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Toileting dysfunction in children with sensory under-responsiveness: the sensory modulation bowel and bladder questionnaire (SM-BBQ)

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Doctoral Project

TOILETING DYSFUNCTION IN CHILDREN WITH SENSORY UNDER-RESPONSIVENESS: THE SENSORY MODULATION BOWEL AND BLADDER QUESTIONNAIRE (SM-BBQ)

by

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DEDICATION

This doctoral project is dedicated to my grandmother, Pauline Henry, who became an occupational therapist in 1948. I did not know she had gotten her degree in occupational therapy until after I had applied to occupational therapy graduate programs. She never practiced occupational therapy, becoming a mother less than 2 months after graduating from college. Yet she lived her life with an occupational therapist's mindset. She promoted participation in meaningful activities, actively engaged with her community, and helped adapt the environment when needed for improved function for herself and others.

I also dedicate this project to the pioneers of sensory integration and pelvic health. A. Jean Ayres was transformative in explaining what and how sensory input and the integration of sensation impacts daily life and function. She also provided occupational therapists with the theoretical framework and tools to improve sensory processing and integration. Holly Herman and Kathe Wallace in their foundational work and the creation of the Herman & Wallace Institute helped me find my way to gaining expertise in pelvic health.

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TOILETING DYSFUNCTION IN CHILDREN

WITH SENSORY UNDER-RESPONSIVENESS:

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BLADDER QUESTIONNAIRE (SM-BBQ)

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ABSTRACT

In pediatric pelvic health, sensory processing is not often considered as a significant factor. The current gold standard for addressing bowel and bladder dysfunction is urotherapy and medication. Urotherapy encompasses education regarding the anatomy and function, behavior modifications including fluid intake, removing or managing bowel and bladder irritants, diet changes, timed or scheduled voids, toilet postures and avoidance of holding maneuvers, manual therapy, and biofeedback. These forms of treatment have shown a roughly 50% success rate six months to several years after treatment is concluded (Pijpers et al., 2010 and Noordhoff et al., 2018). While the previously mentioned treatment methods are often necessary and appropriate, they fail to consider the central role that sensory processing, sensory integration, and emotional regulation play in basic biological functions and homeostasis. This doctoral project involved the creation and piloting of the Sensory Modulation – Bowel and Bladder Questionnaire (SM-BBQ) questionnaire to help diagnose children who have bowel or bladder dysfunction due to sensory under-responsivity. Results demonstrated a strong

positive correlation between children who leaked both urine and stool and demonstrated hypo-responsiveness on the Sensory Processing Measure-2 (SPM-2) and their SM-BBQ scores. Significant findings were also noted between the SPM-2 scale scores and scores on both the SM-BBQ. In contemplating how these findings fit with Ayres Sensory Integration theory, perception and threshold may be more relevant than responsivity, as most participants were noted to be hypo- and hyper- responsive to input. A larger scale follow-up study will need to be conducted to ensure that the SM-BBQ is a reliable and valid measure for identifying children with toileting dysfunction related to sensory perception and helping those families to find appropriate services.

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LIST OF ABBREVIATIONS

ASI	Ayers' Sensory Integration
SM-BBQ	Sensory Modulation – Bowel and Bladder Questionnaire
SPM-2	Sensory Processing Measure-2
THPQ-R	Toileting Habit Profile Questionnaire Revised

CHAPTER ONE

Introduction

Bowel and bladder dysfunction can impact all areas of a child's life, from independence to self-confidence, social skills to academic success. These challenges often not only effect the child, but the family as a whole. When considering the statistics related to this subject, Levy et al., 2017 noted that 10% to 23% of children in North and South America are reported to suffer from constipation. De Sousa et al., 2007 reported that bedwetting affects 12–25% of children age four, 8–10% of children age eight, 2–3% of children age 12, and up to 25% of children suffer from functional abdominal pain disorders (Thaper et al., 2020). While these conditions are a fraction of the challenges that can occur with bowel and bladder dysfunction, they do shed light on the vastness of the problem.

Frequently, it is also noted that bowel and bladder dysfunction are associated with emotional and behavioral problems (Dourado et al., 2018, Joinson et al., 2019, Kodman-Jones et al., 2001, & Zink et al., 2008). It is not known whether the behavior and emotional challenges are causal, comorbid or the result of the dysfunction, but it has been found that children with toileting issues, especially those involving the inappropriate emptying of bowel or bladder often face teasing, bullying and/or shame and aggression (Whale et al., 2018 & Filce et al., 2015).

Background

Basic biological needs assure survival. When such urges are ignored, dysfunction often eventually occurs. In the case of bowel and bladder evacuation, the human body

will do what is necessary to remove waste products, even if the result occurs in a manner different from desired. In such situations the accompanying sensory and/or emotional responses are likely to be intense. When issues arise with defecation or micturition such as constipation, encopresis, incontinence, or withholding, it is common to see sensory and emotional differences as well (Dourado et al., 2019, Kodman-Jones et al., 2001, Pollock et al., 2014, and Zink et al., 2008).

If both bowel and bladder needs are addressed soon after afferent signals (sensory stretch receptors in the rectum and bladder) are processed, the cortical involvement in the process is minimal, if at all. Humans can address basic homeostatic functions with little to no thought, such as using the toilet, and carrying on with life. Typically, during such routine activities, very little sensory or emotional registration or regulation is required. However, in times of busyness or if other sensory input claims attention, the bowel and/or bladder signals might not be noticed or attended to right away. When addressing bowel or bladder urges is delayed for some reason or there is a misinterpretation of the sensation, cortical involvement is required, particularly that of the Insular Cortex, known as the "visceral brain" and Anterior Cingulate Cortex (ACC). These areas of the brain appear to play a crucial role in the sensory and emotional responses to visceral experiences (Lowén et al., 2015, Bonaz 2003, Elsenbruch et al., April & October 2010). Recently, Von Economo Neurons (VENS) have been found to play an important role in the connection between interoceptive/homeostatic input and an individual's emotions, motivations, and memories (Allman et al., 2005, Allman et al., 2010, Cabeen et al., 2020 and Evrard et al., 2012). This disruption of a carefully orchestrated dance occurs when perceptual music is

missed or unheeded and can result in bowel and bladder needs not being met in a culturally expected manner.

Recent advances in research and understanding have provided foundational knowledge upon which this author was able to create a parent questionnaire to improve diagnosis of and appropriate treatment for pediatric toileting dysfunction. Advances over the past decade in the areas of interoception (sensations arising from within the body), the gut-brain axis, and emotional responses related to bowel function in particular, allow for a clearer picture as to how the central and peripheral nervous system, greatly impact homeostasis and successful toileting. Evidenced from numerous studies using functional MRIs demonstrate that when stretch receptors in the rectum are activated a significant emotional response often occurs (Hobday et al., 2001, Remes-Troche et al., 2010, Scott et al, 2011, Guleria et al., 2017 & Mugie et al., 2018).

Impact of Project

Though identifying under-responsiveness to sensory input was the primary aim of the Sensory Modulation – Bowel and Bladder Questionnaire (SM-BBQ), the framework of this project lies in the intersection of sensation, emotion, and motor function. Being able to increase understanding, improve diagnosis of bowel and bladder dysfunction related to sensory processing and modulation, and plan appropriate treatment are the larger impacts of this project. While the initial intention of the SM-BBQ was to identify children with hypo-responsiveness of sensory input impacting toileting, the results of the pilot study helped clarify that hyper- and hypo- responsiveness may be only part of the picture, with sensory perception and an imbalance among internal signals, proprioceptive

signals (input from the muscles and joints), and exteroceptive signals at times competing for attention in a non-optimal manner for bowel and bladder function.

Domain of Occupational Therapy

Toileting difficulties, while often not directly addressed by pediatric occupational therapy, fall into the category of occupation, specifically as an activity of daily living. Occupational therapists, according to the Occupational Therapy Practice Framework (2020) aim to work with the client/patient to help address challenges and enhance the health, well-being, quality of life and ability to participate in daily occupations. If occupational therapy continues to leave bowel and bladder challenges to the domain of biomedical professionals, particularly doctors and physical therapists, toileting will not be addressed in the holistic way in which occupational therapists excel.

