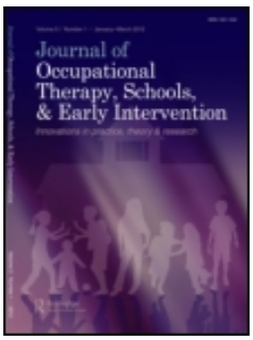

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# The Toileting Habit Profile Questionnaire: Screening for sensory-based toileting difficulties in young children with constipation and retentive fecal incontinence

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**ABSTRACT**

This study examined the face and preliminary content validity of the Toileting Habit Profile Questionnaire, a tool designed to screen for sensory-based defecation difficulties in children. A panel of experts reviewed a pilot version of the questionnaire and responded to probe questions. Two reviewers conducted direct content analysis of responses; 100% agreement was reached. Experts demonstrated a high degree of agreement and their input was useful in establishing this tool for initial research and clinical use. The Toileting Habit Profile Questionnaire appears to capture behaviors that are consistent with problematic toileting behaviors, particularly as they relate to sensory overreactivity.

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Constipation; fecal incontinence; occupational therapy; sensation disorders; toilet training



Occupational therapists are considered experts in understanding and supporting the everyday activities in which people engage, and this includes activities of daily living (World Federation of Occupational Therapists [WFOT], 2012). Bowel management constitutes one important activity of daily living (American Occupational Therapy Association, 2014), and issues in this area can limit an individual´s independence and social participation. Additionally, acquiring continence of bowel is considered an important milestone of childhood. As such, addressing issues related to bowel management is an important component of occupational therapy practice.

## Fecal incontinence and constipation

Fecal incontinence is a common, undertreated, and frequently misinterpreted disorder in children that often leads to impaired social acceptance, relationships, and development (Friman, Hofstader, & Jones, 2006). It is one of the main symptoms of constipation, and constipation is one of the most common gastrointestinal complaints in children (Tabbers, Boluyt, Berger, & Benninga, 2011a). Worldwide prevalence of constipation is estimated to be 12% (range of 0.7% to 29.6 %) in the general childhood population, with peak incidence occurring during toilet training (Mugie, Benninga, & Di Lorenzo, 2011). The term

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Supplemental data for this article can be accessed on the publisher's website.

*retentive fecal incontinence* (RFI) is used to specify the presence of constipation and differentiate it from nonretentive fecal incontinence, a condition that occurs in the absence of stool retention. Children with RFI often soil due to rectal overflow, an involuntary process by which soft stool from the bowel slips around a hard mass of stool that remains accumulated in the rectum (Cohn, 2011). This is highly problematic from an occupational perspective because the unpleasant odors caused by feces are often the cause of rejection and ridicule by peers, which can affect social participation and participation in key activities of childhood (Handley-More, Richards, Macauley, & Tierra, 2009). Importantly, children with long-lasting symptoms of constipation and fecal incontinence are at risk for experiencing lower health-related–quality of life (Kovacic et al., 2015). Children and adolescents with fecal incontinence are at risk of experiencing peer-related abuse and long-lasting psychosocial and emotional health problems (Kovacic et al., 2015). Parents also perceive lower quality of life for themselves (Kovacic et al., 2015).

It is generally accepted that RFI is caused by either physical (e.g., a change in diet) or psychological problems (e.g., birth of a sibling) (Cox et al., 2003). The event results in fecal impaction of hard, large stools that may be painful and difficult to expulse. Subsequently, defecation may be anticipated as painful and/or difficult; the child may ignore the urge to defecate and refuse to go to the toilet (Cox et al., 2003). Although the precipitating event leading to RFI is not always clearly identified, the behavior of children with RFI seems to be partly responsible for the development and/or maintenance of the condition. Stool withholding, possibly due to pain (Cohn, 2011; Tabbers et al., 2011a), avoidance of using a toilet outside the home (Tam et al., 2012), or stool toileting refusal/fear of sitting on the potty (Taubman, 1997) are established as behaviors contributing to RFI. Clinically, occupational therapists have observed that some children develop RFI in the absence of clear physical or psychological factors; they appear to react in an exaggerated way to normal bodily sensations or certain aspects of toileting and come to anticipate defecation with a fearful response (Beaudry, Schaaf, & Ramos, 2013; Beaudry Bellefeuille & Ramos Polo, 2011).



