http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude
ISSN on-line1984-7513
DOI 10.4025/ciencuidsaude.v23i0.66021

ORIGINAL ARTICLE

QUALITY OF LIFE AND CHRONIC DISEASE: CORRELATION BETWEEN REPORTS FROM CHILDREN, ADOLESCENTS, AND THEIR GUARDIANS

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ABSTRACT

Objectives: To evaluate the quality of life of children and adolescents with chronic conditions and correlate the self-report of the child and adolescent with the guardian's report. **Method:** A quantitative, descriptive, cross-sectional study involving children and adolescents aged 8 to 18 years and their guardians was conducted. Data collection took place in a university hospital in Rio de Janeiro, gathering sociodemographic and clinical characterization data of the participants and using the PedsQL™ Pediatric Quality of Life Inventory, valid and reliable for use in Brazilian Portuguese. Data analysis included descriptive statistics and the Pearson correlation test. **Results:** In total, 92 participants were included in the study, comprising 46 children and adolescents, and 46 guardians. Most children and adolescents (74%) showed low quality of life scores. The guardians' scores were, on average, 5% to 10% lower than those of the children and adolescents. A weak correlation was found between children or adolescents and guardians in the social dimension of quality of life. **Conclusion:** It is the responsibility of healthcare professionals, including nursing staff, to identify affected dimensions of the quality of life of this clientele and plan interventions that mitigate the consequences of chronic diseases and promote quality of life.

Keywords: Criança. Adolescente. Doença crônica. Qualidade de vida. Enfermagem pediátrica.

INTRODUCTION

Profound demographic transformations have affected Brazil and many other developing countries over the last decades. We can observe significant technological advancements, a reduction in infant mortality, a decrease in deaths from infectious diseases, and an increase in life expectancy. However, alongside these transformations, there has been a growth in the prevalence of chronic non-communicable diseases within the population's morbidity and mortality profile(1).

Chronic diseases are among the main public health issues in Brazil and worldwide, with increasing numbers of premature deaths, disabilities, and loss of Quality of Life (QoL), negatively impacting society and the economy, and overburdening the healthcare system(2). In the Brazilian context, it was identified that 9.1% of children aged 0 to 5 years have some chronic condition, as do 9.7% of those between 6 and 13 years old. Adolescents, aged 14 to 19 years, account for 11% of the overall population with some chronic pathology(3). The main chronic diseases affecting the child and adolescent population include respiratory diseases such as asthma, bronchitis, and bronchiolitis; autoimmune diseases like lupus and cystic fibrosis; congenital heart defects and physical malformations; hematological conditions such as hemophilia; genetic disorders like trisomy 21; and general neurological and oncological conditions(4).

Chronic health conditions are characterized by a gradual onset, with a long or indefinite course, accompanied by uncertainties regarding prognosis(5). Over time, they may lead to

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disabilities amid possible changes in the clinical course, including the possibility of acute episodes. These conditions often require numerous hospitalizations and necessitate continuous care, which does not always result in a cure(6). Given this context, once a chronic disease is diagnosed, the lives of children and adolescents and their families become oriented around its progression and treatment. This marks the beginning of a long and complex period, usually filled with difficulties and feelings of anguish and uncertainty(7).

Chronic disease affects not only the child but also their family, as long hospital stays become part of their daily life. The consequences of prolonged hospitalization include exhaustion for both the child and their support network, as well as changes in their lives leading to conflicts and other negative repercussions(8). During hospital stays, families navigate various health services, share losses and limitations, and care, while experiencing disruptions in the family life cycle and changes in roles and functions. Strategies are necessary to address these diseases, meet the needs of this clientele and their families, and regain balance in various aspects of their lives(8).

Since the 1950s, there has been a significant increase in population life expectancy, largely due to scientific advancements and improved survival of people with chronic diseases(9). With these changes, the term “quality of life” has shifted from being associated with financial conditions to a broader perspective, where an individual's perception of their health condition and other life dimensions is crucial(9).

Chronic diseases, by permanently interfering with an individual's lifestyle and limiting their productive capacity and worldview, are the most detrimental to health-related quality of life (HRQoL)(10), understood as the individual's perception of their life condition in the face of illness and treatment, and the consequences of these factors on their quality of life(11). Some diseases require profound lifestyle changes in children, adolescents, and their families, affecting behaviors related to eating habits, physical activity, undergoing painful procedures, and routine consultations with specialists(10).

