

Knowledge, attitudes, and practice by caregivers of children and adolescents undergoing hemodialysis or peritoneal dialysis

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ABSTRACT

The objective of this study is to assess knowledge, attitudes, and practice by caregivers of children and adolescents with chronic kidney disease undergoing hemodialysis or peritoneal dialysis and associate them with their socioeconomic conditions. A cross-sectional, inquiry type of study to assess knowledge, attitudes, and practices was conducted by 30 caregivers. The differences in score means, according to socioeconomic conditions, were compared through Student's t-Test or ANOVA, and $p < 0.05$ was considered significant. Caregivers had difficulties in terms of knowledge, attitudes, and practice. A statistically significant difference was seen in the knowledge area related to the type of housing ($p = 0.001$) and schooling ($p = 0.014$). As far as the attitude is concerned, there was no significance. Regarding practice, there was a statistical difference in terms of the housing floor ($p = 0.015$). Socioeconomic conditions were related to knowledge, attitudes, and practice by caregivers of children and adolescents with chronic kidney disease undergoing hemodialysis or peritoneal dialysis.

Descriptors: Caregivers; Nursing; Health Knowledge, Attitudes, Practice.

INTRODUCTION

Chronic kidney disease (CKD), a clinical syndrome derived from the slow, gradual, and irreversible loss of kidney function⁽¹⁾, is characterized by a drop in the glomerular filtration rate, causing the loss of the kidneys' regulating, excretory, and endocrine functions⁽²⁾.

CKD is a frequent pathology. Together with high morbidity and mortality rates, it is considered a worldwide public health problem that has a negative impact on patients' quality of life. Its incidence and prevalence in the pediatric population has been increasing; however, its frequency is less than among adults⁽²⁻⁴⁾.

When CKD is diagnosed early, conservative treatment is applied with dietary restrictions and the use of medicines. At more advanced stages, the use of kidney replacement therapies (KRT) such as hemodialysis (HD), peritoneal dialysis (PD), and kidney transplant is recommended^(2,5).

Children and adolescents with CKD demand complex care; therefore, parents or caregivers take an important role in the caregiving process. This becomes essential for achieving good results in improving these individuals' quality of life, as the care is not limited to hospital extensions⁽⁶⁻⁷⁾.

Nurses are the main link between hospital units and caregivers⁽⁸⁾. They need to be well prepared so that the nursing care given to children and adolescents is as close as possible to the ideal⁽⁹⁻¹¹⁾.

In the educational process, the main goal is to strengthen people's autonomy; thus, it is important to take knowledge and opinions into account, in addition to grouping the context of environmental, social, cultural, and emotional vulnerabilities⁽¹²⁾.

The KAP (knowledge, attitude, and practice) inquiry provides a situational diagnosis of individuals submitted to a particular study. It shows the perspective that health behavior is connected to the acquisition of a scientific knowledge that may lead to a positive attitude and good practices in health, based on the principle that this behavior is related to people's values and beliefs⁽¹³⁾.

The positive attitude favors people's interest in adopting healthy practices. Although knowledge and attitude are not enough to change and maintain behaviors, they are important as part of the awareness process in health⁽¹⁴⁾.

Caregivers almost never receive enough information on the disease and the care needed to continue treatment^(5-8,15-16). It is also known that socioeconomic conditions interfere with understanding and implementing care^(5,10-11,13).

Caregivers must receive and understand information on the various aspects of the disease in order to adhere to the treatment, so that therefore the children and adolescents will remain engaged with the therapy once they become responsible for their own actions.

Because of the findings produced by the KAP Inquiry, this study is justified by the scientific foundations it gives for nurses to create educational actions whose goal is to raise awareness and lead to behavioral changes in terms of practices that are more health friendly.

In view of this scenario, this study's objective is to assess the knowledge, attitudes, and practices by caregivers of children and adolescents with CKD undergoing hemodialysis or peritoneal dialysis, in addition to verifying whether there is an association between the Knowledge, Attitudes, and Practice inquiry and caregivers' socioeconomic conditions.

