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REVIEW ARTICLE

Quality of life of children with stomas and their families: an integrative literature review

Calidad de vida de los niños con ostomías y sus familias: una revisión bibliográfica integradora

Qualidade de vida de crianças estomizadas e suas famílias: revisão integrativa da literatura

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Abstract

The aim was to identify research in national and international literature regarding the challenges to improving the quality of life of children with stomas. This study consisted of an integrative literature review conducted between May and July 2024 using the MEDLINE/PubMed and Cumulative Index of Nursing and Allied Health databases, as well as the Virtual Health Library portal—specifically the Latin American and Caribbean Health Sciences Literature (LILACS), Spanish Bibliographic Index of Health Sciences (IBECS), and Nursing Database (BDENF) databases. The search yielded 150 publications. The following inclusion criteria were applied: scientific publications in Portuguese, Spanish, and English, published between 2019 and 2024. Ten publications were selected. The studies revealed that caring for children with a stoma often has a negative impact on both the child and their family members.

Descriptors: Child Health; Quality of Life; Stoma; Stomatherapy; Pediatrics.

Resumén

El objetivo fue identificar, en la literatura nacional e internacional, investigaciones sobre los desafíos para mejorar la calidad de vida de los niños con ostomías. Este estudio consistió en una revisión bibliográfica integradora realizada entre mayo y julio de 2024 en las bases de datos MEDLINE/PubMed, Cumulative Index of Nursing and Allied Health y Virtual Health Library, así como en las siguientes bases de datos de ciencias de la salud: Literatura Latinoamericana y Caribeña en Ciencias de la Salud, Índice Bibliográfico Español de Ciencias de la Salud y Base de Datos de Enfermería. Las búsquedas arrojaron 150 publicaciones. Se añadieron los siguientes criterios de inclusión: publicaciones científicas en portugués, español e inglés, dentro del período comprendido entre 2019 y 2024. Se seleccionaron diez publicaciones. Los estudios mostraron que el cuidado de los niños con ostomías suele tener un impacto negativo tanto en el niño como en su familia.

Descriptores: Salud Infantil; Calidad de Vida; Ostomía; Terapia de Ostomía; Pediatría.

Resumo

Objetivou-se identificar, na literatura nacional e internacional, pesquisas sobre os desafios à melhoria da qualidade de vida de crianças com estomias. Este estudo consistiu em uma revisão integrativa de literatura entre os meses de maio e julho de 2024 nas bases de dados MEDLINE/PubMed, *Cumulative Index of Nursing and Allied Health* e no portal da Biblioteca Virtual da Saúde, nas seguintes bases das ciências da saúde: Literatura Latino-Americana e do Caribe em Ciências da Saúde, *Índice Bibliográfico Español de Ciencias de la Salud* e Banco de Dados em Enfermagem. Como resultados das buscas, obtiveram-se 150 publicações. Acrescentaram-se os seguintes critérios de inclusão: produções científicas em português, espanhol e inglês, dentro do recorte temporal de 2019 a 2024. Foram selecionadas 10 publicações. Com isso, evidenciou-se nos estudos que o cuidado com crianças que possuem algum tipo de estomia ocasiona, na maioria das vezes, um impacto negativo tanto para a criança quanto para os seus familiares.

Descritores: Saúde da Criança; Qualidade de Vida; Estomia; Estomaterapia; Pediatria.

Introduction

Ostomy is a surgical intervention that involves the creation of an artificial orifice in a hollow viscus, including but not limited to the intestine or urinary bladder, to enable the output of fecal matter or urine, most commonly via an external collecting device, as defined by the Brazilian Society of Stomatherapy[1]. Tracheostomy is a type of respiratory ostomy that involves the creation of an opening in the trachea to facilitate ventilation. Similarly to feeding ostomies, such as gastrostomy and jejunostomy, it is indicated for patients who are unable to achieve adequate nutritional intake via the oral route[2].

