

Difficulties experienced by children/adolescents with chronic kidney disease and by their families

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ABSTRACT

Introduction: This article assesses one of the objectives of a larger study about home peritoneal dialysis (PD) in children/adolescents with chronic kidney disease (CKD). **Method:** Descriptive study carried out on 30 children/adolescents with CKD cared for at the Hospital das Clínicas of the UFMG from March 2004 to May 2006. A questionnaire was applied to their caregivers about the reactions and difficulties experienced by those patients and their families during dialysis programs. **Results:** Their major complaints related to the limitations caused by dialysis to the patients' and caregivers' lives and to peritoneal dialysis itself. **Conclusion:** Knowledge about the reality experienced by children/adolescents with CKD and their families can promote actions and measures to improve the quality of life of all involved and consequently contribute to the success of the dialysis technique.

Keywords: peritoneal dialysis, home visit, caregivers.

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INTRODUCTION

The disease of a family member can affect the others in several ways and different degrees of intensity. The family is a group of individuals closely and continuously related through regular interaction; moreover, they interact individually and collectively with their community and cultural groups.¹ Children interact with their families in physical, emotional, psychological, and social manners.²

Similarly to any other chronic disease, chronic kidney disease (CKD) poses a lot of psychological tension to children/adolescents and their families, a tension present throughout the full course of the disease and its treatment.³

All patients on dialysis find themselves depending on a procedure, on a medical resource, or on a health care team, in addition to being exposed to other stressing conditions.

The psychological response of a certain patient to an illness depends on the following: his/her personality prior to the disease; the extension of the family support; his/her friends; the health care professionals involved; and the course of the underlying disease.⁴

The family has to face the shock of the irreversibility of the disease and imminent life danger. The patient has to undergo innumerable surgeries and painful procedures. Several medical instructions have to be followed, interfering drastically with daily life.³

This article assesses one of the objectives of a larger study on home peritoneal dialysis (PD) in children and adolescents with CKD. It describes and discusses the reports of caregivers about the reactions and difficulties experienced by those patients and their families during PD.

METHOD

This is a descriptive study comprising all 30 children and adolescents with CKD undergoing home PD and cared for at the Pediatric Nephrology Unit of the Hospital das Clínicas of the Universidade Federal de Minas Gerais (HC/UFMG), from May 2004 to March 2006. At the time of data collection, all patients had been on PD for at least three months. This was required to guarantee that the caregiver had already performed the procedure at home several times, being, thus, trained and having already experienced practical difficulties.

Data were collected during home visits through the application of a questionnaire containing closed and open questions. The open questions used were as follows: 1. Which were the difficulties found in correctly performing the dialysis technique? Which were the main complaints of the individual responsible for the procedure? 2. Which were the main complaints of the patient?

A *per capita* income equal to or lower than one minimum wage (value of March 2006 in Brazilian currency, R\$ 300.00) per person was considered inadequate or low.

The interviews were exclusively conducted by a nurse researcher and lasted from 40 to 80 minutes, the longest time resulting from the nurse researcher attending the home PD session.

All caregivers agreed with the study and provided written informed consent after being informed about the objectives and procedures of the study and their rights, according to item IV of the Resolution 196/96 of the National Health Committee.

RESULTS

CHARACTERISTICS OF THE POPULATION STUDIED

This study was conducted from May 2004 to March 2006 and comprised all 30 children/adolescents with CKD undergoing Continuous Ambulatory Peritoneal Dialysis (CAPD) or Automate Peritoneal Dialysis (APD) cared for at the Pediatric Nephrology Unit of the HC/UFMG. Fifteen patients (50%) were of the female sex. Their ages ranged from 1 to 16.5 years (mean age, 8.2 ± 4.0 years). Table 1 shows the distribution of the population studied according to the age range.

Regarding PD performance, the mother was the only person responsible in 24 (80%) cases. Three other (10%) mothers could count on the father and/or an aunt to help with the procedure, and, in one

age range	N	frequency
1 - 4 years	04	13.3%
5 - 10 years	17	56.7%
> 10 years	09	30.0%

of such cases (1/3), the patient herself could help, although, according to her mother, she preferred not to perform the task. Two patients (7%) had the father as the person responsible for PD performance, and one (3%) had the grandmother as the person responsible for that task.

The educational level of 22 (73%) main caregivers was over four years of schooling.

