed as: "They trust in my treatment. They think this is the right path (to take)." (Group1).

Table 5 presents the answers to questions concerning the patients' beliefs, feelings and expectations. In trying to explain the reasons for getting sick, more than 60% of the patients of both groups gave appropriate answers as: "When I was 19 I had nephritis, and I think this is the cause of my disease now." (Group1) or, "I had hypertension, and I didn't have enough information to take appropriate care of myself." (Group2).

Some inappropriate answers were loaded with feelings of guilt, mainly in Group2: "I believe that I became sick because of something I have drunk. I think it was Coke. I'm a Coke addict." However, other inappropriate answers in both groups attributed CKD to unusually hard work: "It was due to my hard work, having to carry very heavy loads. The bad conditions of my work ended in my losing my kidneys." (Group1).

The question about the belief in whether their kidneys would work again elicited positive answers from 74% of Group1 patients and 85% of Group2. The reasons given by the patients could be divided into (1) positive thinking: "I have much trust in the strength of positive thinking... My kidneys will work again thanks to my strength of mind." (Group1) and (2) God's favor: "I know I will not be cured by Medicine. (But) I can be cured by God." (Group1). Some answers were completely devoid of hope: "I think they (kidneys) will not work again. All left to me is the grave. Anyway, I haven't had, since long ago, any will to keep on living." (Group1).

Regarding the expectations about their future progress, only 42% of the patients in Group1 and 45% in Group2 answered that they needed to cope with the treatment. For the others, coping was very difficult or even impossible to imagine. "I think the best (for me) is to die. I'm waiting for my hour (death). Diabetes is killing me little by little." (Group1).

Summarizing, despite previous nephrology care, the negative impact of having CKD on patients' lives was expressed by our patients as denial, dark thoughts, burden to the family or fear of changes in lifestyle.

DISCUSSION

As shown in our study, early nephrology care provided a better metabolic control to patients in Group1 compared to those in Group2. However, it also showed that early care provided by the nephrologist alone was not enough to mitigate the burden of having CKD. The content of the answers given during the interviews showed that having CKD had the same bad impact on patients of both groups.

Recent papers have shown that the longer the nephrology care, the better the outcome.^{14,15} Answering a survey, Canadian nephrologists considered the ideal time for referral to a nephrologist to be more than 12 months.¹⁶ Longer follow-ups allow time for the patients to absorb the information they are given. For example, all patients from our Group1 who had been followed for ≥ 24 months felt informed about hemodialysis, but only 6/10 Group1 patients with < 24 months had the same feeling. Also Finkelstein et al reported that increased frequency of nephrology visits improves the patients' perceived knowledge about hemodialysis and transplantation.¹⁷

Starting maintenance dialysis negatively impacts the patients' lives despite previous nephrology care. However, little attention has been given to a real understanding of the beliefs, perspectives and expectations of CKD patients. Tong et al. described how CKD patients have to adjust to the permanent intrusiveness of the illness into their physical health, identity, lifestyle, family, employment, etc. They also found that the patients complain about lack of integration within the health care system and about the insufficient information and psychosocial support provided to them.¹⁸

Nephrologists alone are unable to provide all the needs of this unique patient, especially the specific needs just mentioned.¹ Our patients attributed their sparse knowledge about dialysis to the limited time spent by the doctors with them and to the language they used "I understand very little. I think they don't have time. They speak always in code" (Group2). Communication between doctors and patients involves inter-personal relationships, and the patients' complaints could be associated with specific doctors. However, this kind of complaint was expressed both by Group1 and Group2 patients. The latter were attended by more than two doctors during their hospitalization in Emergency Service, and Group1 patients were attended to by 10 different nephrologists. This indicates that nephrologists in general should give more attention to their communication with CKD patients. The communication between doctors and patients has been given more attention, but it still requires further study.¹⁹ An evaluation of physicians' counseling to

Table 5 - Beliefs, feelings and expectations.

