# Impacts of Chronic Kidney Disease on occupational performance of children and adolescents on hemodialysis<sup>1</sup>

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Abstract: Introduction: Chronic Kidney Disease (CKD) may cause great impacts on areas of occupational performance of children and adolescents on hemodialysis. The identification of these occupations can guide the practice of occupational therapy, enabling specific interventions as well as the creation of policies and guidelines in the field. Objective: To identify the impact of CKD on the occupational performance of children and adolescents on hemodialysis. Method: Twenty-one children and adolescents with CKD undergoing hemodialysis treatment participated in the study. The tools applied were the profile identification questionnaire and the semi-structured interview *Canadian Measurement of Occupational Performance (COPM)*. Numerical variables were described as measures of central tendency and dispersion, and for categorical variables were calculated the frequencies. Results: 13 impacted occupations were identified, in which 9 are related to play/leisure, 1 to productivity/ school, 3 to self-care. In addition, 57% of the sample dropped out of school and 23% repeated one school year or more. Conclusion: Impacts on different areas of occupational performance, mainly related to play and leisure, have been identified. Children and adolescents present specific demands related to their age ranges. Therefore, the occupational therapist, considering this specificity, can enable these clients to improve their performance in occupations and resume significant roles in their lives.

Keywords: Children, Adolescents, Chronic Renal Insufficiency, Occupational Therapy, Occupational Performance.

# Impactos da Doença Renal Crônica no desempenho ocupacional de crianças e adolescentes em hemodiálise

Resumo: Introdução: O acometimento pela Doença Renal Crônica (DRC) pode trazer impactos importantes em áreas de desempenho ocupacional de crianças e adolescentes em tratamento hemodialítico. A identificação dessas áreas de desempenho prejudicadas pode direcionar a atuação da terapia ocupacional, possibilitando intervenções específicas e criação de políticas e diretrizes na área. Objetivo: Identificar o impacto da DRC no desempenho ocupacional de crianças e adolescentes em hemodiálise. Método: Participaram do estudo 21 crianças e adolescentes com DRC em tratamento via hemodiálise. Os instrumentos utilizados foram o questionário de identificação do perfil da amostra e a entrevista semiestruturada *Medida Canadense de Desempenho Ocupacional (COPM)*. Os dados da pesquisa foram analisados por meio do programa estatístico *SSPS* 22.0. As variáveis numéricas foram descritas como medidas de tendência central e dispersão, e para variáveis categóricas foram calculadas as frequências. Resultados: Foram identificadas 13 ocupações impactadas, das quais, 9 são relacionadas à área do brincar/lazer, 1 produtividade/escola

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e 3 ocupações da área de autocuidado. Além disso, 57% da amostra abandonaram a escola e 23% repetiram um ano escolar ou mais. Conclusão: Foram identificados prejuízos em diferentes áreas do desempenho ocupacional, principalmente relacionadas ao brincar e lazer. As crianças e adolescentes apresentam demandas específicas dessa faixa etária e o terapeuta ocupacional, considerando essa especificidade, pode possibilitar a esses clientes a melhoria de desempenho em ocupações e a retomada de papéis significativos em suas vidas.

Palavras-chave: Crianças, Adolescentes, Insuficiência Renal Crônica, Terapia Ocupacional, Desempenho Ocupacional.

#### 1 Introduction

Chronic Kidney Disease (CKD) is the slow, progressive and irreversible loss of renal function. It is a clinical syndrome that becomes more evident after the loss of 50% of the mass of the nephrons of the individual and, in later stages, the kidneys cannot maintain the metabolic and water balance (MARQUES; PEREIRA; RIBEIRO, 2005). The loss of renal function is assessed by reducing the Glomerular Filtration Rate (RFG) (NATIONAL..., 2017). The most frequent causes of CKD in children and adolescents are congenital malformations of the kidneys and urinary tract, followed by primary glomerulopathies (ROMÁO JUNIOR, 2006).