METHODS

This is a cross-sectional, descriptive, KAP inquiry type of study that is part of an assessment study category called formative assessment, which obtains data from a specific population group and identifies possible ways for efficient interventions. It consists of a set of questions that aim to measure what the population knows and thinks, and how they act when it comes to a predefined subject⁽¹⁷⁾.

This study was conducted at the Pediatric Kidney Unit, one of the first specialized clinics of the Professor Fernando Figueira Comprehensive Medicine Institute (IMIP, as per its acronym in Portuguese), the main kidney illnesses treatment center in Brazil's Northern and Northeastern regions. The data collection period went from July to August 2014.

The population comprised 41 caregivers of children and adolescents with CKD undergoing hemodialysis or peritoneal dialysis at IMIP's Kidney Unit. The inclusion criterion was being a caregiver to children and adolescents undergoing hemodialysis and peritoneal dialysis. The exclusion criteria were: being a caregiver to transplanted patients or patients whose condition was acute; and having participated in the instrument adjustment test. Six caregivers refused to participate in the research. Those who did accept to participate signed a Free Consent Agreement after the objectives of the inquiry had been clarified.

To elaborate the collection instrument for assessing knowledge, attitudes, and practice, three stages were followed⁽¹⁸⁾:

First: creating the initial form based on the researched literature^(1-2,4-5,8,10-11,16,19)

Second: conducting an appearance and content analysis by the five Pediatric Kidney Unit nurses

Third: evaluating the objectivity and clarity of the questions in the form by five caregivers of patients in hemodialysis or peritoneal dialysis who were not part of the sample

All of the questions in the form were scored from zero to three, as follows: 0 = Unnecessary; 1 = Regular; 2 = Good; 3 = Excellent. The questions that scored a minimum of 2 in the second and third stages remained in the instrument.

Thus, the form comprised questions about the children's and adolescents' clinical and biological characteristics, in addition to socio-demographic characteristics, and caregivers' knowledge, attitudes, and practice. There were true and false statements with dichotomous answers (yes/no) to each question.

The dimensions considered for data analysis were knowledge, attitude, and practice: the *adequate questions* were answered "yes" when the statement was true or "no" when it was false; the *inadequate questions* were answered "no" when the statement was true or "yes" when it was false.

To organize the data, a database was created via double entry into the Excel 2003 Program and validated on EpiInfo 3.5.2. The analysis was conducted by Stata 12.1 SE. Absolute and relative values of the studied variables were calculated. To compare the differences among the knowledge, attitudes, and practice means according to socioeconomic conditions, the Student's t-Test was applied when variables were dichotomous, whereas ANOVA was applied in the case of multiple variables. The significance level was $p < 0.05$.

This study followed Brazilian standards for research with human beings and was approved by IMIP's Human Research Ethics Committee n° 4134 on May 14, 2014.

RESULTS

Thirty caregivers of children and adolescents with CKD undergoing hemodialysis or peritoneal dialysis participated in the study. Most were female (93.3%). Participants' age range went from 23 to 59 years and the average age was 40 years. The majority of caregivers (76.7%) said they had previous knowledge of CKD when patients began their treatment. Only two participants (6.7%) stated they had neither the need for nor the interest in knowing about CKD because they considered that their previous knowledge was enough.

Regarding patients, there was a predominance of adolescents (63.3%). The most prevalent gender was male (56.7%) and peritoneal dialysis was the most usual type of therapy (56.7%).

Table 1 presents caregivers' sociodemographic characteristics. Most of them came from the Recife Metropolitan Region (RMR) and did not hold any employment bonds. Their per-capita income was half a minimum salary or below and their schooling level was low. Although most of them had low purchasing power, they had access to basic sanitation and only a minority lived in places where the roof was made of canvas or wood.

Table 1: Sociodemographic characteristics of caregivers to children and adolescents with Chronic Kidney Disease undergoing hemodialysis or peritoneal dialysis receiving care at a reference hospital's Kidney Unit. Recife, Pernambuco, Brazil, 2014.

