

# BLADDER AND BOWEL SYMPTOMS FROM THE PERSPECTIVE OF CHILDREN, THEIR CAREGIVERS AND SPECIALISTS: A QUALITATIVE STUDY IN THE LIGHT OF THE THEORY OF UNPLEASANT SYMPTOMS

SINTOMAS URINÁRIOS E INTESTINAIS NA ÓTICA DE CRIANÇAS, SEUS CUIDADORES E ESPECIALISTAS: ESTUDO QUALITATIVO À LUZ DA TEORIA DOS SINTOMAS DESAGRADÁVEIS

SÍNTOMAS URINARIOS E INTESTINALES DESDE LA PERSPECTIVA DE LOS NIÑOS, SUS CUIDADORES Y ESPECIALISTAS: ESTUDIO CUALITATIVO A LA LUZ DE LA TEORÍA DE LOS SÍNTOMAS DESAGRADABLES

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## ABSTRACT

**Objective:** to understand the experience of urinary and intestinal symptoms in childhood, considering the Theory of Unpleasant Symptoms, through the eyes of children, their caregivers and specialists. **Method:** a descriptive, qualitative study was carried out, recruiting children and caregivers from a specialized nursing outpatient clinic in a public teaching hospital in the Federal District. Specialists, mostly from the same institution, were recruited, as well as professionals from other health establishments using the snowball technique. Data was collected from February 2019 to February 2020 through semi-structured interviews. The thematic analysis followed an inductive approach, based on the theoretical framework. **Results:** a total of 14 specialists, 11 caregivers and 7 children took part. Three thematic categories were identified: verbalization of symptom characteristics by the child; factors that influence the experience of symptoms; repercussions as contributors to the child's symptoms. The interviewees highlighted physiological, psychological and situational factors. As for the repercussions, bullying, school performance and the difficulty of sleeping outside were important points. Simple and accessible language is recommended, using 'pee' and 'poop', and time-related terms, making it easier to collect information from children and include their perspective on urological care. **Conclusion:** the study provided a detailed understanding of the experience of urinary and intestinal symptoms in children, according to the Unpleasant Symptoms Theory. The findings help to improve and qualify care in pediatric urology, adopting a child-centered approach, applicable to both specialized and primary health care.

**Keywords:** Child; Lower Urinary Tract Symptoms; Constipation; Caregivers; Specialization; Nursing Theory.

## RESUMO

**Objetivo:** entender a experiência de sintomas urinários e intestinais na infância, considerando a Teoria de Sintomas Desagradáveis, pelos olhares das crianças, seus cuidadores e especialistas. **Método:** realizou-se um estudo descritivo, qualitativo, recrutando crianças e cuidadores em um ambulatório de enfermagem especializado de um hospital público de ensino no Distrito Federal. Especialistas, em sua maioria da mesma instituição, foram recrutados, além de profissionais de outros estabelecimentos de saúde pela técnica de bola de neve. A coleta de dados foi de fevereiro de 2019 a fevereiro de 2020, por meio de entrevistas semiestruturadas. A análise temática seguiu uma abordagem indutiva, baseada no referencial teórico. **Resultados:** participaram 14 especialistas, 11 cuidadores e 7 crianças. Identificaram-se três categorias temáticas: verbalização das características dos sintomas pela criança; fatores que influenciam a experiência dos sintomas; repercussões como contribuintes para dos sintomas na criança. Os entrevistados destacaram fatores fisiológicos, psicológicos e situacionais. Quanto às repercussões, bullying, desempenho escolar e a dificuldade de dormir fora foram pontos importantes. Recomenda-se linguagem simples e acessível, usando 'xixi' e 'cocô', e termos relacionados ao tempo, facilitando coletar informações das crianças e incluir sua perspectiva no cuidado urológico. **Conclusão:** o estudo proporcionou uma compreensão detalhada da experiência de sintomas urinários e intestinais em crianças, segundo a Teoria de Sintomas Desagradáveis. Os achados ajudam a melhorar e qualificar o cuidado em urologia pediátrica, adotando uma abordagem centrada na criança, aplicável tanto em atenção especializada quanto primária à saúde.

**Palavras-chave:** Criança; Sintomas do Trato Urinário Inferior; Constipação Intestinal; Cuidadores; Especialização; Teoria de Enfermagem.