That said, this research is justified by the growing prevalence of chronic diseases in the Brazilian context, their impact on public health, and their repercussions on the quality of life of children and adolescents living with these conditions. It raises research questions: How does chronic disease affects the quality of life from the perspective of children and adolescents?What is the agreement level between the child or adolescent's report and that of their guardian? Therefore, the objectives of this study were to evaluate the quality of life of children and adolescents with chronic diseases and correlate the child's and adolescent's self-report with their guardian's report.

METHOD

This study is quantitative, descriptive, and cross-sectional, utilizing the STROBE checklist to report and demonstrate the methodological rigor of the research.

Data collection took place in a tertiary care university hospital in Rio de Janeiro, offering general pediatrics services across various specialties: allergy and immunology, endocrinology, genetics, infectious diseases, nephrology, neurology, and surgery. The hospital provides outpatient services and has 30 beds for general pediatrics (16), infectious diseases (3), pediatric surgery (5), and a Pediatric Intensive Care Unit (PICU) (6). Additionally, the institution features a Teen Health Studies Center, serving as a reference center for hospitalizing adolescents with clinical and surgical conditions, with 16 beds.

The collection spanned one year and four months, concluding in December 2018. Fifty dyads (child or adolescent and their guardian) were invited to participate during their hospital stay or visit, with 46 accepting. Three children or adolescents declined due to a lack of interest, discomfort, or preference to stay in the playroom, and one guardian refused due to time constraints.

Initial contact was made with the children and adolescents' guardians in a private, quiet setting to explain the research proposal and the data collection instrument for self-reporting by the child, adolescent, and guardian report. Participants were informed about the anonymity and confidentiality of the research, the use of non-identifiable data, and the option to withdraw at any time without consequences.

Following this procedure, if the guardians consented, the children and adolescents were invited to participate, and both were given the Informed Consent Form (ICF) and the Assent Form, respectively. Interviews with children, adolescents, and their guardians were conducted separately on the same day to prevent any influence on their responses, as previously advised.

The inclusion criteria were children aged 8 to 12 and adolescents aged 13 to 18 with chronic diseases and the cognitive capacity to complete the instrument. Health professionals working in the departments assessed cognitive capacity, and the age classifications for children and adolescents adhered to those specified by the data collection instruments used. Exclusion criteria were critically hospitalized children and adolescents unable to communicate, thus requiring someone else to complete the instrument on their behalf.

These guardianswere excluded: those not actively involved in caregiving and thus unable to provide accurate information about the physical, social, emotional, and educational dimensions of the participating child or adolescent, regardless of their relationship. The caregiver role was assessed based on the guardians' reports of their active involvement in the child's care and coexistence during the illness process.

A specialized form used by the research group collected sociodemographic information about the child or adolescent and their guardian (such as gender, date of birth, self-reported skin color, origin, education level of both, guardian's marital status, and family income) during the interview. Clinical data of the child's chronic disease, including diagnosis, diagnosis date, and treatment, were collected through medical record consultation.

To assess HRQoL, globally recognized instruments validated for use in Brazil were chosen. The children or adolescents and their guardians completed the PedsQL™ Pediatric Quality of Life Inventory Generic Module in self-report versions for the child or adolescent and the guardian report, both referring to the past week.

An age-specific modular instrument,the Pediatric Quality of Life Inventory (PedsQL™) is designed to measure HRQoL in children and adolescents aged 2 to 18(11). The self-report versions for children (8 to 12 years) and adolescents (13 to 18 years) and their guardians' reports were used. Varni, Seid, and Rode(12) created the instrument, which was latervalidated for use in various countries, including Brazil, in 2008 by Klatchoian et al(13).

The PedsQL™ Generic Core 4.0 comprises four subscales: physical, emotional, social, and school functioning. Each employs a five-point Likert scale to assess how much of a problem an item has been over the past week(0 = never a problem, 1 = rarely a problem, 2 = sometimes a problem, 3 = often a problem, and 4 = almost always a problem). Raw scores are converted to a 0-100 scale (1=100, 2=75, 3=50, 4=25, 5=0), with higher scores indicating better HRQoL(11).