	Group1	Group2
What do you think caused your disease?		
Answer did not fit the question	4 (21%)	4 (20%)
He/she gives an appropriate reason	12 (63%)	12 (60%)
He/she gives an inappropriate reason	3 (16%)	4 (20%)
Do you believe your kidneys will work again?		
Yes	14 (74%)	17 (85%)
No	2 (16%)	2 (5%)
He/she doesn't know	3 (11%)	1 (10%)
How do you imagine your life will be from now on, as you undergo treatment?		
One needs to cope	8 (42%)	9 (45%)
It will be difficult to cope	10 (58%)	8 (40%)
He/she can't even imagine	1 (5%)	3 (15%)

their patients on hypertension and lifestyle showed that this kind of counseling was insufficient. When more lifestyle counseling was provided, with longer visits, both the patient and the physician reported greater satisfaction.²⁰

In the care of CKD patients, one must take into account their SES. SES is an important factor in the incidence of ESRD and in access to dialysis and to health care as a whole.²¹ SES also affects the quality of life of patients undergoing dialysis. The assessment, via the SF-36 questionnaire, of quality of life of Brazilian patients entering dialysis, showed that SES was the only independent and significant factor affecting all SF-36 dimensions. Patients with low SES were the most impaired.²² Patients with low SES thus deserve special attention, especially in regards to access to information. Fischer et al showed that among African Americans with chronic kidney diseases sociodemographic factors are strongly associated with higher scores of depression and poorer quality of life.²³ The fear of losing their jobs was common among our patients and brought them a feeling of hopelessness: *"It is complicated going to the hospital almost every day... I don't know if I will be able to work. I'm lost"* (Group2) Psychosocial factors might be involved in CKD patients with low education level and SES like ours, as has been reported in the case of coronary heart disease.²⁴

Studies like ours, with open questionnaires, allow for the investigation of the patients' beliefs about their disease and treatment. Some kinds of explanations about their disease, even though they may help give meaning to the illness, can be potentially destructive. For example, the belief that lack of self-care is a cause of CKD, as expressed by two of our patients, can lead to guilt and depression: *"For me this is God's will. It also means I was careless with my health, with my life"* (Group2).²⁵

Additionally, regarding the psychological aspects involving the CKD patient, it should be noted that the CKD patients almost always consider themselves a burden to their families *"I think they feel me to be a burden for them... They think they will have to care of me"* (Group1). Furthermore, White and Grenyer showed that the partners of CKD patients, when asked about their feelings, expressed pervasive sadness, resentment, guilt and loss.²⁶

Most of our patients, when asked about the "restrictions" brought by CKD, mentioned only the dietary restrictions and considered them "losses." This kind of feeling could explain why knowledge of dietary restrictions is not always predictive of dietary compliance.²⁷ Fluid and diet restrictions are felt as extremely boring, as expressed by our patients. This kind of feeling was also reported by Krespi et al.²⁵

A study evaluating the CKD patients' priorities for health research pointed out eight priorities: prevention of kidney disease, better access to and improvement of kidney transplantation, reduction of symptoms of CKD and complications associated with treatment, new technological therapies, psychosocial aspects of living with CKD, whole-body instead of organ-specific care, improvement in dialysis and caregiver support.²⁸ Curtis et al suggest there may be a survival advantage for patients attending a multidisciplinary clinic compared to patients attending a standard nephrology care.²⁹ Thus a multidisciplinary team-based care could attend to these indicated priorities better.

We must note that our findings and conclusions cannot be generalized to all CKD patients but are restricted to patients such as ours, of low SES status. This condition may imply more difficulties in having access to, understanding, and

applying the information they require on their disease and treatment.³⁰ This may not be the case for patients of higher SES and attending a private service. Other studies with a larger number of patients with different SES status are necessary in order to verify if our findings can be generalized.

In conclusion, early nephrology care improves the clinical conditions of the CKD patients but is not enough to minimize the psycho-social aspects of having chronic kidney disease.

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