## RESUMEN

**Objetivo:** comprender la vivencia de los síntomas urinarios e intestinales en la infancia, considerando la Teoría de los Síntomas Desagradables, a través de la mirada de los niños, sus cuidadores y especialistas. **Método:** se realizó un estudio descriptivo, cualitativo, reclutando niños y cuidadores en un ambulatorio de enfermería especializada de un hospital público universitario del Distrito Federal. Se reclutaron especialistas, en su mayoría de la misma institución, además de profesionales de otros establecimientos de salud mediante la técnica de bola de nieve. La recolección de datos se realizó desde febrero de 2019 hasta febrero de 2020, mediante entrevistas semiestructuradas. El análisis temático siguió un enfoque inductivo, basado en el marco teórico. **Resultados:** participaron 14 especialistas, 11 cuidadores y 7 sintomáticos por parte del niño; factores que influyen en la experiencia de los síntomas; repercusiones como contribuyentes a los síntomas en los niños. Los encuestados destacaron síntomas fisiológicos, psicológicos y situacionales. En cuanto a las repercusiones, el acoso escolar, el rendimiento escolar y la dificultad para dormir a la intemperie fueron puntos importantes. Se recomienda un lenguaje sencillo y accesible, utilizando 'pipí' y 'caca', y términos relacionados con el tiempo, que faciliten recoger información de los niños e incluir su perspectiva en la atención urológica. **Conclusión:** el estudio proporcionó una comprensión detallada de la vivencia de los síntomas urinarios e intestinales en los niños, según la Teoría de los Síntomas Desagradables. Los hallazgos ayudan a mejorar y calificar la atención en urología pediátrica, adoptando un enfoque centrado en el niño, aplicable tanto en la atención primaria como especializada.

**Palabras clave:** Niño; Síntomas del Sistema Urinario Inferior; Estreñimiento; Cuidadores; Especialización; Teoría de Enfermería.

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## INTRODUCTION

Urinary symptoms in childhood can be characterized by storage disorders, such as urinary incontinence, increased or decreased urinary frequency, enuresis, urgency, nocturia, and/or emptying disorders, manifested by dysuria, weak stream, hesitation, straining. Intestinal complaints such as functional constipation (FIC) and/or encopresis, together with urinary symptoms, are clinically prevalent<sup>(1)</sup>. Bladder and bowel dysfunction (BBD) encompasses the combined dysfunction of urinary and bowel symptoms, and can be explained both by the physical proximity between the two systems and by the same embryonic origin<sup>1</sup>. In epidemiological terms, BBD has a lower prevalence than symptoms alone. A Brazilian study of 441 mothers and children identified a prevalence of BBD in 11.6% of the children studied, while 7.9% had only FIC and 31.5% only urinary symptoms<sup>(2)</sup>.

A systematic review of urinary and intestinal symptoms experienced by the child<sup>(3)</sup> indicates a limitation of studies that explore the experience of these symptoms from the child's perspective. Children living with these symptoms have negative repercussions on their quality of life, especially in psychosocial dimensions, making them more likely to develop emotional problems such as insecurity, anxiety, low self-esteem, as well as behavioral problems such as aggression<sup>(3)</sup>. In the social sphere, the child suffers from the effects of bullying and the restrictions on bathroom use imposed by the school environment<sup>(3)</sup>.

The experience of urinary and intestinal symptoms in childhood involves a multitude of factors, such as the child's previous medical history, the characteristics of the symptoms (frequency, intensity, suffering) and the impact on cognitive and psychosocial performance<sup>(4,5)</sup>. Considering this complexity, it is advisable that the investigation of symptoms is also obtained from the child's perspective, in the interaction between the specialist and the child-caregiver binomial.

The Theory of Unpleasant Symptoms (TOUS)<sup>(4)</sup> allows an in-depth understanding of symptoms that occur concomitantly or in isolation, leading the specialist to critically reflect not only on the characterization of symptoms, but also on the factors that can influence them and their consequences. In this way, it is a theoretical reference that is in line with the need to investigate urinary and intestinal symptoms based on verbal expression, captured directly from the child.

In clinical practice, the report is generally only captured from the point of view of the caregiver, who acts as a proxy source of information. However, when discussing the theory of symptom management adapted

for pediatrics, Newcomb<sup>(6)</sup> points out that the experience reported only by the caregiver is a filtered form of the child's real perception, which can lead to fragmented care based only on the biological dimension.

TOUS comprises three key elements: the symptoms, the influencing factors (physiological, psychological and situational) and the consequences on the performance of the individual experiencing the symptoms<sup>(4)</sup>. The application of TOUS could support the development of tools to facilitate communication with children who have urinary and intestinal symptoms, in line with the child's developmental, cognitive and linguistic level. In this way, they support the timely assessment and screening of symptoms, minimizing the known psychosocial impacts.

