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ORIGINAL ARTICLE

Gastrointestinal symptoms and problems in children cared by pediatric palliative care teams. Observational study

Síntomas y problemas gastrointestinales en niños asistidos por equipos de cuidados paliativos pediátricos. Estudio observacional

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What do we know about the subject matter of this study??

Gastrointestinal symptoms and problems (GI-SP) frequently cause discomfort, suffering, and a negative impact on the quality of life in pediatric patients with life-threatening and/or life-limiting diseases, at all stages of the disease. Pediatric palliative care professionals must be aware of them, prevent them, perform a comprehensive assessment, and implement pharmacological and non-pharmacological measures.

What does this study contribute to what is already known??

In this observational, prospective, multicenter study in pediatric palliative care teams, the prevalence of consultations due to GI-SP was determined, the most frequent ones in the population included were identified, and the pharmacological and non-pharmacological measures prescribed were described. Swallowing disorder was the most frequent GI-SP, and problems with gastrointestinal prostheses were the fourth; these could be the subject of further research and training in pediatric palliative care.

Abstract

Gastrointestinal symptoms and problems (GI- SP) frequently cause discomfort and suffering in pediatric patients with life-threatening and/or life-limiting illnesses (LTI/LLI). Pediatric palliative care (PPC) professionals should be aware of them and perform a comprehensive approach. **Objective**: To determine the prevalence of GI- SP in patients treated in PPC units and to describe the pharmacological and non-pharmacological measures prescribed. **Patients and Method**: Observational, prospective, multicenter, prospective study in patients with LTI/LLI, seen by PPC teams in Uruguay. The variables analyzed included age, sex, origin, type of LTI/LLI, presence of mucositis, vomiting, swallowing disorders, abdominal pain, constipation, diarrhea, digestive bleeding, problems with digestive prosthesis, and prescribed pharmacological and non-pharmacological treatment. **Results:** 10 out of 16 PPC teams participated. 96 out of 436 patients seen presented GI- SP (22%). Median age was 4.2 years (1 month-18 years). LTI/LLI: 65% neurological and 7% oncological. The 96 patients had 114 consultations; 50% had 2 or more GI- SP per consultation. GI- SP observed: swallowing

Keywords:

Gastrointestinal Symptoms; Pediatric; Palliative Care; Quality of Life; Swallowing Disorders

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disorders (57%), constipation (53%), nausea and/or vomiting (24%), gastrostomy problems (17%), abdominal pain (10%), digestive bleeding (3%), and diarrhea (2%). There were variable prescriptions of pharmacological and non-pharmacological measures; only 50% of those with swallowing disorder received speech and hearing therapy. **Conclusions:** GI- SP motivated consultations in all PPC settings, frequently due to 2 or more GI- SP. Swallowing disorders and gastrostomy complications are frequent but not very visible problems in PPC. According to the comprehensive approach, pharmacological and non-pharmacological measures were implemented.

Introduction

The main objective of Pediatric Palliative Care (PPC) is the prevention and relief of physical, emotional, social, and spiritual suffering in children^a with life-threatening and/or life-limiting diseases (LTD/LLD)¹. In this context, the anticipation, prevention, and comprehensive management of unpleasant symptoms is one of the main areas of action and contribution of PPC for improving the quality of life of both children and their families.

Gastrointestinal symptoms and problems (GI-SP) are a frequent cause of discomfort and suffering in children with LTD/LLD, whether they have oncological or non-oncological diseases². Approximately 1 in 10 children needing specialized PPC has a primary gastrointestinal (GI) disease, however, many other children with different LTD/LLD suffer from GI-SP that, occasionally, are intense enough to lead to consultations in different care settings, including emergency departments. Feudtner et al. in a study on the symptomatology of children assisted by PPC teams in the United States, with 501 children included, reported the following GI-SP among the 20 most frequent: diarrhea (43%), vomiting (37%), constipation (30%), feeding difficulties (26%), swallowing disorder (20%), and mucositis (8%). Likewise, Wolfe et al. in a study including children aged 2 or older with advanced cancer, found the following prevalences: nausea (35%), diarrhea (27%), vomiting (25%), constipation (16%), and dysphagia (15%)³⁻⁵.

