

QUALITY OF LIFE IN ADOLESCENTS WITH SPECIAL NEEDS IN A CITY OF THE STATE OF PERNAMBUCO

Qualidade de vida em adolescentes com necessidades especiais em um município de Pernambuco

Calidad de Vida de adolescentes con necesidades especiales en un municipio de Pernambuco

Original Article

ABSTRACT

Objective: To evaluate the quality of life (QOL) and its association with demographic variables of adolescents with special needs (physical, visual, and hearing impairments). **Methods:** This was a descriptive, cross-sectional study, with 72 adolescents aged 10 to 19 years in state public educational institutions of Petrolina, in the state of Pernambuco, Brazil, in the period from August to October 2012. For QOL evaluation, the World Health Organization Quality of Life, short version instrument (WHOQOL-BREF), was applied. For data analysis, descriptive and inferential statistics were used, applying the Mann-Whitney and Kruskal-Wallis tests, with $p < 0.05$. **Results:** Lower perception of global QOL was observed in those with physical disabilities (57.36 ± 20.67). The QOV was best perceived by the visually impaired (65.62 ± 22.49). As regards the domains, the lowest scores were obtained in the social relationship for those with physical disabilities (60.41 ± 7.30), visual (55.84 ± 13.34), and hearing (55.00 ± 20.33) impairments. The students placed in special classes and the youngest adolescents reported lower perceived QOL. **Conclusion:** Among the assessed students, quality of life was best perceived by the visually impaired, and the adolescents with physical disabilities presented themselves as the most vulnerable group in the perception of global QOL, and in the physical and environment domains as well. The youngest group and the students of special classes room perceived their QOL to be lower compared to the perceived QOL of older students and the ones placed in general education classes.

Descriptors: Quality of Life; Teenager; Person with Physical Disabilities, People with Visual Impairment, Hearing Impairment.

RESUMO

Objetivo: Avaliar a qualidade de vida (QV) e a associação desta com variáveis demográficas de adolescentes com necessidades especiais (física, visual e auditiva). **Métodos:** Tratou-se de um estudo descritivo, de corte transversal, com 72 adolescentes entre 10 e 19 anos, em instituições de ensino público estadual de Petrolina no estado de Pernambuco, Brasil, no período de agosto a outubro de 2012. Para avaliação da QV, foi utilizado o questionário World Health Organization Quality of Life, versão breve (WHOQOL-BREF). Para análise dos dados, foi utilizada a estatística descritiva e inferencial, aplicando-se os testes Mann-Whitney e Kruskal-Wallis, com $p < 0,05$. **Resultados:** Observou-se uma menor percepção da QV global nos deficientes físicos ($57,36 \pm 20,67$). A QV foi melhor percebida pelos deficientes visuais ($65,62 \pm 22,49$). No tocante aos domínios, entre os deficientes físicos ($60,41 \pm 7,30$), visuais ($55,84 \pm 13,34$) e auditivos ($55,00 \pm 20,33$), os menores escores apresentados foram os de relação social, respectivamente. Os escolares inseridos em sala especial e os adolescentes mais novos obtiveram uma menor percepção da QV. **Conclusão:** A QV foi melhor percebida pelos deficientes visuais, e os adolescentes com deficiência física apresentaram-se como o grupo mais vulnerável na percepção da QV global e nos domínios físico e meio ambiente entre os escolares investigados. O grupo mais jovem e os estudantes de sala especial perceberam sua QV inferior quando comparada com os mais velhos e os alunos de sala regular.

Descritores: Qualidade de Vida; Adolescente; Pessoa com Deficiência Física; Pessoas com Deficiência Visual; Deficiência Auditiva.