Considering the above, our work is based on the following research question: how do children, caregivers and health professionals perceive and report urinary and intestinal symptoms? We chose TOUS<sup>(4)</sup> because it offers us a theoretical framework capable of analyzing the experience of these symptoms in children from the perspective of themselves, their caregivers and specialists, creating an integrated view of this phenomenon from these three essential points of view. Thus, the aim of this study is to understand the experiences of urinary and intestinal symptoms in childhood, considering the Theory of Unpleasant Symptoms, through the eyes of children, caregivers and specialists.

## METHOD

A descriptive study with a qualitative approach was carried out in the Federal District, in a specialized nursing outpatient clinic located in a teaching hospital, in addition to two other health units: one private and one public from the Federal District's Unified Health System. The aim was to enable a variety of specialist professionals to take part. It is important to clarify that the caregivers and children were recruited only from the teaching hospital, while the professionals came from both this hospital and the other two institutions. The research followed the steps recommended by the Consolidated Criteria for Reporting Qualitative Research (COREQ).

The participants were divided into three distinct groups: children, their caregivers and specialists. Children aged 6 to 12 with a confirmed diagnosis of urinary and/or intestinal symptoms using validated instruments, who had been seen for at least one month at the specialized nursing clinic, and their respective caregivers were included. The caregivers had to be the children's main guardians, accompany them regularly to outpatient appointments and be over 18 years old. The third group

included professionals specializing in pediatric urology and/or nephrology, such as doctors, nurses and physiotherapists who have been treating children with this clinical profile for at least a year.

Children with neurological and/or genitourinary tract disorders and/or congenital malformations, as well as their caregivers, were excluded from the study. Specialists who were on vacation or on sick leave during data collection were also excluded.

Recruitment took place at the teaching hospital, where the specialized nursing outpatient clinic is located. From the first interviewees, other experts were nominated for the survey, using the snowball technique<sup>(7)</sup>.

Data was collected between February 2019 and February 2020. The months of February to May 2019 were dedicated to interviews with the experts, and the rest to the children and their caregivers. The interviews were semi-structured and audio-recorded, conducted according to a specific script for each group of interviewees, and supplemented by field notes.

The scripts were drawn up based on the theoretical precepts of TOUS, including questions about the frequency, intensity and impact of urinary and intestinal symptoms in children. Each script had specific topics, developed by the authors. Caregivers and experts were asked to put themselves in the children's shoes, for example by asking which urine or stool symptom bothered them the most and why, as well as which words, terms or expressions were used by the children and their caregivers to describe the discomfort associated with the symptoms.

A trained nursing student conducted the interviews with the experts, while the others were carried out by the first author of the article, a nurse experienced in interviewing children. The mean interview time was 9 minutes and 22 seconds.

Interviews with caregivers and children took place after appointments at the specialized outpatient clinic. The approach was first with the child, to avoid the influence of caregivers on the answers. As for the experts, we tried to respect their working dynamics, and the place and time of the interview were chosen by them. There were no refusals, and the interviews did not need to be repeated.

Communication strategies compatible with child development were used in the interviews with the children, such as pictures with facial expressions so that they could choose the one that best represented their feelings about the symptoms. Another technique was the use of images of environments frequented by the child, related

to the symptoms. At the end of the interview, the child was asked to draw or write about a situation that represented how they felt about their symptoms, a technique known as draw, write and tell<sup>(8)</sup>, which encourages communication through artistic approaches<sup>(9)</sup>.

The data analysis was thematic, based on the assumptions of TOUS, following the stages proposed by Braun and Clarke<sup>(10)</sup>: familiarization with the data, production of initial codes, exploration and review of themes, definition and denomination of themes and preparation of the report. NVIVO PRO 12® software supported the process. The initial analysis was carried out for each group of participants and then for all the data, looking for convergences and divergences between the groups' perspectives.

The study was approved by the Research Ethics Committee of the Faculty of Health Sciences of the University of Brasília, in accordance with Resolution No. 466 of December 12, 2012. Participation in the study was voluntary, with the signing of the Free and Informed Consent Form and the Free and Informed Assent Form. To guarantee the anonymity of the participants, acronyms followed by numbers were used: for the experts: E, children: CR and caregivers: C.