GI-SP may appear at different times throughout the disease trajectory, because of the disease itself, its complications, or treatments, but their prevalence increases in the end-of-life stage⁴⁻⁶. These symptoms generate significant impact and suffering in patients, but also distress and anxiety in their caregivers when they are unable to help their child. Multiple biological, emotional, and environmental factors, individually or simultaneously, can determine them or contribute to their exacerbation or prolongation. Therefore, for their prevention and control, a comprehensive approach to

all causes and mechanisms is essential, including a holistic assessment that considers the physical, pharmacological, and emotional factors possibly involved and that treatment considers and includes pharmacological and non-pharmacological measures⁷⁻¹¹.

No previous studies were found in Uruguay or the region, establishing the prevalence of GI-SP, nor describing the treatments used in this population. Having this information is important to implement initiatives to improve care. The objectives of this study were to determine the prevalence of GI-SP that led to consultations in children with LTD/LLD, assisted by PPC units in Uruguay, and to describe the main pharmacological and non-pharmacological measures used for each symptom.

Patients and Method

Study design

Observational, prospective, multicenter study, from June 1 to December 30, 2020. Children with LTD/LLD, assisted by PPC teams in Uruguay, were included in different settings: home, outpatient clinic, inpatient ward, and teleconsultation.

All existing PPC teams in the country at that time (16 teams) were invited to participate, but the following responded and included patients: Hospital Pediátrico-Centro Hospitalario Pereira Rossell (CHPR), Centro de Asistencia del Sindicato Médico del Uruguay (CAS-MU), Sanatorio Americano, Hospital Británico, Dirección Nacional de Sanidad Policial, Colectivo Médico Rochense (COMERO), Unidad de CPP interinstitucional del departamento de Maldonado [ASSE Centro Hospitalario Maldonado-San Carlos, Intendencia Departamental de Maldonado, Centro Regional de Asistencia Médica del Este-Institución de Asistencia Médica Privada de Profesionales (CRAME/IAMPP) and Asistencia Médica Departamental de Maldonado-Institución de Asistencia Médica Privada de Profesionales (AMDM/IAMPP)], Centro Auxiliar de Las Piedras Alfonso Espínola, Asociación Médica de San José-Institución de Asistencia Médica Privada de Profesionales (AMSJ/IAMPP) and Corporación Médica de Tacuarembó (COMTA/IAMPP).

a In the context of this article, whenever the term child/ children is used, it includes adolescent/adolescents.

Children with LTD/LLD were considered those at risk of dying prematurely and presenting one or more complex health conditions¹. To categorize such conditions, the "Together for Short Lives" (TSL) classification was used¹².

Statistical analysis

Data collection was carried out by the professionals involved in the PPC teams, using a spreadsheet specially designed for this study. The variables studied were age, sex, origin, LTD/LLD and TSL group, presence of one or more of the following GI-SP: mucositis, vomiting, swallowing disorder, abdominal pain, constipation, diarrhea, GI bleeding, problems with gastrostomy or other prostheses, all of them diagnosed according to the treating professionals' criteria, and pharmacological and non-pharmacological treatment established for each GI-SP. The categorical variables were described using frequency, percentages, and mean. Microsoft Excel for Windows was used for data collection and analysis of the results.

Ethical aspects

The study was approved by the directors and technical directors of each participating institution and with the endorsement of the CHPR Research Ethics Committee. Signed informed consent was requested from the father, mother, or guardian of each child included. The research was subject to current national regulations and the data were analyzed anonymously and confidentially.

Results

Information was received and included from patients assisted by 10 out of 16 PPC teams from 6 provinces of the country: Montevideo (5), Maldonado (1), Rocha (1), San José (1), Tacuarembó (1), and Canelones (1).

During the study period, the PPC teams included assisted a total of 436 children or adolescents. Of these, 96 out of 436 (22%) had consultations due to GI-SP. The median age of the children assisted by the PPC teams and presenting with GI-SP was 4.2 years (1 month-18 years). Table 1 describes the demographic characteristics and health conditions for which the included children with GI-SP were eligible for PPC according to the TSL classification.