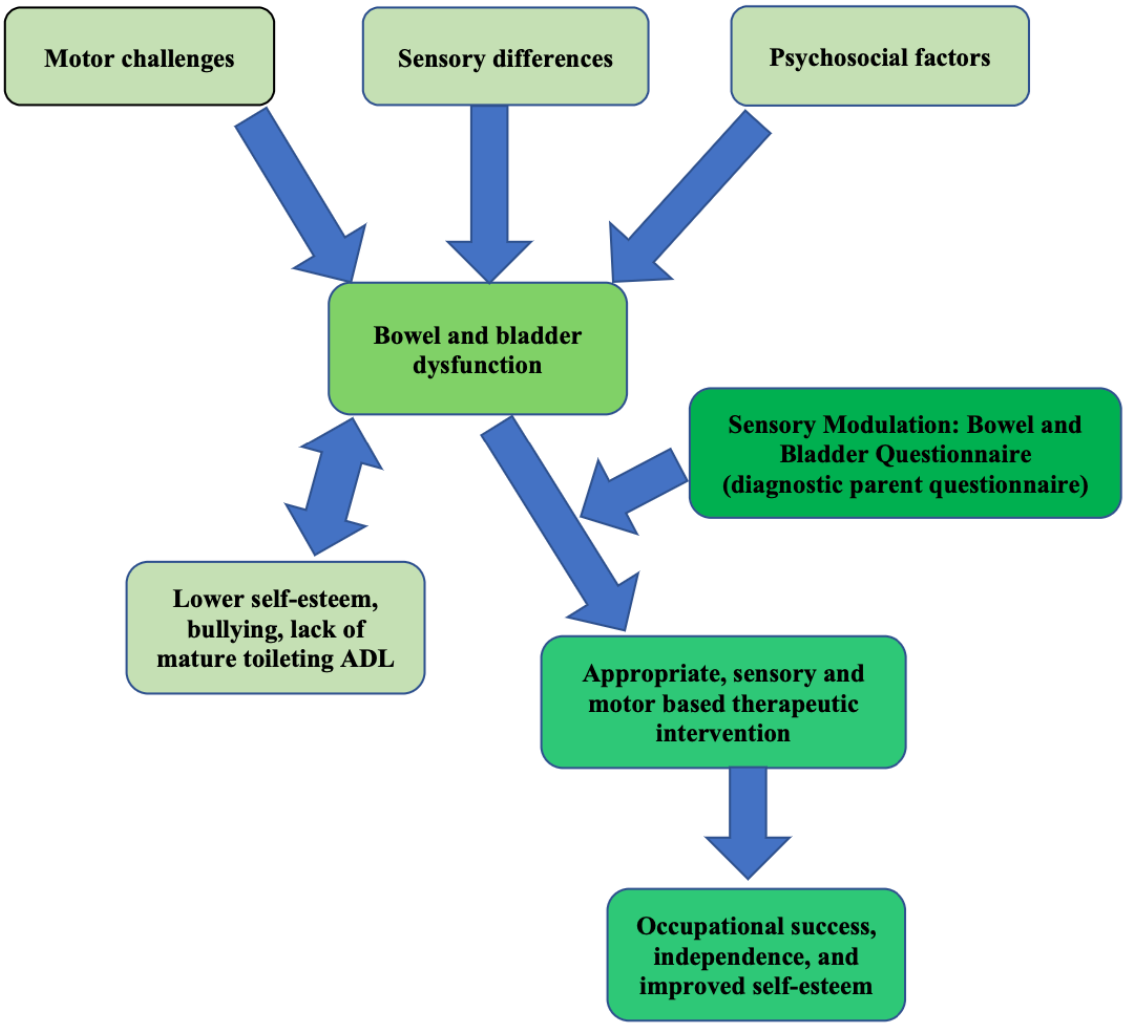
CHAPTER TWO

Theoretical and Evidence Base to Support the Proposed Project

Defining the Problem

A gap in the literature exists in evaluation and treatment tools when considering bowel and bladder dysfunction. A literature review, and guidance from Ayres' Sensory Integration (ASI) theory, have led to the development of an explanatory model (see Figure 2.1 on the following page) that describes factors influencing bowel and bladder/pelvic floor dysfunction and the potential outcomes based on continued dysfunction or successful treatment. The potential influences in bowel and bladder dysfunction can be classified in three distinct areas: 1) motor challenges, 2) sensory differences, and 3) psychosocial factors.

Figure 2.1 Explanatory Model of the Identified Problem



Appropriate motor function requires strong muscles throughout the core, diaphragm, and pelvic floor with appropriate control of pressures within the system (Massery, 2006). Pelvic floor and core muscle training and coordination are key components of the current medical model of pelvic floor therapy. Sensory differences, or difficulties with taking in, processing, and interpreting sensory information from the environment or from within the individual can also play a role in learning and daily occupations (Bundy & Murray 2002 & Smith Roley, 2006) such as toileting. Beaudry-

Bellefeuille and Lane (2017) found a relationship between sensory over-responsiveness and retentive fecal incontinence. The role of sensory integration in toileting is not frequently addressed as either a cause or treatment approach. Psychosocial factors including potential bullying (Tatlow-Golden et al. 2017), stress (Yamada et al. 2019) and worry about smell or sounds of using community-based toilets (Kohyama, 2020) influence successful toileting, willingness to participate in meaningful occupations and one's sense of self-worth/self-confidence.

The proposed diagnostic questionnaire will help identify deficits in toileting dysfunction. In combination with current biomedical and psychosocial measures, it will guide treatment to improve occupational independence and competence, lower the incidents of bullying or negative attention and likely result in higher self-esteem.

Theoretical Framework for the Sensory Modulation–Bowel and Bladder Questionnaire

Bowel and bladder filling, storage, and emptying are universal actions required for homeostasis. This process, while on the surface appearing physiologically straight forward, relies upon sensory and emotional factors that can be quite complex and often disregarded or minimized. When dysfunction occurs, the typical treatment currently utilizes the medical model and in particular pelvic floor therapy, however forms of treatment have shown a roughly 50% success rate six months to several years after treatment is concluded (Pijpers et al., 2010, Noordhoff et al, 2018). While this remains the gold standard, it is clear that something is missing. In some cases, a sensorimotor lens may best address this gap in toileting difficulties (Beaudry-Bellefeuille & Lane, 2017).

Sensory integration is defined as “the organization of sensory input for use” (Spitzer and Smith Roley, p. 5). There are 8 sensory systems: vision, auditory, tactile, olfactory, gustatory, vestibular, proprioceptive, and interoceptive. These are systems that take in and process information from within and outside of the body. Sensory integration disorders can be classified as Sensory Modulation Disorders, Sensory Discrimination Disorders and Sensory-Based Motor Disorders (Bundy et al., 2002 & Miller et al., 2007). Individuals with modulation disorders tend to experience sensations as too intense to tolerate or too mild to provide an accurate picture, while those with discrimination disorders tend to have difficulty with interpreting the meanings of sensations. People with sensory-based motor dysfunction have a form of dyspraxia, or difficulty with ideation, motor planning and execution of novel tasks often involving coordination (Bundy & Murray, 2002).

For bowel and bladder disorders to be addressed from a sensory integration framework, the evaluation and subsequent treatment must incorporate the sensory systems, particularly the interoceptive, tactile, vestibular, and proprioceptive systems. A deeper understanding of sensory input will lead to more accurate awareness of signals from within the body and appropriate motor and emotional reactions. The emotional regulation required for successful toileting and homeostasis must also be directly addressed as the Von Economo neurons connect the Anterior Insula (where interoceptive input is processed) and the Anterior Cingulate Cortex which is involved in quick reactions and insights often known as “gut feelings and gut reactions.” These gut feelings and reactions create a picture in the brain, most specifically related to pain, fear and

social feelings (Allman et al., p. 369). In some cases, in order to overcome bowel and bladder dysfunction, negative feelings, both psychological and physiological must be improved.

The secondary framework that addresses this problem is that of the "brain-gut axis." This theory purports that "the gut-brain crosstalk [has] revealed a complex communication system that not only ensures the proper maintenance of gastrointestinal homeostasis, but is likely to have multiple effects on affect, motivation, and higher cognitive functions" (Carabotti et al., 2015, p. 203). Because of this connection between what happens in the GI tract and its microbiota, and the functions of the brain and nervous system, bowel and bladder difficulties may be more than a physiological/pelvic floor problem.

Through this lens sensory processing of information from gut, bowel, and bladder is seen as highly complex. Mayer et al. (2006) states that "the insular cortex plays an important role in the conscious perception of all sensations arising from the body, while the dorsal anterior cingulate cortex (dACC)…mediates the affective response and motivational drive" (p. 1925). This interaction between sensory input and brain response is part of what this author hopes to address.

Additionally, toileting difficulties, while often addressed in adult and geriatric occupational therapy practice, are frequently overlooked in pediatric occupational therapy services. However, bowel and bladder function fall into the category of occupation, specifically as an activity of daily living, according to the Occupational Therapy Practice Framework fourth edition (OTPF-4) (American Occupational Therapy Association,

2020). As an occupational therapist, this author will be looking at the problem with the OTPF-4 in mind as well, with a focus on addressing the client/patient challenges and enhancing the health, well-being, quality of life and ability to participate in daily occupations.