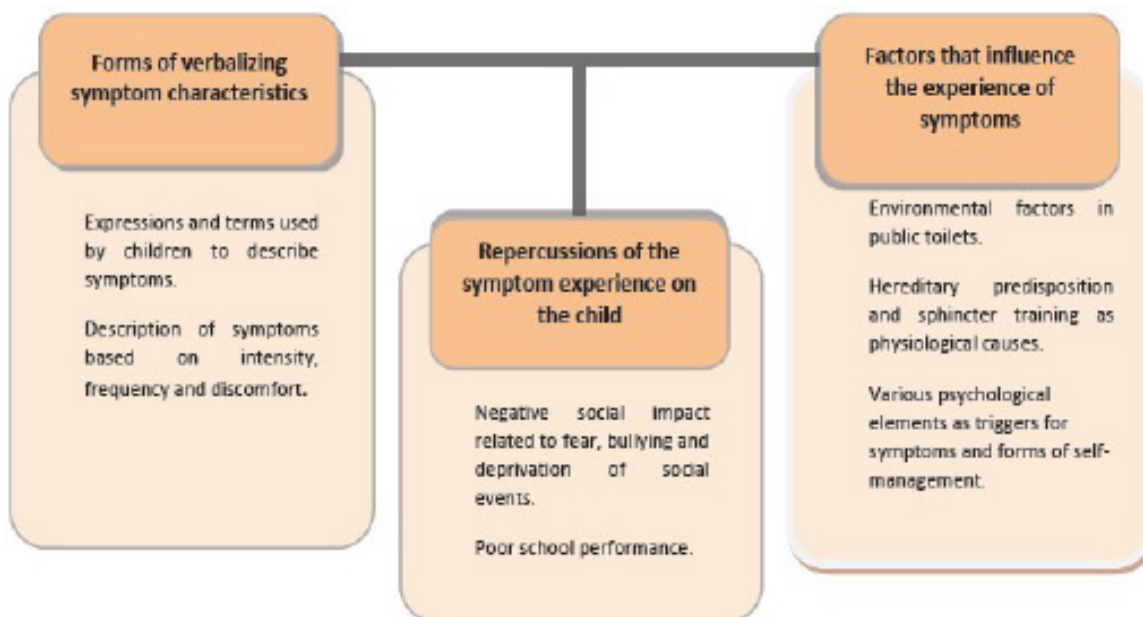
## RESULTS

The study included 32 participants: 14 specialist professionals, 11 caregivers and 7 children. The specialists included nurses (n=4), doctors (n=5) and physiotherapists (n=5), with a mean length of experience of 7 years and 11 months (ranging from 2 to 25 years). All the nurses had postgraduate degrees in areas such as nephrology or urology. Likewise, all the doctors had a residency in pediatric nephrology, and the physiotherapists specialized in pelvic dysfunction, pelvic floor rehabilitation or urogynaecological physiotherapy, as well as some with a master's or doctorate in medical sciences.

As for the caregivers, their ages ranged from 33 to 60, with a mean of 45, and they were 9 mothers, one grandmother and one father. The participating children, three boys and four girls, had a mean age of 11. Three of them had urinary and intestinal symptoms at the same time, three only had urinary symptoms and one reported FIC alone.

The analysis, based on TOUS<sup>(4,5)</sup>, identified three thematic categories: Verbalization of the characteristics of the symptoms manifested by the child, Factors that influence the experience of symptoms, and Repercussions of the experience of symptoms on the child. These themes showed the convergent and divergent perceptions of the interviewees about the experience of urinary and

Figure 1. Thematic tree of the data analysis process. Brasília, DF, Brazil, 2021.



intestinal symptoms in childhood, as well as the terms and expressions used by the children to describe the symptoms. Both experts and caregivers reported the experience from the child's perspective (Figure 1).

In the first thematic category – “Forms of verbalization of symptom characteristics”, the three groups of interviewees highlight the terms and expressions most frequently used by the child when describing urinary symptoms, such as: “wetting my clothes during the night” (E10), “I peed my pants!” (C11), “I squat to hold my pee” (E3), among others. Among the symptoms most frequently reported by those interviewed was intermittent daytime incontinence, with 12 examples of children's expressions, 8 of which were cited by specialists, 4 by caregivers and 1 by a child.

Experts reported a greater number of expressions describing various urinary and intestinal symptoms, while caregivers and children focused only on urinary incontinence (daytime and nighttime), FIC and pain. The pain was described as discomfort, usually associated with bowel movements or diaper rash.

There was unanimous use of the words “pee” and “poop” by the children, as well as expressions such as: “the poop is hard” (E3, nurse) and ‘I can't hold my pee’ (E1, doctor) by the specialists, as well as non-verbal gestures such as pointing to underwear or parts of the body to describe the situation.

According to the experts, the child was also able to express the frequency and intensity of his symptoms. To collect this type of information, they use strategies such

as observing the child's daily routine, temporal expressions (every day, once a week, once in a while, among others) and the number of episodes.

