

## RESEARCH PAPER (ORIGINAL)

# Quality of life in children with kidney disease

Qualidade de vida de crianças com doença renal

Calidad de vida de los niños con enfermedad renal

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### Abstract

**Background:** Chronic kidney disease prevents families and children from enjoying a normal life due to changes in their everyday life.

**Objectives:** To characterize the quality of life perceived by children with kidney disease who attend summer camps.

**Methodology:** Descriptive, correlational, and cross-sectional study, with a mixed-method approach. The nonprobability sample is composed of 42 children (29 Spanish and 13 Portuguese children) aged between 7 and 17 years with a diagnosis of chronic kidney disease and attending summer camps. We used the Portuguese and Spanish versions of the KINDL® scale, sociodemographic and clinical questions, and a notepad.

**Results:** Children had a positive perception of quality of life. The Self-Esteem dimension was the best perceived, and the Emotional well-being dimension was the worst perceived. Spanish children had a better perception of quality of life. Positive feelings emerged from the content analysis.

**Conclusion:** Individualized follow-up up by a multidisciplinary team and summer camps for educational purposes, empowerment and emancipation, peer education, socialization, and entertainment can be beneficial to children and their families.

**Keywords:** quality of life; kidney diseases; camping

### Resumo

**Enquadramento:** A doença renal enquanto doença crónica impede as crianças e famílias de poderem disfrutar de uma vida normal, tendo em conta as modificações que ocorrem no seu quotidiano.

**Objetivos:** Caracterizar a qualidade de vida percebida pelas crianças com doença renal e que frequentam campos de férias.

**Metodologia:** Estudo descritivo-correlacional e transversal, de natureza mista. A amostra é não probabilística composta por 42 crianças (29 espanholas e 13 portuguesas), entre os 7 e 17 anos e com doença renal crónica, que frequentaram campos de férias. Utilizou-se a versão portuguesa e espanhola da escala KINDL®, questões sociodemográficas, clínicas e um bloco de notas.

**Resultados:** As crianças têm uma perceção positiva da qualidade de vida. A dimensão Autoestima foi a melhor percebida e o Bem-estar Emocional a pior. As crianças espanholas perceberam melhor qualidade de vida. Da análise de conteúdo efetuada emergiram sentimentos positivos.

**Conclusão:** Um acompanhamento individualizado da criança por uma equipa multidisciplinar, campos de férias formativos, de autonomização e libertação, de educação por pares, de socialização e lúdicos, poderão ser benéficos às crianças e sua família.

**Palavras-chave:** qualidade de vida; doença renal; acampamento

### Resumen

**Marco contextual:** La enfermedad renal, como enfermedad crónica impide que los niños y las familias puedan disfrutar de una vida normal, dadas las alteraciones que tienen lugar en su vida diaria.

**Objetivos:** caracterizar la calidad de vida percibida por los niños con enfermedad renal que van a campamentos de vacaciones.

**Metodología:** Estudio descriptivo-correlacional y transversal, de naturaleza mixta. La muestra es no probabilística y está compuesta por 42 niños (29 españoles y 13 portugueses) de entre 7 y 17 años con enfermedad renal crónica que estuvieron en campamentos de vacaciones. Se utilizó la versión portuguesa y española de la escala KINDL®, cuestiones sociodemográficas, clínicas y un cuaderno de notas.

**Resultados:** Los niños tienen una percepción positiva de la calidad de vida. La dimensión Autoestima fue la que mejor se percibió y el Bienestar Emocional la que peor. Los niños españoles percibieron mejor la calidad de vida. Del análisis de contenido realizado surgieron sentimientos positivos.

**Conclusión:** Un seguimiento individualizado del niño por un equipo multidisciplinar, así como campamentos de vacaciones formativos, de autonomía y liberación, de educación por pares, de socialización y lúdicos pueden ser beneficiosos para los niños y su familia.