## RFI and sensory processing

It has been hypothesized that difficulty processing and integrating sensory information could be a factor contributing to the development of some problematic behaviors in children (Dunn, 2007; Hazen et al., 2008; Schaaf et al., 2010). Exaggerated responses to normal sensory stimuli, sensory overresponsivity, have been associated with refusal to comply with parental demands or atypical habits in relation to other types of self-care activities such as dressing or feeding (Dunn, 2007; Hazen et al., 2008; Nadon, Ehrmann-Feldman, Dunn, & Gisel, 2011; Schaaf et al., 2010). Occupational therapists working with children with RFI have suggested that some of the previously mentioned behaviors typical of children with RFI could be related to sensory overresponsivity (Beaudry Bellefeuille & Ramos Polo, 2011; Beaudry et al., 2013; Handley-More et al., 2009). Recent research supports a relationship between sensory issues, fecal incontinence, constipation, and other gastrointestinal problems in children (Bakker, Boer, Benninga, Koelman, & Tijssen, 2010; Beaudry et al., 2013; Beaudry-Bellefeuille, 2014; Beaudry Bellefeuille & Ramos Polo, 2011; Mazurek et al., 2012; Pollock, Metz, & Barabash, 2014). Clearly defining these relationships would lay the groundwork for an occupational

performance approach to treatment in conjunction with the more common medical management for children with RFI.

Assessment of the sensory responsivity basis for RFI is in its infancy. However, conducting valid assessments to gain information about sensory processing factors that may be affecting the child´s participation in daily life is critical (Schaaf & Mailloux, 2015). Tools such as the Sensory Profile (Dunn, 2014) or the Sensory Processing Measure (Parham, Ecker, Miller-Kuhananeck, Henry, & Glennon, 2007) examine the relationship between sensory responsivity and the behaviors of young children during activities of daily living such as feeding and grooming. However, currently no measure of sensory responsivity relative to participation in bowel-management habits is available for either clinical or research use.

The Toileting Habit Profile Questionnaire (THPQ) is a tool designed to address this gap, screening for sensory-based defecation difficulties. The THPQ was developed by an occupational therapist in collaboration with a gastroenterologist. This team had observed that response to sensations related to the evacuation of stool seemed to impact the acceptance of toilet training and the response to the urge to defecate in some children (Beaudry Bellefeuille & Ramos Polo, 2011; Beaudry et al., 2013). The purpose of this study was to refine questions on the THPQ and examine its face and preliminary content validity.

The research questions posed were (1) Do experienced pediatric gastroenterologists and occupational therapists working with young children with RFI consider the behaviors outlined in the THPQ to be characteristic of this population? (2) Do experienced pediatric gastroenterologists and occupational therapists working with young children with RFI consider the behaviors outlined in the THPQ to be related to issues in sensory reactivity?



## Methods

Based on available literature and parent description of behaviors that are common to many children who are referred to OT for constipation and fecal incontinence, a clinical screening tool, the Toileting Habit Profile Questionnaire (THPQ), was developed. It has been used clinically for nearly 10 years and found to be highly useful in defining sensory concerns relative to constipation and fecal incontinence. In the current investigation, the face and preliminary content validity of the THPQ was assessed through expert panel consultation.

### *Measure*

The THPQ was developed in a bilingual (Spanish-English) format using simple and understandable wording (Grade level = 5.8 as determined through Microsoft Word). The questionnaire is meant to be a screening tool to help differentiate typical defecation behaviors and reactions from those that are associated with constipation and fecal incontinence potentially related to sensory-processing concerns. The original THPQ consisted of 11 questions, divided into two sections: (1) overreactivity (9 questions) and (2) underreactivity (2 questions). Scored using a five-point Likert scale (*almost always* through *never*), questions on the prestudy version of the TPHQ included the following:

(1) My child hides while defecating.
(2) My child asks for a diaper when he feels the need to defecate.
(3) My child refuses to sit on the potty or the toilet to defecate.
(4) My child always follows the same ritual when defecating.
(5) My child seems to feel pain when defecating.
(6) My child defecates only when paying attention to something else (while playing or watching television for example).
(7) My child refuses to go to the toilet outside of the home.
(8) My child´s reaction to the odor of his/her feces is exaggerated.
(9) My child refuses to wipe or be wiped after defecating.
(10) My child does not seem to feel the urge to defecate.
(11) My child does not realize he has soiled (feces) his clothes.