*I usually ask about the routine, both at home and at school... when you go into school, if there's a break, if there's playtime, if the teacher tells you to go to the toilet, what time you leave, what time you get home [...] (E1, doctor)*

To assess intensity, experts consider the amount of urine lost on the child's clothes or bed and use validated symptom severity scales such as the Dysfunctional Voiding Scoring System (DVSS)<sup>(1)</sup>:

*Urine leakage is only in the panties, or it wets the clothes, or it wets the sofa [...] Is it only in the panties? - it doesn't get dirty... Is it really so much that it weighs down your panties? Do you have to wear a diaper? Don't you have to wear a diaper? (E7, doctor)*

*I use DVSS, right? I can pick it up from there. (E9, nurse)*

As for the discomfort or inconvenience caused by the symptoms, the interviewees mentioned two different contexts. One in which the child suffers and reports the negative impact of the symptoms and another in which the episodes are normalized by the child, with no apparent discomfort from urinary leakage. In cases of negative perception on the part of the child, there was unanimity in describing sadness and shame as the predominant feelings:

*Embarrassed! I think she's afraid people might find out. (C6, grandmother)*



*They say it bothers them, that they're ashamed... it's the non-verbal means of communication, you know... they lower their heads (E3, nurse)*

*I was ashamed of having peed on my clothes (CR3, 12 years old).*

In FIC situations, the greatest discomfort was related to the pain felt when evacuating, making the event traumatic:

*Yeah, we've had several cases where he's been locked up for a long time, it's very traumatizing, right, because he's had to take medication, everything, because he didn't do it, and when he did, it hurt a lot! So that's what he complained about a lot! (C4, mother);*

*It's only once in a while that I feel [discomfort] that I feel a pain in my stomach (CR1, 12 years old)*

Some children expressed themselves only with drawings or images of emotions shown by the interviewer. Experts and caregivers have also mentioned that the child may feel irritation, guilt and fear.

*If the problem makes her very sad, if it makes her upset, if it makes her angry, I try to take on a more psychosocial dimension (E9, nurse)*

*He gets embarrassed! He often says - oh I'm not going to say it, because I was afraid you'd fight, you'd say something (C5, mother)*

*I feel sad because I wet the bed sometimes... (CR4, 7 years old)*

Fear can be linked to the reaction of caregivers to symptoms. While some children get irritated and annoyed by the symptoms, others see the experience as a "normal" event in their routine. Some experts find it difficult to accept the child's account of their experience with the symptoms.

*His father gets upset, I get upset too because I need to sleep! (C5, mother)*

*[...] I find it strange that they don't care about their symptoms (E8, physiotherapist)*

The second thematic category is 'Factors influencing the experience of symptoms'. Depending on the type of symptom the child reported, the justification, especially the physiological one, varied. For example, the causes of urinary symptoms included unsuccessful weaning, a history of parental enuresis, heavy sleeping that prevents waking up at night and straining or coughing as triggers for urinary leakage.

*She was three years old [...] she couldn't take her diaper off, so I started to see that it was difficult, there was something wrong, it wasn't normal (C9, mother)*

*I've changed the mattress several times, but I understand why I was like that too! I was 18! (C8, mother)*

As for intestinal symptoms, the participants did not suggest any possible physiological factors that could cause FIC or encopresis. Only one mother associated the onset of symptoms with confirmation of her child's lactose intolerance:

*It started with constipation, you know, he's lactose intolerant and then he gets constipated (C8, mother)*

In relation to situational factors, environmental and social restrictions were seen as triggering symptoms. The school environment and public spaces were mentioned by participants as places where there is a ban on using the toilet at school and toilets in an inadequate state of cleanliness, contributing to a behavior of withholding needs outside the home:

*[...] when we come home from school she walks up and says: "Let's get going soon because I'm cramped because my aunt won't let me go to school, to the toilet"... she always complains that the teacher won't let her go to the toilet! (C6, grandmother)*

*It's because sometimes I'm cramped [at school], because sometimes the teacher lets me and sometimes she doesn't (CR6, 10 years old)*

Psychological factors were also pointed out as potential influencers of the occurrence of symptoms, and caregivers said that anxiety and attention deficit hyperactivity disorder were correlated with urinary leakage:

*[...] he doesn't do it for a long time, then comes the anxiety... he's very anxious! And now that it's the week before school starts, my anxiety has taken over! Then he started wetting the bed again (C8, mother)*

*He's in treatment, he has attention deficit! (C10, mother)*

Examples of traumatic or stressful situations were listed by the participants and correlated with the experience of urinary and intestinal symptoms. They reported both serious situations, such as domestic violence and sexual abuse, and changes in family dynamics, such as their parents separating and moving to another state. It was pointed out that referrals for psychological counseling are a routine part of the clinical treatment.