**Palabras clave:** calidad de vida; enfermedades renales; acampada

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## Introduction

The concept of quality is subjective and difficult to define. It is directly associated with each individual's perceptions, needs, or goals. The meaning that each individual assigns to the most diverse situations will influence how he/she perceives and interprets them. According to the World Health Organization (WHO), scales should be used for this purpose, since quality of life is a subjective concept, which depends on several factors (Heath et al., 2011).

Several scales have proven to be effective in assessing children's quality of life, namely components related to physical functioning, emotional well-being, and social and school activity (Figueiredo, 2015).

Children with a chronic disease face physical, social, emotional, and developmental challenges, and summer camps can truly help improving their quality of life (McCarthy, 2015).

Therefore, based on our belief that children with chronic kidney disease may benefit from summer camps, we developed this study with the aim of characterizing the perceived quality of life of children with kidney disease who attend summer camps. The purpose of this study is to contribute towards the development of recommendations for improving the quality of life of children with chronic kidney disease.

## Background

The onset of a disease often entails changes in the daily life of patients and those who are close to them. In the case of a chronic disease such as kidney disease, changes are even greater. Thus, children with this disease and their families are often prevented from enjoying a normal life, thereby limiting their quality of life (Laplane, Jajbhay, & Frederico, 2015).

According to WHO, chronic diseases are the leading cause of death worldwide, being responsible for 38 million deaths, with 16 million of them occurring before the age of 70 years (World Health Organization, 2015).

Chronic kidney disease in children has several causes such as congenital anomalies of the kidney and the urinary tract, hereditary dis-

eases, or primary glomerular diseases (Gomes, 2014; Sociedade Portuguesa de Pediatria, Secção de Nefrologia Pediátrica, 2014). Chronic kidney disease is characterized by an irreversible deterioration of renal function, which can be sudden or slow. The treatment often consists of dialysis and, subsequently, kidney transplantation. There are two types of dialysis: hemodialysis and peritoneal dialysis (Trentini et al. as cited in Frota, Machado, Martins, Vasconcelos, & Landin, 2010). In our clinical practice, the most common type of dialysis in children is peritoneal dialysis. In the initial stage of the disease, treatment may consist only of a diet and an appropriate lifestyle, with or without medication.

Summer camps can be a positive experience for children with chronic kidney disease because they promote peer contact and the development of friendship bonds, improve their self-concept, increase their knowledge about the disease, and its management (McCarthy, 2015).

Children with chronic disease often have markedly negative experiences in several areas. Some of the barriers that these children have to overcome include physical changes, negative body image, social isolation, decreased emotional function, and overall development (McCarthy, 2015). In view of the above, offering children these moments outside of the hospital setting can be extremely rewarding on several levels.

## Research questions

What is the perceived quality of life of children with kidney disease who attend summer camps?

What is the influence of sociodemographic variables (gender, age, number of siblings, education, nationality, and previous participation in summer camps) and clinical variables (type of treatments) in the perceived quality of life of children with kidney disease?

## Methodology

This is an Iberian study with a descriptive-correlational and cross-sectional design

and a mixed-method approach (quantitative and qualitative).

The nonprobability sample is composed of 42 children with kidney disease: 29 Spanish and 13 Portuguese children, aged between 7 and 17 years who were attending a summer camp. The Spanish children were in the summer camp CRECE (Vacaciones socioeducativas para niños y jóvenes com enfermedad renal) promoted by the Spanish Federation of Associations for the Fight against Kidney Disease (*Federación Nacional de Asociaciones para la Lucha Contra las Enfermedades del Riñón* - ALCER), in León (Spain) in June 2015. The Portuguese children were in the summer camp CRESCE promoted by the Portuguese Association of People with Chronic Kidney Disease (*Associação Portuguesa de Insuficientes Renais* - APIR), in Tocha, Coimbra, Portugal, in September 2015.