## Study design

This investigation assessed the face and preliminary content validity of the THPQ by requiring a panel of experts to respond to five probes relative to each THPQ item. The panel comprised six experts: three pediatric gastroenterologists with expertise in RFI and three occupational therapists with expertise in Ayres Sensory Integration and knowledge of potential issues related to activities of daily living, including toileting, in children. Consistent with the bilingual nature of the THPQ, all experts were bilingual (English-Spanish). The gastroenterologists represented private practice and the major hospitals of the province of Asturias (Spain). The occupational therapists represented private practice and academia in diverse areas of Europe. No one on the panel was from the facility where the THPQ was developed and used clinically. Approval by the Virginia Commonwealth University Institutional Review Board was obtained before the beginning of the study.

Face validity, an initial step in test development, substantiates that the content of a tool appears to be measuring constructs of interest. Although a relatively weak reflection of validity, face validity is strengthened by approaching it systematically (Trochim & Donnelly, 2007). In the current study it reflects the judgment of the carefully selected experts from two professional fields. Content validity moves the process one step further, examining the relevance of each test item and considering the relevance of each item to the overall construct being measured (Sireci & Sukin, 2013). Using panel members with both subject matter and experiential expertise strengthened this initial examination of content validity (Sireci & Sukin, 2013).

The THPQ and probe questions were distributed to the panel using the REDCap electronic data capture tools hosted by Virginia Commonwealth University (Harris et al., 2009). As suggested by Sireci and Sukin (2013), probes asked experts to examine many elements of the THPQ, including item interpretation (How do you interpret what the item is asking?), potential reasons for behavior (Why do you think a child would have such a behavior?), likelihood of the behavior to be seen in typical children (Do you think typically developing children have this behavior?), likelihood of the behavior in children with constipation and fecal incontinence (Do you think this behavior is common in children with constipation and fecal incontinence?), and potential links to sensory overresponsivity (Do you think this behavior could be related to overresponsivity to the sensations related to

defecation—for example, feel of potty/toilet on skin, anal/rectal distention, smell of feces?). Responses to the open-ended questions were narrative. All comments made by the respondents were taken into account. The feedback from the expert panel was used to modify THPQ questions as needed. As suggested by Hseih and Shannon (2005), both an open-ended question (2) and a targeted question (5) were used to gain insight concerning the relationship between the constructs of interest, in this case sensory responsivity and toileting behaviors.

Direct content analysis methodology was used to establish coding of narrative responses from the experts (Hseih & Shannon, 2005). A direct content analysis approach is useful to extend conceptually an existing theoretical framework and determine the initial coding scheme (Hseih & Shannon, 2005). Ayres sensory integration theory served as the theoretical framework for this study. This framework considers emotional and behavioral reactions to the sensory aspects of daily occupations to be a valid measure of sensory responsivity (Dunn, 2014; Parham et al., 2007). As such, the responses of the experts on Question 2 were coded in accordance with manifestations hypothesized to be indicators of atypical sensory responsivity. Based on Schaaf and Lane´s (2014) review of sensory features, sensory overresponsivity is often described in terms of negative emotional reactions to sensory stimuli such as fear or anxiety. Further, avoiding, withdrawing, feeling pain, or experiencing stress in relation to sensory stimuli are common descriptors of sensory overresponsivity (Schaaf & Lane, 2014). Expressing distress, dislike, repulsion, or unusual and restricted preferences toward sensory stimuli and following rituals in personal hygiene are also considered signs of sensory overresponsivity (Dunn, 2014). Diminished awareness, or lack of reaction to sensory stimuli, are common descriptors of sensory underresponsivity (Schaaf & Lane, 2014). Responses not related to sensory reactivity were classified together. Based on these theoretical guidelines, the authors separately coded the experts' responses. Coding for Question 1 (interpretation of question) included "accurate," "proposed reasons," "inaccurate," and "no response." Coding for Question 3 (Is this behavior seen in typical children?) included "yes" along with qualifiers and "no." Coding for questions 4 (Is this behavior common in children with constipation and fecal incontinence?) and 5 (Is this behavior related to overreactivity to the sensations related to defecation?) included options for "yes," "no," and "don't know." Coding for Question 2 included "sensory overresponsivity," "sensory underresponsivity," and "other"; other included such things as cognitive limitations and motor-control concerns. Authors coded independently, reviewed coding together, and engaged in discussion to reach agreement; 100% agreement was reached on all coding.