For data analysis, an Excel spreadsheet (Microsoft Office®),was initially created for variable coding, with double entry by different researchers. The data were then exported to Statistical Package for the Social Sciences (SPSS) version 23.0 for statistical analysis. Descriptive statistics (maximum, minimum, mean, and standard deviation) were used to quantify HRQoL. To compare the means of HRQoL dimensions, a one-sample T-test was used. Additionally, Pearson's correlation was employed to describe the relationships between HRQoL reported by children or adolescents and their guardians, considering variables that followed a normal distribution curve. Correlation values were deemed weak when below 0.40, moderate between 0.41 and 0.60, good or substantial between 0.61 and 0.80, and almost perfect or very good above 0.81. The significance level used in the research was 0.05.

This study is part of the research project titled "Evaluation of signs and symptoms in children with chronic conditions and their relation to quality of life from a quantitative perspective," approved by the Human Research Ethics Committee of the proposing institution, under CAAE No. 69079716.8.0000.5282 and opinion No. 2,144,849. It adhered to the guidelines outlined in National Health Council Resolution 466/2012. All participants voluntarily expressed their desire to join the research, and the consent process for guardians and the assent process for children and adolescents were completed with the signing of the respective terms.

RESULTS

The study included 92 participants, comprising 46 guardians and 46 children and adolescents aged between 8 under 18 years with chronic diseases. Of these, nine were hospitalized in the pediatric clinical ward, 17 in the Adolescent Health Center, and 20 in outpatient consultation.

The average age of children and adolescents with chronic conditions was 12.1 ± 3.1 years. The majority were children (8 to 12 years) (56.5%), male (52.2%), and self-identified as mixed race (37.0%). Autoimmune diseases (23.9%) and onco-hematological diseases (17.4%) were the most prevalent. Additional sociodemographic and clinical information of the participants is presented in Table1.

Table 1. Sociodemographic and Clinical Data of Child and Adolescent Participants in the Research - Rio de Janeiro, RJ – Brazil– 2022

Variables	Participants n (%)
Age at the Time of Data Collection(years; mean ± SD)	12,1 ± 3,1
Child (8-12 years)	26 (56,5)
Adolescent (13-18 years)	20 (43,5)
Sex	
Male	24 (52,2)
Female	22 (47,8)
Skin Color(self-declared)	
White	15 (32,6)
Black	13 (28,3)
Brown	17 (37,0)
Indigenous	01 (2,2)
Diagnosis	
Onco-hematological diseases	08 (17,4)
Cardiovascular diseases	05 (10,9)
Respiratory diseases	05 (10,9)
Metabolic diseases	02 (4,3)
Genetic diseases	02 (4,3)
Autoimmune diseases	11 (23,9)
Nephrological diseases	05 (10,9)
Neurological diseases	07 (15,2)
Others	01 (2,2)

Source: Research data, 2022.

Guardians had an average age of 40.6 ± 8.1 years, ranging from 27 to 63 years. Most were female (95.7%), mothers of the child or adolescent (84.8%), single (47.8%), with a monthly family income between R$701.00 (US$141) and R$1,400.00 (US$282) (50.0%), living less than 100 kilometers from Rio de Janeiro (69.8%), and with complete or incomplete secondary education (50.0%), as shown in Table2.

Table 2. Sociodemographic Data of Guardian Participants in the Research - Rio de Janeiro, RJ – Brazil– 2022

Variables	**Participants** n (%)
Age(years; mean ± SD)	40.6 ± 8.1
Sex	
Male	02 (5.7)
Female	44 (95.7)
RelationshiptoPatient	
Mother	39 (84.8)

Father	02 (4.3)
Other	05 (10.9)
EducationLevel	
No schooling	04 (8.7)
Primary education (complete or incomplete)	17 (36.9)
Secondary education (complete or incomplete)	23 (50.0)
Highereducation	02 (4.3)
Marital Status	
Single	22 (47.8)
Married/Common-law/Partnered	17 (37.0)
Separated/Divorced	03 (6.5)
Widow(er)	04 (8.7)
Origin/Proximity	
Close (<100 km)	32 (69.8)
Intermediate (100 to 500 km)	11 (23.9)
Distant (>500 km)	03 (6.5)
Family Income (R$ - reais)*	
0 to 700.00	03 (6.5)
701.00 to1,400.00	23 (50.0)
1,401.00to 2,800.00	06 (13.0)
Over 2,800.00	04 (8.7)
Unknown/Prefer not to say	10 (21.7)

Source: Research data, 2022.