According to the Ministry of Health, intestinal ostomy may be indicated in cases of inflammatory bowel diseases, neoplasms, abdominal trauma, among other clinical conditions[3]. According to a study[2], the tracheostomy provides improvement in ventilation and bronchial hygiene, in addition to reducing the risk of upper airway injury resulting from prolonged use of endotracheal tubes, and is indicated in cases of upper airway obstruction and neuromuscular diseases that compromise respiratory function. Conversely, feeding ostomies are essential in cases of dysfunction to ensure adequate nutrition in patients with swallowing disorders, head and neck cancer, or other conditions that preclude safe oral intake[4].

Ostomies play a crucial role in improving the quality of life of patients requiring this type of intervention; they not only provide immediate physical benefits but also foster a sense of emotional and social well-being, which is essential for recovery and the maintenance of a good quality of life. In this context, quality of life (QoL) is a complex construct that involves individuals' self-satisfaction regarding their lives and the multiple factors that comprise it, such as health, cultural, social, and psychological values. QoL may be modified by the occurrence of a stoma, since this procedure alters bodily functioning and body image, which may cause physical and psychological damage, as well as social impact[5,6].

In this regard, individuals with an ostomy are protected under Law No. 13,146 of July 6, 2015, which establishes the Brazilian Law for the Inclusion of Persons with Disabilities (Statute of Persons with Disabilities). Its Article 18 establishes: "Comprehensive health care is ensured for persons with disabilities at all levels of complexity, through the Unified Health System (SUS), guaranteeing universal and equal access"[7:11]. Individuals with an ostomy are also protected under Law No. 400 of June 27, 2007, which represents a significant milestone in the defense of the rights of persons with ostomies in Brazil. This law guarantees a series of fundamental rights, such as access to materials and equipment necessary for stoma maintenance, specialized medical care, as well as provisions in the social and labor spheres, and further aims to provide quality of life, inclusion, and dignity to these individuals, recognizing their specific needs and promoting equity in access to health services. The implementation of this law has been crucial for improving living conditions and for the social integration of persons with ostomies[8].

Quality of life in patients with an ostomy has been associated with factors such as duration of stoma implantation, education, sex, and concomitant chronic disease. The literature indicates that interventions including preoperative skin site marking, education on stoma care, and the involvement of qualified ostomy nursing support may contribute to the quality of life of patients with a stoma. Ostomies may cause heightened discomfort and suffering in patients as a result of skin irritation (76%), pouch leakage (62%), unpleasant odor (59%), reduction in pleasurable activities (54%), and depression/anxiety (53%). Under these circumstances, it is worthwhile to assess quality of life in the evaluation of outcomes from various therapeutic procedures, along with their impact on the lives of pediatric patients[9,10].

It is estimated that in Brazil there are between 80,000 and 100,000 children with intestinal and urinary ostomies. According to the Brazilian Unified Health System Database (DATASUS), R$ 153,749,490.36 were spent on ostomy procedures between 2002 and 2008. Overall stoma-related morbidity occurs in 20–38% of pediatric patients, considering both stoma creation and closure[11,12].

In view of this scenario, nursing professionals play a fundamental role in the comprehensive care of children with an ostomy, since ostomy involves an alteration that extends beyond physiological function, to which the child must adapt; it entails changes to both the body and corporeality, two concepts that appear similar but are not. The body signifies an objective reality with a defined form, corresponds to an instrument of the Self, and is perceived with greater physical awareness under conditions of illness, whereas the concept of corporeality refers to the subjective realities that are experienced across the physical, intellectual, social, and affective dimensions[13].

The object of study of this research is based on the quality of life of children with stomas. Thus, the present study aimed to identify, in the national and international literature, research on the challenges for improving quality of life in children with ostomies. The research problem was grounded in the following question: "What are the challenges present in the national and international literature for improving quality of life in children with ostomies?". The interest in focusing the research on this theme arose due to the scarcity of studies on the well-being of children with stomas and on the various physical, psychosocial, educational, and familial factors, as well as to fill this gap, with the purpose of bringing knowledge about the QoL of this age group in living with this condition.