The total number of included children (96) presented 114 consultations due to GI-SP. It was found that in 57/114 (50%), the consultation was due to one symptom, in 42/114 (37%) due to two symptoms, in 10/114 (9%) due to 3 symptoms, and in 5/114 (4%), the consultation was due to 4 or more GI-SP. The

scenarios of consultations due to GI-SP were hospitalization 63/114 (55%), outpatient 19/114 (17%), home care 17/114 (15%), and teleconsultation 15/114 (13%). The GI-SP that motivated these consultations were swallowing disorders 65/114 (57%), constipation 61/114 (53%), nausea and/or vomiting 27/114 (24%), gastrostomy problems 20/114 (17%), abdominal pain 11/114 (10%), GI bleeding 4/114 (3%), and diarrhea 2/114 (2%). During the study period, no patient presented mucositis.

Of the total number of children and adolescents assisted with GI-SP, 89 of 96 (93%) had non-oncologic health conditions. In them, the main GI-SP reported were swallowing disorder (64), constipation (60), nausea/vomiting (21), problems with prostheses (20), abdominal pain (11), GI bleeding (4), and diarrhea (2).

Among the children and adolescents assisted with GI-SP, 7 out of 96 (7%) were carriers of oncologic diseases. In them, the main GI-SP reported were nausea/vomiting (6) and swallowing disorder and constipation (1). None of the children presented mucositis.

In relation to the treatments indicated, it should be noted that for a swallowing disorder, which was the most frequent GI-SP, an enteral feeding tube was indicated in 46 of 61 children and a feeding thickener in 10 of 61. Table 2 shows all pharmacological and non-pharmacological treatments indicated to the patients included, according to the GI-SP.

Discussion

Of the children with LTD/LLD assisted by PPC teams in Uruguay during the study period, 22% presented GI-SP that motivated their consultation. In a study based on the work of a home PPC team, Hauch et al. also reported the presence of GI-SP at different times in the course of the disease, including the end-of-life stage, when they were even more frequent.

Regarding the type of LTD/LLD that motivated the assistance by PPC teams, as in previous national studies, the health conditions of the children included were very varied¹³⁻¹⁶. It is noteworthy that more than 60% had some neurological disease. It is known that, for multiple reasons, children with severe neurological impairment very frequently present GI-SP, and it is recommended that these should always be considered in the framework of their evaluation and comprehensive approach since they are a very frequent cause of discomfort and suffering^{17, 18}.

Although there are variations in the percentage of children with oncologic and non-oncologic diseases assisted by PPC teams, depending on the level of development of these teams in each country and the type of institution in which the teams operate, this

| | | | n = 96 | % |
|-------------|---|------------|--------|----|
| Age | | | | |
| 1 | month – 11 months | | 15 | 16 |
| 1 | year – 5 years 11 months | | 39 | 40 |
| | years – 11 years 11 months | | 19 | 20 |
| | 2 years – 14 years 11 months | | 15 | 16 |
| ≥1 | 5 years | | 8 | 8 |
| Sexo | | | | |
| Male | | 57 | 60 | |
| Fe | male | | | 40 |
| | graphical origin | | | |
| | ontevideo (capital) | | 78 | 81 |
| Ot | ther provinces | | 18 | 19 |
| Heal | th conditions for which children were susceptible to PPC | | | |
| l. | Diseases that require curative or intensive treatment to prolong life and that may fail. | | | |
| | a. Oncological disease | (7) | 10 | 10 |
| | b. Congenital heart diseases | (3) | | |
| II. | Diseases that require prolonged treatments to improve and maintain quality of life. | | | |
| | a.Digestive malformation | (4) | | |
| | bSevere chronic kidney failure with complications | (3) | | |
| | c. Genetic syndrome | (3) | | |
| | d. Chronic respiratory failure | (1) | 13 | 14 |
| | e. Duchenne muscular dystrophy | (1) | | |
| | f. Chronic enterocolitis | (1) | | |
| | g Severe genito-nephro-urinary malformation | (1) | | |
| III. | Progressive diseases for which treatment is exclusively palliative. | ` , | | |
| | a. Metabolopathy | (4) | | |
| | b. Type I spinal cord atrophy | (3) | | |
| | c. Demyelinating polyneuropathy | (1) | 10 | 10 |
| | d. Are syndrome | (1) | | |
| | e. Krabe syndrome | (1) | | |
| I\ / | | | | |
| IV. | Severe, non-progressive neurological disease that results in vulnerability and complications cause premature death. | liial Cali | | |
| | a. Chronic non-progressive encephalopathy of unclear etiology | (44) | | |
| | b. Refractory epilepsy | (3) | | |
| | c. Epileptogenic encephalopathy | (2) | | |
| | d. Chronic non-progressive encephalopathy secondary to: | (-/ | | |
| | Hypoxia ischemia | (4) | 63 | 66 |
| | Unintentional injuries | (3) | 35 | 00 |
| | Prematurity | (2) | | |
| | Central nervous system infection | (2) | | |
| | Child abuse | (1) | | |
| | Cerebrovascular accident | (1) | | |
| | Interventricular hemorrhage | (1) | | |
| Hso | of digestive prosthesis | () | | |
| | asogastric tube | | 35 | 36 |
| Gastrostomy | | 34 | 35 | |
| lleostomy | | 1 | 1 | |

