

QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS WHO LIVE WITH ASTHMA

Alessandra Praia Ferreira do Nascimento

Universidade Federal do Amazonas
Manaus-AM

<http://lattes.cnpq.br/0261791111736061>

Arinete Verás Fontes Esteves

Enfermeira. Doutora de Ciências
em Psicologia. Docente da Escola de
Enfermagem de Manaus/ Universidade
Federal do Amazonas.

Manaus-AM

<https://orcid.org/0000-0002-3827-6825>

Marcos Vinícius Gusmão da Silva

Enfermeiro. Especialista em Urgência e
Emergência.

Manaus-AM

<https://orcid.org/0000-0002-4888-4795>

Thaís dos Santos Martins

Universidade Federal do Amazonas
Manaus-AM

<https://lattes.cnpq.br/7895022433819522>

Yasmin Ferreira Rodrigues

Universidade Federal do Amazonas
Manaus-AM

<http://lattes.cnpq.br/4966144907418720>

Mayane Furtado Campos

Universidade Federal do Amazonas
Manaus-AM

<https://lattes.cnpq.br/9555531967328220>

Tássia Santos do Vale

Universidade Federal do Amazonas
Manaus-AM

<http://lattes.cnpq.br/0531450851544591>

All content in this magazine is licensed under a Creative Commons Attribution License. Attribution-Non-Commercial-Non-Derivatives 4.0 International (CC BY-NC-ND 4.0).



Gisele Praia Pereira Nóbrega

Enfermeira. Universidade Paulista-UNIP
Manaus-AM
<https://lattes.cnpq.br/4264956100731914>

Ana Caroline Narvaes Souza

Universidade Federal do Amazonas
Manaus-AM
<https://lattes.cnpq.br/5862328802950185>

Anne Grace Andrade da Cunha Marques

Nurse. Master in Nursing. Teacher at the
Center for Health and Sport / Universidade
Federal do Acre.
Rio Branco- AC.
<http://lattes.cnpq.br/0921454248655050>

Marcos Vinícius Costa Fernandes

Nurse. Master in Nursing. Nurse at State
Department of Health of Amazonas.
Manaus-AM
<http://lattes.cnpq.br/9015855895299610>

Abstract: Introduction: Asthma is one of the most common respiratory diseases in childhood and is generally associated with a worsening of the quality of life, bringing negative aspects to the physical development of its sufferers and the possibility of recurrent hospitalizations, in rarer cases, the aggravation and death. **Objective:** to evaluate the health-related quality of life of children and adolescents undergoing treatment for asthma at a health unit in Manaus-AM. **Methodology:** A quantitative study was carried out with children and adolescents diagnosed with asthma, aged between 08 and 17 years, 11 months and 29 days, who were being followed up at a public health unit in Manaus-AM. Those who presented limitations that hindered their verbal expression were excluded. For data collection, the Disabkids Chronic Generic Measure long form 37 (DCGM-37) questionnaire, adapted and validated for Brazil, was used, which assesses the Health-Related Quality of Life (HRQoL) of children and adolescents with chronic diseases. **Result/discussion:** Collected interviews are coherently associated with the researched literature, showing that the more controlled the disease and the lower its severity, the lower the impact it will have on the patient's quality of life (QoL). **Conclusion:** Children and adolescents who suffer from fewer signs and symptoms of the disease have a better quality of life, taking into consideration, physical, emotional and social aspects.

Keywords: Quality of life; Asthma; Nursing; Children and Adolescents.

INTRODUCTION

Chronic Respiratory Diseases (CKD) are those that affect the respiratory tract and may affect the upper or lower airways. Both CKD'S and respiratory allergies are considered serious health problems, as they affect many

people around the world, especially children and the elderly. Some are said to be common, such as allergic rhinitis, Chronic Obstructive Pulmonary Disease (COPD) and asthma (BRASIL, 2010).

Caused by multiple factors, one of the main characteristics of asthma is inflammation of the lower airways, specifically the bronchi. The interaction between genetic and specific factors, irritating substances and infections, in addition to environmental exposure to 8 allergens, results in an increase in the frequency and severity of the disease (FONTAN et al., 2020). This inflammation is characterized by a process that affects the whole organism and not just the bronchi, increasing the production of secretions and narrowing the airways, thus impairing the flow of air. Asthmatics may have nocturnal episodes of frequent coughing, wheezing, tiredness and chest tightness that lead to difficulty breathing; symptoms that may appear together or in isolation (BRASIL, 2019).