Thus, this study contributes to education and to the expansion of adequate knowledge from the training phase onward, in order to promote better practices and interventions that may improve treatment and daily care for children with ostomies, as well as to provide appropriate support for living with greater comfort, fewer complications, and reduced stigma. It also contributes to research by highlighting studies on the quality of life of the pediatric population with ostomies, which remains insufficiently investigated, thereby supporting the development of new products and technologies that facilitate stoma

management and stimulating discussion on the creation of inclusive educational policies and practices that facilitate integration and full access to education and school activities. The study further contributes to nursing care by enabling a holistic approach to children with ostomies, providing a deeper understanding of the physical, emotional, and social needs of these children, allowing for more comprehensive and patient-centered care, as well as the development of specific skills for stoma management, improving technical and communication competencies, resulting in more efficient and safer care through more effective guidance and coping strategies that enhance the quality of life of patients and their caregivers.

Methodology

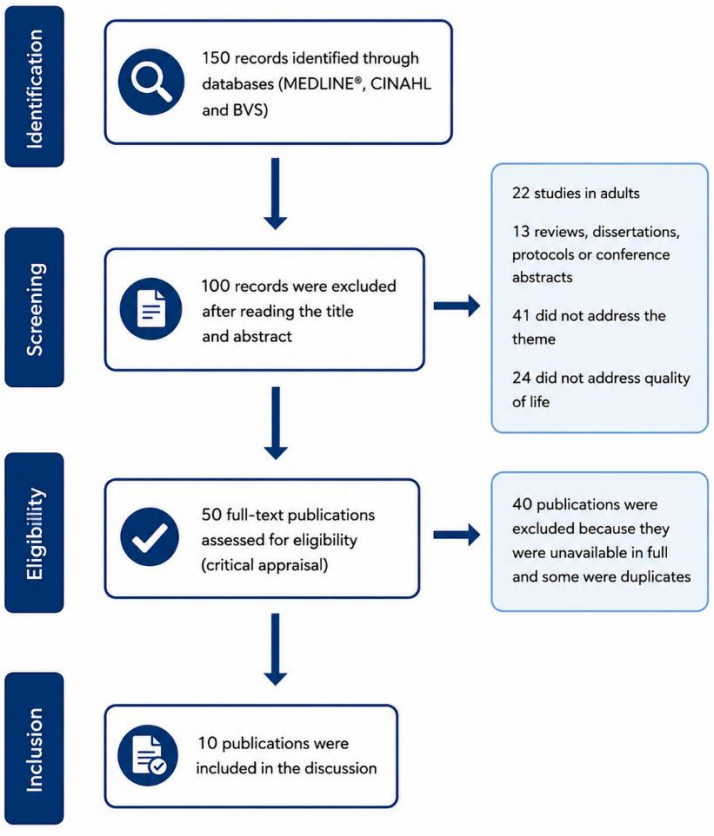
This study consisted of an integrative literature review. The integrative review is the broadest methodological approach among review types, allowing for the inclusion of both experimental and non-experimental studies to achieve a comprehensive understanding of the phenomenon under analysis. It also combines data from theoretical and empirical literature, in addition to incorporating a wide range of purposes: concept definition, review of theories and evidence, and analysis of methodological problems pertaining to a particular topic[14].

The topic was defined as the challenges faced in improving QoL in children with ostomies, aiming to answer the following guiding question: "What are the challenges present in the national and international literature for improving quality of life in children with ostomies?". According to Schardt et al.[15], the construction of an appropriate question to address the researched issue is based on the PICO strategy – with "P" corresponding to the population (children with ostomies); "I" to the intervention (challenges present in the national and international literature); "C" to comparison (not applicable, as this is not a comparative study); and "O" corresponding to the outcome (improvement of quality of life).

The following descriptors were used for the search: Health Sciences Descriptors (DeCS), Medical Subject Headings (MeSH), and CINAHL Headings: "criança" (child), "qualidade de vida" (quality of life), and "estomia" (ostomy). The search strategy was conducted using different combinations of these terms, employing the Boolean operator "AND" in Portuguese, English, and Spanish, depending on the database being searched.

The search for national and international journals was conducted between May and July 2024. The databases searched were MEDLINE (PubMed), the Cumulative Index to Nursing and Allied Health (CINAHL), and the Virtual Health Library portal, in the following health sciences databases: Latin American and Caribbean Literature in Health Sciences (LILACS), Spanish Bibliographic Index in Health Sciences (IBECS), MEDLINE (BVS), and Nursing Database (BDENF). Original studies whose thematic content addressed the guiding question were included, in English, Portuguese, and Spanish, published between 2019 and 2024. Excluded were studies focusing on other themes, editorials, theses and dissertations, reflective texts, and studies not available in full text.