Literature Review of the Problem

In examining the causes of bowel and bladder dysfunction, this author believes that there are a few potentially related, yet distinct underlying factors. Motor-based challenges, sensory differences and psychosocial factors can each play a role in toileting struggles. The author's proposed explanatory model is based on the belief that deficient motor skills, sometimes related to physiology can result in bowel and or bladder issues. Sensory differences can lead to children being under-responsive, over-responsive or confused by signals coming from their body. Additionally, psychosocial challenges can cause physiological responses related to bowel and bladder dysfunction. These toileting difficulties often result in lower self-esteem/self-confidence, limited independence and bullying. The goal of this chapter is to better understand what existing research supports the identified problems so that diagnosing and treating toileting dysfunction with skilled therapy is comprehensive, effective and efficient. The evidence in the literature was robust and supported each of the areas mentioned above.

Motor-Based Challenges

For motor-based dysfunction there appear to be many factors at play. When examining pelvic health concerns, congenital anomalies, muscle tone, breathing patterns, muscle strength and coordination and reflex responses must be considered. Also, it often

appears to be true that if constipation exists, urinary incontinence is a resulting symptom. Averbeck and Maderbacher (2011) found that dysfunction in the bowel and bladder often occur together as "the urinary bladder and rectum share a common embryological origin…[and] the close proximity of these two organ systems could suggest that dysfunction in one may influence, also mechanically, the function of the other" (p. 16).

Massery (2006) described in her Soda-Pop Can model of respiratory and postural control that "when the patient has lost the ability to generate, regulate, and/or maintain appropriate internal pressures in both the thoracic and abdominal chambers, the mechanics of breathing, as well as numerous other body functions, may be impaired" (p. 706). And in specifically addressing pelvic floor, Massery states that while "these dysfunctions may not be caused solely by the lack of normal pressure support…the lack of pressure support is a major cause of the dysfunction" (p. 705).

Other physiological factors influencing bowel and bladder function include reflexive actions such as peristalsis, the recto-anal inhibitory reflex (Poojari et al., 2021 & Rajinajith, D. & Benninga, M. 2013), micturition reflexes (Fowler et al., 2008 & Seseke et al. 2006), as well as spinal reflexes (Vollmer, H., 1958). These reflexive actions occur seamlessly to help with continence, however when there are issues, the presence or absence of significant reflexes can be life-altering and challenging to overcome.

Muscle tone (Pekbay et al., 2019 & Nijman et al., 2008), strength and coordination (Skardoon et al., 2017) are other factors to consider. Children with excessively high or low muscle tone may have difficulty with appropriate sphincter and outlet control.

Sensory Differences

With regard to sensory-based bowel and bladder difficulties, a number of studies found correlations between children with dysfunctional voiding/elimination and those with sensory processing differences (Pollock, Metz, & Barabash, 2014, Beaudry-Bellefeuille, & Lane, , 2017, Little et al., 2019, Mazurek et al, 2013, and Cupelli et al., 2014). The ability to accurately sense and act upon various forms of input from the environment or from within the body appears to impact bowel and bladder function.

Within the general category of sensory processing dysfunction, two main themes emerged in the literature. Children with toileting challenges were either noted to be over-responsive or under-responsive to sensory input. Sensory over-responsiveness and sensory sensitivities, both resulting from input feeling too intense and were common in children with chronic constipation and/or retentive fecal incontinence (Beaudry-Bellefeuille, & Lane, 2017; Little et al., 2019, & Mazurek et al., 2013). Specifically, Little et al, found that "young children with high sensory registration, high oral sensitivity, and increased sensory avoidance behaviors may be at risk for toileting over-responsiveness" (p. 144). The fact that certain children exhibited a constellation of heightened responses across sensory systems and toileting over-responsiveness indicates that the sensory over-responsiveness must be considered when looking at bowel dysfunction. Much of the research thus far has looked at children who are over-responsive to sensory input resulting in withholding, constipation and encopresis. There is also often an anxiety component related to this pattern that will be discussed later in this chapter.

There have been a few articles examining children who are under-responsive to certain types of sensory input. Cupelli et al. found that children with dysfunction related to urination did demonstrate overall greater sensory processing differences. More specifically they found that "the odds for low tactile sensitivity scores were five times greater for children with [urinary dysfunction] and [dysfunctional voiding]" (YEAR, p. 880). Similarly, Little et al. found attentional difficulties also to be a predictor for under-responsiveness. Little explained that "attention difficulties have been previously identified as markedly higher in children with soiling difficulties. However, attention has been investigated through a psychological lens rather than a sensory processing lens (p. 144). This understanding of attention as a part of being aware of sensory input from within the body (vestibular, proprioceptive, tactile and interoceptive input) is a new way to frame this consideration. Foo et al., 2016, also found that "children with faecal impaction have sensation of defecation less often and when present the feeling is weaker and emptying less complete than in [healthy children] and the posterior area of sensation was reduced" (p. 934). This decreased sensory responsiveness seems to play a factor in bowel and bladder leaks related to under-awareness of sensory input and incomplete emptying.

Psychosocial Factors

A variety of psychosocial factors impact toileting. While some of these influences are related to individual psychological makeup (Zink et al., 2008 & von Gontard et al., 2011), they are often exacerbated by environmental conditions. Stress in daily life has repeatedly been linked to constipation (Kohyama, J., 2020, Yamada et al., 2018). Other

elements that have also been found to play a role in constipation are depression (Lembo, A. & Camilleri, M., 2003), and anxiety (Ahmad et al., 2003). With fecal retention of unknown etiology, often a painful or worrying bowel movement leads to the child fearing future bowel movements (Van Dijk et al., 2007 & Olaru et al., 2016). Olaru et al. also found that for encopresis (frequently linked to fecal retention), poor socioeconomic status, low levels of parent education and minimal parent involvement all played a role.

While the connection between the brain and the enteric nervous system (part of the autonomic nervous system in the gastrointestinal tract) is complex, there is clear evidence that brain-based challenges can impact digestion, and conversely that gut dysbiosis can impact mental health (Mayer et al., 2015, Enders, G., 2018, Carabotti et al., 2015 & Coss-Adame, E. & Rao S., 2013).

When examining urinary dysfunction, there are some psychosocial differences and similarities in comparison to bowel function. Several studies have shown a correlation between voiding postponement (the delaying of urination) and behavioral conditions (von Gontard et al., 2014, Lettgen, B. 2002, von Gontard et al., 2015, & Zink et al., 2008). Dourado et al. (2018) found that emotional and behavior problems occurred in children and adolescents with all types of lower urinary tract dysfunction. However several other studies showed that unlike voiding postponement, incontinence appears to have greater links to constipation (von Gontard et al., 2014, Acikgoz et al., 2021), having a safe environment in which to use the toilet (Tatlow-Golden et al., 2017) and stress (Nascimento Martinelli Braga et al., 2019). In a kindergarten study, Tatlow-Golden et al., stated that “a lack of privacy, being unsure which toilet to use, being laughed at, and

being alone, suggest the possibility that, despite teachers' policy that children are free to go as needed, social anxiety or peer factors may inhibit them from doing so" (p. 218). A multitude of factors appears to play a part in the psychosocial complexities of toileting behaviors.

Impacts of and on bowel and bladder dysfunction

The final elements considered by this author were those of decreased independence, bullying by adults and peers and punishment (Tatlow-Golden et al., Acikgoz et al., 2021, and Olaru et al., 2016) and lower self-esteem (Natale, N. et al., 2009, Neveus, & Sillen, , 2012, and Olaru et al., 2016) for those with toileting difficulties. These factors have been reported repeatedly and often lead to an interconnected web of negative emotions, behavioral responses and societal effects. High levels of encopresis and urinary incontinence have been noted in the prison population (Neveus, & Sillen, 2012) and are likely related to shame and stigma associated with incontinence (Grzeda et al., 2016). Olaru et al. state that "encopretic patients have fragile personalities that need tolerance, intercommunication, and a lot of trust from other people" (p. 5). A common thread among all bowel and bladder disorders appears to be the understanding that many layers of challenge likely exist, and bridging the physiological, psychosocial, and sensory elements requires careful and complete differential diagnosis and caring, evidence-based treatment.

Overall, this inquiry found that identifying, appropriately diagnosing, and treating children with bowel and/or bladder dysfunction is complex. A biomedical approach alone appears to have limited success (Pijpers et al., 2010, Noordhoff et al, 2018). Similarly,

when a behavioral approach is taken, long-term negative consequences are a liability (Bongers et al., 2010, Van Dijk et al., 2007, and Freeman et al., 2014). To best meet the needs of children, families and medical professionals, knowledge of the comprehensive nature of the problem, along with appropriate tools and processes must be widely disseminated and discussed.