wide range of conditions for which children are susceptible to PPC is an epidemiological characteristic worldwide^{13-16,19,21,22}. In the included population, only 7 children were carriers of oncologic diseases. In Uruguay, this could be determined by organizational issues of the health system, beyond the control of the PPC teams, but it certainly underestimates the place of cancer in the population eligible for PPC. In any case, it is important to keep in mind that GI-SP, particularly nausea, vomiting, constipation, and mucositis are very

frequent in children with cancer as demonstrated by multiple authors^{4,5,8,25}.

Of the children with LTD/LLD who consulted due to GI-SP, in 50% of the consultations, they presented 2 or more GI-SP, up to more than 4, simultaneously. It should be considered that, in this study, the possible concomitance with symptoms in another area was not considered. The polysymptomatology of children with LTD/LLD was previously described by Wolfe and Feudtner in studies conducted in different populations

| Symptom | Non-pharmacological treatment | Pharmacological treatment • Food thickener: 10 | |
|---|---|---|--|
| Swallowing disorder n = 65 (57%) Confirmed: 28 (43%) Suspected: 37 (57%) | NGT feeding: 31 Speech therapy: 29 Realization of GST: 15 Fractional feeding: 3 | | |
| Constipation n = 61 (53%) | Diet rich in fiber: 27 Abdominal massages: 14 Fecal disimpaction: 2 Physical activity: 1 | Lactulose: 43 Polyethylene glycol: 24 Enemas: 7 Bisacodyl: 6 Vaseline: 2 Multiflora 1 | |
| Nausea/ vomiting n = 27 (24%) | Fractional feeding: 23Digestive rest: 5Abdominal massages: 3 | Ondansetron: 17 Diphenhydramine: 3 Metoclopramide: 2 Dexamethasone: 1 Lorazepam: 1 Cannabis: 1 | |
| Problems with prostheses (in all cases GST) n = 20 (17%) Local peri-ostoma infection: (9) Gastric fluid leak: (3) Pain (3) Difficulty in handling (1) Expulsion (1) Button break (1) Granuloma (1) Obstruction 1 | Set or button change: 13 GST withdrawal: 3 | Antibiotic (PO/ topical): 8 Antibiotic (IV): 10 | |
| Abdominal pain n = 11 (10 | Abdominal massage: 3Diet: 2Surgery: 1 | NSAIDs: 7Morphine: 3Antispasmodic: 2Gabapentin: 2Lactulose: 2 | |
| Digestive bleeding n = 4 (3%) | | Antacids: 2Omeprazole: 2Sulcralfate: 2Vitamin K: 1 | |
| Diarrhea n = 2 (2%) | • Diet: 1 | • Rehydration: 2 | |

and was highlighted as one of the causes of the complexity in the evaluation and treatment of these children, given that, among other challenges, it frequently determines the need for polypharmacy^{4,5,19}.

At the same time, it was found that consultations due to GI-SP were made both during hospitalization (50%) and in any of the other care settings, whether outpatient clinic, home care, or by telephone. Health professionals assisting children with LTD/LLD at all levels of care must have the skills, knowledge, and competencies for the anticipation, prevention, comprehensive assessment, and treatment of these symptoms and problems. Unlike the study by Hauch et al., our study did not consider the life stage of the child, but it is repeatedly pointed out that the prevalence of bothersome gastrointestinal symptoms increase in the end-of-life period^{5,6}.