Figure 1. Flowchart of the search and selection process of studies. Rio de Janeiro, RJ, Brazil, 2025



Title and abstract screening were independently performed by two authors to ensure that the texts addressed the guiding research question and met the established inclusion criteria. Research data were organized descriptively and condensed into a chart developed by the authors, thereby enabling the reading and identification of relevant data obtained from the analyzed literature, as well as the establishment of relationships between this information and the object of study. Following the mapping of studies, thematic content analysis was applied, grouping them into three categories.

As a result of the searches, 150 publications were obtained. Proceeding with the search, the following inclusion criteria were added: scientific productions in Portuguese, Spanish, and English, published between 2019 and 2024. After this refinement, 100 works were found. Following the reading of the titles of the retrieved productions and their abstracts, 50 publications were selected. Upon full reading of these articles, incompatibility was identified in 20 manuscripts due to unavailability in full text. Of the remaining 30 manuscripts, 20 were excluded for being editorials, theses, and dissertations, resulting in a total of 10 scientific publications included in the review (Figure 1).

Results and Discussion

A synthesis of the 10 selected studies was performed: 100% of the publications were in English, 0% in Portuguese, with patients using gastrostomy (30%), tracheostomy (70%), colostomy (0%), and ileostomy (0%). According to the selected publications, 3 categories were identified, subsequently discussed in the Discussion section, which were: Quality of life of children with ostomies, Quality of life of family members/caregivers, and Instruments used for the assessment of quality of life.

Chart 1. Characterization of the selected studies. Rio de Janeiro, RJ, Brazil, 2025

Citation, year, and country	Participants	Objectives	Method	Main results	Level of evidence
Chandran et al., 2021, India	Children under 16 years of age	To assess the impact of the presence of a child with a tracheostomy on the quality of life of caregivers in a home care setting.	Combined retrospective and prospective cohort study.	It was observed that caregivers and children with tracheostomy presented good health-related quality of life in the physical, emotional, and social activity domains (74%).	A2
Westwood, Hutchins e Thevasagayam, 2019, USA	25 families	To describe quality of life outcomes in pediatric patients with tracheostomy and their caregivers; to verify the association between the quality of life of children and their caregivers; to analyze the relationship between quality of life and demographic and clinical variables.	Cross-sectional study.	The quality of life of caregivers and children with tracheostomy was affected by anxiety related to the future of the clinical condition, directly interfering with the well-being of both.	A1
Glasson et al., 2020, USA	21 caregivers	To explore the perceived value of gastrostomy for the quality of life of children with intellectual disabilities and their families.	Qualitative study.	Family quality of life was influenced by factors such as family interactions, parenting, available resources and support, health, safety, and support for advocacy of the rights of persons with disabilities.	A2
Franken et al., 2020, USA	128 patients	To evaluate health-related quality of life in children with severe feeding difficulties undergoing gastrostomy.	Cross-sectional study.	Gastrostomy-related complications that required surgical reintervention were the factors that most negatively impacted the quality of life of family members and children.	A1
Din et al., 2020, USA	68 families	To evaluate the quality of life of children with tracheostomy and their families in a low-resource setting.	Descriptive and observational study.	The impact on the quality of life of children with an ostomy was mainly related to socioeconomic aspects.	A2
Faleh, 2023, Saudi Arabia	24 patients	To evaluate quality of life following tracheostomy in pediatric patients and their caregivers in the Kingdom of Saudi Arabia.	Cross-sectional and descriptive study.	Families of children with significant medical comorbidities presented poorer quality of life scores when compared to families of children without relevant comorbidities.	A2
Acorda et al., 2023, USA	14 records	To identify instruments for measuring psychosocial outcomes of caregivers following their children's tracheostomy and to report the findings obtained.	Systematic review.	Caregivers presented lower quality of life when compared to other groups of caregivers of children with ostomies, in addition to elevated levels of stress, difficulties in individual and family coping, regret, and decisional conflict.	A1
Figueiredo et al., 2020, USA	30 caregivers	To describe the health-related quality of life of caregivers of patients with cerebral palsy fed via gastrostomy, to assess mental health-related outcomes, and to verify the interference of gastrostomy on the quality of life of this population.	Cross-sectional study.	Moderate hopelessness was identified in 20% of caregivers, and moderate to severe anxiety in 33.33% of the sample. An association was observed between a greater number of residents per household and higher levels of hopelessness.	A1
Mirza et al., 2021, USA	53 patients	To evaluate the quality of life of children with tracheostomy and the factors that influence it.	Cross-sectional study.	Children with tracheostomy presented lower quality of life than healthy children. Regular follow-up by respiratory therapists	A2