In the terminal phase of the disease, various modalities of dialysis are treatments currently available. These treatments partially replace renal function, alleviating the symptoms of the disease and preserving the individual's life, but none of them are curative (SOCIEDADE..., 2017).

Children and adolescents with CKD experience recurrent hospitalization procedures, painful medical procedures, and restrictions on daily activities, which can lead to changes in several aspects of development, increasing the risk of behavioral changes, non-adherence to treatment, exclusion by their peers, absenteeism and school repetition (BIZARRO, 2001; DUQUETTE et al., 2009). There is also a reduction of the learning capacity, besides the commitment in the physical and cognitive development (WONG et al., 2012).

In a quantitative study conducted in the United States (VARNI; LIMBERS; BURWINKLE, 2007), for the analysis of quality of life in 2500 children diagnosed with chronic diseases, CKD was one of the worst self-report quality of general life among 33 conditions analyzed, when compared with healthy children and other chronic diseases. This study also showed that these children suffer varied and significant impacts on physical, emotional, social and school functioning.

A number of studies have examined the impact of CKD on the quality of life of children

and adolescents (MARCIANO et al., 2010; KILIŚ-PSTRUSIŃSKA et al., 2013; KUL et al., 2013; MOREIRA et al., 2015), but there is a limitation in the literature on studies that identify occupations impaired by kidney disease and hemodialysis. These studies are necessary to point out the areas/problem in the occupational performance, enabling the establishment and quantification of the intervention priorities and the recognition of the target outcome of each population (PIOVESAN; TEMPORINI, 1995; LAW et al., 2009). This type of research is used to obtain information that shows the characteristics of a reality, assisting in the construction of a consistent practice and reflected in the real needs of the target public (PIOVESAN; TEMPORINI, 1995).

The achievement of independence and autonomy of significant occupations is essential for the individual to have quality of life and integral health. Occupational therapy is the health profession that focuses on improving occupational performance and can be defined as the ability to efficiently perform routines, perform meaningful roles and tasks, and promote the personal satisfaction of these individuals, who, for some reason, have ceased to perform their occupations (CLARK; LAWLOR, 2009; CALDAS et al., 2011).

The occupational performance results from the interaction between the *person*, the *environment* and the *occupation*, according to the Canadian Model of Occupational Performance (MCDO) (LAW et al., 2009). For these authors, the *person* is recognized by physical, affective and cognitive components, having the spiritual as a central element, the *environment* is characterized by the physical, social, cultural and institutional components and the *occupations* are classified into three categories: self-care, play, leisure, and productivity.

Considering that CKD has multidimensional impacts, including physical, social and psychological spheres, the significant occupations of these subjects undergoing hemodialysis may be of different orders, including the three categories proposed by MCDO (MARCIANO et al., 2010). Considering

the need to intervene in these occupational losses, the occupational therapist is a trained professional to intervene in such demands (LAW et al., 2009).

A study evaluating the impact of occupational therapy intervention on adult clients on hemodialysis, identified treatment benefits related to improved emotional function, increased work participation, productive, daily and social activities, as well as a significant increase in autonomy and sensation of capacity, and empowerment (DELLÊ MADALOSSO; MARIOTTI, 2013). Finally, the authors emphasize the need for the inclusion of occupational therapy in care teams for hemodialysis patients. Faced with this demand, it is necessary for a greater foundation of the practice of this profession in this area, as well as the creation of public policies that effectively include this professional in the care of people with CKD and include the children and youth.

The performance of occupational therapy in the treatment of CKD is fundamental since it promotes independence and autonomy in the occupational performance of its patients in occupations impacted by the disease (GOTO, 2017). Thus, the objective of this exploratory study is to identify the areas impacted by chronic kidney disease in children and adolescents from 9 to 19 years old on hemodialysis, in Belo Horizonte, MG.