According to the Global Initiative for Asthma (GINA), asthma has four levels of severity, which are based on symptoms presented by the individual and how these affect their lung function, and can be classified as: intermittent, persistent mild, moderate and severe. Most patients have mild persistent asthma and a minority among them suffer from severe asthma, however, it is these patients with severe asthma that lead to high morbidity rates and greater application of health resources (SIMÕES et al., 2010). To analyze this level of severity, some findings are observed, such as the level of consciousness ranging from agitation, confusion to drowsiness, oxygen saturation that indicates difficulty in the ability to ventilate, whether the individual is breastfeeding or not, and whether there is respiratory failure, which can lead to central cyanosis (VIVIAN et al., 2015).

In 1999, the Ministry of Health, together

with the Brazilian Society of Pneumology and Phthysiology (SBPT) and some other institutions established guidelines for the National Plan for Asthma Control (PNCA), thus creating the so-called Asthma Programs, which aim to better control and management of the asthmatic patient, thus reducing both morbidity and mortality and causing a decrease in demand for emergency services. Involving a multidisciplinary health team, the program intends to provide a more effective and quality treatment to these patients with actions integrated to the basic system and the primary health care network (CERCI NETO et al., 2008).

Involving both patients and their families in the treatment and control of the disease, asthma education programs include nurses in their multidisciplinary team, who act as intervenors between the community and the health system, bringing about an improvement in the patient's quality of life. and in health education (BETTENCOURT et al., 2002). Therefore, these professionals are expected to have the perception to provide clearer and more precise guidance on asthma, to develop strategies for health promotion, as well as to carry out periodic follow-ups with patients through home visits, planned consultations and referrals when necessary to specialists. (COSTA et al., 2018).

Even though there are several other factors that influence the way the disease will develop, one of its main repercussions is associated with the quality of life of this population, in which there is evidence of a worsening in the behavioral problems of children with persistent asthma in relation to healthy children, these problems are directly related to the severity of asthma and inadequate control of its symptoms (MONTALBANO et al., 2020).

Asthma is a disease of a multidimensional nature and, in general, the degree of disease

activity is more or less proportional to the improvement or worsening of the patient's quality of life (QoL). As it encompasses several aspects, QoL is difficult to estimate through objective parameters, but some objective measures such as lung function and symptoms are used to assess its level of control (PEREIRA et al., 2011). Children and adolescents who have better control of the disease or less severe forms, have an attenuation in the number of symptoms and less use of medication. A better understanding of these levels of control, emotional and physical limitations, as well as their levels of severity, helps to establish new therapeutic, environmental and behavioral methods that imply actions for a better result in the treatment of the disease (MATSUGANA et al., 2015).

Patients with chronic diseases need special care and QoL plays an important role in both the individual and collective perception of patients, which must take into consideration, the subjectivity of the disease and the proportion of morbidity achieved (RONCADA et al., 2018). For this reason, it is important to adopt pharmacological and non-pharmacological measures to control inflammatory, clinical and functional symptoms and the asthmatic's notion about the proper use of their medications, the triggering factors and how to avoid them (STIRBULOV, 2006).

The general objective of this work is to evaluate the health-related quality of life of children and adolescents undergoing treatment for asthma at a health unit in Manaus-AM. And for specific objectives to characterize children/adolescents with asthma in a health unit in the city of Manaus-AM; To describe the influence of certain sociodemographic, physical and disease characterization variables on general and disease-specific Quality of Life Related to Health (HRQL) levels.

METHODOLOGY

TYPE OF STUDY

This is an observational, correlational and cross-sectional study that evaluated the quality of life of children and adolescents with asthma treated at a public health unit in Manaus-AM, using the Disabkids Chronic Generic Measure long instrument. form 37 (DCGM-37) version ("Self" and "Proxy").

STUDY PLACE

The study was carried out in a Hospital Health Unit in the West Zone of the city of Manaus that provides care to children and adolescents with chronic asthma who are undergoing treatment in the city of Manaus-AM.

STUDY POPULATION

Study participants were children and adolescents (Group I) undergoing asthma treatment at the reference unit. The parents and/or legal guardians (Group II) of the respective children and adolescents also participated in the research, since the DISABKIDS instrument has a version ("self" and "proxy"), as the "proxy" version is considered relevant. in situations where children have difficulty understanding or are weakened to complete the instrument (DISABKIDS, 2006).