Variables	n=30	f(%)
Origin		
Recife Metropolitan Region	16	53.3
Inland/Another State	14	46.7
Housing type		
House	27	90.0
Apartment	3	10.0
Wall		
Masonry/brick	29	96.7
Adobe	1	3.3
Floor		
Ceramics/slab/wood	20	66.7
Cement	10	33.3
Ceiling		
Concrete roof slab	8	26.7
Ceramic roof tile	13	43.3
Asbestos roof tile	4	13.3
Others	5	16.7
Waste		
Recommended destination	24	80.0
Does not go to sewage system	6	20.0
Water supply		
Internal piping system	27	90.0
No piping system	3	10.0
Number of people in household		
≤4	19	63.3
>4	11	36.7
Per-capita income (MS)*		
≤0.5	25	83.3
>0.5	5	16.7
Working		
Yes	11	36.7
No	19	63.3
Schooling		
None/did not finish elementary school	15	50.0
Finished elementary school/did not finish high school	6	20.0
Finished high school or above	9	30.0

* Minimum salary.

Table 2 describes caregivers' knowledge. Most of them did not know where kidneys were located in the body, their functions, illnesses that could lead to CKD, or treatment types. Many believed that a biopsy was a treatment and thought the illness had a cure. They were unaware that treatment success did not depend solely on the type of KRT used but also on the multi-professional team, caregivers, and patients. However, all of them had the knowledge needed to care for the access device, both catheters and fistulas.

As far as the attitude is concerned, all caregivers said they knew what patients' medications were for. Nevertheless, when tracing a parallel of the dimension on the practice when they were asked about the action of calcium carbonate, sevelamer, and calcium acetate, most of them did not answer correctly. One-third of the caregivers were unaware of the amount of sodium in various foods even when it was not added to them (Table 3).

Table 2: Distribution of adequate answers on the knowledge of caregivers to children and adolescents with Chronic Kidney Disease undergoing hemodialysis or peritoneal dialysis receiving care at a reference hospital's Kidney Unit. Recife, Pernambuco, Brazil, 2014.

Knowledge	Adequate answers	
	n=30	f(%)
Care for fistula or catheter	30	100.0
Dietary restrictions regarding CKD	29	96.7
Need to use medication	28	93.3
Complications of CKD	28	93.3
Number of kidneys	26	86.7
Causes of chronic kidney disease	23	76.7
Location of kidneys	13	43.3
Treatment success depends on patients, caregivers, and KRT	12	40.0
Illnesses that lead to CKD	7	23.3
Type of treatment for CKD (biopsy)	7	23.3
CKD has no cure	5	16.7
Kidney function	2	6.7

Table 3: Distribution of adequate answers on the attitude of caregivers to children and adolescents with Chronic Kidney Disease undergoing hemodialysis or peritoneal dialysis receiving care at a reference hospital's Kidney Unit. Recife, Pernambuco, Brazil, 2014.

Attitude	Adequate answers	
	n=30	f(%)
Why medications were prescribed to the patient	30	100.0
Calcium and phosphorus control	29	96.7
Excess meat intake is good for the patient	28	93.3
It is important to keep the potassium balance	25	83.3
Problems in liquid excess	24	80.0
Moment when the patient's treatment occurs	19	63.3
Presence of sodium in foods	10	33.3

Also in terms of attitude, five caregivers of the children and adolescents who underwent HD (38.5%) and four caregivers of those who underwent PD (23.5%) knew the treatment complications. Of the total population of children and adolescents, only one (3.3%) had a fistula and 29 (96.7%) had catheters. All of the caregivers answered positively about their responsibilities in the care needed to keep these access devices functioning and prevent complications. Only five (17.2%) of the 29 caregivers of patients who had catheters said that only the professional staff were responsible for the care of these devices and contradicted their previous reply.

Regarding the assessment of their practice, 17 (56.7%) caregivers allowed patients to eat any foods they liked. The majority, 22 (73.3%), were unaware that the adequacy of dialysis reflected on the KRT success. Many of these believed that physical activity would harm the treatment (Table 4).

