

Children and adolescents with chronic kidney disease in haemodialysis: perception of professionals

Crianças e adolescentes com insuficiência renal em hemodiálise: percepção dos profissionais
Niños y adolescentes con insuficiencia renal en hemodialise: percepción de los profesionales

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ABSTRACT

Objective: to identify aspects impacting on quality of life for children and adolescents with chronic kidney disease on hemodialysis, from the perspective of health professionals, as an essential step for the construction of a specific module of the DISABKIDS® instrument. **Method:** methodological study. Data was collected between May and June 2012, through personal interviews with 12 participants, in two dialysis centers. The empirical material was analyzed according to the thematic content analysis, using the program MAXQDA - Qualitative Data Analysis Software. **Results:** we identified seven themes: self-care, family support, impact of diagnosis, expectation of kidney transplant, truancy, socialization and stigma, grouped into three domains. **Conclusion:** the results showed aspects that impact the quality of life of these customers and, therefore, will be considered in the development of specific DISABKIDS® module. In addition, these aspects are relevant to the preparation and planning of actions directed towards children and adolescents with chronic kidney disease.

Key words: Quality of Life; Chronic Kidney Disease; Child; Adolescent.

RESUMO

Objetivo: identificar aspectos impactantes na qualidade de vida de crianças e adolescentes com insuficiência renal crônica em hemodiálise, sob a ótica de profissionais de saúde, como etapa essencial para a construção do módulo específico do instrumento DISABKIDS®. **Método:** estudo metodológico. Coleta de dados entre maio e junho de 2012, por meio de entrevistas individuais com 12 participantes, em dois centros de diálise. Analisou-se o material empírico segundo análise de conteúdo temática, com a utilização do programa MAXQDA - Qualitative Data Analysis Software. **Resultados:** foram identificados sete temas: autocuidado, apoio familiar, impacto do diagnóstico, expectativa do transplante renal, evasão escolar, socialização e estigma, agrupados em três domínios. **Conclusão:** os resultados evidenciaram aspectos que impactam a qualidade de vida dessa clientela e, portanto, serão considerados no desenvolvimento do módulo específico DISABKIDS®. Além disso, esses aspectos são relevantes para elaboração e planejamento de ações direcionadas a crianças e adolescentes renais crônicos.

Descritores: Qualidade de Vida; Insuficiência Renal Crônica; Criança; Adolescente.

RESUMEN

Objetivo: identificar los aspectos que afectan la calidad de vida de niños y adolescentes con insuficiencia renal en hemodiálisis, desde la perspectiva de los profesionales de la salud como un elemento esencial e indispensable para la construcción del módulo específico DISABKIDS®. **Método:** estudio metodológico. Los datos fueron recogidos entre mayo y junio de 2012, a través de entrevistas individuales, incluyendo 12 participantes. El material empírico fue analizado de acuerdo al análisis de contenido

temático, utilizando el programa de MAXQDA - Cualitativa Software de Análisis de Datos. **Resultados:** se identificaron siete temas: el auto-cuidado, el apoyo familiar, el impacto del diagnóstico, las expectativas de un trasplante renal, el absentismo escolar, la socialización, el estigma. **Conclusión:** los resultados muestran, aspectos que inciden en la calidad de vida de los clientes. Estos aspectos son pertinentes para la preparación y planificación de las acciones dirigidas a los niños y adolescentes con insuficiencia renal crónica.

Palabras clave: Calidad de Vida; Insuficiencia Renal Crónica; Niño; Adolescente.

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INTRODUCTION

End stage kidney disease (ESKD) is considered to be a major public health problem, of increasing incidence and prevalence. It leads to high costs for health systems as a consequence of the complexity of its treatment and therapeutic resources⁽¹⁾.

From the moment of diagnosis and beginning of living with the disease, chronic kidney failure (CKF) causes changes in habits and provokes emotional changes in children and adolescents. These changes may manifest through feelings of insecurity and fear, in addition to limitations on quality of life (QOL), resulting in a higher incidence of psychological changes than in the general population⁽²⁻³⁾.

In childhood and adolescence, repercussions are even more serious, because different attention is required. During these stages of development, transformations suffered are particularly uncomfortable due to the limitations imposed by the disease. The changes affecting children and adolescents with CKI trigger stress, disrupt their lives, affect their self-image, as well as modify their perceptions of life⁽⁴⁾.