#### 2 Method

#### 2.1 Study design

An exploratory study was carried out to identify the occupations impacted by chronic kidney disease in children and adolescents.

#### 2.2 Procedures

Data from individuals on hemodialysis were collected between August/2015 and January/2016. The collections occurred in the two largest public health centers in the city of Belo Horizonte/MG, Hospital das Clínicas and Santa Casa de Misericórdia, which assist patients of the capital and the metropolitan region. Data collection was performed on the days of the hemodialysis session of the participants, without affecting the treatment of the patients or burdening the families.

#### 2.3 Ethical considerations

This research was approved by the Ethics Committee in Research/Federal University of Minas Gerais, CAAE no 47233415.7.00005149, meeting

the requirements established in Resolution no 196 of October 10, 1996, of the Ministry of Health, regarding the development of research involving human beings. The research was registered in the Brazilian Registry of Clinical Trials (REBEC) under the number RBR-9zqwhv. The Consent and Assent Forms were previously sent to those responsible and children/adolescents. Only those who signed the Assent Form were included in the study, and the parents signed the Consent Form, authorizing the participation of children and adolescents.

# 2.4 Participants

The sample consisted of 21 children and adolescents with terminal CKD, of both genders, any socioeconomic level, who underwent hemodialysis in Belo Horizonte, Hospital das Clínicas and Santa Casa de Misericórdia. Children and adolescents underwent hemodialysis sessions three times a week for four hours per day of treatment.

The inclusion criteria were children and adolescents undergoing hemodialysis treatment who presented formal authorization of those responsible for participation through the signing of the Free and Informed Consent Form (FICF) and which allowed their participation through the Free and Informed Assent Form (FIAF).

The exclusion criteria were inability to understand the study objectives; severe auditory or verbal impairment; medical contraindication for participation; associated severe neuropsychiatric comorbidity.

#### 2.5 Instruments

The structured questionnaire for the construction of the sample profile was prepared by the researchers. It was filled out by the guardians of the children and adolescents of the sample. Data were collected on the age of the participants, time of illness and treatment. There were also questions related to school attendance, failed years, and dropout. To complement the sample profile, the questionnaire was applied to classify the socioeconomic level of the participants (ASSOCIAÇÃO..., 2014).

The Canadian Occupational Performance Measure (COPM) was used to investigate the areas of impaired occupational performance in the study participants. The COPM is a semi-structured interview used to help the patient to list the occupations impaired due to their health condition and allows also the participants to inform about their self-perception of their occupational performance. After identifying the impaired activities due to CKD and hemodialysis

treatment, the participants score the importance of these activities in their lives from 1 to 10, then they score their performance in these activities from 1 to 10 and, finally, they score the satisfaction of the performance in these activities from 1 to 10.

First published in 1990, the instrument has since been translated into several languages and used in several countries, including Brazil, for both research and clinical practice (LAW et al., 2009). The measure covers three areas of occupational performance: self-care, productivity, and leisure (LAW et al., 2009).

The use of COPM in children and adolescents with CKD in hemodialysis treatment can enable the identification of impaired areas and occupations since the instrument offers quantitative data regarding the participant's priorities and assists in the structuring of therapeutic projects (LAW et al., 2009). Thus, due to this research is an exploratory study, this instrument was used only to identify occupations impacted by CKD in children and adolescents on hemodialysis.

# 3 Statistical Analysis

Data analysis was performed using the statistical program SPSS 22.0 (Statistical Package for the Social Sciences). For both discrete and continuous numerical variables, the data were described as measures of central tendency (mean and median) and dispersion (standard deviation, minimum and maximum values). Absolute and relative frequencies (percentage) were calculated for the categorical variables.

#### 4 Results

All children and adolescents with CKD undergoing hemodialysis at Hospital das Clínicas and at Santa Casa de Misericórdia were invited to participate in the study, totalizing 26 participants. Five of them were excluded since four had no cognitive ability to understand the objectives of the study and one refused to participate, totaling 21 participants.