Table 4: Distribution of adequate answers on the practice of caregivers to children and adolescents with Chronic Kidney Disease undergoing hemodialysis or peritoneal dialysis receiving care at a reference hospital's Kidney Unit. Recife, Pernambuco, Brazil, 2014.

Practice	Adequate answers	
	n=30	f(%)
Allows patients to eat any foods	13	43.3
Dialysis adequacy	8	26.7
Action of medications	5	16.7

Also regarding practice, although all caregivers stated they had responsibilities in terms of care for vascular access devices for HD and catheters for PD, 12 caregivers of patients with catheters and the one whose patient had a fistula were unaware of the exact nature of these cares. Eight (61.5%) caregivers of patients undergoing HD did not know how to help prevent complications deriving from the treatment.

Table 5 shows differences in the means of knowledge, attitude, and practice rates by caregivers according to their socioeconomic conditions.

Table 5: Distribution of knowledge, attitude, and practice means by caregivers to children and adolescents with Chronic Kidney Disease undergoing hemodialysis or peritoneal dialysis receiving care at a reference hospital's Kidney Unit. Recife, Pernambuco, Brazil, 2014.

Characteristics	Knowledge		Attitude		Practice	
	Mean \pm PD	p value	Mean \pm PD	p value	Mean \pm PD	p value
Sex*		0.387		0.761		0.434
Male	6.0 \pm 1.0		6.5 \pm 0.5		3.0 \pm 0.0	
Female	7.1 \pm 0.3		6.2 \pm 0.2		2.4 \pm 0.2	
Origin **		0.124		0.834		0.073
RMR	7.4 \pm 0.5		6.2 \pm 0.3		2.7 \pm 0.2	
Inland/Another State	6.5 \pm 0.3		6.3 \pm 0.3		2.1 \pm 0.3	
Housing type*		0.001		0.417		0.328
House	6.7 \pm 0.2		6.3 \pm 0.2		2.4 \pm 0.2	
Apartment	9.7 \pm 1.4		5.6 \pm 0.3		3.0 \pm 0.0	
Floor*		0.165		0.184		0.015
Ceramics/slab/wood	7.3 \pm 1.5		6.4 \pm 1.0		2.7 \pm 0.9	
Cement	6.4 \pm 1.8		5.8 \pm 1.5		1.8 \pm 0.9	
Ceiling**		0.299		0.776		0.507
Concrete roof slab	7.8 \pm 1.9		6.5 \pm 0.7		2.7 \pm 1.3	
Ceramic roof tile	6.5 \pm 1.4		6.3 \pm 1.5		2.5 \pm 0.9	
Asbestos roof tile	7.2 \pm 1.2		5.7 \pm 1.2		2.0 \pm 0.8	
Others	6.8 \pm 1.9		6.0 \pm 1.2		2.0 \pm 1.0	
Waste*		0.279		0.220		0.548
Recommended destination	7.2 \pm 0.3		6.4 \pm 0.2		2.4 \pm 0.2	
Does not go to sewage system	6.3 \pm 0.7		5.6 \pm 0.7		2.6 \pm 0.3	
Water supply*		1.000		0.886		0.864
Internal piping system	7.0 \pm 0.3		6.2 \pm 0.2		2.4 \pm 0.2	
No piping system	7.0 \pm 0.6		6.3 \pm 0.3		2.3 \pm 0.3	
N^o people in household*		0.503		0.100		0.661
≤ 4	7.1 \pm 0.4		5.9 \pm 0.3		2.4 \pm 0.2	
> 4	6.7 \pm 0.4		6.7 \pm 0.2		2.5 \pm 0.4	
Per-capita income*(MS)^{to}		0.564		0.750		0.397
$\leq 0,5$	6.9 \pm 0.3		6.2 \pm 0.3		2.4 \pm 0.2	
$> 0,5$	7.4 \pm 1.2		6.4 \pm 0.4		2.8 \pm 0.5	
Working*		0.503		0.671		0.054
Yes	7.3 \pm 0.5		6.4 \pm 0.2		2.9 \pm 0.2	
No	6.8 \pm 0.4		6.1 \pm 0.3		2.1 \pm 0.2	
Schooling**		0.014		0.215		0.136
None/did not finish elementary school	6.3 \pm 1.4		5.9 \pm 1.4		2.1 \pm 0.9	
Finished elementary school/did not finish high school	7.0 \pm 1.3		7.0 \pm 0.8		2.3 \pm 1.6	
Finished high school or above	8.2 \pm 1.7		6.2 \pm 0.9		3.0 \pm 0.5	