In this context, the construction of QOL and health-related quality of life (HRQOL) instruments for children and adolescents has been growing, although there remains an absence of validated instruments for use in these populations. The paucity of research in the field of the HRQOL for children comes primarily from difficulties in building instruments targeted at this age group. Among these are the researchers' questions about the ability of children to express their opinion, attitudes and feelings⁽⁵⁾.

Given the above, this study aimed to identify aspects impacting on HRQOL for children and adolescents with chronic kidney disease on hemodialysis, from the perspective of health professionals. This is an essential and indispensable step in the construction of a specific instrument for measuring HRQOL for this population.

METHOD

Methodological study, conducted according to the reference used by the European Group DISABKIDS^{®(6-7)}, which studies and develops instruments for measuring HRQOL in children and adolescents with chronic conditions. Investigations covering the development, validation and evaluation of research tools and methods⁽⁸⁾. For the elaboration of an instrument, the group recommends the following steps: 1) literature review: national and international literature search, with the

objective of identifying domains and relevant concepts already described for HRQOL in children and adolescents with chronic conditions; 2) focus groups (FG): technique used for data collection, in order to identify relevant concepts of QOL/HRQOL from the point of view of the participants; 3) selection of items: step developed based on testimonials from the FG, selecting the items according to criteria of importance, relevance, clarity and applicability; 4) translation: the instrument is translated and retranslated, coming to a consensus version; 5) pilot study: the data are collected for psychometric analysis; 6) field study: stage when the data are collected to test the psychometric performance of the instrument under construction; 7) implementation of study: phase in which the instrument is applied and implemented⁽⁹⁾.

This study presents empirical procedures, comprising the technique used for the collection of data within the target population, with a view to the construct on screen. For data collection at this stage, individual interviews were held with 12 professionals in the field of Nephrology, three doctors, three nurses, two social workers, two psychologists and two nutritionists.

The interviews took place in two dialysis centers, one in the city of Curitiba and one in the countryside of the state Parana, which provide assistance to children and adolescents with chronic kidney disease on hemodialysis. The interviews had an average duration of 40 minutes and were conducted by the leading researcher between the months of May and June 2012. They were previously scheduled with nurses responsible for the dialysis units based on timetables and on the work routine of each professional participant, respecting their availability.

To carry out the interviews, we chose a private location, defined by the participants. The interviews were recorded with consent. Before starting, each participant read the consent form (CF) for clarification of ethical aspects, research objectives, average duration and form of conduct. After that, the CF was signed in two copies and one of them was taken by the participant. In compliance with the legislation that regulates research with humans, the research protocol was submitted to the Research Ethics Committee of the institutions where the study was conducted.

In the interviews, we focused on the HRQOL of children and adolescents with CKF on hemodialysis, from the participants' perspective. The interviews were guided by an instrument developed by the DISABKIDS[®] group, specifically for this purpose, called Interview Focus Group. It was translated and adapted to Brazil in Portuguese and to the study by the

research group on Health measures-GPEMSA, and registered in the National Council for Scientific and Technological Development - CNPq. The instrument consists of 12 direct questions, from which the participants were motivated to talk about the targeted topic. The guiding questions were: What do children and adolescents like in their lives? What makes these children and adolescents happy? What bothers these children and adolescents in their lives? How CKF affects these children and adolescents in terms of activities at school or at home?

It is worth pointing out that question formulation could be modified at the time of asking, as long as the perception of professionals on children and adolescents was considered.

We analyzed the empirical material resulting from interviews with reference to the qualitative approach. For the categorization of items, we used the technique of content thematic analysis proposed by Bardin⁽¹⁰⁾, composed of: pre-analysis, which corresponded to the step of organization, with the object of operationalizing and systematizing initial ideas; exploration of the material, which consisted of the coding of the data, which were processed systematically and aggregated in thematic units and, finally, the analysis of the results, which comprised the inference and its interpretation.

As a support tool for the analysis of empirical data, we used the program MAQXDA (Computer Aided Qualitative Data Analysis Software). After reading the empirical data, the researchers selected fragments of statements considered relevant, importing them into the software. This was done on the basis of each domain and corresponding dimensions, from the definition of health by the World Health Organization (WHO), followed by DISABKIDS[®] group. The domains considered were: physical (dimensions: limitation and treatment), mental (dimensions: independence and emotional) and social (dimensions: social inclusion and exclusion), which emerged and were considered as main categories.

The statements presented to illustrate the results are represented by the letter p (participant), followed by numbers associated with the order in which the participant was integrated into the research, in order to protect the identities of the subjects.