The data collection instrument was a self-administered questionnaire composed of the KINDL® questionnaire for measuring Health-Related Quality of Life (Ravens-Sieberer, & Bullinger, 2000a, 2000b), which was culturally adapted and validated for the Portuguese population (Ferreira, Almeida, Pisco, & Cavalheiro, 2006). The authors of this scale have made it available in their website in three versions: 4-6 years, 7-13 years, and 14-17 years, both in Portuguese (Ravens-Sieberer & Bullinger, 2000a) and Spanish (Ravens-Sieberer & Bullinger, 2000b). We added six questions to the questionnaire for socio-demographic characterization (gender, age, number of siblings, education, nationality, and previous participation in summer camps) and two questions on medical history and treatments. We have also included a notepad where children were able to briefly describe their most significant experiences during the summer camp.

The KINDL® questionnaire measures children's quality of life and is composed of 30 questions, distributed into seven dimensions of quality of life: Physical well-being, Emotional well-being, Self-esteem, Family, Friends, School, and Disease. The first six dimensions are composed of four questions each, and the final dimension is composed of six questions.

The grouping of answers and the cutoff point

followed the indications provided in the manual for analysis of the scale, which was developed by the authors (Ravens-Sieberer & Bullinger, 2000c).

Each question in the KINDL® questionnaire is scored on a 5-point Likert scale, where 1 corresponds to *never* and 5 corresponds to *all the time*. For the analysis and interpretation of the results, the scale was recoded from five to three levels, in which 1 corresponds to the total number of negative answers (combining points 1 and 2 of the above-mentioned scale), 2 corresponds to neutral answers, and 3 corresponds to positive answers (combining points 4 and 5).

Results were grouped by dimensions and we found that the mid-point for each dimension is a 50% score. We believe that children's perceptions of their quality of life are positive with scores above this mid-point; on the other hand, scores below this mid-point represent a lower quality of life/functionality.

For the quantitative analysis, data were analyzed using the statistical software International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS), version 23. The significance level was set at 5% ( $p = .05$ ).

The Shapiro-Wilk test was used to analyze the distribution of the various dimensions, which proved to be very different from normal ( $p < .05$ ) in the vast majority of the dimensions (with the exception of the Disease dimension) and in the total scale.

Spearman's correlation matrix was used to analyze the correlation between the total scale and its dimensions.

The Mann-Whitney  $U$  test was used to check for any statistically significant correlations between gender, type of treatment and nationality and the perceived quality of life in children/adolescents with kidney disease.

The Kruskal-Wallis test was used to check if the number of siblings, education, and previous participation in summer camps had a statistically significant correlation with quality of life.

We used Bardin's content analysis technique (2009) for qualitative analysis, and performed data categorization.

All ethical principles inherent to the study were taken into account, namely the request

to the Ethics Committee of the School of Health of Viseu (Polytechnic Institute of Viseu) which issued a favorable opinion. We also requested authorization to the authors of the data collection tool for its use and made a formal request to the Presidents of the AL-CER and APIR. Parents were asked to sign the informed consent for the children's participation in the study and, in the summer camps, children were explained the purpose of the study and given some information about the correct completion of the questionnaires. For data collection, the researcher visited each of the summer camps and, after the children's consent, delivered the questionnaires. The children answered the questionnaires by themselves. Almost all of them were able to read and write and any doubts related to interpretation during its completion were clarified by the researcher. Only one child had difficulty in reading, so the summer camp monitor read him/her the questions and answers, and the child chose them. After completion, each questionnaire was placed in an unidentified envelope, thus ensuring children's anonymity. Data were collected in June and September 2015.

## Results

### Sociodemographic characterization

Participants were mostly boys (52.4%). The

minimum age was 7 years, the maximum age was 17 years, and the mean age was 12.9 years ( $\pm 3.05$ ). With regard to the number of siblings, 50% of them had one sibling and 14.3% had no siblings. As to education, 47.6% of the participants were in the 5<sup>th</sup> to 9<sup>th</sup> grades. With regard to nationality, 69% of them were Spanish and 30.9% were Portuguese and 52.4% had already participated in summer camps.