				and nurses was associated with significant improvement in quality of life in children dependent on mechanical ventilation.	
Baddour et al., 2021, USA	140 patients	To measure the prevalence and factors associated with financial toxicity and caregiver burden in families of children dependent on tracheostomy.	Experimental study.	Caregivers presented high financial toxicity and burden. Consequently, some families adopted harmful strategies, such as forgoing prescribed treatments or failing to acquire necessary supplies due to costs.	A1

Quality of life of children with ostomies

The quality of life of children with ostomies is an area of growing interest in clinical research, given the complexity of the challenges faced by these children. Studies have shown that children with ostomies may experience significant impacts on various aspects of their lives, including physical health, emotional well-being, and social integration. Proper stoma management and ongoing support are crucial to minimizing adverse effects and improving the quality of life of these children[16].

The combined retrospective and prospective cohort study[17] with caregivers of children under 16 years of age who underwent tracheostomy, following hospital discharge and after completing 6 months of home care, evidenced that 85 children presented impacts on QoL related to emotional function (53.2%) and to aspects of the caregiver's social relationships (56.9%). Corroborating research[17], a cross-sectional study with 25 families of children with tracheostomy identified deficits related to the caregiver's social functioning (54.9%), communication problems (56.3%), intense worries (49.1%), and family relationship problems (79.6%). All these situations negatively impacted the QoL of both the caregiver and the child with tracheostomy[18].

In a cross-sectional study conducted at two pediatric centers with patients with tracheostomy, using the Pediatric Quality of Life Inventory, clinical and demographic patient data, as well as parental socioeconomic factors, the following results were obtained: mean patient age was 6.85 years, and 21 patients were ventilator dependent. The authors identified that the total pediatric health-related quality of life score was 59.28, and the family impact score was 68.49. In non-ventilator-dependent patients, multivariate analyses indicated that social functioning and health-related quality of life were negatively affected by the duration of tracheostomy. The QoL of ventilator-dependent patients was influenced by follow-up consultations and the presence of pulmonary comorbidities[19].

Dependence on a mechanical ventilator influences not only mobility and physical independence but may also affect the emotional and social well-being of patients. Studies indicate that the quality of life of mechanically ventilated patients may be impacted by several factors, including the severity of the underlying condition, the presence of associated complications, and the level of support and care available. Quality of life may be improved through a multidisciplinary approach that includes palliative care, psychological support, and rehabilitation programs tailored to the individual needs of patients[20].

However, in a study[21], twenty-one primary caregivers of children with intellectual disabilities aged 2 to 18 years participated in semi-structured telephone interviews. The main impact for the child with gastrostomy was on physical health, whereas for the caregiver, impacts were related to family interactions, parenting, resources, health, and disability advocacy support. The difficulty in securing the rights for these children with ostomies significantly compromises the quality of life of these young patients. Despite existing legislation, such as Law No. 400/2007, which aims to guarantee access to specialized care and necessary materials, many families encounter barriers in the implementation of these rights, including lack of adequate information, excessive bureaucracy, and insufficient resources within certain health systems, hindering continuous and efficient access to the benefits guaranteed by law[22].

In a cross-sectional study with 128 children undergoing gastrostomy, the authors evidenced that, although gastrostomy is generally considered a safe procedure, minor complications such as hypergranulation, infection at the gastrostomy site, or leakage around the catheter occur frequently. These minor complications may be a reason for reintervention or hospital readmission, as occurred in 16% of the patients in the study. Complications of gastrostomy in children may vary in severity and impact, requiring careful attention and appropriate management to minimize risks[23]. The implementation of standardized care practices and the ongoing education of caregivers and healthcare professionals are essential to prevent and manage these complications[24].