Inclusion criteria: children and adolescents diagnosed with asthma, aged between 08 and 17 years, 11 months and 29 days, regardless of gender, hospitalized and/or undergoing outpatient care, and their respective parents and/or legal guardians, present at the time of the collection and who have the cognitive capacity to understand the guidelines about the objective of the study. Children and adolescents diagnosed with asthma who had difficulty expressing themselves verbally were excluded from the study. The adopted age

group was established according to the Child and Adolescent Statute and by the DISABKIDS GROUP, which determines the development of studies with defined age groups and is associated with the fact that children from the chosen age group and adolescents find in the phase of logical and coherent thinking, being able to communicate with their ideas and meanings (DISABKIDS GROUP, 2006; BRASIL, 1990).

DATA COLLECT

Data collection took place from the end of July 2021 to January 2022, the instruments were applied when the patients attended the unit to follow up their treatment, in a cross-sectional way, where parents/guardians and children and/or adolescents who have criteria to participate in the research, were approached and became aware of it. The term of free and informed consent and the term of free and informed assent were applied, which after being signed, one copy remained with the participant and the other with the researcher, to those who agreed to participate, the Disabkids questionnaire was applied.

DATA ANALYSIS

For the quantitative analysis, the collected data were entered twice, to minimize possible errors, and were stored in the Microsoft® Office Excel software database, version 2010.

For descriptive statistical analysis, data were described by calculating absolute (N) and relative (%) frequencies, which were presented in tables and discussed according to the relevant literature.

ETHICAL ASPECTS

The project was approved by the Research Ethics Committee (CEP) of ``Universidade Federal do Amazonas`` – UFAM, under registration CAAE: 45171321300005020. Term of Free and Informed Consent (TCLE),

complying with the recommendations of Resolution n° 466/12.

RISKS AND BENEFITS

The risks were minimal, as the study was conducted using a semi-structured and easy-to-understand interview. The benefits, on the other hand, were due to the possibility of finding, in the perception of children and adolescents with asthma, their day-to-day needs, thus helping them to improve their quality of life, resulting in positive repercussions for nursing care, also serving on the foundation of the production of studies and investments in health education.

RESULTS

In the analyzed period, 7 patients were hospitalized due to asthma-related conditions, of which 4 were female (57%) and 3 were male (43%) with a mean age of 12.28 years. According to the anamnesis, all participants in the present study claimed to have asthma without another associated chronic condition, as well as using medication for this condition (Table 1).

In table 2, it is observed that of the children and adolescents who undergo medical treatment, 4 (57.1%) claimed that they never hated or were worried when using the medication, even stating that they sometimes feel uncomfortable.

Table 3 shows that 6 (87.5%) of the patients, despite their condition, never became afraid of the future, as well as 4 (57.1%) of them mention that they do not mind having their lives planned despite having to live with the changes caused by the disease. In addition, the study revealed that taking into account their pathology and the limitations imposed by it, 3 (42.9%) of the 7 respondents feel tired when carrying out daily tasks, as well as sometimes having difficulty sleeping, a factor that can relate to symptoms of the disease such as

PROFILE OF RESPONDENTS

ID	GENDER	AGE	SCHOLARITY	CONDITION	MEDICATION
1	Feminine	12	7th grade	Asthma	yes
2	Feminine	9	3rd year	Asthma	yes
3	Masculine	11	5th year	Asthma	yes
4	Masculine	13	8th grade	Asthma	yes
5	Feminine	17	3rd high school	Asthma	yes
6	Masculine	15	1st high school	Asthma	yes
7	Feminine	9	4th year	Asthma	yes

Table 1: Table with the profile of interviewed patients

MEDICAL TREATMENT

QUESTIONS	FREQUENCIES									
	NEVER		ALMOST NEVER		SOMETIMES		OFTEN		EVER	
	N	F%	N	F%	N	F%	N	F%	N	F%
Are you concerned about the use of medication?	4	57,1	1	14,3	1	14,3	0	0	1	14,3
Does using medication bother you?	2	28,6	1	14,3	4	57,1	0	0	0	0
Do you hate using your medicine?	4	57,1	0	0	1	14,3	1	14,3	1	14,3

Table 2: Table with the medical treatment performed by the asthmatics interviewed

DAY TO DAY

QUESTIONS	FREQUENCIES									
	NEVER		ALMOST NEVER		SOMETIMES		OFTEN		EVER	
	N	F%	N	F%	N	F%	N	F%	N	F%
Does your condition make you irritable?	2	28,6	2	28,6	2	28,6	1	14,3	0	0
Are you afraid of the future because of your condition?	6	85,7	1	14,3	0	0	0	0	0	0
Do you mind that your life has to be planned?	4	57,1	3	42,9	0	0	0	0	0	0
Do you feel tired because of your condition?	0	0	0	0	2	28,6	2	28,6	3	42,9
It's hard to sleep because of her condition?	1	14,3	3	42,9	3	42,9	0	0	0	0
Do you feel able to play or do other things with other children/adolescents (such as sports)	0	0	0	0	3	42,9	1	14,3	3	42,9
Do you think you can do most things as well as other children/teenagers?	1	14,3%	0	0	2	28,5	2	28,5	2	28,5

Table 3: Chart about the day-to-day life of the interviewed asthmatics

cough and shortness of breath that often become exacerbated at night.