RESULTS

After reading and analyzing the material from the interviews, the data were organized into seven themes, grouped into three domains: self-care, representing the physical domain; family support, impact of diagnosis and expectation of kidney transplant, corresponding to the emotional domain; school dropout, socialization and stigma, expressing the social domain.

Physical Domain

Self-care

The presence and the appreciation of the importance of care of their own body and health, primarily by adolescents were aspects highlighted by the professionals.

[...] adolescents often stay alone in the room, they take care of themselves, they know the medication, some complain that the mother does not give the medicine. They end up taking care of themselves, they have this awareness [...]. (p1)

[...] they take care of themselves. If we understand the care as taking medication, it is more difficult to say, but if you take global health, they take care of themselves. They take care of the fistula, some get the ball for the fistula to work, they are careful not to touch the arm, that is the thing they are most concerned about. This is the first thing they do [...]. (p1)

[...] they are also careful with the catheter. They don't move much, a little due to fear, but also because they try to be careful. They also take care of their own body [...]. (p2)

[...] they take care of the access, they know the importance of the access. The diet - we know it's hard. They try to take care of it, but we know they have this difficulty. They know what they cannot have [...]. (p3)

In the professional view, despite the challenges and changes faced by patients, many have health care concerns, especially with regard to vascular access.

Mental Domain

Family support

The statements of the participants showed that children and adolescents appreciate their families. Emphasis was given to the importance of the presence and attention of family members in such sensitive moments, as during the revelation of the diagnosis, the monitoring sessions of dialysis, besides the support during follow-up and in other areas of social life:

[...] I think the family part for them is very important [...]. (p1)

[...] one thing they take advantage of is the family, with all the difficulties and benefits that the family has. I think you can even say that family daily life is essential to them [...]. (p2)

On the other hand, the following statement highlights the perception of professionals about the absence of family support, common among adolescents:

[...] There's also the lack of family support. You notice when the child is well, when they are well cared for and have support. You notice when the child and the adolescent are sadder, when they don't have the protection of the family, and that's very common. Mainly with the adolescent, the family does not show up. Some of them I hardly know their moms and dads; they are always alone. Even being adolescents they need the support and, often, the family sees it like this: Oh, they can take care of themselves [...]. (p3)

The issue related to overprotection of the parents with respect to children was also highlighted by the participants. They highlighted that this attitude towards the child's disease can, frequently, be harmful to their emotional and physical

development, considering that many may act in regressed and infantile ways:

[...] we notice that the family creates a dome, protects the child too much. They cannot speak, the parents respond, the child won't even talk. It is also not good. And when he has no more mom and dad... He was always protected because he was sick [...]. (p3)

Impact of diagnosis

Professionals reported that, upon being informed of the diagnosis of kidney disease, the children, adolescents and their families are affected by a "shock" in their lives, because the disease itself, and the required treatment, meant changes and adaptations in their daily routines:

[...] it is really hard when they start [...]. (p1)

[...] the beginning of hemodialysis treatment shakes everyone. There's a great irritability or a deep sadness. The start of hemodialysis shakes everyone because they are stuck to a machine [...]. (p2)

Thus, in the perception of professionals, the lives of these patients and their families is guided by the disease and its treatment. This translates into a long path, permeated by difficulties, and a set of feelings represented, at least in a first moment, by anguish, uncertainty and sadness generated by the revelation of the diagnosis.

Expectation of renal transplantation

The perspective of the kidney transplantation performance means hope of cure and represents the "break free" of dialysis and all the related implications:

[...] There is great hope for transplantation. It is hard when they start and a joy when they get a transplant. It is an important part of treatment for them [...]. (p1)

When there is the possibility of a transplant and, for some reason, this cannot happen, feelings of disappointment and frustration emerge, with consequent loss of the hope of "healing" and moving on from hemodialysis:

[...] the situation of being called for a transplant and not making it... We see their sadness when we screen a donor and he doesn't make it. They become very sad, creating a pretty big expectation that it will work and, suddenly, everything goes down the drain. This is something that makes them very sad [...]. (p3)

[...] When the transplant news is not good, we feel like crying. They [children] are shaken, they became sad for a while [...]. (p2)

So, for professionals, the appreciation of transplant is directly linked to their lack of necessity for more hemodialysis sessions and everything that involves the treatment of CKI, as the drug therapy, strict diet, the limitations in relation to school, playing,

traveling, and so on, the unfettered desire to live as a "normal" child or adolescent, improving their quality of life in general.