CHAPTER THREE

Review of Current Approaches and Methods

Introduction

In examining current approaches to, and methods of diagnosing functional bowel and bladder dysfunction, the author noted a lack of discriminatory tools. While a limited number of tools exist, only one considers the role of sensory processing with regard to toileting dysfunction. Beaudry-Bellefeuille and Lane (2017) found a relationship between sensory over-responsiveness and retentive fecal incontinence. Following her research, Beaudry-Bellefeuille created the Toileting Habit Profile Questionnaire (THPQ), a parent questionnaire for identifying children who are hyper-sensitive to sensory input that impacts toileting. In 2019 Beaudry-Bellefeuille et al. noted that while the THPQ-R (the revised version of her tool) was able to identify children with bowel dysfunction related to over-responsivity to sensory input, "the THPQ-R cannot be used to clearly identify sensory under-reactivity and/or poor perception and its relationship with challenging defecation behavior. This is something to consider for future work" (pp. 244). Meinds et al., (2018) also noted that "current questionnaires on defecation disorders are often brief and fail to include questions considering causative factors" (pp. 790). No diagnostic tools exist for identifying a relationship between urinary tract challenges and potential sensory underpinnings or sensory under-responsivity and bowel and bladder dysfunction in general, or as a combined pelvic floor/elimination problem.

Searching the Literature

In an attempt to find out what methods and approaches have been used for creation, evaluation, and distribution of a tool; this author searched the literature. The specific questions hoping to be clarified were: 1) What is required for the creation of diagnostic parent questionnaires for bowel and bladder dysfunction? 2) What is required for the implementation of diagnostic parent questionnaires for bowel and bladder dysfunction? 3) What are effective tools for healthcare professionals to collaborate with other professionals for appropriate referral and diagnosis? 4) Is it a burden for parents to fill out questionnaires for diagnosis?

The following search terms were used: "pediatric urinary incontinence questionnaire," "pediatric fecal incontinence questionnaire," "healthcare professionals improve use of patient questionnaires," "patient questionnaire for appropriate referral," and "improve diagnostic parent questionnaire." These searches produced a variety of different tools related to either pediatrics and/or toileting dysfunction.

The author located 12 articles discussing the creation, trialing and implementation of questionnaires that were created for the pediatric population regarding bowel and/or bladder dysfunction. Most of these questionnaires are to be filled out by parents, but some are filled out by the children themselves. Farhat et al. (2000) mentioned noticing that there is a "lack of a standardized reporting system for voiding symptoms." Several other studies agreed with that sentiment (Akbal et al. 2005, Sureshkumar et al. 2001, De Gennaro et al. 2010, Meinds et al. 2018, Beaudry-Bellefeuille et al. 2016, and Nelson et al. 2007). Additionally, Anwar et al. (2019) described their goal as helping remove

confusion while simultaneously improving diagnosis of a variety of bowel and bladder conditions. This goal was also noted by Kelly et al. (2016), and Akbal et al. (2005).

Six other articles were not specifically related to toileting dysfunction but were relevant for understanding the creation and use of questionnaires in healthcare to help with appropriate diagnosis, referrals and improve speed of accessing the most effective and efficient care. These articles mentioned ideas of "combining plain language and medical terminology…to improve accuracy of items interpretation" (Macefield et al. 2019), the importance of getting information directly from the individual or their caregiver (Greenlaw et al. 2020, Reijneveld et al. 2006, and Sherman et al. 2015), patient burden with the use of a tool as well as the individually perceived welfare that is provided with the use of a tool (Kim et al., 2011), improved accuracy of diagnosis and accessing of care (Drzewiecki et al. 2012, 2012, Greenlaw et al., 2020, Reijneveld et al., 2006, Sherman et al., 2015, & Vogel et al., 2012). Several of these themes were consistent with those in the bowel and bladder specific questionnaires as well.

Synthesis of the Literature

The articles found for this literature review address each of this author's research questions. The process for creation, piloting a tool, revision and dissemination for greater use were all discussed in these articles. Additionally, several of these articles provide clarity as to why such a diagnostic questionnaire would be useful and necessary. These tools each addressed an area of need where no specialized means of diagnosis were previously available (Akbal et al. 2005, Beaudry-Bellefeuille et al. 2016, Sureshkumar et al. 2001, De Gennaro et al. 2010, Meinds et al. 2018, and Nelson et al. 2007). These gaps

often result in parents/caregivers being required to do their own research and/or have faith that their healthcare providers have advanced knowledge in specialized areas to accurately diagnose and recommend appropriate next steps. This lack of necessary diagnostic tools also often results in increased suffering and the creation of chronic conditions. While the creation of new tools is not simple, the existing literature provides a variety of examples for issues that can arise and how to ensure success.

Creation of the Tool

In creating a new tool, De Gennaro et al. (2010) stated that their process included "a combination of literature review, expert option and patient testing." This process of literature review followed by expert panel weighing in was also used by Beaudry-Bellefeuille et al. (2016), Macefield et al. (2019), and de Bruijn et al. (2022). de Bruijn et al., in the initiation of their process for making Pediatric Bowel Management Scoring Tool (PBMST) formed questions following a review of already created questionnaires and having a panel of experts vote on the most important/clinically relevant questions in each area. Nelson et al., (2007) also started with an existing instrument and then consulted with a panel of experts for the creation of the Incontinence System Index-Pediatrics. This process of literature review, identification of content domains and expert opinion appears to be standard practice in the creation of a new tool.

Piloting of the Tool

Pilot studies of tools appears to be the next phase in ensuring that the questionnaires are measuring what is intended (Beaudry-Bellefeuille & Lane, 2017, Sureshkumar et al. 2001, Anwar et al. 2019, Kelly et al. 2016, and Macefield et al. 2019).

These pilot studies use varying, but typically relatively small sample sizes to gain initial data about their tool's success at measuring intended factors. Some studies utilized a patient group and a control group (Beaudry-Bellefeuille & Lane, 2017, Akbal et al. 2005, Kelly et al. 2016, Drzewiecki et al. 2012, Farhat et al. 2000, Anwar et al. 2019, Mathias et al. 2016, Meinds et al. 2018, De Gennaro et al. 2010, Kim et al. 2010, and Tavassoli et al. 2014). Other studies had participants from the intended audience only (Macefield et al. 2019, Sherman et al. 2015, Reijneveld et al. 2006, Vogel et al. 2012, Greenlaw et al. 2020, de Bruijn et al. 2022, Nelson et al. 2007, and Sureshkumar et al. 2001). Macefield et al. (2019) stated that "the development of any new measurement involves pretesting with a sample of participants from the target population" (pp. 3) and they recruited only from within their intended demographic.

For the studies that had a patient and control group, a noted limitation of some researchers was the difference in size between the two groups (Beaudry-Bellefeuille & Lane, 2017, Farhat et al. 2000, and Anwar et al. 2019). However their results did show a significant difference in scores between the two groups resulting in the researchers feeling comfortable stating that the questionnaires were reliable and valid.

In all of the above-mentioned cases the questionnaires were then revised, or the researchers note a plan to revise and then disseminate for a larger study and/or general use. Noted differences among pilot studies included comparing clinical groups with control groups, comparing the new tool with existing standardized tools, examining medical history with questionnaire findings, or using a test/retest format. This phase is an important step in the process of making sure the tool is measuring what it is intended to

measure.

Revision of the Tool

All of the articles that discussed a pilot study mentioned the importance of analyzing and understanding a results of the pilot study, ensuring that the items in the questionnaire address the intended issues, and making revisions to the questionnaire. This process of testing and revision appears to be iterative and can happen with feedback from the participants, correlations with standardized tests, and/or discussion/analysis of preliminary results with a panel of experts. Beaudry-Bellefeuille et al. 2019 noted that after the pilot phase they created new items, modified the questionnaire's scale, and altered one item. This revised version was then studied on a larger scale to examine structural validity. This was similar to Anwar et al. (2019) stating that "the questionnaire was then modified an additional 11 times based on this feedback and tested in an additional 30 participants" (pp. 528.e3) and Macefied et al. (2019) noting that their tool went through eight revisions.

de Bruijn et al. (2022) used a different format for revision. After they piloted the Pediatric Bowel Management Scoring Tool with 13 parents and children, they interviewed the participants to "ensure that the children and parents understood the content, that they all interpreted the questions similarly, and to identify any missing items" (pp. 108). They then met with the group of experts with whom they had formulated the initial questions and made revisions.

Benefits of the Tool

There appear to be numerous benefits to questionnaire style tools that are completed by individuals or family members of those with healthcare needs. Some of the advantages included improved early and accurate diagnosis (Sureshkumar et al. 2001, Farhat et al. 2000, Akbal et al. 2005, Meinds et al. 2018, Beaudry-Bellefeuille et al., 2016, Drzewiecki et al. 2012, Greenlaw et al. 2020, Kim et al. 2010, Reijneveld et al. 2006, Sherman et al. 2015, and Tavassoli et al. 2014) appropriate referrals (Farhat et al. 2000, Akbal et al. 2005, Meinds et al. 2018, de Bruijn et al. 2022, Nelson et al. 2007, De Gennaro et al. 2010, Anwar et al. 2019, Kelly et al. 2016, and Vogel et al. 2012) and ongoing monitoring of an individual's symptoms, especially in response to treatment (Meinds et al. 2018, Nelson et al. 2007, Sureshkumar et al. 2001, and Kelly et al. 2010).