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RESUMEN

Objetivo: Evaluar la calidad de vida (CV) y su asociación con las variables demográficas de adolescentes con necesidades especiales (física, visual y auditiva). **Métodos:** Se trató de un estudio descriptivo, de corte transversal, con 72 adolescentes entre 10 y 19 años de instituciones de enseñanza pública del estado de Petrolina-PE entre agosto y octubre de 2012. Fue utilizado el cuestionario World Health Organization Quality of Life, versión breve (WHOQOL-bref) para la evaluación de la CV. Para el análisis de los datos fue realizada la estadística descriptiva e inferencial con la aplicación de la prueba de Mann-Whitney y Kruskal-Wallis, con $p < 0,05$. **Resultados:** Se observó baja percepción de la CV global de los deficientes físicos ($57,36 \pm 20,67$). Los deficientes visuales tuvieron mejor percepción de la CV ($65,62 \pm 22,49$). Respecto a los dominios entre los deficientes físicos ($60,41 \pm 7,30$), visuales ($55,84 \pm 13,34$) y auditivos ($55,00 \pm 20,33$) las menores puntuaciones fueron las de la relación social, respectivamente. Los escolares de clases especiales y los adolescentes más jóvenes presentaron baja percepción de la CV. **Conclusión:** De los escolares investigados, los deficientes visuales percibieron mejor la CV y los adolescentes con deficiencia física fueron los más vulnerables en la percepción de la CV global y los dominios físicos y medio ambiente. El grupo más joven y los estudiantes de clase especial percibieron que su CV era inferior al compararse a los mayores y los alumnos de clase regular.

Descriptor: Calidad de Vida; Adolescente; Personas con discapacidad; Personas con daño visual; Pérdida Auditiva.

INTRODUCTION

Adolescence is the stage of human development that is marked by the biological changes of puberty and related to biopsychosocial maturity; this stage is critical since it involves moments of identity and values definition. This period cannot be analyzed without considering the social, cultural or political context in which the individual is inserted, and it has a great influence on the quality of life of adolescents⁽¹⁾.

For adolescents with disabilities, this stage has its own nuances. In addition to the conflicts that occur in this stage, they have to form their identity as people with disability who are not often given the autonomy of adulthood. They are considered by society as dependent – in terms of care and protection – and excluded from opportunities for access to programs targeted to people without disabilities⁽²⁾.

With the growing life expectancy, the numbers of people with disabilities continue to expand. The World Health Organization (WHO) estimates that about 10% of the population of any peacetime country has some form of disability⁽³⁾. However, according to the 2010 census of the Brazilian Institute of Geography and Statistics⁽⁴⁾ (*Instituto*

Brasileiro de Geografia e Estatística – IBGE), in Brazil, about 45.5 million people declare that they have some type of disability, accounting for 23.9% of the population. Although people with disabilities account for a significant proportion of the population, they are still seen as a minority from a social and political perspective, which justifies the lack of literature related to the subject⁽⁵⁾.

Currently, the term “quality of life” (QoL) is widely reported in the current language and literature, with a growing interest in its concept. Over the years, it has been defined in many different ways by journalists, politicians, professionals in various areas, and public policy-makers, as well as in different areas of knowledge: economics, sociology, education, medicine, nursing, psychology, and health. The theme also became part of the market for goods and services since the foundation of the Brazilian Quality of Life Association (*Associação Brasileira de Qualidade de Vida*) and the creation of the Brazilian Institute of Quality of Life (*Instituto Brasileiro de Qualidade de Vida - IBQV*) in 1995. These are nonprofit institutions that, according to what they advertise, aim at the protection, preservation and conservation of environment, ethics, peace, citizenship, human rights, and universal values⁽⁶⁾.

The WHO, in turn, defines quality of life as the individuals’ perception of their position in life in the context of their culture and values and in relation to their goals, expectations and standards; it can also be affected by the person’s physical health, psychological state, level of independence, social relationships, environmental factors and personal beliefs⁽⁷⁾.

Although QoL is a subjective concept, instruments were developed to measure it more objectively for research purposes⁽⁸⁾. As an example, there is the World Health Organization Quality of Life, brief version (WHOQOL-BREF), proposed by the WHO in 1995⁽⁷⁾, whose Portuguese version has been validated⁽⁹⁾. This item has been used to measure quality of life in different world populations, including adolescents. However, there is a lack of studies to characterize QoL in adolescents with disabilities.

Despite education and health advances in recent decades, much remains to be achieved regarding comprehensive care of adolescents with disabilities, as they need differentiated assistance to experience the changes within the limitations imposed⁽¹⁰⁾. It is necessary to ensure that the general system of society, such as the physical and cultural environment, housing, transportation, social and health services, educational and work opportunities, cultural and social life, are made accessible to them so they can have a satisfactory quality of life. From this premise, it is essential to discuss and reflect on the QoL of adolescents with disabilities in order to provide interventions for their emancipation and contribute to a healthier adolescence. Thus, the present study aimed

to evaluate the QoL and its association with demographic variables of adolescents with special needs (physical, visual, and hearing impairments).

METHODS

This is a descriptive, exploratory cross-sectional study conducted with students of public schools in the city of Petrolina, PE, in the period from August to October 2012.