According to the structured questionnaire for the construction of the sample profile, a predominance of males among the 21 participants was observed, with 16 boys (76% of the sample) and mean age of 13.4±2.8 years old. The characterization of the sample, considering clinical aspects, gender and socioeconomic conditions are available in Table 1.

Table 2 shows the characteristics of the participants of their school life.

Through the application of the COPM questionnaire, participants cited impaired occupations as a result of CKD and hemodialysis treatment. The most cited occupations were: playing football (57.1%), traveling (19%), going to school (19%), cycling (14.3%), swimming (14.3%) and drawing (5%), (Table 3). The occupation with the highest average grade of importance was "going to school" (9.0±2.0); Among the most cited occupations, the worst performance score was for "cycling" (1.00±0.0) and the worse satisfaction was also "cycling" (1.0±0.0), (Table 3).

**Table 1.** Characterization of the participants in the research, clinical aspects, gender, and socioeconomic conditions.

	SAMPLE (n=21)		
AGE			
Mean in years old $\pm$ standard	$13.4 \pm 2.8$		
deviation			
Median (min-max)	13.4 (9-19)		
TIME OF THE DISEASE			
(DAYS)			
Average ± standard deviation	$2179.7 \pm 1072.8$		
Median (min-max)	1826.0 (7-5110)		
TIME OF THE TREATMENT			
(DAYS)			
Average ± standard deviation	$778.1 \pm 736.9$		
Median (min-max)	665.0 (3-2922)		
MALE	16 (76.2%)		
FEMALE	5 (23.8%)		
SOCIOECONOMIC			
CONDITION			
From B1 to C2*	9 (42.8%)		
D**	12 (57.2%)		

<sup>\*</sup> B1 to C2 = from middle class to vulnerable class. \*\*D = poor but not extremely poor.

**Table 2.** Characterization of the research participants in relation to schooling.

	SAMPLE (n=21)
HELD BACK	8 (38.1%)
RETENTION FREQUENCY	
1 year	4 (50.0%%)
2 years or more	4 (50.0%)
STOPED TO STUDY	12 (57.1%)
EDUCATION (years)	
Average ± standard deviation	$6.7 \pm 2.4$
Median (min - max)	6 (3-11)

OCCUPATIONS	FREQUENCY	IMPORTANCE	DEVELOPMENT	SATISFACTION
Playing football	12 (57.1%)	$9.0 \pm 2.4$	$2.8 \pm 2.2$	$2.8 \pm 1.9$
Traveling	4 (19.0%)	$8.8 \pm 2.5$	$4.0 \pm 3.8$	$3.0 \pm 3.4$
Going to school	4 (19.0%)	$9.0 \pm 2.0$	$2.0 \pm 2.0$	$1.8 \pm 1.5$
Cycling	3 (14.3%)	$7.0 \pm 3.0$	$1.0 \pm 0.0$	$1 \pm 0.0$
Swimming	3 (14.3%)	$8.7 \pm 2.3$	$2.3 \pm 2.3$	$1.7 \pm 1.2$
Drawing	2 (9.5%)	$8.0 \pm 2.8$	$2.0 \pm 1.4$	$1.0 \pm 0.0$
Walking	1 (4.8%)	10	5	3
Shopping	1 (4.8%)	5	6	5
Going to parties	1 (4.8%)	10	10	10
Preparing food	1 (4.8%)	10	6	7
Jumping rope	1 (4.8%)	6	1	1
Working out in the gym	1 (4.8%)	3	1	2
Bathing	1 (4.8%)	10	1	1

**Table 3.** Occupations identified as impaired due to CKD and hemodialysis treatment.

### 5 Discussion

There was a predominance of male in the sample of this study. According to Nogueira et al. (2011), this proportion between the female and male can be represented by the ratio of 1:1.5. The literature justifies male predominance for CKD due to the higher frequency of congenital urinary tract alterations in this people (BECHERUCCI et al., 2016).