Quality of life of family members/caregivers

Family members who care for children with ostomies also face considerable challenges that affect their own quality of life. The caregiving burden may lead to stress, anxiety, and physical and emotional exhaustion. It is noteworthy that caregivers often report feeling overwhelmed and isolated, which may compromise their mental health and well-being[19]. In their studies, authors[17] showed that families and caregivers are challenged and intimidated by the responsibility of caring for a child with a tracheostomy, and adaptation to these responsibilities constitutes a major burden for them, affecting their lifestyle and family dynamics. Other points to be discussed include lack of time and energy to complete daily activities, social isolation, worries, as well as communication difficulties and the perception of a lack of understanding regarding their children's health, all of which become fundamental factors in the reduction of caregivers' quality of life[18].

Caregivers of children with ostomies frequently report difficulties in balancing their caregiving responsibilities with other tasks, such as work, care for other

family members, and leisure activities. Lack of time may lead to chronic stress, fatigue, and mental health problems, such as anxiety and depression[25]. Families have greater home care responsibilities, higher healthcare costs, and suffer psychological and emotional trauma. The authors also evidenced that marital dissolution results from the increasing demands in the care of these children[26].

Household routines are modified to meet the needs of the entire family, not only the child with a tracheostomy, requiring training and instructions before hospital discharge. For the child and their family, undergoing a tracheostomy means learning a new way of life[27]. In the study, caregivers reported lower QoL when compared to other groups of chronic caregivers. They experienced high degrees of stress, struggled to cope both individually and as a family unit, and experienced decisional regret and conflict. Such feelings result from the ongoing responsibility and complexity of the required care, which may lead to questioning their own abilities, as caregivers strive to balance their own needs with the demands of child care[28].

It is stated that caregivers of children dependent on tracheostomy suffer from socioeconomic instability and caregiver burden. As a result, harmful financial coping mechanisms, such as forgoing necessary care components or renouncing prescribed treatments, may be adopted due to prohibitive costs. The need to care for a child with a chronic condition often prevents caregivers from maintaining regular employment or working full-time, resulting in low household income, consequently creating a vicious cycle of poverty, in which the lack of financial resources affects the ability to provide the best possible care, which in turn exacerbates stress and pressure on caregivers. Furthermore, socioeconomic precariousness may lead to inadequate living conditions, such as cramped or unsanitary housing, which are not ideal for children with chronic needs. These living conditions may increase the risk of infections and other complications, placing even further pressure on caregivers[29,30].

The need for psychological and social support for these family members/caregivers is evident. Public policies and specific interventions are necessary to address these disparities; community support that offers emotional and educational assistance may be extremely beneficial in improving the quality of life of caregivers and, consequently, in providing the necessary support to care for their children in an effective and sustainable manner[30].

Instruments used for the assessment of quality of life

The instruments used to assess the quality of life of children with ostomies are varied, but all aim to comprehensively measure the physical, emotional, and social impacts of the condition. The study[17] utilized the Pediatric Quality of Life Version 4.0 (PedsQL v 4.0) questionnaire, with the purpose of capturing the child's perception of their health and well-being across different domains, and of assessing the impact of having a child with a tracheostomy on the caregiver's quality of life in a home care setting, as well as identifying the association of caregiver quality of life with various study variables. Corroborating the authors, it is stated that the PedsQL questionnaire was used as an instrument for quality-of-life assessment. These questionnaires cover social, emotional, physical, and cognitive functioning[18].

In a study[23], the PedsQL TM 4.0 Generic Core Scales were used for the assessment of quality of life of children with ostomies. The PedsQL TM is subdivided into four age-adjusted questionnaires (ages: 2–4; 5–7; 8–12; and 13–18 years) and a parallel self-report for children (ages: 5–7; 8–12; and 13–18 years). The inventory comprises 23 items. The total HRQoL score is divided into two main health summary scores: physical health summary score (8 items) and psychosocial health summary score (15 items). Researchers[27] utilized the Pediatric Tracheotomy Health Status Instrument (PTHSI) to assess QoL following tracheostomy in pediatric patients and their caregivers. In a study[26], the validated Pediatric Tracheotomy Health Status Instrument (PTHSI) was used, in which a higher score implied a better outcome.