Twenty-eight families (93%) studied had an inadequate per capita income, lower than one minimum wage per person (value of March 2006 in Brazilian currency, R\$ 300.00), relying on a Brazilian social benefit program.⁵

COMPLAINTS ASSOCIATED WITH PERITONEAL DIALYSIS AND RELATED ISSUES

The complaints of the caregivers were grouped as follows:

- Fears and concerns regarding health complications in children/adolescents related to PD performance. In this category, the caregivers reported mainly the fear of peritonitis and other infections (5 reports).
- Concerns related to the PD technique itself. In this category, the mothers reported discomfort when opening and closing the catheter (1 report), and fear of bag perforation when applying the anticoagulant (1 report).
- Inconveniences associated with the procedure. The caregivers complained of the following: having to perform PD (8 reports); a feeling of excessive responsibility (3 reports); time spent with the procedure encompassing the number of daily exchanges (6 reports); performing preparatory tasks, such as washing and ironing compresses (1 report), cleaning of the draining bag and the room (6 reports); need for two people to perform dialysis (2 reports); the heavy weight of the PD boxes and bags (3 reports); difficulty in using the elbows to turn faucet on and off because of the soap (1 report); allergy to the PVPI solution (11 reports).

- Inadequate conditions for performing PD. In this category, the caregivers complained of the following: poor conditions of the dialysis room (2 reports); lack of a sink for hand washing (1 report); storage conditions of the bags (1 report); difficulty in accessing potable water (1 report); defective materials provided for PD (2 reports).

- Repercussions on family and social life. In this category, the caregivers' complaints were as follows: having to be constantly available for the children/adolescents, taking up much of their personal time and leaving less time available for working (4 reports), travelling (1 report), studying (1 report), and leisure (4 reports); transformations in their family routine and dynamics (1 report); increase in costs/expenses and decrease in financial autonomy (4 reports).

- Five caregivers claimed "to have gotten used to their task" and reported no complaints.

The complaints of the children/adolescents reported by the caregivers were as follows:

- Inconveniences related to PD. In this category, the caregivers reported that the children/adolescents complained of the following: having to undergo dialysis (6 reports); having to wear a mask (especially children under the age of 5 years - 2 reports); using bags with content sufficient for two, three, or more exchanges, preventing the patient's disconnection from the equipment (1 report); pain and itching in the orifice and trajectory of the catheter (8 reports); having to leave the bedroom to go to the dialysis room (1 report); having to stop watching TV or any other activity to undergo dialysis (4 reports).

- General inconveniences associated with CKD. In this category the caregivers reported that the children/adolescents complained of the following: having to take medications (1 report); presence of fluid in the abdomen (2 reports); abdominal pain (7 reports); inappetence or appetite reduction (4 reports).

- Limitations of daily activities and desires imposed by CKD and PD: In this category, according to the caregivers, the children/adolescents complained of the following: not being able to play (9 reports), to ride a bicycle (2 reports), to run and swim (3 reports); not being able to eat what they wanted (1 report), to sleep over at a friend's house (1 report), to travel (1 report), to go for a walk (3 reports), to spend time at a friend's house (1 report), to go to school (1 report).

- Complaints of the psychological repercussions of CKD and PD: the caregivers reported the following situations: depression and sadness (2 reports); shame

of the catheter in the abdomen (1 report); anxiety and nervousness (3 report); and apprehensiveness (2 reports).

- Three caregivers reported that the children/adolescents did not complain and were "quiet".

DISCUSSION

For Ferreira ⁶, the word "fear" means a feeling of great disturbance in face of a real or imaginary danger, a threat. This concept explains some of the reactions and complaints reported by the caregivers regarding PD. Real or imaginary fears and apprehensions may be important to keep caregivers alert to avoid flaws in the PD process; when excessive, however, they may be harmful, generating other types of flaws.

The fear of infections is usually related to interpretations of the consequences to the lives of the children/adolescents and even of the caregivers and families, such as the need for hospitalization, medication, time spent retraining, in addition to suggesting an apparent carelessness with the patients.

In this study, the complaints reported by the caregivers could indirectly indicate inappropriate or insufficient compliance with treatment or risk for future inadequate compliance with treatment.

Some studies have reported that the concept of compliance is relative.⁷ A consensus about it still lacks and no validated method for measuring the patient's compliance with treatment exists. Thus, the incidence of noncompliance may be underestimated.

Even in the absence of a standardized assessment of compliance with dialytic treatment, Reichwald-Klugger and Rosenkranz ⁷ have reported some possible reasons for poor compliance with treatment, such as:

- Misunderstanding or violation of the instructions provided during trainings and medical visits;

- Non feasible instructions due to lack of equipment required for dialysis or inadequate environment. It is worth stressing the importance of knowing the reality of each patient and family, to adequate the instructions to the situation assessed, without jeopardizing the quality of care;

- Doubts about the dialysis process may lead to modifications in the instructions provided and put the patient at risk;

- Human stress (fatigue, excessive activities and responsibilities for the caregiver, altered family relationship ⁸ due to the patient's disease or other daily problems);

- Denial of the disease, family resistance to treatment (religious issues) or patient's resistance to treatment, especially if adolescent.