The study population comprised adolescents aged 10-19 years enrolled and regularly attending 22 public educational institutions of Petrolina, PE, that provided special education. Of these, 18 were located in urban areas and 4 in rural areas. According to the 2010 census of the State Secretariat for Education (*Secretaria Estadual de Educação - SEDUC-PE*)⁽¹¹⁾, there were 180 students with visual, physical and hearing impairments enrolled.

The minimum sample size was estimated considering a 5% margin of error and 95% confidence interval (CI95%); standard deviation of the variable of interest was estimated based on the pilot-study and set to 24.16 and more 20% due to possible losses during data collection. From this calculation, we obtained a sample of 72 subjects: 56 with hearing impairments, 8 with visual impairments, and 8 with physical impairments. The number of participants by disability was proportional to the SEDUC census⁽¹¹⁾. The study included adolescents with physical, visual and hearing impairments enrolled in regular and special classes and attending classes during the period of data collection. The research excluded adolescents with intellectual and multiple disabilities, and those who failed to understand the instrument applied.

Students were selected by simple random sampling considering the proportionality of students with physical, visual and hearing impairments informed by the Pernambuco State Secretariat for Education (*Secretaria de Educação do Estado de Pernambuco - SEDUC -PE*)⁽¹¹⁾. Students who were not present during data collection or refused to participate were replaced by picking a random name from the list of students. This replacement strategy was used to minimize sample losses in schools with a small number of students, which could derail the research due to lack of representativeness.

Two instruments were used for data collection: a sociodemographic questionnaire⁽¹²⁾ to characterize the sample and an instrument for the assessment of QoL developed by the WHO, the WHOQOL-BREF⁽⁵⁾. This instrument consists of 26 questions about the past 15 days lived by the respondent and answers are presented on a 5-point Likert scale. It includes two questions about individuals' perception of quality of life; the other questions

are divided into four domains (physical, psychological, social relationships and environment) and represent each of the 24 facets. Its Portuguese version was validated and adapted to the Brazilian language and culture⁽⁵⁾.

The instrument is self-explanatory and can be self-administered; it can be assisted or even administered by the interviewer⁽⁵⁾. In our study, the application of the instrument obeyed the limitations imposed by each disability. Thus, the instrument was applied to students with visual and physical impairments as an interview conducted by previously trained researchers. The instrument was self-administered by students with hearing impairments with the aid of a *LIBRAS* (Brazilian Sign Language) interpreter who worked at the educational institution and helped maintain the dialogue between researchers and participants.

Before the application of this instrument, a preliminary study was carried out to know the population and the instrument and also the possible difficulties arising from the research in order to minimize them in the final study.

The WHOQOL-BREF scores were computed using the Statistical Package for Social Sciences (SPSS) version 20.0, as suggested by the WHO⁽¹³⁾. First, we used descriptive analysis for sample characterization using absolute and relative frequencies, as well as measures of central tendency - median and interquartile range. Then, nonparametric inferential statistics - Mann-Whitney U test and Kruskal-Wallis test, with a 5% significance level - was used to compare the results of perceived quality of life in each domain and the sociodemographic characteristics between the groups or categories. These tests were chosen because normality of data was not proven and sample sizes were small⁽¹⁴⁾.

Following the guidelines of the Ministry of Health Resolution No. 466/12, which provides for research involving human beings in Brazil, the present study was submitted and approved by the Research Ethics Committee of the University of Pernambuco under Opinion No. 150/11. All the participants were informed about the research objectives and signed the Free Informed Consent Form. In case of minor participants, the consent form was signed by their legal guardians.

RESULTS

The sample comprised 72 adolescents, 72.2% (n=52) of whom were aged 15-19 years. Regarding the origin of disability, most of them - 73.6% (n=53) - were congenital. With regard to gender, 54.2% (n=39) of the participants were male. As to education, the majority of participants - 73.2% (n=52) - were 6th-9th graders, and 77.8% (n = 56) were enrolled in regular education classes, i.e., they studied with other adolescents without disabilities (Table I).

The descriptive analysis of the overall QoL of the whole sample, without differentiating disabilities, revealed a median of 63.28. Among the domains, the social domain had the lowest score, followed by environment, whereas the physical domain had the highest score (Table II).

Regarding the domains of QoL, the lowest scores observed in both the adolescents with hearing impairments and those with visual impairments were in the social relationships domain; the lowest scores obtained by students with physical impairments were in the environment domain. The highest scores obtained by students with physical and visual impairments were in the psychological domain, and

the group of students with hearing impairments presented the best score in the physical domain (Table III).