The quality of life and mental health instruments applied and analyzed exclusively for caregivers were the Medical Outcomes Study (MOS) 36-item Short Form Health Survey (SF-36), the WHOQOL-BREF, and Beck scales[31]. STudy[19] used the Pediatric Quality of Life Inventory as an instrument to assess the quality of life of pediatric patients with ostomies. The authors[29] used three instruments to assess quality of life: the Comprehensive Score for Financial Toxicity (COST) and the Financial Distress Questionnaire (FDQ), both directed at primary parents/caregivers, and the Burden Scale for Family Caregivers - short version (BSFC-s).

Final Considerations

The majority of studies evidenced a negative impact on the quality of life of children with an ostomy and on their family context, showing the main challenges encountered in the care of children with an ostomy and how they interfere with their QoL. The impacts on QoL are related to factors such as interpersonal relationships, financial resources, self-care deficits, comorbidities, socioeconomic conditions, stoma-related complications, level of education, family dynamics, communication, and financial resources. In this context, it is observed that the child and family require support from the multidisciplinary team to minimize this impact, which may compromise the care provided to the child.

In view of this, the Enterostomal Therapy Nurse plays a fundamental role in stoma care and in reducing the factors that impact QoL, seeking viable treatment alternatives according to the family's socioeconomic reality, promoting support and autonomy, thereby reducing the stress resulting from the current condition of these individuals. Furthermore, instruments should be used to measure the quality of life of children with ostomies, such as: PedsQL, PTHSI, MOS, SF-36, WHOQOL-BREF, Beck Scales, COST, FDQ, and BSFC-s, for a more comprehensive assessment. Therefore, further studies should be conducted to fill gaps regarding the challenges faced by children with colostomy or ileostomy, which were not addressed in the studies on ostomies.