Raj² has reported other forms of evidencing poor compliance as follows: intermittent dialytic exchanges (irregularly performed); a reduction in the time and number of dialytic exchanges in case of CAPD, or a reduction in the number of cycles in APD; non compliance with dialysis hours. According to that author, even the difficulty in accepting body image (especially among adolescents) and the presence of abdominal discomfort or pain during PD may impair adequate compliance with the treatment proposed.

One common complaint from both patients and caregivers related to the number of daily exchanges in PD. It was associated with others, such as those related to time, interruptions of activities, and inconveniences and discomfort related to the procedure. A smaller number of daily exchanges in PD could result in an increase in compliance. Bernardini *et al.*⁹ have reported that the risk of no compliance is higher in CAPD than in APD, probably due to the lower number of procedures required by APD. Therefore, the use of cyclers in PD, requiring less connections and disconnections, could also contribute to increase compliance. The process involves one night connection and one disconnection on the following day, 10 to 12 hours after, and can significantly contribute to improve the quality of life, leaving the child free to play and perform other activities, even if limited by CKD. Consequently, the caregiver is also more available for his/her own needs and those of the family. A few caregivers resist to using cyclers in APD due to both difficulties related to manipulating the machine and their belief that the use of cyclers increases the expenditure of electricity. Most individuals responsible for dialysis, however, can already identify the benefits of the use of cyclers, such as the lower risk of clinical interurrences and a better quality of life for children and their families.

In addition to the routine chores of the caregivers (particularly of the mothers), including those related to other children in the family, they are overloaded with the tasks regarding the dialysis procedure. Such tasks comprise the thorough cleaning of the dialysis room, the walls up to the ceiling, the floor and utensils at least once a week. This represents great physical and sometimes psychological effort, potentially jeopardizing the dialysis process and causing harm to the patient.

Similarly, Oliveira¹ has reported the following alterations in the daily family life of chronically ill patients after diagnosing the disease: changes in the physical structure of the house; changes in the social, physical, school, and work lives; and changes in the

relationships within the family. According to that author, those limitations actually bother the children/adolescents. In addition, the disease itself and the treatment regimen have a time schedule that must be followed, requiring greater availability from every family member. The changes affect the whole family, but mainly the patient and his/her mother, who is mostly often the main caregiver.

It is also worth noting the restrictions imposed by the special diet, required for maintaining the patient in good general health. One of the major problems is salt restriction, especially when ultrafiltration during dialysis is not adequate, leading to fluid retention. Then, fluid ingestion restriction is also recommended. In addition, not being able to have chocolate, savory snacks, cookies, and soda may represent a tremendous sacrifice for some individuals.

The children have special difficulty in accepting the medications prescribed, usually do not understand the importance of their use and reject them.

Sometimes the caregivers are not able to change that situation, hence the importance of creating strategies to reduce the poor compliance with medications, such as their administration during meals or with some food that the patient is fond of.

Among the prescribed medications, calcium carbonate and vitamin D prevent the metabolic bone disease associated with CKD, an alteration present in almost 100% of the children with that disease. Those medications help with the bone disease associated with CKD, reducing the risks of fractures and deformities.¹⁰

The erythropoietin level, a hormone produced by the kidneys (responsible for controlling the production of red blood cells), is reduced in patients with CKD. It should be administered subcutaneously or intravenously, representing an additional problem for younger children. To be pierced by a needle once to three times a week represents more suffering, not only for patients, but for caregivers as well. Despite knowing its importance, the caregiver is disturbed by the obligation of submitting the child to pain.

Nevertheless, in the present study, some caregivers reported having gotten used to that treatment, and that some patients do not even complain of the dialysis.

Those findings should be carefully analyzed, considering that the conditions of the interview could have influenced the answers of the interviewees. The fact that the interviewer was a member of the hospital team caring for the patients and following them up may have consciously or unconsciously led the

interviewees to simulate an “under control” situation so as to please the interviewer. In addition, especially in the case of a caregiving mother, there may have been a tendency towards denying the “negative” perceptions and feelings regarding the care of the ill child.

Therefore, those reports could indicate that despite all real objective and subjective difficulties pointed out in this study and in the literature relating to home PD, adaptation to the situation is possible with preservation of a satisfactory quality of life according to the patient’s and/or family’s perception.

CONCLUSION

The reactions and difficulties experienced by the family and children/adolescents with CKD here described are believed to stimulate the search for strategies that may serve as an instrument of assessing compliance with treatment and improving the patients’ quality of life. Knowledge about reality promotes actions and measures that can positively influence the dialysis technique success and the well-being of all those involved.

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