## Results

Rather than offer their individual interpretation of the THPQ questions, requested by the first probe question (How do you interpret what the item is asking?), experts generally proposed reasons for the behaviors described by the items. One expert systematically left this question blank. Responses to the remainder of the probe questions suggested that all questions were accurately interpreted.

Responses to the second probe question (Why might such a behavior be present?) were examined to gain insight concerning the relationship between sensory reactivity and toileting behaviors. Experts frequently responded with more than one rationale, although general

agreement between experts was found. For all items, a majority of experts (≥ 66.7%) considered that sensory factors contributed to the behaviors described (Table 1).

Probe Question 3 (Do you think typically developing children have this behavior?) revealed that many behaviors hypothesized to be associated with defecation difficulties may occur, albeit infrequently, in typically developing children (Table 2).

The fourth probe question (Do you think this behavior is common in children with constipation and fecal incontinence?) sought to examine the inclusion of items on the basis of frequency of occurrence. Responses showed high agreement among experts: over 90% of the items obtaining at least 66.7% agreement in the direction expected by the investigator (Figure 1). Item 8 (My child´s reaction to the odor of his/her feces is exaggerated), although not considered a common behavior, was maintained on the revised version of the THPQ as there was 100% agreement on its relationship to sensory over-responsivity (Probe Question 5).

Our final probe question (Do you think this behavior could be related to overresponsivity to the sensations related to defecation—feel of potty/toilet on skin, anal/rectal distention, smell of feces?) showed high agreement in the expected direction on items 1, 2, 3, 4, 7, 8, and 9 (Figure 2).

The experts were divided when responding to the final probe question for items 5, 6, 10, and 11. On Item 5 (My child seems to feel pain when defecating), although there was high agreement in manifestations of sensory overresponsivity in the narrative responses of Probe Question 2, only half of the experts indicated that pain felt while



**Table 1.** Expert panel responses to Probe Question 2: Why do you think a child would have such a behavior?

| Item | Why do you think a child would have such a behavior? |
|---|---|
| My child hides while defecating. | SOR: 5 (83.3%*)<br>OTHER: 4 (embarrassment: 3; behavioral issue: 1) |
| My child asks for a diaper when he/she feels the need to defecate. | SOR: 4 (66.7%*)<br>OTHER: 2 (overconscious: 1, poor toilet training: 1) |
| My child refuses to sit on the potty or the toilet to defecate. | SOR: 6 (100%*)<br>OTHER: 2 (motor/cognitive issues: 1, overconscious: 1) |
| My child always follows the same ritual when defecating. | SOR: 5 (83.3%*)<br>OTHER: 1 (behavioral/emotional disorders) |
| My child seems to feel pain when defecating. | SOR: 5 (83.3%*)<br>OTHER: 1 (constipation) |
| My child defecates only when paying attention to something else. | SOR: 4 (66.7%*)<br>SUR: 1<br>OTHER: 1 (TV as a reward) |
| My child refuses to go to the toilet outside of the home. | SOR: 5 (83.3%*)<br>OTHER: 1 (associated with parental behavior) |
| My child´s reaction to the odor of his/her feces is exaggerated. | SOR: 5 (83.3%*)<br>OTHER: 1 (behaviorally reinforced response) |
| My child refuses to wipe or be wiped after defecating. | SOR: 5 (83.3%*)<br>OTHER: 2 (motor impairments: 1, behavior: 2) |
| My child does not seem to feel the urge to defecate. | SUR: 6 (100%*)<br>OTHER: 1 (developmental delay) |
| My child does not realize he/she has soiled (feces) his/her clothes. | SUR: 6 (100%*)<br>OTHER: 2 (ignores: 2, intellectual disability: 1) |

*Notes*: Numbers refer to number of responses (in some cases experts gave more than one rationale); SOR (sensory overresponsivity): fear, anxiety, pain, stress, repulsion, avoiding, withdrawing, dislike, unusual and/or restricted preferences toward sensory stimuli following rituals in personal hygiene; SUR (sensory underresponsivity): diminished awareness, lack of reaction.