Farhat et al. (2000) stated that their questionnaire, "may help identify patients easily and rationally likely to harbor dysfunctional voiding, select and direct treatment and investigation, and stratify treatment intensity" (pp. 1014). Per Kim et al. (2010), "patient completed tools provide a structured framework for screening or aiding communication, to guide clinical visits and decision-making while encouraging patients to be more actively engaged" (pp. 191). Vogel et al. (2012), stated the belief that using a patient completed tool can be more efficient with regard to time and ease of the referral process. Sherman et al. (2015), echoed the above sentiment of efficiency by specifying that if the diagnostic process can be more accurate then better care can be given. All of these studies noted that their tools offer the possibility of improving the healthcare experience and process.

While the articles reviewed noted that the knowledge gained from questionnaires is often more helpful than harmful and can lead to improved diagnosis and treatment, there is sometimes a hesitancy by healthcare professionals to give such tools (Kim et al. 2010, Reijneveld et al. 2006, Meinds et al. 2018, and Greenlaw et al. 2020). Kim et al., (2010) mentioned that there may be a reluctance to use questionnaire style tools if healthcare professionals feel that such tools are just one more thing for the patient to do: "patients must perceive an increase in personal welfare when using a tool, as compared with not using it" (pp. 191). They also argued that "professional health providers should not make unwarranted assumptions about the tools for self-reporting of symptoms, and to what extent a particular tool is a burden for patients. Burden is only half of the calculus; improved welfare is the other half" (pp. 195). Similarly, Reijneveld et al. (2006), explained that if earlier diagnosis and treatment are able to be performed, the benefits can be significant, both from a health and financial perspective. And Greenlaw et al. (2020), stated that their "screen offers a cost-effective means to improve access to care. The screen is useful not only for the content of the questions, but also for creating workflow that connects primary care providers directly with [specialists]" (pp. 488). This awareness of weighing the cost/benefit of a questionnaire is important.

One more reason a parent questionnaire is likely to be a worthwhile tool is that as Nelson et al. (2007) state, "it is now recognized that patient reported outcomes frequently differ from physician reported outcomes and patient reported outcomes are considered more reliable and accurate (pp. 1765)." While Nelson et al. were specifically discussing their questionnaire which is filled out by the child themself, having the child's parent fill

out the questionnaire is noted to be an important screening tool as the parents likely know their child well (Sherman et al. 2015, Reijneveld et al. 2006, Greenlaw et al. 2020, Meinds et al. 2018, and Beaudry-Bellefeuille et al. 2016). Drzewiecki et al. (2012), also concluded that "a validated bladder/bowel dysfunction questionnaire is a useful tool in the pediatric urology clinical setting…The questionnaire can help patients and their families better define their bladder bowel symptoms before their visit" (pp. 1578). This parent involvement in the process means that they are both assisting with providing information and being actively invested in the process.

When thinking of the role of occupational therapy in the creation and use of a new parent questionnaire, the role of function within a daily occupation framework must be considered. Parents must be actively engaged in their child's success with health and activities of daily living. When specifically looking at a toileting questionnaire, Beaudry-Bellefeuille et al. (2016) noted that while

> "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…these tools do not include items related to toileting, a crucial childhood occupation" (pp. 172).

This lack of caregiver questionnaires for such a vital daily occupation means that understanding, diagnosis, and treatment of sensory-based toileting dysfunction leaves many families with no idea of where to turn for help and most occupational and physical therapists under-trained for the task.

CHAPTER FOUR

Description of the Study

Introduction

The purpose of this doctoral project is to create and pilot a questionnaire that will identify children who have bowel and/or bladder dysfunction due to sensory under-responsivity. A pilot study was conducted to collect data on the validity of the Sensory Modulation Bowel and Bladder Questionnaire (SM-BBQ). See Appendix A for the questionnaire.

The study utilizes 3 parent/caregiver questionnaires — the Toileting Habit Profile Questionnaire-Revised (THPQ-R) (Beaudry-Bellefeuille et al., 2019), the Sensory Processing Measure-2 (SPM-2) (Parham et al., 2021), and this author's questionnaire, the SM-BBQ. The two validated measures, the THPQ-R and the SPM-2 were given in order to correlate scores with the author's new measure to determine if it is successfully capturing under-responsiveness to sensory input that is leading to bowel and bladder dysfunction. The participants also filled out a demographic form and a daily Stool Questionnaire for seven days, adapted from the MCRI-Barts-London Stool Sheet by Adeline Foo for her doctoral project regarding hypo-responsiveness and defecation (Foo et al., 2016).

Twenty participants took part in this pilot study. The participants were parents of children with identified bowel and bladder dysfunction with no known physiological cause. The study had three phases, and data was collected between June 2022 and March 2023 (9 months). Participants were enrolled in the study on a rolling admission basis. In

phase 1, participants were recruited into the study. Candidates were screened by the principal investigator to ensure that they met inclusion criteria. In phase 2, informed consent was administered, and participants completed the THPQ-R, the SPM-2 and the SM-BBQ. A demographic information form (which did not contain the name or other identifying information) and the daily stool questionnaire were also completed. All forms were filled out and returned to the primary investigator in person, by mail or by email. In phase 3, data was analyzed.

The demographics of the participants are shown in Table 4.1 with their gender, age grouping, and bowel and bladder leaking status noted. There were significantly more males than females in the study, with no participants of gender non-binary or gender fluid status. The participants skewed more toward an elementary and middle school age range with a minority of participants in the 3–5-year-old age range. Half of the participants leaked both urine and stool, while one quarter of them did not leak either urine or stool and a minority of participants only leaked urine or stool.

Table 4.1 Demographics of Participants

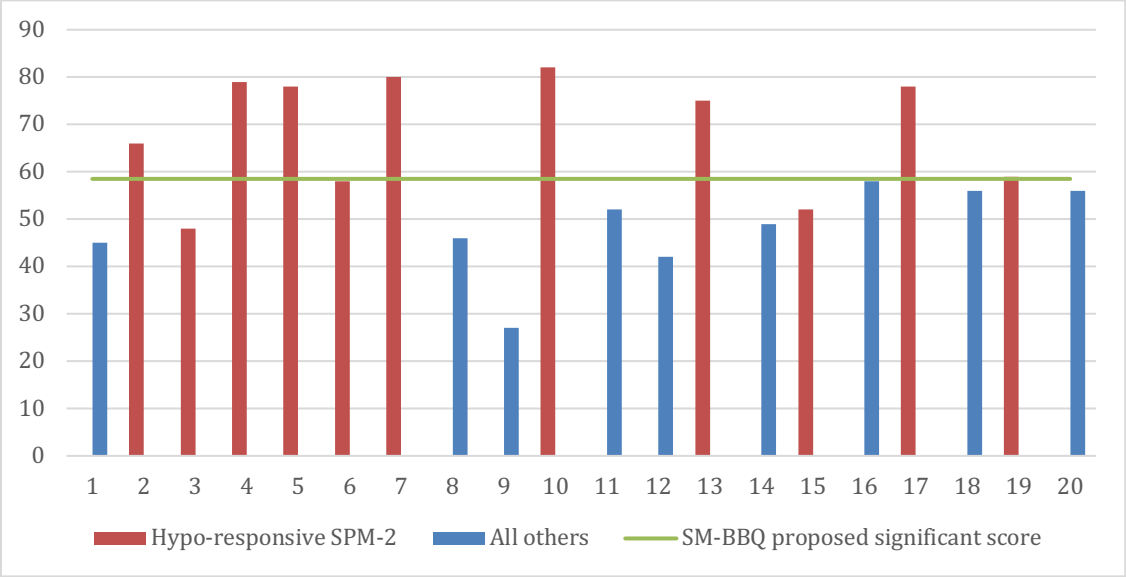
Gender	Male	Female	Gender Non-binary	Gender fluid
	14	6	0	0
Age group	3–5 years old	5–12 years old		
	6	14		
Leaking status	All leakers	Non-leakers	Urine leakers	Stool leakers
	10 (2 younger)	5	3	2

Results

The results of this pilot study focus on a few specific areas. Since the purpose of the study was to create and pilot a tool that could help identify children who have bowel and/or bladder dysfunction due to sensory under-responsivity, a current tool that could help determine sensory hypo-responsivity was needed. Questions from the SPM-2 were analyzed by the author and a panel of experts in Sensory Integration. This analysis was performed while referencing the SPM-2 manual (Parham et al., 2021). Eighteen questions in the 3–5-year-old SPM-2 were determined to be indictive of hypo-responsivity in a variety of sensory systems. Sixteen questions in the 5–12-year-old SPM-2 were associated with hypo-responsivity in a variety of sensory systems. The questions used to determine hypo-responsivity are listed in Appendix B.