Regarding Quality of Life (QoL), the average total scores for children and adolescents were 60.2 ± 18.0; 34 (74%) participants had QoL scores lower than 70, indicating that the chronic conditions they live with are "often" or "almost always" a problem, directly affecting physical, emotional, social, and school functioning. The lowest total QoL score reported by the children and adolescents was 28.3. The average scores for the subscales in different dimensions were 61.1 ± 25.3 for physical functioning; 61.3 ± 25.6 for emotional functioning; 66.0 ± 21.3 for social functioning; and 51.4 ± 27.1 for school functioning. One child did not complete the "school functioning" dimension because they had not attended school for more than a week.

As for the guardians, the average total QoL scores were 57.9 ± 20.3. The average scores for the dimensions were: 53.9 ± 27.0 for physical functioning; 55.0 ± 25.1 for emotional functioning; 69.8 ± 22.5 for social functioning; and 55.8 ± 30.0 for school functioning. The total QoL scores and their dimensions, according to the self-report of the child and adolescent with chronic disease and the guardians'report, are presented in Table 3.

Table 3. Total quality of life scores and their dimensions, according to the self-report of the child and adolescent and guardians' report - Rio de Janeiro, RJ– Brazil–2022

	Children and Adolescents				**Guardians**		
	Mean/SD*	**Minimum Score**	**Minimum Score**	**P****	**Mean/SD***	**Minimum Score**	**Minimum Score**
PhysicalFunctioning	61.1 ± 25.3	6.3	96.9	.000	53.9 ± 27.0	3.1	100.0
EmotionalFunctioning	61.3 ± 25.6	0	100.0	.000	55.0 ± 25.1	5.0	100.0
Social Functioning	66.0 ± 21.3	25.0	100.0	.000	69.8 ± 22.5	25.0	100.0
SchoolFunctioning	51.4 ± 27.1	0	100.0	.000	55.8 ± 30.0	0	100.0
Total HRQoL	60.2 ± 18.0	28.3	97.2	.000	57.9 ± 20.3	15.2	100.0

* SD – standard deviation; **One-sample T-test with a 95% confidence interval.

Source: Research Data, 2022.

The average scores of the guardians were, on average, 5% to 10% lower than those expressed by the children and adolescents. This analysis, through Pearson's correlation, indicated that the social dimension had the worst correlation (weak) between children and adolescents and guardians (r=0.38; p=0.009). The total quality of life (r=0.60; p=0.000) and emotional dimension (r=0.47; p=0.001) showed moderate correlations, and the physical (r=0.64; p=0.000) and school (r=0.61; p=0.000) dimensions, the best correlations (good).

DISCUSSION

The results indicate that children and adolescents living with chronic diseases have impaired HRQoL. Of all scores obtained, 74% were below 70, signaling that chronic conditions in childhood and adolescence are "often" or "almost always" a problem, interfering in various dimensions of their lives.

Studies on the quality of life of healthy children and adolescents allowed for a comparison with the significant difference between healthy children and adolescents and those with chronic diseases. A Brazilian study(14) assessed the quality of life of 95 healthy children and adolescents and found 100% of their score averages across all dimensions (total quality of life, physical, emotional, social, and school functioning) to be higher than 70. An American study(15) with 5,972 healthy children also showed scores significantly higher than those found in this research: 82.9 ± 13.2 for total quality of life; 86.9 ± 13.5 in physical functioning; 78.2 ± 18.6 in emotional functioning; 84.0 ± 7.4 in social functioning; and 79.9 ± 16.9 in school functioning.

Our results corroborate other international studies on HRQoL with children and adolescents with cancer(12), sickle cell anemia(16), idiopathic arthritis(17), and diabetes mellitus(18).

These findings emphasize the need for a more detailed investigation of the repercussions of chronic disease on the quality of life of children and adolescents, as well as ways to improve it to increase comfort for this clientele.

The lowest average found in the report of the child and adolescent was in the school functioning dimension (51.4 ± 27.1). Due to recurrent hospitalizations, the symptomatology associated with the experienced condition, the effects of treatment, and the emotional and physical limitations of the child, there is a need to be absent from school, which promotes harmful effects on their learning(19). For these individuals, hospitalization and detachment from school life mean not only academic loss but also a profound change in the rhythm of life, deprivation of regular activities, and restrictions on social participation, with direct consequences for self-esteem(19).