*It's because of the things that happened, right, a lot of things there, a lot of abuse from her father and everything [...] then as he drank, he started drinking a lot, hitting, mistreating a lot, she says, but I can't say because I didn't see it, I just wasn't there! (C6, grandmother)*

*We've had a few cases related to abuse as well... then we... I ask psychology to come in and help them (E5, physiotherapist)*

The appearance of urinary and intestinal symptoms may be related to risk behaviors. Caregivers and experts point out that eating behaviors, usually addressed in urotherapy and treatment protocols for FIC, have a major impact. Inadequate diet and low fluid intake are highlighted in the following statements:

*I think the problem with poop is food! He only eats junk food! You've eaten a lot of junk food, you know... yogurt, cookies, snacks, that sort of thing! (C6, grandmother)*

*And he doesn't drink water, which he should! (C10, mother)*

Retentive behavior, i.e. the act of voluntarily delaying urination, was pointed out by all the participants as being highly related to episodes of urinary urgency and urinary leakage. For the child, this type of practice is related to distractions with other activities or the inconvenience of interrupting activities to go to the bathroom. This risky behavior is adopted by the child on certain occasions and is often monitored by caregivers:

*That's what he does, because he's busy with something, let's say, he's busy and has to go to the bathroom! [...] he doesn't like it! – 'Oh, I'm wasting time' - mother simulates child's speech (C4, mother)*

*It only happens during the day when I'm distracted. (CR4, 7 years old)*

The child's denial of urinary leakage episodes and unsupervised changing of clothes were the coping strategies most often mentioned by caregivers.

*Oh, sometimes she lies, saying it was the dog that peed on her bed! (C2, mother)*

*I notice that she's changed her panties, that her panties are wet! (C3, mother);*

*sometimes he even hides the fact that he got wet! (C7, mother)*

The third category, "Repercussions of the symptom experience for the child", highlights the impacts and

consequences that urinary and intestinal symptoms have on children, affecting their social and cognitive performance. The social dimension was the most mentioned by all three groups of interviewees. The child faces social exclusion, including the fear of having their symptoms discovered by their peers and the feeling of being different. As a result, he avoids playing games that could lead to urinary leakage, resulting in social isolation.

Caregivers can also contribute to this isolation by keeping children's symptoms a secret and forbidding overnight stays away from home to avoid embarrassing situations for enuretic children who suffer from nocturnal urinary incontinence.

*Like sleeping at other people's houses [...] I can't go, because I pee and then I'm ashamed (CR7, 11 years old)*

Caregivers and experts are on the lookout for possible bullying practices, such as when a child exudes the smell of urine or feces, which can cause embarrassing situations and trigger offenses. There are cases in which this situation occurs within the family itself:

*Her sister laughs at her, doesn't she? And I think it makes her a little angry at the time (C2, mother)*

*Then his classmates [at school] might think... laugh at him, right? (C7, mother)*

As for the impact on the child's performance, cognitive impairment, especially in school performance, has been reported. One caregiver correlated nocturnal urinary leakage and tiredness due to impaired sleep with the child's poor school performance:

*He's been getting very low marks at school lately! Gets some red notes. Because of his tiredness (C5, mother)*

Based on the perspectives of the three groups of interviewees and from a TOUS perspective, we sought to identify points of convergence and divergence in their views, as illustrated in figure 2. This comparative analysis provides a broader understanding of the phenomenon. The adults' view separately provides details that the child may not have been able to express in the interview, but which are relevant to understanding the experience of symptoms. The children's unique contributions offer a unique perspective on the main people affected by the situation being studied.

## DISCUSSION

Investigating the experience of urinary and intestinal symptoms is challenging, especially when it depends on the child's account. The children, caregivers and experts

who took part in this research reported different ways of accessing and promoting children's self-reporting. It was possible to identify points of alignment with the TOUS

Figure 2. Points of convergence and divergence on the experience of urinary and/or intestinal symptoms in childhood, according to the perspectives of the three groups of interviewees. Brasília, DF, Brazil, 2021.