Based on the comparison of overall QoL and some sociodemographic characteristics of all the adolescents in the sample, we found that the students in the older age group (15-19 years) have a better perception of QoL in relation to their younger peers ($p=0.05$).

With regard to the domains and the general characteristics of the subjects, statistical differences were found in the social ($p=0.025$) and physical ($p=0.046$) domains when compared to age - older students had a better perception of QoL in the two aforementioned domains.

Table I - General characteristics of adolescents included in the sample. Petrolina, PE, 2012.

Variables	Disability			All
	Physical(n=8)	Visual(n=8)	Hearing(n=56)	
Age				
10-14 years (%)	4 (50.0)	3 (37.5)	13 (23.2)	20 (27.8)
15-19 years (%)	4 (50.0)	5 (62.5)	43 (76.8)	52 (72.2)
Gender				
Male (%)	4 (50.0)	4 (50.0)	31 (55.4)	39 (54.2)
Female (%)	4 (50.0)	4 (50.0)	25 (44.6)	33 (45.8)
Origin of disability				
Acquired	4 (50.0)	1 (12.5)	14 (25.0)	19 (26.4)
Congenital	4 (50.0)	7 (87.5)	42 (75.0)	53 (73.6)
Income				
Up to two wages (%)	4 (50.0)	1 (12.5)	22 (43.1)	27 (40.3)
Three or more wages (%)	4 (50.0)	7 (87.5)	29 (56.9)	40 (59.7)
Class				
Regular (%)	8 (100.0)	8 (100.0)	40 (71.4)	56 (77.8)
Special (%)	-	-	18 (28.6)	16 (22.2)
Area of residence				
Urban (%)	6 (75.00)	6 (75.00)	54 (96.40)	66 (91.70)
Rural (%)	2 (25.00)	2 (25.00)	2 (3.60)	6 (8.30)
Education				
6 th -9 th grade (%)	6 (75.00)	6 (75.00)	40 (72.70)	52 (73.20)
Secondary Education (%)	2 (25.00)	2 (25.00)	15 (27.30)	19 (26.80)

Table II - Descriptive analysis of the quality of life of all the adolescents with disabilities. Petrolina, PE, 2012.

	Quality of life			
	1 st Quartile	2 nd Quartile	3 rd Quartile	4 th Quartile
Physical Domain	60.71	71.43	78.57	100.00
Psychological Domain	65.20	66.67	79.17	100.00
Social Domain	41.67	58.33	66.67	100.00
Environment Domain	53.13	59.38	68.75	98.88
Overall	57.30	63.28	69.07	99.22

Table III - Overall quality of life and domains of the brief version of the quality of life assessment instrument of the world health organization in adolescents with physical, visual and hearing impairments. Petrolina, PE, 2012.

Domains	Disabilities			p
	Physical	Visual	Hearing	
Physical	56.92 ± 24.16	68.38 ± 17.81	70.28 ± 20.37	0.034*
Psychological	62.50 ± 43.75	75.00 ± 29.17	63.67 ± 14.58	0.098
Social	60.41 ± 7.30	55.84 ± 13.34	55.00 ± 20.33	0.210
Environment	49.62 ± 17.93	58.25 ± 10.94	56.25 ± 21.87	0.014*
Overall	57.36 ± 20.67	65.62 ± 22.49	63.82 ± 18.62	0.036*

*Statistically different from adolescents with physical impairments, Kruskal-Wallis test.

Table IV – Comparison of sociodemographic factor in the quality of life of all the adolescents with disabilities. Petrolina, PE, 2012.