Regarding the type of GI-SP, like other authors, although with different prevalences, consultations were associated with nausea, vomiting, constipation, abdominal pain, and GI bleeding^{3,5,24,25}. During the study period, no consultation due to mucositis was recorded, which is probably related to the low number of children with cancer assisted by PPC teams in Uruguay, as already mentioned.

In terms of prevalence, the first and second places were occupied by swallowing disorders and constipation, respectively, being present in more than half of the children included. "Swallowing disorders are defined by the presence of an alteration in one or more of the 3 phases of swallowing (oral, pharyngeal, esophageal)". The mainstay for diagnosis is direct observation, with or without the use of standardized classification systems and studies such as videofluoroscopy and endoscopy¹⁸. In this study, only 43% were confirmed by swallowing study and/or consultation with a speech therapist.

Swallowing disorders are very common in children with neurological involvement, as well as in those with neuromuscular diseases. In these populations, prevalences of up to more than 90% have been described, which vary directly proportional to the severity of the motor impairment^{3,18,26}.

Among children with LTD/LLDD who may receive PPC, there are many others at an increased risk of presenting swallowing disorders such as extreme preterm newborns²⁷ tracheostomy users²⁸⁻³⁰, carriers of complex congenital heart disease³¹, and children with malformations and/or tumors of the aerodigestive tractss²⁶, among others.

Despite the possible high prevalence, swallowing disorders are poorly visible in the literature specific to PPC and only scarcely included as bothersome problems³. However, they can be an important source of discomfort, suffering, and impact for the child and

the family for multiple reasons such as the symptoms themselves (drooling, choking, coughing, pain, etc.); their complications (aspiration, respiratory infections, apneas, malnutrition, need for alternative feeding routes, etc.); for the family, the time dedicated to feeding, among others. For this reason, it is important that the professionals of the PPC teams and others who assist children with these health conditions, keep them in mind, anticipate, actively seek, and establish timely contact with a speech therapist with experience in swallowing for their prevention and/or early detection, for a comprehensive and integrated approach to the total care of the child^{3,26}.

Among the reasons for consultation due to GI-SP of children with LTD/LLD assisted by PPC teams, problems related to digestive prostheses, particularly gastrostomy, also stand out in fourth place. Most of the children included had such prostheses and, among them, half had a gastrostomy. Cerebral palsy and other diseases with neurological impairment are the health conditions in which gastrostomy is most frequently indicated as an alternative form of feeding. But it can also be necessary in children with cancer, congenital heart disease, and prematurity, among others. In these children, the most frequent reason for gastrostomy placement is a swallowing disorder^{32,33}. A thorough review of the literature between 1994-2017 reported evidence of multiple possible complications of percutaneous endoscopic gastrostomy placement. Of the children included in the articles reviewed, 33% (1518/4631) had presented minor complications such as granuloma, local infection, leakage of gastric contents, and peri-gastrostomy erythema. Also, 10% (464/4631) presented major complications such as systemic infection, cellulitis, and esophageal or intestinal perforation³⁵. During the study period, the children with LTD/LLD included only presented minor complications.

In 2/20 children who consulted due to prosthesis problems, the consultation was motivated by "handling difficulties". Parents and caregivers of children with LTD/LLD and prostheses should add to the usual parental care, those typical of health care personnel, such as prostheses and medical technology devices. This implies that health professionals responsible for these children should include parent and caregiver education as an essential component of care. In the case of children with gastrostomy, this means teaching them cleaning of the peristomal skin and lumen, device manipulation, monitoring of the device's state, and the permeability of the lumen, as well as techniques for feeding, medication administration, and subsequent washing, among others³4.