*Student's t-Test; **ANOVA

A statistically significant difference was seen in the knowledge area related to the type of housing ($p=0.001$) and schooling ($p=0.014$). As far as the attitude was concerned, there was no significance among the analyzed variables. Regarding practice, there was a statistical difference in terms of the housing floor ($p=0.015$). Although it was not considered significant, because of the proximity, it is worth highlighting that the practice mean by those who had an employment bond was higher than that by those who did not.

DISCUSSION

The predominance of women, in general mothers, as responsible for the care of patients with chronic illnesses has also been observed in other studies^(8,10,16). Although male caregivers have been participating in the care, perhaps because of the complicity developed in marital relationships, this role is still directed toward women because men are considered suppliers to the household, according to cultural anthropology⁽¹⁰⁾.

Similarly to another study⁽¹⁰⁾, there was a prevalence of per-capita income of half a minimum salary or below. This is a characteristic of patients at the institution where the study was conducted and whose care is provided 100% by the Comprehensive Health System. Moreover, it is difficult to reconcile paid work and daily caregiving activities.

In this study, similarly to other studies^(5,8,16), interviewees showed little knowledge that was generally fragmented, disconnected, and sparse. Lack of knowledge is not solely related to the causes of the illness, complications, and the lasting nature of conditions and treatment; it is also related to adequate care⁽⁵⁾. Caregivers must be understood as units of care; thus, it is necessary to identify their difficulties in order to offer the best assistance to everyone⁽⁷⁾. It is possible to identify complexity and multiplicity in factors that are intrinsic and extrinsic to caregivers that relate to the sick people, the environment, and so on which demand education and information⁽¹⁵⁾.

Even so, articles with similar CKD-related themes have not been found in studies that used the KAP model^(13,17), and interviewees also showed a poor attitude. Consequently, the multi-professional team needs to get to know caregivers' main doubts and thus perform health care educational actions to develop caregivers' positive attitudes. This will result in healthy practices⁽¹³⁾, preparing caregivers for challenging daily situations that involve specific patient profiles⁽¹⁶⁾ and enhancing the care provided.

The first guidelines must be given at the doctor's office in parallel with the nursing consultation, which will later outline the care extension process. The nursing consultation will establish a direct follow-up of the patient and enable caregivers' involvement in the health-illness process⁽¹³⁾.

A study conducted with 57 caregivers showed that only eight of them (14.0%) did not know what medications had been prescribed for⁽¹¹⁾. This result differs from that of this research, where 25 (83.3%) were unaware of the reason for prescribing medicines. This may certainly influence in the administration schedule mistakes and consequently affect the treatment. It is worth stressing that caregivers with a lower schooling level have more difficulty in understanding the treatment. Not grasping the information given by

professionals or failure in providing it may result in nonadherence to the therapy, which highlights the importance of adequate guidance⁽¹¹⁾.

Another study found that caregivers who were family members had superficial knowledge of the hemodialysis treatment and did not understand its complications and consequences⁽¹⁶⁾. This result was not different from the findings of this study, where 20 (66.7%) caregivers were not aware of indispensable care for chronic kidney patients—for instance, the care for vascular access devices for HD and for PD catheters, which are essential to prevent infection, and care to preserve the access in order to actualize the treatment. They were also unfamiliar with some of the metabolic and mechanical complications of PD and HD. It is known that complications such as acute lung edema and hypertension can be prevented if nutritional guidelines are followed^(1,20).