Social Domain

School dropout

The commitment to the performance of daily hemodialysis causes changes in the routine of these patients. The loss of school activities is evidenced by health professionals, in addition to the difficulties experienced by the school team such as how they should act with respect to the experience of these children and adolescents:

[...] the amount of children who are out of school because of dialysis is great - it is alarming. First, because the school does not know how to deal with patients who are on dialysis... That's hard. They are not people who have difficulties in learning. They only have a catheter in the belly or neck; they require physical care, but the child will learn just like any other kid, but the school doesn't know how to deal with it [...]. (p2)

For participants, the school must be guided and informed about the conditions and needs of these patients and compose the support network, avoiding placing them in a differentiated situation. Health professionals perceive themselves in the role of guiding the team at school, in order to alleviate the difficulties that lead to school dropouts. So, they encourage the learning of these people, in addition to providing something essential - socialization - through leaving them daily with their peers and teachers:

[...] we try to keep them in school. This year, I insisted and, with the help of the teachers, we contacted the Education Ministry, we sent a letter to keep him in school. However, we see the errors of parents who don't send them to school. They come to ask for sick leave certificates and I provide them; I have to know why they are missing school. The school contacts us and we have to give them an answer; I think it's important, there's no reason to miss school [...]. (p1)

The fact that parents worry about dialysis, drug therapy and the necessity for frequent hospitalization makes them devalue the importance of other activities that integrate the lives of these children and adolescents. Among them, school activities are important, but are relegated to second priority, or abandoned entirely.

Socialization

As regards social conviviality, participants highlighted some difficulties experienced by children and adolescents as a result of the disease:

[...] the difficulty of growth for adolescents of 15, 16, 17 years. They are younger children and it isn't helpful for the socialization process [...]. (p2)

[...] I think the disease interferes more in the lives of these children in the educational and social part - socially, they get isolated [...]. (p4)

[...] the relationship with friends is important. They feel the need to be part of a group, but they leave aside the commitments with friends to be here three times a week [...]. (p5)

The need to perform hemodialysis three times a week, for a period of four hours, interferes with the relationships and social lives of these patients, particularly adolescents.

Stigma

According to professionals, the prejudice suffered by these patients and how they face their disease affect their lives, making them feel outside the standards of "normality", misunderstood and not accepted by their peers. This situation brings difficulties and limitation to social relationships:

[...] they wish to be treated as an equal, equal to any adolescent in anyplace [...].(p4)

[...] many are closed, suffer bullying out of here, are different from the other, even the skin color is sometimes a little different, they have a fistula in the arm; There's a few that use long sleeves to hide it. The girls, especially, are more embarrassed, sometimes become more closed, in adolescence they close more [...]. (p5)

[...] there was a kid who was beaten at work. I don't know if it was because of the disease. We have to change the way the population in general view chronic renal disease [...]. (p6)

From the perspective of professionals, how patients are seen and treated by others is significant. The lack of knowledge about CKF within the general population can generate difficult situations in relation to coexistence and acceptance in the environment in which patients live. In an attempt to protect themselves, they hide the fact that they have chronic kidney disease and perform dialysis.

[...] they require understanding; people who do not know and don't know about the treatment, they think it's a big deal, as if they were contaminated [...].(p7)

[...] the treatment imposes impairments and, to be accepted by the group, they don't say they can drink little water, they try to disguise the limitations that they have and don't point out the kidney problem [...]. (p8)

[...] they don't want people to point out their problem; they don't want them to remember it. They expect to be treated as any person [...].(p8)

DISCUSSION

According to the perspective of the professionals in the field of Nephrology, it was possible to understand how and in what way CKF and its treatment are associated with the lives of children and adolescents, punctuating each impact attributed to QOL/HRQOL.

From the diagnosis of the disease and the impact generated, patients suffer disruption in their lives, abruptly, affecting

their daily routines, now permeated by commitments relating to the required treatment, dialysis, diet, and medical tests⁽¹¹⁾. The shock upon receiving the news of the kidney disease raises feelings of fear about the future, insecurity, anger and rejection of the disease and its treatment.

This whole process results in dependence and need for family support. This was mentioned in statements as crucial and relevant to the recovery and maintenance of the health of children and adolescents. It is important that they receive the support of their family members, feeling protected at this time when they are fragile and sensitive.

In this regard, it is noteworthy that this support has not been perceived by professionals, especially in the case of some adolescents. It also expresses the fragility of the family members' relationships, as evidenced by parents' lack of attention, understanding and support, leading to sadness, fear, stress and insecurity. More than children, adolescents value this aspect, they perceive attitudes and family reactions, attaching great importance to them, and this affects them substantially⁽¹²⁾.