Almost 10% of the patients included presented abdominal pain, and most of them were children with neurological disease. In addition to the causes directly

related to the digestive system, such as gastritis, gastroenterocolitis, and constipation, which are frequent in these patients, it is important to consider the also frequent visceral hyperalgesia, currently also called gastrointestinal dystonia^{8,17}. These clinical pictures are digestive manifestations of the neurological disease itself. Visceral hyperalgesia is considered a manifestation of central neuropathic pain; it is an exaggerated response to physiological visceral stimulation, resulting in a decreased pain threshold. It is characterized by an exacerbated and unpleasant perception of the normal physiologic activity of the GI tract such as the passage of the bolus through the esophagus, the gastric and intestinal activity, defecation, etc. It is very important for health professionals who assist children with severe neurological disease to be aware of it and actively research it since it is a very frequent source of pain and impacts on their quality of life. In addition, when pain persists despite the use of the usual treatments for GI symptoms such as ranitidine, omeprazole, etc., visceral hyperalgesia and/or gastrointestinal dystonia have a specific pharmacological and non-pharmacological approach, which includes a therapeutic test with Gabapentin^{20,35}.

In relation to the treatments reported, it was found that according to the recommendations of the comprehensive approach in PPC, pharmacological and non-pharmacological measures were mostly used^{3,24}. The comprehensive symptom management from the perspective of PPC implies a thorough assessment that considers the physical, emotional, environmental, social, and spiritual aspects involved in the generation, perception, and impact of the symptom but also a multimodal treatment that includes non-pharmacological and pharmacological measures. To make this possible, the coordinated and aligned work of an interdisciplinary team with common objectives is necessary since no health professional in isolation is capable of perceiving and responding to the enormous number and complexity of the symptoms and problems of children with LTD/LLD. In all cases, the first non-pharmacological measure includes explaining to the child and family the possible causes of the symptoms, the pharmacological and non-pharmacological measures to be implemented, and involving them actively in the treatment.

There are multiple protocols and treatment guidelines for the comprehensive approach to GI-SP in children with health conditions susceptible to PPC, whose reference exceeds the objectives of this study, but they are crucial to reducing the impact on the quality of life of the children^{2,3,7-9,11,18}.

Regarding the treatment of the most frequently found GI-SP, swallowing disorder, it is noteworthy that only half of the children who presented it were seen by a speech therapist. Given that this is a multicenter study that included children from 6 provinces of the country, this could be due to the lack of professionals specialized in the management of this disorder in the provinces of origin or in the institutions of which the children were users but also to the lack of visibility of this disorder, as a symptom or bothersome problem from the perspective of the PPC. Although, to date, more methodologically appropriate research is needed, it is accepted that these children benefit from the care of an interdisciplinary team that includes a professional specialized in swallowing disorders. They can perform oral sensory-motor interventions, and lip strengthening exercises, as well as appropriate and personalized recommendations regarding the consistency of the food and the best ways to administer it, among others^{26,35}.

It is hoped that our results, with due consideration for the methodological limitations they present, will contribute to the knowledge, understanding, and approach to symptoms and problems frequently encountered in the daily task of assisting and accompanying children and adolescents with LTD/LLD but also that they serve as a basis for more exhaustive national or regional research on these and other causes of children's suffering.

Conclusions

As in other regions of the world, among the included children with LTD/LLD, GI-SP motivated consultations with PPC teams in all care settings. In half of the consultations, children presented 2 or more GI-SP simultaneously, which increases the negative impact on quality of life. In children with non-oncologic conditions, swallowing disorders, and gastrostomy complications stand out as frequent problems, but they are not very visible in PPC research and education. Following the comprehensive approach of PPC teams, the implementation of pharmacological and non-pharmacological measures was observed in most of the GI-SP.

Limitations of the study

The sample was small which, in part, may be related to multiple causes such as the population size of Uruguay; the fact that, despite a growing and promising development of PPC, to date, most of the country's provinces and institutions do not have specialized teams; the non-participation of 6 of 16 invited PPC teams; the pandemic situation at the time, which greatly altered both the consultations by parents and the work dynamics of the teams. Therefore, the results may not be inferable to the entire population of children with LTD/LLD.

The scarce inclusion of children with cancer for reasons external to the teams surely determines biases with respect to the results found.

Also, the lack of description of the life stage of the patients, considering that other authors report differential prevalence in the end-of-life stage.

In any case, the fact that patients assisted by the PPCU-CHPR, which is the unit with the largest number of patients and the national reference in PPC, added to institutions from 6 of the 9 provinces where such teams operate, means a relative representation of the population.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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