This study has also shown that caregivers did not follow nutritional guidelines for patients. Other studies showed⁽²¹⁻²²⁾ that dialysis therapy patients faced difficulties regarding the treatment because of water and food restrictions caused by their condition, turning this into one of the most difficult stages in the therapy. The nutritional guidance must be individual⁽¹⁶⁾ and depends on the residual kidney function and the type of therapy used. A study showed that parents, caregivers, and children and adolescents undergoing HD realized the importance and need of following an adequate diet; however, they often failed to follow it⁽²¹⁾. Adherence to the therapy, including dietary restriction, is paramount for treatment success and helps improve these patients' quality of life^(8,21,23).

This study showed that many caregivers were unaware that physical exercise could benefit patients. A study⁽²⁾ that assessed the quality of life in terms of the health of 64 children and adolescents submitted to HD or PD found that their physical capacity was compromised. In spite of the need for studies focusing on this age range, physical exercise has been observed in adult patients during the inter-dialysis period thanks to the recommendations by some nephrology services for patients undergoing HD⁽¹⁹⁾. Physical activity can be extended for patients undergoing PD, as long as they are supervised by physiotherapists and/or undergo physical education, following the model by HD patients. Exercise produces respiratory benefits, improving some indicators of sudden death risk in this population. Physical activity also improves physical conditioning, reduces fatigue, anxiety, and resting blood pressure, and increases the clearance of urea⁽⁴⁾. Thus, the survival rate and quality of life of chronic kidney patients increases⁽¹⁹⁾.

Although researchers have not found studies connecting housing and floor types with the KAP inquiry, they believe that a better housing aspect is probably associated with caregivers' better socio-economic condition; consequently, it is also related with better schooling and remuneration. Therefore, that factor reflects in more adequate knowledge acquisition that will possibly lead to better attitudes and correct caregiving.

In this study, interviewees' schooling was statistically associated with insufficient knowledge, which ratifies data from another study⁽⁵⁾ that states that knowledge must always be taken into consideration when seeking to adjust educational strategies. Another study⁽¹³⁾ relates the lack of information about some illnesses

and their treatment to low schooling levels and smaller purchasing.

CONCLUSION

This study was limited by patients' and caregivers' noncompliance/attendance to the nursing consultation, making interviews more difficult and increasing the data collection period.

This research showed caregivers' limitations in terms of knowledge, attitudes, and practice in the care of children and adolescents with CKD undergoing HD or PD, probably because of low socioeconomic and schooling levels.

The collection of information concerning the knowledge that caregivers have on health care needs by CKD patients enables a redesign of educational actions directed toward caregivers. One understands, therefore, that even though knowledge is not enough to lead to behavioral changes, it is *sine qua non* to provide people with elements that will foster autonomy in decision-making aligned with health situations and needs.

Not only should health professionals perform direct care to patients, but they should also guide and stimulate caregivers to continue the care once the illness dimension goes beyond the biological aspects experienced at health care services. These involve the social, psychological, cultural, and religious contexts of people in their household.

Educational actions allow for knowledge improvement; however, for them to be efficient, it is necessary to consider different cognitive capacities and cultural aspects in the caregivers' group. Although nurses are the main link between hospital units and caregivers, and despite the fact that they are health educators, the responsibility for the care must be distributed to the entire multi-professional team. All must learn about the knowledge gaps of each caregiver, develop suitable educational actions to fit these individuals' level of understanding, and assist them in developing satisfactory attitudes and practices.

Therefore, the association among the KAP inquiry components showed weaknesses in health care promotion in terms of the caregiver-patient relationship. This study has also shown that caregivers may have knowledge and positive attitudes that lead them to adopt preventive behaviors. Nonetheless, that does not guarantee that a behavioral changes will occur and practices will be maintained, especially if caregivers lack adequate conditions and constant support.

The results found through the KAP inquiry will enable nurses to identify the flaws in the health education process that hinder the continuity of care, fostering new actions that will lead to behavioral change.

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