### Clinical characterization

Kidney transplantation was the type of treatment for kidney disease reported by most of the children/adolescents (71.4%), followed by the conservative treatment (19%), and dialysis (11.9%). Most of the five children on dialysis (80%) were aged between 13 and 17 years.

### Quality of life

In order to answer the research question What is the perceived quality of life of children with kidney disease who attend summer camps, we found that participants showed a positive perception of their quality of life, with a mean score of 53.02% of the total scale ( $\pm 7.93$ ; Table 1). It should be noted that the scores ranged between a minimum of 34.52% and a maximum of 74.70%.

Self-Esteem was the best perceived dimension (73.06%  $\pm 22.28$ ) and Emotional Well-Being was the worst perceived dimension (32.74%  $\pm 10.67$ ).

Table 1

*Statistics related to children's perceived quality of life*

Quality of life	Min	Max	Mean	SD	CV (%)	Sk/error	K/error	S/W
Physical well-being	18.75	68.75	36.16	13.28	36.72	0.840	0.090	0.002
Emotional well-being	12.50	56.25	32.74	10.67	18.97	0.812	0.399	0.001
Self-esteem	18.75	100.00	73.06	22.28	30.49	-0.513	-0.590	0.006
Family	18.75	81.25	57.15	13.77	24.09	-0.707	0.741	0.027
Friends	25.00	100.00	69.94	13.61	19.45	-0.717	2.402	0.002
School	25.00	100.00	68.60	21.58	31.46	-0.490	-0.485	0.022
Disease	0.00	79.17	33.93	16.16	47.63	0.200	0.300	0.562
Quality of life (Total)	34.52	74.70	53.02	7.93	14.96	0.098	1.007	0.405

With regard to the data from the seven dimensions of the scale (Table 2), we underline the fol-

lowing results:

In the Physical Well-Being dimension, 57.1% of

the participants *never* felt ill and 59.5% *never* was in pain.

In the Emotional Well-Being dimension, 57.1% of the participants reported “I had fun and laughed a lot at all time”. In the same line, 45.2% reported “I was never bored”, 76.6% “never felt alone”, and 64.3% “never felt scared or unsure of myself”.

In the dimension Self-Esteem, 47.6% “was proud of myself at all time”, 40.5% “felt on top of the world”, and 57.1% “felt pleased with myself”.

In the dimension Family, most of the participants (59.5%) stated “got on well with my parents at all time” and 61.9% “felt fine at home at all time”.

The dimension Friends was well rated by the participants, and 69% of them reported “was a “success” with my friends at all time” and “got

along well with my friends”. “Never felt different from other people” was reported by 52.4% of the children.

In the dimension School, 54.8% of the children/adolescents found that “doing the schoolwork was easy at all time” and 47.6% “found school interesting at all time”.

In the dimension Disease, it should be emphasized that 66.7% of the participants reported that “parents never treated me like a baby because of my illness” and 59.5% said that “I never wanted nobody to notice my illness”.

The total score of the quality of life scale was positively correlated with all dimensions and was statistically significant with the dimension Self-Esteem ( $p = .658$ ), School ( $p = .668$ ), Friends ( $p = .439$ ), and Physical well-being ( $p = .400$ ).