*percent agreement among experts

defecating could be related to sensory overresponsivity. Among those who felt it was not related, two clarified that feeling pain was probably due to the hard consistency of feces.

Responses concerning Item 6 (My child defecates only when paying attention to something else) included three participants supporting a relationship with overresponsivity, two indicating this was not related, and one not responding. A review of our recent clinical data on this item has shown that it is neither common nor related to overresponsivity. Considering this information, Item 6 was eliminated from the revised version of the THPQ.

Items 10 (My child does not seem to feel the urge to defecate) and 11 (My child does not realize he/she has soiled (feces) his/her clothes) were included on the THPQ to reflect underresponsivity to sensory input; experts showed 100% agreement in this direction in their narrative responses to Question 2. When experts were asked, Do you think this behavior could be related to overresponsivity to the sensations related to defecation?, it was expected that they would unanimously respond *no*; not feeling the urge to defecate or not noticing that one is soiled with feces is not a behavior that is expected to be related to sensory overresponsivity. Surprisingly some experts responded affirmatively to Probe Question 5 for items 10 and 11.



**Table 2.** Expert panel responses to Probe Question 3: Do you think typically developing children have this behavior?

| Item | Do you think typically developing children have this behavior? |
|---|---|
| My child hides while defecating. | Yes, but infrequently: 4# (66.7%*)<br>No: 2# |
| My child asks for a diaper when he feels the need to defecate. | Yes, but infrequently: 3# (50%*)<br>No: 3# |
| My child refuses to sit on the potty or the toilet to defecate. | Yes, but infrequently: 5# (83.3%*)<br>No: 1# |
| My child always follows the same ritual when defecating. | Yes: 1#<br>Yes, but infrequently: 2#<br>No: 3# (50%*) |
| My child seems to feel pain when defecating. | Yes, if constipated: 3# (50%*)<br>Yes: 2#<br>No answer: 1# |
| My child defecates only when paying attention to something else. | Yes but infrequently: 2#<br>No: 4# (66.7%*) |
| My child refuses to go to the toilet outside of the home. | Yes: 4# (66.7%*)<br>Yes but infrequently: 1#<br>No: 1# |
| My child´s reaction to the odor of his/her feces is exaggerated. | Yes: 2#<br>Yes but infrequently: 2#<br>No: 1#<br>No answer: 1# |
| My child refuses to wipe or be wiped after defecating. | Yes but infrequently: 3# (50%*)<br>No: 3# |
| My child does not seem to feel the urge to defecate. | Yes: 1#<br>No: 4# (66.7%*)<br>No answer: 1# |
| My child does not realize he/she has soiled (feces) his/her clothes. | Yes: 1#<br>Yes but infrequently: 2#<br>No: 3# (50%*) |

*Note*: # = number of responses
*percent agreement

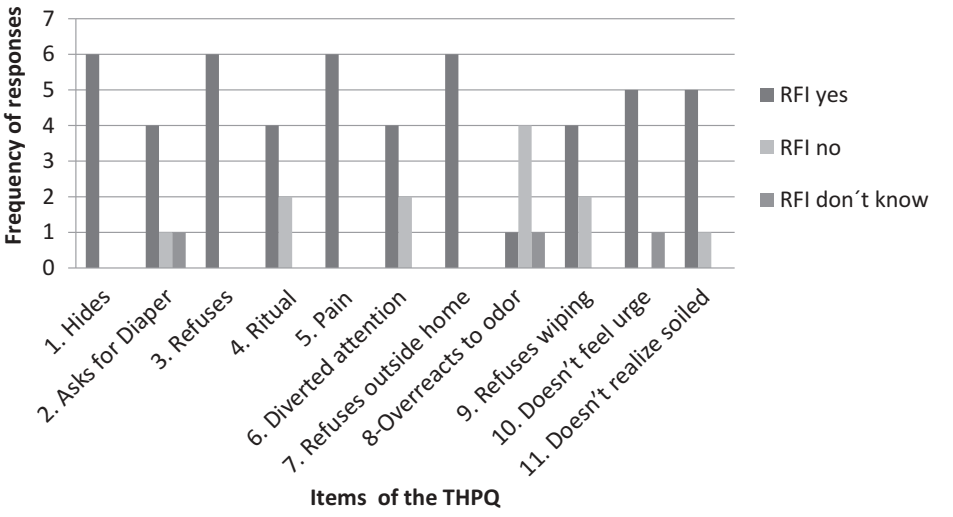


**Figure 1.** Expert panel responses to Probe Question 4: Do you think that this behavior is common in children with constipation and fecal incontinence?
THPQ = Toileting Habit Profile Questionnaire; RFI = Retentive fecal incontinence.