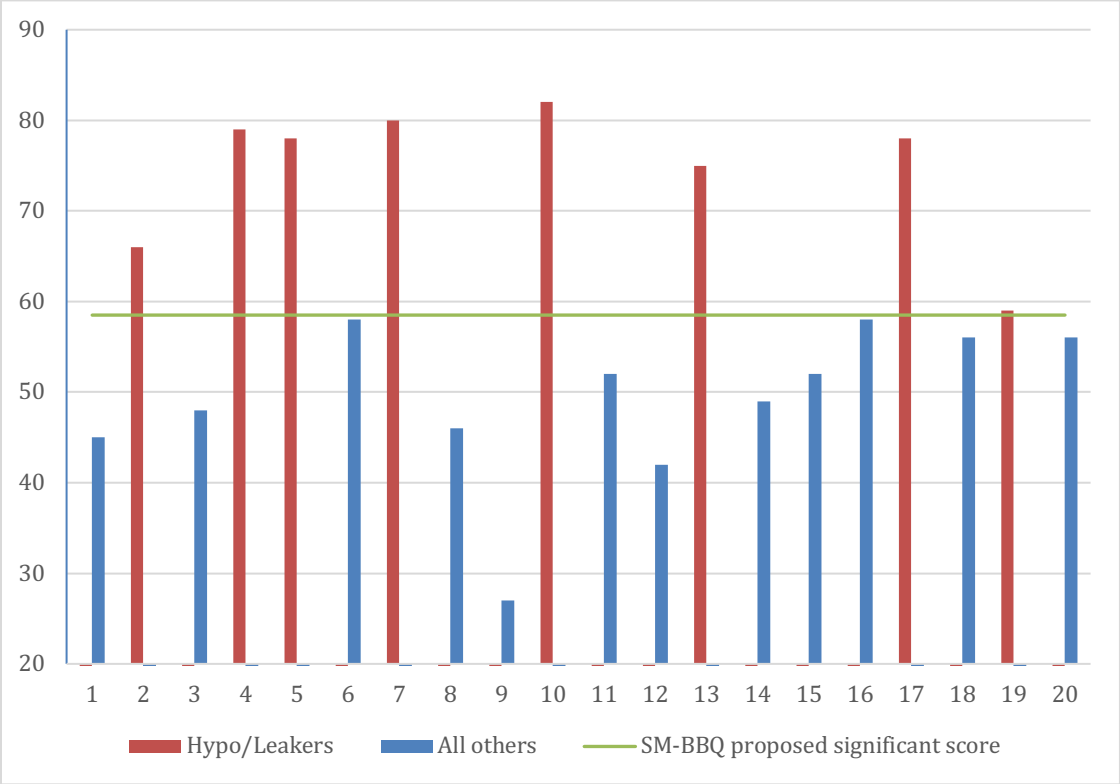
A correlation coefficient was then calculated to determine the correlation between the children who demonstrated hypo-responsiveness on the SPM-2 and their SM-BBQ score and was found to be 0.60. A correlation coefficient between 0.50 and 0.70 is a moderate correlation. These findings are represented in Table 4.2. While some of the hypo-responsive children fell below a score of 59 on the SM-BBQ, which is what the author believes to be a likely significance score, all participants above the line scored as hypo-responsive on the SPM-2.

Table 4.2 Hypo-Responsivity on SPM-2 and SM-BBQ scores



A correlation coefficient was calculated to determine the correlation between the children who leaked both urine and stool and demonstrated hypo-responsiveness on the SPM-2 and their SM-BBQ score. The correlation coefficient is 0.84. A correlation coefficient between 0.70 and 0.90 is a strong correlation. These findings are represented in Table 4.3. All the hypo-responsive children who leaked both urine and stool had an SM-BBQ of 59 or higher, which is what the author believes to be a likely significant score.

Table 4.3 Hypo-Responsivity on SPM-2 who leak urine and stool and SM-BBQ scores



The other data included for consideration is the link between the SPM-2 scale scores and the scores on both the SM-BBQ and the THPQ-R. This is included in Appendix C. A higher score on the SPM-2 scales indicates more sensory challenges but does not identify if the challenges are hypo- or hyper-sensitivity. For this reason, this author did not have an expectation about how the data on the SM-BBQ or the THPQ-R and the SPM-2 scale scores would correlate. Also, a higher score on the SM-BBQ appears to indicate more challenges and a lower score on the THPQ-R is indictive of more challenges. A correlation coefficient was calculated for each SPM-2 scale score with both the SM-BBQ and the THPQ-R.

The five most significant correlation coefficients in the 3–5-year-old age group for the SPM-2 scale scores and the SM-BBQ were in Balance and Motion (Vestibular) 0.90, Taste and Smell 0.88, Planning and Ideas (Praxis) 0.85, Touch 0.71 and Vision 0.65. In the 5–12 age group the five most significant correlation coefficients were in Planning and Ideas (Praxis) 0.87, Social Participation 0.74, Balance and Motion (Vestibular) 0.73, Body Awareness (Proprioception) 0.68 and Vision 0.58. One important note is that for Social Participation a higher score indicates more social aptitude, not social challenges. A positive correlation thus indicates that children with more toileting challenges likely have more social challenges as well.

For the SPM-2 scale scores and the THPQ-R, the five most significant correlation coefficients in the 3–5-year-old age group were in Planning and Ideas (Praxis) -0.96, Body Awareness -0.92, Taste and Smell -0.83, Balance and Motion (Vestibular)-0.79 and Vision -0.73. In the 5–12 age group no significant correlation coefficients were found between the SPM-2 scale scores and the THPQ-R.

Conclusions

The SM-BBQ is a tool that can help identify toileting dysfunction in children that is correlated with sensory hypo-responsivity, especially when the child is leaking both urine and stool. Based on the results of this pilot study, the author hypothesizes that a score of 59 or higher on the SM-BBQ indicates significant hypo-responsivity that may impact toileting.

In contemplating how these findings fit in with Ayres Sensory Integration theory, it is important to note that perception and threshold may be more relevant than

responsivity. Several of the same participants were noted to be both hypo- and hyper-responsive, scoring in the significant range on both the SM-BBQ and THPQ-R, and on the SPM-2 items that denote hypo- and hyper-responsivity. This can be explained in two meaningful ways. One reason appears to be that for children with toileting dysfunction there is a narrow window of "just right awareness." These children do not feel sensations until they rise to an almost "boiling point" at which time the sensations are felt intensely and often becomes painful, uncomfortable, or otherwise noxious. At this point the sensations are often both unbearable and need to be dealt with immediately. If the sensations relate to toileting and are not felt until that boiling point is reached, urine or stool may be leaking out before the situation is remedied by cognitively driven action.

The other explanation is that the internal sensory signals (interoception) are competing with signals from the proprioceptive system related to the pull of gravity on one's body, and sensory signals from outside one's body. When internal signals are weaker than expected and proprioceptive input is poor, one's attention is likely to be pulled outward. This is especially true in the cases of hyper-sensitivity to visual or auditory input. In such situations, with perception being skewed and attention being a limited commodity, the result is that relevant sensory input may not be attended to until after the child leaks urine or stool.

Limitations and Future Research

While 20 participants is a meaningful number for a pilot study, a larger scale follow-up study will need to be conducted to ensure that the SM-BBQ is a reliable and

valid measure for identifying children with toileting dysfunction related to sensory perception and helping those families to seek appropriate services.

Additionally, while the majority of the 26 questions on the SM-BBQ correlated well with the tool overall, item 13, which relates to hypo-responsivity to taste, did not correlate significantly with the tool as a whole or the toileting specific questions which are the first ten items. Item 19 which related to auditory hypo-responsivity did demonstrate a strong positive correlation with the SM-BBQ as a whole but did not for the toileting specific questions. With these results, item 13 will be removed, and item 19 will be watched closely in the next phase of data collection.

CHAPTER FIVE

The Sensory Modulation - Bowel and Bladder Questionnaire (SM-BBQ) Program Evaluation Research Plan

Program Scenario and Identified Stakeholders

A new diagnostic tool, the Sensory Modulation - Bowel and Bladder Questionnaire SM-BBQ was created by the author for the purpose of assisting in the identification of root causes of toileting accidents for children, in particular hypo-sensitivity to sensory input. A pilot study was performed in which parents of children with toileting dysfunction filled out the SM-BBQ, as well as the Toileting Habit Profile Questionnaire (THPQ) which is diagnostic for sensory hypersensitivity related to toileting difficulties, The Sensory Processing Measure-2 (SPM-2) which measures sensory processing difficulties, and the Stool Questionnaire which qualitatively looks at hyposensitivity. Following data analysis, some revisions were made. This current dissemination program of the SM-BBQ is intended to evaluate the effectiveness of its use for parents and healthcare professionals.