DISCUSSION

The assessment of quality of life has assumed an important role, with regard to the perception of both individual and collective implications of patients with asthma and other chronic diseases (RONCADA et al., 2013). One way to assess the implications caused by the disease is through the quality of life (QoL), because over the years, with age and experiences, the perception that the individual has about the disease undergoes several changes. (LA SCALA et al., 2005).

ARAÚJO et al., (2014) shows that the use of drug therapy causes changes such as sleep disorders, which are often motivated by nocturnal exacerbations and lack of symptom control; causing chest pain and shortness of breath; which explains drowsiness, daytime attention deficit and tiredness, symptoms that were also observed in the course of this research.

As it is a limiting disease in many ways, asthma poses many challenges in everyday life and hinders some social relationships, preventing these same social bonds from being strengthened (SILVEIRA et al., 2017). Social interaction proved to be a factor of great relevance for quality of life. Children/adolescents with asthma who reported greater social interaction and greater ability to talk about their condition, judged themselves to be less unhappy, having less discomfort when planning their lives.

The efficiency of the treatment, as well as the quality of life, is directly related to psychosocial factors more than the severity of their physical state, since the chronic disease influences the perception of the world and the way in which the individual sees his future. Patients with greater control of their symptoms and emotions have better life

satisfaction and greater ability to cope with their illness (REPPOLD et al., 2014). These findings are in line with those of the present study, which confirm that the more controlled the asthma, the less severe it is, the better the patient's confidence in his future, freedom and living conditions.

Furthermore, with the passage of time and the decrease in episodes of asthmatic crises, the patient's understanding of their care and day-to-day issues showed significant improvements, a fact evidenced by the direct relationship between the decrease in signs and symptoms and improved quality of life, thus increasing your well-being.

As a limitation of the study, it is worth highlighting the difficulty encountered when looking for patients with an age profile greater than 8 years, since with the increase in the age group; signs, symptoms and episodes of asthma attacks are minimized.

CONCLUSION

Based on the data collected in this study, it was possible to observe the great influence that asthma, as a chronic disease, has on the Quality of Life (QoL) of patients in the pediatric age group.

It is important to highlight that those patients who have a better perception of their condition, disease and therapeutic methods, end up having more favorable outcomes in terms of disease management, their perception and QoL.

Thus, the health care of children and adolescents with asthma must go beyond maintaining the patient's survival, but also the quality of life extension, covering the effects that the disease has on their daily lives, their level of satisfaction and well-being. Therefore, guaranteeing a holistic and adequate care for the reality of these children and adolescents.