	Symptom characterization	Influencing factors	Repercussions
Unanimous views among children, caregivers and experts	<ul style="list-style-type: none"> <li>- Pain is a very relevant symptom and scored as a nuisance (Pain when evacuating; pain from diaper rash)</li> <li>- Feelings of sadness and shame in children with urinary or intestinal symptoms.</li> <li>- Some children report not being bothered by their bladder or bowel problems.</li> <li>- 'Pee' and 'poop' are words widely used by children when referring to their eliminations.</li> </ul>	<ul style="list-style-type: none"> <li>- Children sometimes postpone urination because they are doing other activities.</li> </ul>	<ul style="list-style-type: none"> <li>- Children sometimes postpone urination because they are doing other activities.</li> </ul>
Perspectives expressed only by specialists and caregivers	<ul style="list-style-type: none"> <li>- The caregivers were irritated and uncomfortable with the children's symptoms.</li> <li>- They report irritation, guilt, fear and anxiety.</li> </ul>	<ul style="list-style-type: none"> <li>- Children hide their episodes of urinary leakage by changing clothes or blaming others (such as pets), which can be related to fear or shame.</li> </ul>	<ul style="list-style-type: none"> <li>- Children are often questioned by experts about the occurrence of bullying. While some caregivers have reported cases of bullying even in the family environment, contradictorily, others say</li> <li>- that their children's symptoms are a family secret.</li> </ul>
Children's perspectives only	-	<ul style="list-style-type: none"> <li>- Ban on using the toilet at school</li> <li>- Traumatic episode of urinary leakage at school.</li> </ul>	-

framework<sup>(4,5)</sup> in the reports of the three groups, from a perspective experienced by the child. These points were based on the characterization of the symptoms (frequency, intensity, suffering, quality), the causal factors related to the symptoms and the repercussions on cognitive and social performance.

As for the terms and expressions used by the children to describe urinary and bowel symptoms, the interviewees mentioned most of the symptoms listed by the International Children's Continence Society<sup>(1)</sup>, except nocturia and weak jet. The expressions suggested for identifying symptoms, according to the TOUS<sup>(4,5)</sup>, can support and guide the development of communication strategies and guidelines for clinical interviews by specialists.

In our study, there was a greater number of reports of urinary incontinence during the day and during sleep (enuresis), possibly due to the greater occurrence of these symptoms. For example, a study of 6568 Chinese school children<sup>(11)</sup> estimated the prevalence of monosymptomatic enuresis at 3.9%, and a study in Bangkok of 3009 children<sup>(12)</sup> recorded a percentage of 9.7%.

The children's description of these symptoms mainly included the words "pee" and "poop", terms commonly used in Brazil to describe urinary and intestinal elimination in childhood. To describe frequency, a symptom characteristic in TOUS<sup>(4,5)</sup>, terms such as "every day", "every night", "every week" are used. Experts use the technique of recalling the daily routine with the child to identify the occurrence of episodes, whether at home or at school. Considering that the child is in the concrete operative stage, developing an understanding of abstract terms (the notion of time), they are unable to accurately report the times of incidents. This recall technique is a low-cost communication strategy that is viable for the daily care of school-age children<sup>(9)</sup>.

In addition, the suffering caused by one or more of the symptoms experienced, another aspect characterized in the TOUS<sup>(4,5)</sup>, was represented mainly by negative feelings. The interviewees mentioned sadness, shame, guilt and anger, feelings that are in line with the literature on the negative emotional impact of urinary and bowel symptoms<sup>(2,13)</sup>. Enuresis has a negative impact on quality

of life, mainly affecting self-esteem, emotional well-being and relationships with family and friends<sup>(14)</sup>. In addition, children with enuresis are more likely to have emotional and behavioral problems<sup>(15)</sup>, a situation that can be exacerbated by the intensity of the symptom, since the impact on the quality of life of the family and the child is directly proportional<sup>(16)</sup>.

As for the situational factors described by the TOUS<sup>(4,5)</sup>, the physical environment's limitations, especially the rules for using the toilet in the school environment and the inadequate hygiene conditions of public toilets, are highlighted in the interviewees' complaints<sup>(17,18)</sup>. A study of 19,577 children showed a significant relationship between reluctance to use the school toilet and hygiene conditions<sup>(18)</sup>.

In relation to physiological factors, sphincter training is pointed out as the moment when the first urinary symptoms in childhood are identified. This stage requires organic maturation and the demonstration of readiness by the child, suggesting that problems at this stage may be related to a lack of readiness. The maturation of the nervous system and the increase in bladder capacity up to the age of 3 are determining factors for sphincter continence<sup>(19)</sup>, representing a potential risk factor for urinary and intestinal symptoms, according to the TOUS<sup>(4,5)</sup>.

The bladder fullness perceived by the child gradually develops control of the pelvic muscles and sphincters, along with cortical control. As children mature, their capacity for control increases. Thus, the child should only be weaned when there are signs of cognitive readiness and readiness of the urinary and intestinal tracts. The risk lies both in training early and in delaying the development of these skills<sup>(20,11)</sup>. Continence is achieved through a combination of physiological, psychological and situational factors, according to the TOUS<sup>(4,5)</sup>.

In addition to the biological aspects, the symptoms were also associated with psychosocial triggers such as violence, abandonment and family breakdowns, elements aligned with the situational TOUS factors<sup>(4,5)</sup>. Sexual violence, with its proven statistical association with the severity of symptoms<sup>(21)</sup>, highlights the importance of psychological monitoring alongside urotherapy treatment.