In examining current approaches to, and methods of diagnosing sensory based bowel and bladder dysfunction, the author noted a lack of discriminatory tools. Beaudry-Bellefeuille and Lane (2017) found a relationship between sensory over-responsiveness and retentive fecal incontinence. Following her research, Beaudry-Bellefeuille created the Toileting Habit Profile Questionnaire (THPQ), a parent questionnaire for identifying children who are hyper-sensitive to sensory input that impacts toileting. In 2019, Beaudry-Bellefeuille et al. noted that while the THPQ-R was able to identify children

with toileting dysfunction related to over-responsivity to sensory input, “the THPQ-R cannot be used to clearly identify sensory under-reactivity and/or poor perception and its relationship with challenging defecation behavior. This is something to consider for future work” (p. 244). Meinds et al. (2018) also noted that “current questionnaires on defecation disorders are often brief and fail to include questions considering causative factors” (p. 790).

The stakeholders for this program are the tool creator (this author), the parents completing the questionnaire, the professionals providing this tool to parents and making treatment recommendations based on the results. There was also a group of professionals who were a sounding-board/ panel of advisors for refining the SM-BBQ and assisted in the formative phase. The children who are assessed by this tool are also stakeholders but with different considerations. The children will likely not know about the SM-BBQ (as their parents fill it out) and will not be filling it out (though perhaps an adolescent/adult version will be created in the future).

Vision for the Program Evaluation Research

The vision for this program is to determine how to best help as many families as possible who have children struggling with bowel and bladder dysfunction. In the short-term, the goal is for healthcare professionals to familiarize themselves with the SM-BBQ, identify appropriate sources and make appropriate referrals. With regard to the parents, the goal is to have them gain an improved understanding of their child’s toileting difficulties. The long-term vision is that healthcare professionals utilize the SM-BBQ to streamline their process of diagnosing and referral and to make sure that toileting

challenges are addressed as best as possible in a precise and efficient manner.

Figure 5.1 provides an example situation of a child who might visit their pediatrician and benefit from the use of the SM-BBQ. This scenario gives an overview of what the ideal patient might look like and how with a streamlined approach could lead to improving or curing bowel and/or bladder deficits. This is an example of what a successful case might look like

Figure 5.1 Case Scenario for SM-BBQ

Josh is a 5-year-old boy, struggling with daily urine and feces accidents. His parents report that when he does use the toilet it is either because they tell him to go, or he remembers at the very last second and races off to the bathroom, sometimes leaking urine or feces on the way. He also tends to bump into people and objects, has difficulty sitting in a chair unsupported (quickly slouching, fidgeting, or resting his head on his hands), and can go from not hungry to "hangry" without warning signs. When given the Sensory Modulation – Bowel and Bladder Questionnaire (SM-BBQ) his mom's answers placed him in the under-responsive to signals from within his body category, including the need to urinate or defecate. After scoring the SM-BBQ, his pediatrician was able to refer him to an occupational therapist who uses a sensorimotor approach to pediatric pelvic health. He was treated weekly for 3 months, then 2 times a month for the next 3 months, before being discharged from therapy with no ongoing bowel or bladder difficulties noted.

Simplified Logic Model for Use with Stakeholders

To provide stakeholders with context for using the SM-BBQ, the author has created a full and simplified logic model. See Appendix F and G for these models. Being able to share such a logic model will enable the stakeholders to better understand the SM-BBQ, its uses, and benefits. The model provides a succinct description of the expected inputs and outputs this process; as well as the intended short-term, intermediate, and long-term outcomes.

Engagement of Stakeholders in the Program Evaluation Research

Each group of stakeholders will participate to a different degree and at different points in the process of planning, implementing, and reflecting on the SM-BBQ. This dissemination program's stakeholders will only be participating in the outcomes portion of the research.

Table 5.1 provides a description of each kind of stakeholder's role in the program. Prior to this program, in designing and refining the SM-BBQ, an advisory council of Sensory Integration Certified occupational therapists and pelvic health based physical therapists were engaged. They helped provide input as to what the findings meant and any potential changes that were warranted. They do not have a role in this program evaluation research.

The stakeholders for this program, along with the author are healthcare professionals and parents. Several healthcare providers will be trained prior to beginning use of the SM-BBQ. They will either get training via a brief pre-recorded video or virtual synchronous training. Then they will be identifying patients with toileting difficulties and will have the parents of their patients fill out the SM-BBQ. The healthcare professionals will participate in the first stage of the program by giving the SM-BBQ, score it, and provide proper next steps. They will also participate in the program evaluation by each filling out the program evaluation survey to determine how the process has gone for them.

The primary users, the parents of children with toileting challenges will engage in the program by filling out the SM-BBQ and in the program evaluation by answering a

program evaluation survey immediately after completing the SM-BBQ. They will also be contacted by email at two points in the intermediate and long-term (3 and 6 months later) to determine if use of the SM-BBQ led to an appropriate referral and meaningful treatment.

Table 5.1 ***Matrix for Organizing Stakeholder Information***

Stakeholder or Stakeholder Group	**Type of Involvement (Planning, Implementing, Reflecting)**	**Possible Role(s)**	**Specific Interests**
The author/primary researcher	Planning, implementing, reflecting	Overseeing and coordinating logistics	Successful implementation, usable data.
Healthcare providers (physicians, psychologists, therapists)	Reflecting, feedback, recruitment	Consultation on methodology, analysis, logistics	Successful implementation, appropriate referrals, satisfaction
Primary intended users: Parents of children with toileting challenges	Reflecting, feedback	Participating in Filling out SM-BBQ and outcome surveys	Experience of success, satisfaction
*Advisors: OTs and PTs helping with refinement of tool	Planning and reflecting	Consultation on methodology, analysis, logistics	Usability of tool and generation of appropriate referrals

*The advisors will not have a role in the program evaluation phase.

Eliciting Stakeholder Involvement and Ensuring Evaluation Results will be Used

The author will be recruiting healthcare professionals to be trained in the SM-BBQ and what to look for to determine if it is relevant for a specific patient. Following use of the SM-BBQ the healthcare professionals will be asked to fill out a survey regarding their experience with the tool after giving it. The healthcare professionals will

also be asked to share a link to the outcomes survey with the parents filling out the SM-BBQ so they too can provide input.

Regarding the parents who fill out the SM-BBQ, their healthcare providers will be giving them a link to the outcomes survey. They will also receive follow-up surveys 3 and 6 months later to determine whether they have received an appropriate referral and if the bowel and bladder challenges and quality of life have improved.

Program Evaluation Research Questions by Stakeholder Group

Considering the interests of stakeholders' is vital for successful implementation of both the SM-BBQ and an understanding of whether or not the tool is helping healthcare professionals to better do their jobs and parents and their children achieve successful toileting skills. Appendix H contains a listing of potential research questions to be used as part of the program evaluation process. Note that the questions for the author are guidelines for thought and overall next steps but will not be evaluated in a formal manner.

Research Design

The format of this program is a single group, nonexperimental design. The single independent variable is the use of the SM-BBQ. There is no experimental group in this program. The participants will all be completing surveys after either providing (healthcare professionals) or filling out (parents) the SM-BBQ. Since this program will be looking at the outcomes data, only summative data will be collected.

Methods

The method of data collection will be the use of Google Forms surveys that are

provided to the healthcare professionals trained to use the SM-BBQ and parents who fill out the SM-BBQ. The inclusion criteria for healthcare workers who want to participate will be that they participate in a 15-minute training to learn the why, when, how and who for giving, scoring and referring based on results of the SM-BBQ. With regard to the parents, inclusion criteria will be their child having toileting dysfunction that leads to them filling out the SM-BBQ.

The link for the Google Forms surveys will be given to the healthcare professionals once they have completed the initial training in how to use the tool. They will be filling out the program evaluation survey one time after giving the SM-BBQ. However, parents who fill out the SM-BBQ will be filling out their version of the survey, which they will receive the initial link to from their healthcare provider 3 times – immediately after filling out the tool, and then again after 3 and 6 months.

Formative Design

No formative program evaluation will be used in this program. In creation of the SM-BBQ formative data was gathered from my council of advisors. A focus group occurred via Zoom to discuss tool creation, the findings of the pilot study and tool revision.

Summative Design

Summative program evaluation will be conducted via surveys. The summative evaluation questions will be a mix of Likert scale and other fixed-choice questions. The stakeholders completing these surveys will be asked questions about their experience using the tool, their understanding of the underlying dysfunction and appropriate next

steps. The healthcare professionals will only fill out the survey one time each. The parents who provide an initial survey response will receive follow-up surveys via email at 3 and 6 months after to the first survey.