Table 2

*Children's perceived quality of life*

During the past week...	Never		Rarely		Sometimes		Often		All the time	
	No.	%	No.	%	No.	%	No.	%	No.	%
Physical well-being										
I felt ill	24	57.1	11	26.2	6	14.3	1	2.4	-	0.0
I was in pain	25	59.5	5	11.9	11	26.2	1	2.4	-	0.0
I was tired and worn-out	16	38.1	10	23.8	12	28.6	2	4.8	2	4.8
I felt strong and full of energy	-	0.0	3	7.1	4	9.5	12	28.6	12	28.6
Emotional Well-Being										
I had fun and laughed a lot	-	0.0	1	2.4	5	11.9	12	28.6	24	57.1
I was bored	19	45.2	12	28.6	12	28.6	1	2.4	-	0.0
I felt alone	32	76.2	5	11.9	5	11.9	-	0.0	-	0.0
I felt scared or unsure of myself	27	64.3	6	14.3	6	14.3	1	2.4	1	2.4
Self-Esteem										
I was proud of myself	1	2.4	6	14.3	8	19.0	7	16.7	20	47.6
I felt on top of the world	2	4.8	4	9.5	10	23.8	9	21.4	17	40.5
I felt pleased with myself	2	4.8	2	4.8	6	14.3	10	19.0	24	57.1
I had lots of good ideas	-	0.0	7	16.7	11	26.2	10	23.8	14	33.3
Family										
I got on well with my parents	-	0.0	2	4.8	7	16.7	8	19.0	25	59.5
I felt fine at home	2	4.8	2	4.8	6	14.3	6	14.3	26	61.9
We quarreled at home	17	40.5	7	16.7	13	31.0	4	9.5	1	2.4
I felt restricted by my parents	12	28.6	12	28.6	11	26.2	3	7.1	4	9.5

Friends										
I did things together with my friends	2	4.8	2	4.8	4	9.5	13	31.0	21	50.0
I was a "success" with my friends	1	2.4	1	2.4	7	16.7	4	9.5	29	69.0
I got along well with my friends	-	0.0	-	0.0	2	4.8	11	26.2	29	69.0
I felt different from other people	22	52.4	5	11.9	11	26.2	2	4.8	2	4.8
School										
Doing the schoolwork was easy	2	4.8	4	9.5	6	14.3	7	16.7	23	54.8
I found school interesting	2	4.8	4	9.5	7	16.7	9	21.4	20	47.6
I worried about my future	7	16.7	4	9.5	4	9.5	6	14.3	21	50.0
I worried about getting bad marks or grades	7	16.7	7	16.7	9	21.4	8	19.0	11	26.2
Disease										
I was afraid that my illness might get worse	22	52.4	4	9.5	11	26.2	4	9.5	1	2.4
I was sad because of my illness	25	59.5	6	14.3	7	16.7	3	7.1	1	2.4
I was able to cope well with my illness	3	7.1	-	0.0	4	9.5	10	23.8	25	59.5
My parents treated me like a baby because of my illness	28	66.7	5	11.9	4	9.5	-	0.0	5	11.9
I wanted nobody to notice my illness	25	59.5	5	11.9	7	16.7	1	2.4	4	9.5
I missed something at school because of my illness	15	35.7	9	21.4	10	23.8	3	7.1	5	11.9

The inferential analysis showed that gender and age had no discriminating power on the quality of life and that Spanish participants had a better perception of quality of life than Portuguese participants ( $p = .040$ ). No statistically significant differences were found ( $p > .05$ ) regarding the number of siblings, level of education, previous participation in summer camps, and type of treatment (transplantation and dialysis).

Based on the content analysis of the texts that the children wrote in the notepad on their experiences during summer camp, several categories and subcategories emerged. We identified three categories: positive aspects, negative aspects, and gratitude-related aspects.

With regard to the positive aspects, we

identified a personal perspective, where we found feelings of happiness, well-being, and fun. We also identified a social perspective, with reference to the importance of building friendships, peer identification, feelings of camaraderie and complicity, experiences of empowerment, and the experienced adventures. In the subcategory on the clinical perspective, a clear importance was assigned to the sharing of individual experiences, peer education, identification with others, feelings of emancipation, and learning experiences, particularly in relation to medication and the principles of kidney disease prevention.

With regard to the negative aspects, one child reported feelings of anguish and fear and another one reported getting bored sometimes. The feelings of gratitude were mainly direct-



ed to nurses, camp monitors, and organizing institutions.

We found expressions like “I felt very good . . . We had a wonderful time.” (J.; June, 2015); “I felt good and I had a lot of fun” (M.; June, 2015). It was also interesting to note that children recognized the benefits of this experience and felt grateful, using words expressing affective recognition: “I would like to return next year” (M.; June, 2015); “I liked everything! We always had nurses caring for us, monitors who had an important task. I would like to be invited to attend other summer camps. It is something that I really want to do again.” (T.; September, 2015).