It is common for children and adolescents with chronic conditions, as well as their respective families, to center their activities around the treatment of the disease. They begin to neglect important aspects relating to other spheres of their lives, such as the school activities. This often leads to school dropout or consecutive missed days, impairing the education process and interfering with relationships with friends and other members of the school. There is, therefore, significant injury to social relationships, already significantly affected by commitment to hemodialysis and treatment demands.

School is of fundamental importance for this age group, meaning that changes are felt more sharply. Social relationships occur in this space, and the child misses them. Physical, emotional, social and family instability make students vulnerable to poor school performance⁽¹³⁾. Parents need to be instructed on the importance of continuity in their children's school activities. This requires the joint action of professionals in the dialysis unit, encouraging and valuing school for these patients. So, they could promote the continuity of education by means of reinforcing teaching during dialysis, as occurs in some dialysis units, or booster classes at school or at home.

To approach the topic of kidney transplant, professionals reported patients' expectations for them to be undertaken, and their frustration when it does not happen. The possibility of transplant represents, for these people, a better QOL, as they return to their lives without hemodialysis, opening them up to new possibilities⁽¹⁴⁾. Kidney transplant is considered the best treatment for CKF compared to other dialysis methods. The survival rate of transplanted adult or pediatric patients is superior to those on dialysis, which in fact confers better quality of life⁽¹⁵⁾.

The expectation for a transplant triggers different emotional reactions in patients: fear, doubt, worry and anxiety related to the procedure itself and the risks involved, among them the chance for it not to work. When hope becomes real, various issues come into play, such as fear of the unknown, among other aspects that influence the experience lived by the patient regarding the procedure⁽¹⁶⁾.

Statements highlight the importance of socialization and how hemodialysis and the CKF interfere in this process, especially for adolescents. They are going through a new phase of life that requires contact with their friends in school or during other activities. The child and the adolescent with chronic kidney failure often have their social network limited to family members or close friends⁽¹⁷⁾. Isolation is also quite common and occurs, especially, due to the attempt not to reveal that they have chronic kidney disease, or shame of body modifications, expressed through an arteriovenous fistula (AVF) on the arm or by a catheter located in the neck. These characteristics are outside of normal standards, arousing the curiosity of others and generating embarrassing situations. The fact that they present peculiar characteristics in light of the disease makes them feel different and identified as sick people. Often, their stature is incompatible with their chronological age, and they experience skin problems and the presence of visible vascular access. In these cases, feelings of prejudice may emerge as well as low self-esteem and social isolation.

Such feelings are related to stigma and show that, in general, people are either unaware of CKF, express curiosity or stay away from those who do not fit into the standards of normality. This often accentuates the feelings of isolation experienced by these children and adolescents and may generate low self-esteem and feelings of discrimination⁽¹⁸⁾. In general, patients with CKF present physical and emotional fragility and, therefore, require palliative care strategies that promote emotional resilience, a sense of well-being and greater self-esteem⁽¹⁹⁾.

The topic was emphasized in the statements of the participants, especially in those regarding assistance with vascular access, particularly with the AVF. It was observed that the AVF assumes a role for these children and adolescents because it allows them to carry out the hemodialysis treatment with more freedom, comfort and less difficulty. When compared to the catheter, the AVF represents the maintenance of their lives,

and they recognize its importance in their treatment and the dispensing of their care⁽²⁰⁾.

FINAL CONSIDERATIONS

This study made the identification of the most influential attributes impacting the QOL/HRQOL of children and adolescents with CKF on hemodialysis possible, based on the perspective of working professionals in the area of nephrology. According to the experience of each professional, we addressed relevant aspects related to CKF and its treatment, which allowed us to understand how to associate the QOL/HRQOL of children and adolescents.

The mental and social domains were the ones which presented more negative impacts, taking into account the repercussions from the moment that these people receive the news of the diagnosis of the disease, the stigmatization, the interruption of school activities and impaired socialization.

This scenario can be minimized through other aspects also identified, such as the importance of family support, in some cases not detected, and the hope for kidney transplant, which represents recovery and freedom from hemodialysis and the demanding nature of the disease and its treatment.

The themes identified through the analysis of the professionals' statements can contribute to the importance of the construction of the instrument for measurement of QOL of children and adolescents with CKF on hemodialysis, in addition to the promotion of knowledge of the studied population and proposed research methodology.

The concepts and dimensions included in this study, based on the experiences and knowledge of professionals in the field of nephrology, should be considered in the development and planning of actions targeted for children and adolescents with chronic kidney disease.

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