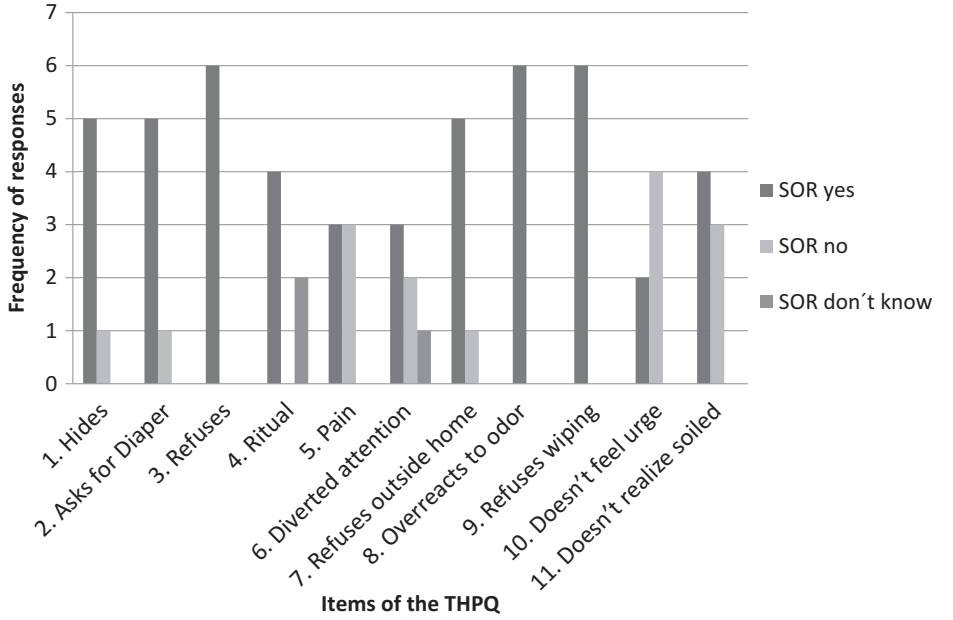


**Figure 2.** Expert panel responses to Probe Question 5: Do you think that this behavior could be related to overresponsivity to the sensations related to defecation (feel of potty/toilet on skin; anal/rectal distention; smell of faeces, etc.)?
THPQ = Toileting Habit Profile Questionnaire; SOR = Sensory over-responsivity.

## Conclusions

Face and preliminary content validity of the THPQ was established in this investigation using a panel of experts consisting of pediatric gastroenterologists and occupational therapists with expertise in Ayres Sensory Integration. Based on directed content analysis, we found a high degree of agreement among the members of the expert panel on the relevancy of items and their relationship to sensory responsivity. Findings were considered relative to existing clinical experience, and some changes have been incorporated into the THPQ, noted below, improving this tool before its use in a pilot study and in clinical practice.

Item 5 was not fully clear to all panel members. Our clinical experience shows that many children continue to manifest pain even when they take medications that soften stools. We hypothesize that feeling pain while defecating could be due to overresponsivity to typical bodily sensations. Item 5 was modified to include a reference to the consistency of the stool: My child seems to feel pain when defecating even if the stool is soft.

Experts agreed that items 10 and 11 tapped into sensory underresponsivity; this was as expected. However, such behaviors are not usually present in children who present with overresponsivity, yet some experts indicated they might be identified. These questions were maintained in the revised version of the THPQ, and incompatible responses between the first section of the THPQ (overresponsivity) and the last two items (underresponsivity) would alert the examiner to possible misunderstanding by the respondent. For example, clinical experience shows that some children with sensory overresponsivity ignore or deny that they are soiled for fear of punishment or ridicule and this behavior may be interpreted as underresponsivity. Detailed observation and interview with caregivers is needed to fully understand the child's behavior.