## Discussion

Most children/adolescents with kidney disease who attend summer camps and who were part of this study were Spanish (29), while 13 children were Portuguese. This is not surprising since until 2014 there were only summer camps for children with kidney disease in Spain. In 2015 and 2016, these summer camps took place both in Portugal and in Spain. The first European meeting occurred in Poland in 2016.

We found that children and adolescents have a positive perception of their quality of life, with a mean score of 53.02% of the total scale ( $\pm 7.93$ ). The Self-esteem dimension was the best perceived, and the Emotional well-being dimension was the worst perceived.

The lack of studies on the quality of life of children with kidney disease prevented us from comparing the obtained data with other studies. However, we can compare our data from the Emotional well-being dimension, which was the worst perceived dimension, with the data obtained by Kul et al. (2013), where most children reported a lower health-related quality of life in the physical and psychosocial dimensions.

Another study mentioned the physical component as one of the most affected, particularly in children undergoing hemodialysis (Aparicio López, Fernández Escribano, Izquierdo García, Luque de Pablos, & Garrido Cantanero, 2010).

Self-Esteem was the best perceived dimension in our study. Kiliş-Pstrusińska et al. (2013) argued that kidney disease influences the child's mental state; therefore, psychological support is essential from disease onset, both at school education and at Emotional levels.

In addition, a study conducted with Iranian transplanted children revealed that psychological factors have a greater influence on the quality of life than the socioeconomic status or even the clinical variables; thus, the authors of the study suggest psychological support to improve children's quality of life (Malekhamadi et al., 2011).

Anthony et al. (2010) reported that family cohesion affects the quality of life. In fact, the scores obtained in the Family dimension are quite positive in our study.

In the School dimension, our data are also positive. Aparicio López et al. (2010) concluded that one of the most affected variables of the quality of life of children with chronic kidney disease is school performance, especially in children undergoing hemodialysis.

Aparicio López, Fernández Escribano, Garrido-Cantanero, Luque de Pablos, and Izquierdo-García (2013) found that the analytical variables and the children's clinical status influence their quality of life. However, in our study, quality of life did not change in result of the Disease dimension.

Gender and age have no discriminating power on quality of life.

Spanish participants had a better perception of quality of life than Portuguese participants. No statistically significant differences were found ( $p > .05$ ) regarding the number of siblings, level of education, previous participation in summer camps, and type of treatment.

The qualitative analysis showed mainly positive feelings, being clear that this type of activity had a personal, social, and clinical impact on these children. This allows us to infer that the summer camp is a recreational group activity that contributes to the sharing of experiences and improves these children's quality of life.

We are aware that this study had some limitations, so caution is needed in interpreting and generalizing the results.

First, sample size was small, given the shortage of summer camps for children with kidney disease. Therefore, since this small is not

representative of the population, it is impossible to generalize the results.

Another important aspect relates to the results, which may have been influenced by the fact that data were collected in a single moment. During summer camp, children's clinical condition was stable, thus creating an emotional predisposition to well-being.

## Conclusion

This analysis found that children who participate in summer camps have a positive perception of their quality of life and that self-esteem was the best perceived dimension.

Spanish participants have a better perception of quality of life than Portuguese participants. In addition to the results obtained through the questionnaire, the children's accounts clearly showed their satisfaction in participating in these events and the benefits of summer camps.

Based on these results, we suggest a personalized follow-up performed by a multidisciplinary team focused on each child's specific needs. Summer camps for educational purposes, empowerment, peer education, emancipation, entertainment, and socialization can be beneficial to children and their families. Therefore, we suggest providing access to more people and provide incentives for their participation. More research in this area will certainly be relevant. As a proposal for future studies, it would be interesting to apply the questionnaire before and after summer camp or compare groups who attended summer camps with groups who have never attended a summer camp.

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