Regarding the occupational performance problems mentioned by children and adolescents with CKD on hemodialysis, the highest number of affected occupations was in the areas of occupational performance related to play, leisure and productivity. Leisure can be conceptualized as occupations that are intrinsically motivated and are not compulsory, that is, it does not occupy the time of daily responsibilities such as work, self-care or sleep. Playing corresponds to the spontaneous occupations that provide well-being, joy, and fun (SOUSA CARLETO et al., 2011).

Children and adolescents report through the COPM that they are facing barriers and difficulties in playing the role of playwrights and enjoying leisure occupations. Considering that play activities in childhood and adolescence are the basis for the good construction of intellectual contents and for the establishment of skills necessary for competence in adult life, changes in these areas can cause changes in development (REZENDE, 2008).

A high frequency of the number of individuals who cited "playing football" as an impaired play/leisure occupation was also identified. According to Finco (2003), playing is a cultural experience and therefore, conceptions and behaviors are expected

and stimulated according to gender. Considering the greater number of male individuals, due to the higher incidence of CKD on this people, this could be a justification for high citation of "playing football" as impaired in COPM, which, culturally, is an occupation related to male.

The hospital context can make the child feel in an unknown environment, together with a routine of several invasive procedures, bringing a range of negative feelings about the changes that have occurred (GIARDIN et al., 2010). Thus, the occupational therapist has as a central objective to act within these service units, promoting autonomy and independence in the routine of their patients, collaborating for the mental health of the patients of the service (GIARDIN et al., 2010). This professional also promotes a re-humanization of the service practices in this context, not only stimulating the functional capacity and occupational performance but also performing guidelines for discharge and accompanying their re-adaptation to the home environment (DE CARLO, 2006).

The children and adolescents interviewed in the study do the hemodialysis process three times a week and each session lasts for approximately four hours in the service. Consequently, the routine of the participants is impaired because they cannot carry out the daily occupations, which collaborate for the overall development of the human being. A solution to the breakdown of this treatment standard may be related to the insertion of play activities within the hospital context, an intervention frequently cited in the literature for its efficacy and importance for child development (VIEGAS; SANTOS, 1997; PAULA; GIL; MARCON, 2002;

MITRE; GOMES, 2004; DRUMMOND et al., 2009). Through studies publications that identify the deficit occupations, it is possible to construct public measures and intervention strategies that benefit this people.

The self-care occupation area was also affected by CKD and the hemodialysis process, with emphasis on bathing, preparing food and shopping. Within this context, Occupational therapy may seek to assess the factors that impede or hinder the achievement of these occupations, and thereby draw up an intervention plan that promotes autonomy and independence for this individual, helping him to perform these occupations in the best way possible (SOUSA CARLETO et al., 2011). Therefore, there is a range of interventions that this professional can use, such as the treatment of neuromuscular components to improve function, pain management, cramps and fatigue in the upper limbs, cognitive stimulation, improvement of fine or gross motor coordination, among others. The occupational therapist can also work with the training or adaptation of occupations such as bathing, writing, dressing, among others (NUSSBAUM; GARCIA, 2009).

The results of this study show that "going to school" occupation was cited with a high level of importance and it was impaired by the occurrence of CKD and hemodialysis process and more than half of the individuals interviewed reported dropping out. This may be due to the frequency of hemodialysis sessions and the length of time that the participants stay in the hospital, impairing school participation. However, the school environment is fundamental for the development of children and adolescents, since the school enables to build, expand and maintain links, promote social interaction and increase intellectual knowledge (ABREU et al., 2014).

A similar result on the importance of the school for adolescent children who undergo hemodialysis was found in the descriptive exploratory study of Abreu et al. (2014). After a qualitative analysis of the collected statements, the authors observed that the interruption of school activities of great importance variable in the life of these children and adolescents mentioned in several moments by the participants. In the qualitative study of Santos Pennafort, Queiroz and Jorge (2012), the participants showed their desire to continue studying and reported obstacles to attend school.