Variables (%)	Domains				
	Physical	Psychological	Social	Environment	Overall
Age					
10-14 years	67.86 ± 16.07	64.58 ± 11.46	50.00 ± 16.67	54.69 ± 24.22	57.53 ± 12.42
15-19 years	73.21 ± 14.29	66.67 ± 20.83	58.33 ± 29.17	62.50 ± 14.84	65.48 ± 12.22
p value	0.046*	0.304	0.025*	0.053	0.005*
Gender					
Male	75.00 ± 17.86	66.67 ± 16.67	50.00 ± 25.00	65.63 ± 12.50	62.91 ± 10.46
Female	71.43 ± 14.29	62.50 ± 20.83	58.33 ± 20.83	56.25 ± 17.19	64.17 ± 14.24
p value	0.543	0.121	0.344	0.058	0.619
Income					
Up to two wages	71.43 ± 14.29	70.83 ± 16.67	58.33 ± 25.00	65.63 ± 15.63	65.35 ± 11.98
Three or more wages	69.64 ± 14.39	62.50 ± 14.58	54.17 ± 25.00	56.25 ± 17.97	61.33 ± 12.57
p value	0.258	0.094	0.882	0.035*	0.114
Area of residence					
Urban	71.43 ± 17.86	66.67 ± 16.6	54.17 ± 25.00	60.94 ± 15.63	62.95 ± 12.54
Rural	66.07 ± 12.50	64.58 ± 9.37	70.83 ± 20.83	56.25 ± 17.97	66.29 ± 11.34
p value	0.122	0.551	0.069	0.474	0.783
Education					
6 th -9 th grade	71.43 ± 17.86	66.67 ± 16.67	50.00 ± 25.00	59.38 ± 15.63	62.52 ± 13.00
Secondary education	71.43 ± 7.14	66.67 ± 8.33	58.33 ± 25.00	62.50 ± 12.50	66.30 ± 11.61
p value	0.845	0.906	0.072	0.279	0.137

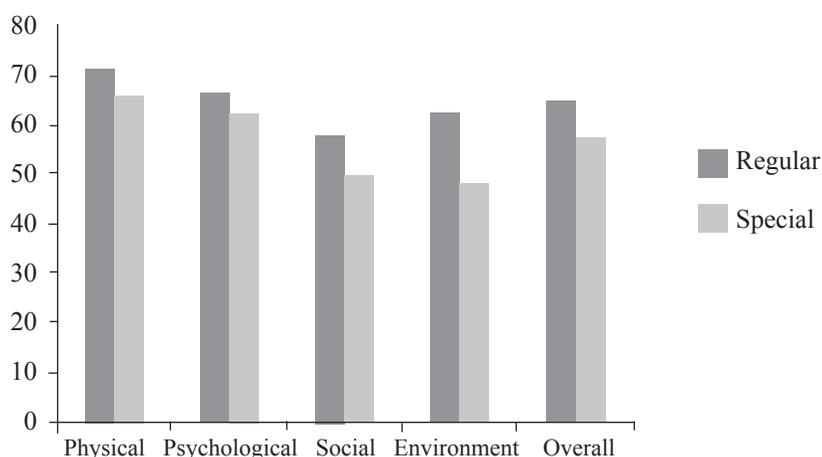


Figure 1 - Comparison of quality of life domains and type of classes of adolescents with hearing impairments. Petrolina, PE, 2012.

Regarding gender, women had a lower perception of QoL in the physical, psychological and environment domains, although it was not statistically significant. Only the social relationship domain presented higher scores among women than men (Table IV).

The variable “inclusion in regular and special class” was analyzed only for the students with hearing impairments, given that it is the only disability that is provided with a special class in the public education system of Petrolina. Thus, it was noticed that both overall QoL ($p=0.025$) and all the domains present better results in adolescents enrolled in regular classes with other adolescents without disabilities. The physical ($p=0.027$) and environment ($p=0.001$) domains showed significant differences (Figure 1).

DISCUSSION

There has been growing interest in studying quality of life in several domains of human activity. Although there is no consensus on the definition of QoL, most authors agree that its assessment should consider the physical, social, psychological and spiritual domains, seeking to capture the personal experience of each individual⁽⁹⁾.

In the present study, “social relationships” followed by “environment” were the most affected domains from the perspective of the adolescents with disabilities. The same occurred in a study conducted in Germany to verify the quality of life in 26 adolescents with autism-spectrum disorder found that QoL was worse in the “social relationships” domain and better in the “physical” domain⁽¹⁵⁾.

The social relationship is a very common feature of adolescence, given that there is a peer group tendency at this stage of development. Adolescents identify with other young people; they start to walk around together and even wear the same clothes, forming a group with its own identification and characteristics – some are easily identifiable by their customs and habits^(16,17). For adolescents with disabilities this feature is somewhat distorted because sometimes they cannot see themselves as part of a group for being different; therefore, they keep a certain distance from other young people because of their fear of being rejected⁽¹⁷⁾.