The fact that children may fluctuate in their responses to sensation or manifest overresponsivity to some sensations and underresponsivity to others must also be considered (Baranek, David, Poe, Stone, & Watson, 2006; Kientz & Dunn, 1997; Parham & Mailloux, 1996). However in the case of children with retentive fecal incontinence who do not respond to conventional medical management, difficulties accepting toileting and defecation appear to be related mainly to overresponsivity in the tactile system; normal sensations such as the passage of feces or the contact of the potty/toilet on the skin are interpreted as painful. Further research is needed to clarify the sensory-response patterns of children with different types of defecation issues.

Based on content analysis of these expert responses, the revised version of the THPQ includes 10 items. The first eight items are hypothesized to be related to sensory overresponsivity, and items 9 and 10, to sensory underresponsivity.

(1) My child hides while defecating.
(2) My child asks for a diaper when he/she feels the need to defecate.
(3) My child refuses to sit on the potty or the toilet to defecate.
(4) My child always follows the same ritual when defecating.
(5) My child seems to feel pain when defecating, even if the stool is soft.
(6) My child refuses to go to the toilet outside of the home.
(7) My child´s reaction to the odor of his/her feces is exaggerated.

(8) My child refuses to wipe or be wiped after defecating.
(9) My child does not seem to feel the urge to defecate.
(10) My child does not realize he/she has soiled (feces) his/her clothes.

The construct of sensory under- and overresponsivity is well established (Dunn, 2014; Lane, Reynolds, & Thacker, 2010; Parham et al., 2007; Reynolds, Bendixen, Lawrence, & Lane, 2011; Su & Parham, 2014). Caregiver questionnaires are available to systematically document behavioral manifestations of passiveness, discomfort, distress, or intolerance in relation to daily occupations that include specific sensory input (Dunn, 2014; Parham et al., 2007). For example, expressing distress in relation to grooming is considered a sign of tactile overresponsivity and may be a factor related to a child´s difficulty participating in dressing and bathing. However, these tools do not include items related to toileting, a crucial childhood occupation. Such items could be useful to better understand difficulties participating in toileting routines, a frequent complaint of parents of children with retentive fecal incontinence.

The THPQ has been used clinically to screen for sensory-processing concerns in children with RFI that has not responded to first-line medical management. Developed based on careful documentation of the behaviors and the progress of the children referred for possible sensory-processing deficits relative to RFI, the THPQ appears to capture behaviors that are consistent with problematic toileting behaviors, particularly as they relate to sensory overreactivity (Beaudry Bellefeuille & Ramos Polo, 2011; Beaudry-Bellefeuille, 2014).

This study was part of a larger study in which toileting behaviors reported by parents of typically developing children were shown to be significantly different from those reported by parents of children with RFI (Beaudry-Bellefeuille, 2014). This finding supports the discriminative validity of the THPQ. Interestingly, sensory responsivity as measured by the Spanish version of the Short Sensory Profile was also significantly different between the two groups, suggesting that the behaviors described in the THPQ may be useful to identify sensory-based defecation issues (Beaudry-Bellefeuille, 2014). Further investigation is warranted.

There is growing evidence that OT is successful in improving participation in children with sensory issues (Pfeiffer, Koenig, Kinnealey, Sheppard, & Henderson, 2011; Schaaf, 2011; Schaaf et al., 2013). There is also some evidence that addressing the sensory issues that appear to be at the root of the behaviors related to the development and maintenance of constipation and fecal incontinence may contribute to more-successful treatment outcomes for children who experience this complex and often chronic condition (Beaudry Bellefeuille & Ramos Polo, 2011; Beaudry et al., 2013; Handley-More et al., 2009). The THPQ may provide a structure useful in identifying and tracking these behaviors over the course of treatment.

## Limitations and future research

The main limitation to this study was the relatively small size of the expert panel. However, having bilingual experts with substantial clinical experience in pediatric gastroenterology and Ayres Sensory Integration was seen as a strength in establishing face and content validity. Additionally, although feedback from the parents was

obtained during the development of the THPQ and during a preliminary study using the tool, formal consultation on face validity did not include parents. Future research will need to strengthen the validity of this tool and include the consumer perspective.

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