According to the American Occupational Therapy Association (AOTA) that proposed a uniform terminology for services in occupational therapy: According to the American Occupational Therapy Association (AOTA) that proposed a uniform terminology for services in occupational therapy: Occupations are the different types of everyday activities in which individuals, groups or populations are involved, including ADL [Activity of Daily Living], AIVD (Instrumental Activity of Daily Living), rest and sleep, education, work, play, leisure, and social participation (AMERICAN..., 2015, p. 19).

Therefore, for occupational therapy is an object of evaluation and intervention of the occupational therapist. Within the context of education, the profession historically began its trajectory through "Special Education". However, with the process of re-democratization in the country in the 1980s and the institution of inclusion policies, there is a rupture of the point of view about pathologies and dysfunction, which moves to the teaching-learning processes. Recently, a new configuration for occupational therapy within education was proposed: understanding this individual in his/her daily life and context, the individual becomes collective and the intervention takes relational connotations. Therefore, it is up to the occupational therapist to assume the role of facilitator of constructing solutions for the performance of this occupation by the individual in context (ROCHA, 2007).

Within the school context, the occupational therapist can help this population in the rescue of the student role, helping them to perform this occupation, cited in this study as significant. Thus, it is up to this professional to develop dialogues with educators, students, community and parents, identifying and undoing the possible barriers to the performance of this occupation. These barriers can pass through different architectural blocks, furniture/pedagogical material, professional qualification, curriculum adaptation and the introduction of new forms of participation in occupations (ROCHA; LUIZ; ZULIAN, 2003).

The health process and the concept of quality of life are directly linked to the patients's ability to engage in meaningful occupations and to be in interaction with different environments, such as domicile, school, community, and so on. Facing the reality of children and adolescents on hemodialysis, the occupational therapist is the professional responsible for the identification and intervention of impaired occupations, as well as the factors that

may interfere in them and in the health process (SOUSA CARLETO et al., 2011).

This study had limitations due to the restricted number of participants and the origin of the sample of children and adolescents with CKD, there were only two specific centers without randomization and diversification of the origin of the analyzed population. Also, the great variation of dialysis time of the patients may be a confounding variable. However, despite the limitations, this is an important step for the improvement of care for children and adolescents with CKD in hemodialysis treatment.

#### 6 Conclusion

Chronic kidney disease and treatment through hemodialysis bring several consequences to the daily life and development of children and adolescents who live this reality. In this study, there were harmful effects identified in different areas of the occupational performance of the participants and the occupations impacted by this process, related mainly to play, leisure and productivity.

Children and adolescents on hemodialysis treatment also have difficulties in continuing their studies. A high rate of school dropout was possible to identify due to hemodialysis treatment, hindering to have an adequate school attendance and prevents the active participation of the learning and social interaction process. Also, "going to school" was cited as a high-level occupation that was impaired by the pathology and its treatment.

Pediatric patients have inherent needs for their age group and, consequently, they require a different therapeutic approach for the occupational areas typical of this phase of development. When surveying the main impacts on occupational performance experienced by children and adolescents with CKD, this study could facilitate the creation of public policies and the improvement of specific interventions for this people. Also, it could improve the quality of life of both the patients of the dialysis service as the direct guardians and family members, through the promotion of autonomy and independence in the daily activities of individuals who had their occupations impaired due to the disease process.

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#### **Author's Contributions**

Thaís Thaler Souza - Text conception, sources organization, and analysis, text writing and review. Arthur Melo Kummer – Text review. Ana Cristina Simões e Silva – Text review. Ana Amélia Cardoso – Text review and writing. Carla Ribeiro Lage – Source organization and analysis, text writing and review. All the authors approved the final version of the text.

## **Notes**

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