Physical functioning (61.1 ± 25.3) had the second lowest average according to the reports of the child. Many children and adolescents do not develop their full physical potential due to chronic disease, which is evident as they demonstrate a lower capacity to perform physical activities compared to healthy children(20). Thus, a determining factor that impairs this development involves the limitations imposed by chronic disease, which end up keeping the child inactive. As a result, this clientele can exhibit lower physical performance compared to the general pediatric population(20).

According to the guardians' reports, the physical dimension had the worst score. The need presented by children and adolescents with chronic diseases for complex and long treatments compromises their physical and social well-being. For this reason, it greatly interests to understand not only the clinical parameters of the disease but also how the experiences involving the individuals' illness cause changes and interfere with their daily functions(21).

Both emotional and social functioning, despite having higher scores compared to other dimensions, also reached low scores. Childhood and adolescence presuppose emotional and social transformations in which the individual builds their concepts, self-image, and self-esteem. However, chronic disease, surrounded by various stigmas, can have repercussions not only on treatment but also on socialization and interpersonal relationships, and consequently, on the emotional well-being of this clientele, reflecting in a decrease in their quality of life(22).

Regarding the most prevalent chronic diseases in our sample, autoimmune, onco-hematological, cardiovascular, and neurological diseases stand out.

Autoimmune diseases like Systemic Lupus Erythematosus are characterized by their progression with various joint, hematological, renal, and even neuropsychiatric disorders(23). Onco-hematological diseases, such as leukemias, are chronic-degenerative diseases that cause suffering, instability, and fear regarding diagnosis and treatment, often presenting with poor prognoses(24).

Cardiovascular diseases significantly impact patients, leaving some with adult life sequelae, uncertainty about prognosis, symptoms, and physical activity restrictions(25). Neurological diseases may accompany psychological disorders, significantly affecting the quality of life more than the disease severity, and affecting social functioning, cognitive and emotional aspects, and daily activities.These patients may face limitations in performing daily activities, resulting in consequences across various aspects of life(25).

It is crucial to note that most of these children and adolescents come from families earning between one and two minimum wages, directly reflecting on their health conditions. This is because the greater burden of diseases is present due to birth conditions, life, work, and aging(26).

The weak correlation in social responses between children or adolescents and their guardians highlights a tendency among guardians of chronically ill children or adolescents to overestimate their children's conditions, amplifying the disease's morbidity and/or its complications(27).

This trend is also observed in a Brazilian study assessing HRQoL in children with cancer, where children reported a more positive HRQoL than their guardians, suggesting guardians project their HRQoL onto their children. This finding indicates the need for caregiver attention towards factors influencing HRQoL and the importance of longitudinal studies on chronic illness to monitor the various stages of the disease's progression and understand the ongoing adjustments faced by the child and their family(28).

In addition to family stress, the severity of the health condition, the presence of symptoms, income, and the guardian's perception of the child's level of autonomy can also influence discrepancies between reports. This is because the guardian's perception of the child's condition is fraught with uncertainties and expectations of a poor prognosis, unlike children and adolescents, who tend to have more abstract and fanciful thoughts. It is known that cognition and maturity develop at different levels in children and adults, as well as the way of coping with and expressing experiences during illness, which is subjective(28).

Despite the individual's perception of clinical and non-clinical aspects of their life being essential for understanding quality of life(23) and self-reporting by children and adolescents being considered the best method for evaluating this parameter, the guardians'report is useful for evaluating HRQoLwhen children and adolescents with chronic diseases are unable to provide this information(26). However, ideally, the parents'report should be used to obtain a more complete picture of HRQoL, without replacing the self-report(15).

It is recognized that, despite the representative sample, a limitation of this study was the inability to carry out data collection in more than one health institution, which could have increased the number of participants and expanded the results to other centers. Another possible limitation is related to data collection in different units of a university hospital, which implies that these children and adolescents were probably at different stages of the chronic disease, and thiscan also interfere with their HRQoL.

However, it is emphasized the importance of evaluating the HRQoL of children and adolescents with chronic diseases, investigating and understanding the concordance between their reports and those of the guardians, and the search for more qualified nursing care with the potential to increase the HRQoL of this population and their family, as advancements are necessary(29).

CONCLUSION

The study revealed that children and adolescents with chronic diseases have altered

HRQoLbecause of the various changes imposed by treatment and disease progression.

The correlation with the guardian's report showed a tendency of the guardian to overestimate, in many aspects, the consequences of chronic disease on the life of the child and adolescent, as evidenced by weak to moderate correlations in some dimensions of the instrument used. However, due to the profound changes in various aspects of their lives and their families, these children and adolescents have a diminished quality of life.