The “environment” was the second most affected domain; however, most national and international studies using the WHOQOL-BREF point that the QoL of adolescents from different nationalities is mostly affected in such domain⁽¹⁸⁻²²⁾. It encompasses aspects such as physical safety and security, home environment, financial resources, health and social care, opportunities for acquiring new information and skills, participation in recreation/leisure, physical environment and transportation; some of these

aspects are not controlled individually and depend on government investments, making them difficult to be improved⁽²²⁾.

Regarding the analysis of the domains and the global perception of QoL in the study population, there were significantly lower scores among adolescents with physical disabilities in the environment and physical domains as well as in overall QoL compared to those with visual and hearing impairments. Some studies conducted with adolescents without disabilities showed that the physical domain had the highest scores, differing from the present study, which involved adolescents who had physical limitations. These studies also indicate that the physical domain is an important contributor to the positive QoL among young people^(23,24). As this domain includes items such as the presence of pain or discomfort, dependence on medication, satisfaction with sleep, work capacity and activities of daily living, among others, its scores may suffer some interference due to the fact that these adolescents have some type of disability. The primary limitations imposed by the disability increases their vulnerability to secondary effects, and survival, health and well-being of these adolescents depend on the interaction of many factors, including the physical and social domains⁽²⁴⁾.

Age affects quality of life - the older age group was more satisfied with life. The adolescent experiences several losses and achievements in the transition from child to adult identity, influencing the consolidation of the basic structure of personality. As time goes by, these changes are consolidated and adolescents achieve certain maturity with the acquisition of a system of personal values and own identity that promotes a better QoL^(25,26).

The results also revealed that adolescent females had a lower perception of QoL for the psychological, physical and environment domains when compared to male adolescents. A study conducted in Paraná⁽¹⁹⁾ to assess the environment domain of the QoL of 608 adolescent students identified that female adolescents are a vulnerable group since they have a greater tendency to psychological problems such as depression and anxiety in addition to having lower physical strength. A study in Kuwait with 4,467 adolescent students found that girls have a lower perception of QoL in the psychological domain and suggested that school programs in friendly learning environments may help promote a better perception of the psychological domain, reducing the symptoms of anxiety and depression among girls⁽²⁷⁾.

In our study, most of the students with disabilities were enrolled in classes with students who did not have disabilities, i.e., they were attending regular classes. The inclusion of students with disabilities in regular classes is important because it allows them to socialize with other students and provides opportunities for their development.

This could be observed in the present study, whose subjects obtained higher scores in both overall QoL and all its domains; this has also been found by other studies⁽²⁸⁻³⁰⁾.

Educational inclusion requires clarity about one's own condition regarding disabilities, abilities and weaknesses. In the present study, we propose a look at other aspects that are involved in the quality of life of disabled people, taking the focus off of the changes in body functions and structures and thinking about the environmental and personal factors that influence the performance of activities and participation and enable functionality. The school, as an institution devoted to information and education, is the most effective and favorable collective means for building a healthy and friendly environment where everybody can be part of the same educational process based on the respect for singularities and the valorization of its members, because education takes place through the contact and exchange of experiences⁽³¹⁾.

This study has some limitations that should be considered, such as the number of participants, who were divided into smaller groups for the analysis of results. This may have led to the lack of statistically significant differences in some of the domains assessed; however, it does not take away the value of the differences between the groups⁽¹⁴⁾. Another limitation refers to the quantitative assessment of a concept intrinsically marked by subjectivity, such as the QoL construct. One should bear in mind that the indicators and indexes can only measure "aspects" of QoL. In this sense, the results observed in this study need to be carefully analyzed taking into account that the "objective" measure of QoL was measured subjectively through a questionnaire. However, it is important to highlight that the instrument used has been a practical and reliable opportunity to assess QoL - WHOQOL-BREF is recommended by the WHO for the assessment of QoL.

Another limitation of this study lies in the fact that the sample was selected in state public schools of Petrolina, PE. Thus, the extrapolation of results to adolescents attending other educational institutions is limited. Finally, this study has a cross-sectional design and cannot establish a cause and effect relationship between disability and QoL of adolescents.

CONCLUSION

QoL was best perceived by the visually impaired students, and the adolescents with physical disabilities were the most vulnerable group in the perception of overall QoL, and in the physical and environment domains among the students assessed. The social relationship domain was the most affected domain considering all disabilities. The youngest group and the students enrolled in special classes

perceived a lower QoL in relation to older students and regular class students.

Further studies on this issue should be carried out addressing aspects that were not noticed or studied in this research, since this population is often overlooked and have no rights to express their perception of quality of life.

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