REFERENCES

- ARAÚJO, D. L. *et al.* **Avaliação da qualidade do sono e da qualidade de vida na asma.** Brazilian Journal Allergy and Immunology. v.2. n.3. p.107-111,2014.
- BETTENCOURT, A. R. C. *et al.* **Educação de pacientes com asma: atuação do enfermeiro.** J. Pneumologia, São Paulo, v. 28, n. 4, p. 193-200. 2002.
- BRASIL. **Doenças obstrutivas crônicas.** Biblioteca Virtual em Saúde-Ministério da Saúde (BVS), Brasília. 2010. Disponível em: https://bvsmms.saude.gov.br/bvs/publicacoes/doencas_respiratorias_cronicas.pdf
- BRASIL. Lei 8.069, de 13 de Julho de 1990. **Estatuto da Criança e do Adolescente.** Brasília: Ministério da Justiça,1990.
- BRASIL. Ministério da Saúde. **Asma.** Biblioteca Virtual em Saúde Ministério da Saúde (BVS). Brasília. 2019. Disponível em: <http://bvsmms.saude.gov.br/dicas-em-saude/482-asma>
- BULLINGER, M. *et al.* **The DISABKIDS questionnaires. Quality of life questionnaire for children with chronic conditions.** Germany: Pabst Science Publishers, v. 14 n. 10. P. 343-355. 2006
- CERCI NETO, A.; FERREIRA FILHO, O. F.; BUENO, T. **Exemplos brasileiros de programas de controle de asma.** J. bras. pneumol., São Paulo, v. 34, n. 2, p 103-106, 2008. Disponível em: <https://www.scielo.br/j/jbpneu/a/fKwzxxmY3SFC8pz8hhYHRFj/?lang=pt&format=pdf>
- COSTA, R. S.; ZANOLLI, M. L.; NOGUEIRA, L. T. **Vivência materna no cuidado da criança com asma.** Revista Enfermagem UERJ, v. 26, p. e16983, 2018. ISSN 0104-3552. Disponível em: <https://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/16983>
- FONTAN, F. C. S. *et al.* **Avaliação da qualidade de vida e fatores associados em crianças e adolescentes asmáticos atendidos em ambulatório especializado.** Revista Paulista de Pediatria. São Paulo, v.38, e2 018172, 2020. Disponível em: <https://www.scielo.br/j/rpp/a/TfwDQB5SK3jwYWCgqYWmSjL/?lang=en>
- LA SCALA, C.S.; NASPITZ, C.K.; SOLÉ, D. **Adaptação e validação do Pediatric Asthma Quality of Life Questionnaire (PAQLQ-A) em crianças e adolescentes brasileiros com asma.** J. Pediatria (Rio J) 2005;81:54-60. Disponível em: <https://www.scielo.br/j/jped/a/hZcqqVGCN3333wVHmSkJb5L/?lang=pt>
- MATSUNAGA, N. Y. *et al.* **Avaliação da qualidade de vida de acordo com o nível de controle e gravidade da asma em crianças e adolescentes.** J. bras. pneumol., São Paulo, v. 41, n. 6, p. 502-508, 2015.
- MONTALBANO, L. *et al.* **Relação entre qualidade de vida e distúrbios comportamentais em crianças com asma persistente: um modelo de múltiplos indicadores de causas múltiplas (MIMIC).** Sci Rep 10, 6957 (2020). <https://doi.org/10.1038/s41598-02062264-9>
- PEREIRA, E. D. B. *et al.* **Controle da asma e qualidade de vida em pacientes com asma moderada ou grave.** Jornal Brasileiro de Pneumologia. v. 37, n. 6 p. 705-711. 2011. Disponível em: <https://doi.org/10.1590/S18067132011000600002>
- REPPOLD, C. T. *et al.* **Características clínicas e psicológicas de pacientes asmáticos de um Ambulatório de Pneumologia.** Psico-USF . v. 19, n. 2. p. 199-208. 2014. Disponível em: <https://doi.org/10.1590/1413-82712014019002005>
- RONCADA, C. *et al.* **Avaliação da qualidade de vida de pais e cuidadores de crianças asmáticas.** Revista Paulista de Pediatria, v. 36, n. 04 p. 451-456. 2018. 2018;36;4;00012 ISSN 19840462; Disponível em: <https://doi.org/10.1590/1984-0462/>
- RONCADA, C. *et al.* **Instrumentos específicos para avaliar qualidade de vida em crianças e adolescentes com asma.** Jornal de Pediatria, v. 89, n. 3, p. 217-225. 2013. Disponível em: <https://www.scielo.br/j/jped/a/MznpH3kFwT9SvQHNhrsHVHN/abstract/?format=html&stop=previo%us&lang=pt>
- SILVEIRA, A. *et al.* **Cuidado à criança com asma: o discurso de familiares / Caring for the child with asthma: relatives discourse.** Journal Nurse and Health; 7(2): 127-136, ago.2017. Disponível em: <https://periodicos.ufpel.edu.br/ojs2/index.php/enfermagem/article/view/10104>
- SIMÕES, S. M. *et al.* **Distribuição da gravidade da asma na infância.** J. Pediatr. (Rio J.) Porto Alegre, v. 86, n. 5, p. 417-423, out. 2010. <https://doi.org/10.1590/S0021-75572010000500011>

STIRBULOV, R.; BERND, L. A.; SOLE, D. **IV Diretrizes Brasileiras para o Manejo da Asma**. Revista Brasileira de Alergia e Imunopatologia, vol. 29, no. 5, pp. 222–245, 2006.

VIVIAN, V. T.; KLEIN, P. C.; STRZKALSKI, M. H.; PINTO, L. A. **Manejo da asma em crianças na sala de emergência/Asthma management in children at emergency room**. Acta méd. 36: [6] . Porto Alegre 2015. Disponível em: <https://docs.bvsalud.org/biblioref/2018/02/879718/manejo-da-asma-em-criancas-na-sala-de-emergencia-virginia-troncook.pdf>