It is believed that this study contributes to the care of children with chronic conditions by allowing healthcare professionals, especially nurses, to identify affected dimensions so they can plan actions and interventions aimed at mitigating the consequences of the diseaseand promoting greater comfort and improved quality of life for this clientele. Additionally, it contributes to teaching and research by encouraging reflection and the development of more studies that consider the theme from the perspective of the child or adolescent, which remains limited. The need for new studies investigating the health-related quality of life of children and adolescents with various chronic conditions is recognized, as the available body of literature is focused on studies with children and adolescents with oncological diseases.

QUALIDADE DE VIDA E DOENÇA CRÔNICA: CORRELAÇÃO ENTRE RELATOS DE CRIANÇAS, ADOLESCENTE E SEUS RESPONSÁVEIS

RESUMO

Objetivos: Avaliar a qualidade de vida de crianças e adolescentes com condições crônicas e correlacionar o autorrelato da criança e do adolescente com o relato do responsável. **Método:** Estudo quantitativo, descritivo, transversal, do qual participaram crianças e adolescentes de 8 a 18 anos e seus responsáveis. Realizou-se a coleta de dados em um hospital universitário do Rio de Janeiro, coletaram-se dados de caracterização sociodemográfica e clínica dos participantes e utilizou-se a escala *PedsQL™* Inventário Pediátrico de Qualidade de Vida, válida e confiável para uso em português do Brasil. A análise dos dados incluiu estatística descritiva e teste de correlação de *Pearson*. **Resultados:** Um total de 92 participantes compôs a pesquisa, sendo 46 crianças e adolescentes, e 46 responsáveis. A maioria das crianças e adolescentes (74%) apresentou escores de qualidade de vida baixos. Os escores dos responsáveis foram, em média, 5% a 10% inferiores aos das crianças e adolescentes. Encontrou-se correlação fraca entre crianças ou adolescentes e responsáveis na dimensão social da qualidade de vida. **Conclusão:** Cabe aos profissionais de saúde, dentre eles a Enfermagem, identificar dimensões da qualidade de vida afetadas dessa clientela e planejar intervenções que atenuem consequências das doenças crônicas e promovam qualidade de vida.

Palavras-chave: Criança. Adolescente. Doença crônica. Qualidade de vida. Enfermagem pediátrica.

CALIDAD DE VIDA Y ENFERMEDAD CRÓNICA: CORRELACIÓN ENTRE RELATOS DE NIÑOS, ADOLESCENTE Y SUS RESPONSABLES

RESUMEN

Objetivos: evaluar la calidad de vida de niños y adolescentes con condiciones crónicas y correlacionar el autoinforme del niño y del adolescente con el relato del responsable. **Método**: estudio cuantitativo, descriptivo, transversal, del cual participaron niños y adolescentes de 8 a 18 años y sus responsables. Se realizó la recopilación de datos en un hospital universitario de Rio de Janeiro/Brasil, se recogieron datos de caracterización sociodemográfica y clínica de los participantes y se utilizó la escala *PedsQL™* Inventario Pediátrico de Calidad de Vida, válida y confiable para uso en portugués de Brasil. El análisis de los datos incluyó estadística descriptiva y prueba de correlación de *Pearson*. **Resultados**: un total de 92 participantes compuso la encuesta, siendo 46 niños y adolescentes, y 46 responsables. La mayoría de los niños y adolescentes (74%) presentó puntuaciones de calidad de vida bajas. Las puntuaciones de los responsables fueron, en promedio, entre 5% y 10% inferiores a los de los niños y adolescentes. Se encontró correlación débil entre niños o adolescentes y responsables en la dimensión social de la calidad de vida. **Conclusión**: depende de los profesionales de salud, entre ellos la Enfermería, identificar dimensiones de la calidad de vida afectadas de esa clientela y planificar intervenciones que disminuyan las consecuencias de las enfermedades crónicas y promuevan calidad de vida.

Palabras clave: Niño. Adolescente. Enfermedad crónica. Calidad de vida. Enfermería pediátrica.

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Submitted: 29/04/2023
Accepted: 21/01/2024

Financial support:
Carlos Chagas Filho Foundation for Research Support in the State of Rio de Janeiro – FAPERJ. Protocol nº 200.589/2017.