References

1. Sociedade Brasileira de Estomaterapia (SOBEST). Definição de estomia. São Paulo: SOBEST; 2022.
2. Torres A, Díaz E, Ferrer M. Traqueostomia: indicações e cuidados. Rev Bras Ter Intensiva. 2019;31(1):12-20. https://doi.org/10.5935/0103-507X.20190012
3. Brasil. Ministério da Saúde. Procedimentos de estomia. Brasília: Ministério da Saúde; 2021.
4. Silva MA, Ribeiro AC. Estomias de alimentação: gastrostomia e jejunostomia. Rev Nutr Clin. 2020;35(2):101-10.
5. Sociedade Brasileira de Estomaterapia (SOBEST). Importância das estomias para a qualidade de vida. São Paulo: SOBEST; 2021.
6. Diniz IV, et al. Factors associated to quality of life in people with intestinal stomas. Rev Esc Enferm USP. 2021;55:e20200377. https://doi.org/10.1590/S1980-220X202003770377
7. Brasil. Lei nº 13.146, de 6 de julho de 2015. Lei Brasileira de Inclusão da Pessoa com Deficiência. Brasília: Câmara dos Deputados; 2015.
8. Andrade MJ. Os direitos das pessoas ostomizadas e a importância da Lei nº 400/2007. Rev Bras Direito Sanit. 2010;12(2):45-56.
9. Karhu EK, et al. O uso do cinto de ostomia melhora a qualidade de vida em pacientes com estoma. Cirurgias. 2024;5(1):92-102.
10. Zewude WC, et al. Quality of life in patients living with stoma. Ethiop J Health Sci. 2021;31(5):993-1000. https://doi.org/10.4314/ejhs.v31i5.13
11. Egito ETBN, et al. Estado nutricional de pacientes pediátricos ostomizados. Rev Paul Pediatr. 2013;31(1):58-64. https://doi.org/10.1590/S0103-05822013000100010
12. Vogel I, et al. Major stoma related morbidity in young children following stoma formation and closure: a retrospective cohort study. J Pediatr Surg. 2022;57(10):4023-8. https://doi.org/10.1016/j.jpedsurg.2022.04.013
13. Duque PA, et al. Efeitos de intervenções socioeducativas na qualidade de vida de pessoas com estomia digestiva. Sage Journals. 2023;9(1):e123456. https://doi.org/10.1177/0000000000000000
14. Souza MT, Silva MD, Carvalho R. Revisão integrativa: o que é e como fazer. Einstein (São Paulo). 2010;8(1):102-6. https://doi.org/10.1590/s1679-45082010rw1134
15. Schardt C, Adams MB, Owens T, Keitz S, Fontelo P. Utilization of the PICO framework to improve searching PubMed for clinical questions. BMC Med Inform Decis Mak. 2007;7:16. https://doi.org/10.1186/1472-6947-7-16
16. Marino P, Santos LR, Sousa A. Impact of ostomy in children's life. Pediatr Nurs J. 2020;45(2):123-30.
17. Chandran A, et al. The impact of pediatric tracheostomy on the quality of life of caregivers. Int J Pediatr Otorhinolaryngol. 2021;149:110854. https://doi.org/10.1016/j.ijporl.2021.110854
18. Westwood EL, Hutchins JV, Thevasagayam R. Quality of life in paediatric tracheostomy patients and their caregivers: a cross-sectional study. Int J Pediatr Otorhinolaryngol. 2019;127:109606. https://doi.org/10.1016/j.ijporl.2019.109606
19. Mirza B, et al. Factors influencing quality of life in children with tracheostomy with emphasis on home care visits: a multi-centre investigation. J Laryngol Otol. 2023;137(10):1102-9. https://doi.org/10.1017/S0022215123000841
20. Chao PW, Tsai TY, Huang YT. Quality of life of ventilator-dependent patients: a systematic review. BMC Pulm Med. 2018;18(1):130. https://doi.org/10.1186/s12890-018-0676-z
21. Glasson EJ, et al. Gastrostomy and quality of life in children with intellectual disability: a qualitative study. Arch Dis Child. 2020;105(10):969-74. https://doi.org/10.1136/archdischild-2020-318967
22. Oliveira M, Silva R. The burden of caregiving for children with ostomies. Fam Health J. 2018;12(4):205-10.
23. Franken J, et al. Health-related quality of life in children after laparoscopic gastrostomy placement. Qual Life Res. 2020;29(1):171-8. https://doi.org/10.1007/s11136-019-02263-0
24. Sullivan PB, et al. Gastrostomy tube feeding in children with cerebral palsy: impact on caregiver quality of life. Dev Med Child Neurol. 2018;60(9):963-8. https://doi.org/10.1111/dmcn.13746
25. Lima MC, Santos LR. The impact of caring for a child with a stoma on family caregivers. J Fam Health Care. 2019;29(3):150-7.
26. Din TF, et al. The assessment of quality of life in children with tracheostomies and their families in a low to middle income country (LMIC). Int J Pediatr Otorhinolaryngol. 2020;138:110319. https://doi.org/10.1016/j.ijporl.2020.110319
27. Faleh MA, et al. Pediatric tracheostomy: a quality-of-life assessment study in Saudi Arabia. Cureus. 2023;15(10):e47235. https://doi.org/10.7759/cureus.47235
28. Acorda DE, et al. Psychosocial measures and outcomes among caregivers of children with tracheostomies: a systematic review. Otolaryngol Head Neck Surg. 2023;168(5):979-87. https://doi.org/10.1002/ohn.184
29. Baddour K, et al. Exploring caregiver burden and financial toxicity in caregivers of tracheostomy-dependent children. Int J Pediatr Otorhinolaryngol. 2021;145:110713. https://doi.org/10.1016/j.ijporl.2021.110713
30. Oliveira M, Silva R. Socioeconomic challenges faced by caregivers of children with chronic conditions. J Pediatr Nurs. 2020;45(1):33-40. https://doi.org/10.1016/j.pedn.2019.12.005
31. Figueredo AA, et al. Quality of life in caregivers of pediatric patients with cerebral palsy and gastronomy tube feeding. Arq Gastroenterol. 2020;57(1):3-7. https://doi.org/10.1590/S0004-2803.202000000-02