The children showed a greater impact on social performance than on cognitive performance, with the fear of discovery of symptoms inhibiting interpersonal relationships and participation in social activities. Compromised socialization reflects the shyness and shame linked to the stigma of elimination problems<sup>(3,22)</sup>. Despite the obstacles to social relations, children and families develop strategies for self-management and accident prevention,

such as controlling fluid intake and identifying toilets, as well as having extra clothes or sheets available<sup>(13)</sup>.

Bullying has been mentioned in previous studies and brought together in a systematic literature review<sup>(3)</sup>. Schools, because they are also social environments, expose children to experiences linked to (in)continence, including the decision of whether or not to tell their teachers and friends about their symptoms, the fear of being discovered by other children and becoming the target of mean jokes and bullying<sup>(17)</sup>, as well as the imposition of strict rules regarding bathroom use during lessons. To date, the psychological impact of bullying in this context has not been fully understood, but some studies suggest that it can contribute to the development of conduct problems<sup>(14)</sup> and, in a way, intensify the factors that cause urinary and intestinal symptoms.

The impossibility of the child sleeping outside the home environment was pointed out as a relevant social impact by three groups of interviewees in our study. Similarly, a qualitative study on the experience of 30 children with urinary symptoms also identified this effect. The deprivation of this activity occurs to avoid accidental nocturnal or daytime urinary leakage<sup>(13)</sup>. Another impact reported was the irritation and anger of caregivers, mainly due to sleep deprivation and the negative feelings that episodes of urinary leakage cause in children. The stress burden and exhaustion of caregivers of enuretic children have been linked to more severe punitive attitudes and overprotective and disciplinarian parenting styles<sup>(23)</sup>. These facts reiterate the direct interference of these symptoms in the psychosocial domain and in family dynamics.

As for the child's performance, but now from a cognitive perspective, a significant impact on school performance was noted. This impact is possibly linked to social aspects and sleep disruption in cases of enuresis. Other reasons mentioned in the literature include frequent trips to the toilet and difficulty concentrating due to urinary leakage<sup>(13)</sup>. A Chinese study of 6,568 enuretic children showed that 13.49% of the sample had poor academic performance<sup>(11)</sup>, which may be associated with reduced concentration due to poor nights' sleep as a result of urinary leakage.

The views of the three groups of interviewees broadened our understanding of the phenomenon experienced by children. During our research, we tried to understand everyone involved in an integrated way in order to fully describe the experience. However, we also observed aspects mentioned only by the children, such as the ban on going to the toilet and the occurrence of urinary



leakage at school<sup>(17,18)</sup>. Thus, the school turned out to be a crucial social setting for the child, not necessarily perceived in the same way by caregivers or specialists. This finding suggests that the child may be the best source of information for specialists providing care<sup>(6)</sup>.

The main limitation of this study concerns the groups of caregivers and children interviewed, who represent cases seen in a single specialized nursing service. This may not reflect the dimensions of the symptom experience perceived by those who have not yet accessed a specialized service. Furthermore, the group of experts did not include representatives from a multidisciplinary team, which would have included nutritionists and psychologists. Therefore, future studies in other pediatric urology services may provide a broader understanding of the diversity of experiences of urinary and bowel symptoms in childhood and possible organizational, regional and cultural differences.

## CONCLUSION

This study allowed us to gain a unique and broader understanding of the phenomenon of the experience of urinary and intestinal symptoms in children, by observing the perspectives of the children themselves, their caregivers and specialists. The results made it possible to identify commonalities and differences between these three visions, offering a basis for improving and qualifying pediatric urology care in a child-centered way. This approach benefits both primary health care professionals and specialists.

In addition to helping the specialist define the care plan, the aspects identified as part of the experience of urinary and intestinal symptoms can also be addressed with caregivers. This facilitates both the early detection of symptoms and their consequences and the development of coping strategies by caregivers, who are emotionally and financially impacted by the symptoms.

In terms of research and clinical assessment of symptoms, it is recommended to use simple and accessible language, using common terms such as 'pee' and 'poop'. In order to collect information on frequency and intensity, experts can resort to recording the daily routine, mentioning moments of the day such as 'waking up', 'after school', etc. These techniques can also be adopted in future research aimed at obtaining information directly from children with urinary and/or intestinal symptoms. In addition, some children are able to express themselves through drawings or images of emotions, and it is suggested to use this resource when interacting with them. This knowledge can be applied in training courses, clinical

guidelines and information booklets, valuing and incorporating children's views into the pediatric urology care process.

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