Confidentiality

Confidentiality will be ensured by encoding each individual survey with a number and removing all identifiable information. The author will need to know who is submitting the survey to ensure that healthcare professionals and parents are only filling out my survey once (even if they are using it with multiple parents or parents are using it for multiple children). By then giving each respondent a unique numerical identifier, the author will make sure that their information is secure and confidential. The surveys will be collected with Google Forms, the data will be aggregated securely within the author's Google Workspace account. It is HIPAA compliant. Participants will be given access to the survey through an email link provided by their healthcare provider.

Summative Data Collection

Independent Variable. The independent variable is providing the SM-BBQ to parents of children with toileting challenges and then having the healthcare professional give an explanation of the results and an appropriate referral if needed.

Dependent Variable.

The parents' dependent variables are as follows:

1. *Improved sensory/interoceptive processing:* This would be defined by having the child be able to identify signals from within their body such as the need to urinate or defecate and then acting upon those feelings.

2. *Improved quality of life for the parents and the child:* This would be tracked by using a Likert scale of how the parent would rate their own and their child's quality of life.
3. *Fewer or no toileting challenges:* This variable would be examined by having the parent state how many times in the past week their child had had urine or feces accidents.

   The providers' dependent variables are as follows:

   1. *Knowledge of toileting dysfunction*: This variable will be examined by the healthcare professional rating whether and by how much their knowledge of toileting dysfunction improved from before training on SM-BBQ to the point where they have given the tool.
   2. *Diagnostic skill with bowel and bladder dysfunction:* This variable will be analyzed by asking with a Likert Scale for the healthcare professional to rate how much (if at all) their skill in diagnosing bowel and/or bladder dysfunction has improved since being trained in and giving the SM-BBQ.
   3. *Ability to make appropriate referrals:* This variable will be assessed by asking with a Likert Scale how easy or difficult it is for healthcare professional to make appropriate referrals based on the results of the SM-BBQ.

The summative data will be collected from the healthcare professionals on one occasion, following training for how to give and then giving the SM-BBQ, scoring and providing feedback to the family. For the parents, summative data will be collected at 3

distinct points in time. The first time will be after initially completing the SM-BBQ, the second time will be 3 months later, and the third time will be 3 months after the second time. All summative data will be collected via survey.

Methods for Summative Data Management and Analysis.

This program is being initiated following the author's completion of a doctoral program in which the reliability and validity of the SM-BBQ were piloted. Therefore, no IRB approval will be sought. Data will be aggregated securely in Google Sheets. Participants will be given access to the survey through an email link provided by their healthcare provider.

The data will be summative, numerical in nature, and nonexperimental analysis. Since the survey will have Likert Scale types of answers as well as other fixed-choice or numerical responses, the data will be ordinal and thus a t-test will be used for analysis of the mean. The author plans to use SPSS to complete this data analysis.

Disseminating the Findings of Program Evaluation Research

The dissemination of the findings for this program presents complexities due to the disparate interests of healthcare professionals and parents. With regard to the healthcare providers, the dissemination will occur through an infographic that includes the program's findings and a QR code for them to go to a website that has the SM-BBQ for them to download for free, the brief training video, information on how to score and refer based on the findings of the tool, and a few testimonials.

For parents of children with toileting challenges, dissemination will not be the main aim. They will likely only find their way to the SM-BBQ through a provider who

has the parent fill it out. There will be a portion of the SM-BBQ website that is meant for parents and can answer their questions regarding what it is, what resources exist, and some testimonials of outcomes with appropriate treatment. The aim of this program is to increase knowledge and use of the SM-BBQ after better understanding program outcome data and potential challenges.

CHAPTER SIX

Dissemination Plan

Introduction

The Sensory Modulation - Bowel and Bladder Questionnaire (SM-BBQ) will help as a diagnostic tool for identification of toileting dysfunction related to under-responsiveness to sensory input. The author's methods for creating, piloting, and distributing this tool are based on best practices, having searched the literature to better understand the problem, address it and share this resource with the greater healthcare community.

Dissemination Goals

The dissemination goals for this diagnostic tool are to help healthcare professionals better diagnose and refer children with sensorimotor based bowel and bladder dysfunction, and for families to get the help they need for their children.

Long-Term Goals

- Dissemination will provide healthcare professionals with a diagnostic tool that fills a gap in understanding and identifying toileting dysfunction.
- Dissemination will help therapists who provide sensory integration-based bowel and bladder therapy to be more readily located and utilized.

Short-Term Goals

- Pediatric pelvic health therapists (typically occupational and physical therapists) will have a much-needed tool for screening purposes.

- This tool will provide a greater connection between sensory modulation and toileting accidents (bowel and bladder leaks).
- Linking sensory underpinnings to bowel and bladder dysfunction will help make the case for sensory integration-based treatment.

Target Audiences

Primary Audience

The primary audience for dissemination of this tool is healthcare professionals. In the short-term, pelvic health therapists would be the most likely to use the SM-BBQ to assist in the evaluation process. In the long-term, once standardizing or norm referencing is complete a website will be available for the greater healthcare community to access the SM-BBQ. The author anticipates that pediatricians, gastroenterologists, urologists and psychologists would be likely to use the SM-BBQ and would have the ability to download it for free after viewing a brief training video on the website. They would also be provided with information on how to score the tool and referral options based on results.

Secondary Audience

The secondary audience is parents of children with bowel and/or bladder dysfunction. While dissemination to the parent and caregiver community will not be the main aim, a portion of the website will address their questions and concerns. They will likely find their way to the SM-BBQ through a provider who has them fill it out.

Key Messages

Pediatric occupational therapists

Bowel and bladder management is an activity of daily living. Understanding dysfunction, its basis, and best practices for treatment is essential for providing comprehensive care. Utilizing the SM-BBQ as part of an evaluation when concerns are mentioned regarding toileting will help with finding qualified professionals and formulating appropriate treatment plans.

Pelvic heath therapists

For pelvic health therapists (primarily occupational and physical therapists) the SM-BBQ fills a gap in diagnosis. While the Toileting Habit Profile Questionnaire (THPQ-R) provides an opportunity for identification of children with over-responsiveness to sensory input related to toileting, no tool existed for under-responsiveness. Many pelvic health therapists who were previously unaware of the impact of sensory modulation to toileting may now feel more empowered to identify this connection and gain training to address the challenges from the sensory integration framework.

Pediatric healthcare providers

Pediatric healthcare providers frequently are the first to be asked about toileting expectations and challenges. Providing these professionals with a tool to better understand sensory based toileting dysfunction will lead to earlier detection, more appropriate referrals and faster treatment. In the long-term informing healthcare

professionals is likely to do the most for helping children and their families have improved quality of life.

Parents and caregivers of children

Children with toileting dysfunction often cycle through periods of improvement and regression based on temporary fixes. Traditional treatments have shown a roughly 50% success rate six months to several years after treatment is concluded (Pijpers et al., 2010; Noordhoff et al., 2018). This can be very discouraging for parents and caregivers. The SM-BBQ will offer a chance to find out if sensory modulation plays a role in their child's toileting challenges, and thus if a different method of treatment may be more beneficial.

Sources/Messengers

This author will be the primary messenger. Sahana Baker-Malone is a pelvic health certified therapist through Herman & Wallace as well as a sensory integration certified therapist through University of Southern California & Western Psychological Services. These advanced certifications position the author to both be a reputable spokesperson and resource.

Dr. Isabelle Beaudry-Bellefeuille, an occupational therapist and mentor of this author will be an appropriate messenger. Dr. Beaudry-Bellefeuille is the creator of the Toileting Habit Profile Questionnaire (THPQ-R) a similar tool for sensory over-responsivity. She has stated that she believes the SM-BBQ will fill a gap in understanding and hopes to use it in the future.

Dissemination Activities

Written information

A journal article summarizing the results of this research and pilot study will be completed and submitted to peer-reviewed journals such as *The American Journal of Occupational Therapy*, *The British Journal of Occupational Therapy, The Journal of Urology, The Journal of Pediatrics,* and *The Gastroenterology Research and Practice* within six months of completion of this study. Such an article will help disseminate the results of the study and information about the SM-BBQ to a wider healthcare community.

With regard to the healthcare providers, the dissemination will also occur through a brochure that includes the program's findings and a QR code that directs them to the website. This brochure can be mailed, hand delivered and emailed to professionals.

Electronic Media

A website dedicated to the SM-BBQ and more broadly sensory modulation-based toileting dysfunction will also serve as an ongoing source of information. Professionals and families will be able to access the website for educational purposes, diagnostic tools and a directory of therapists most appropriate for identified difficulties.

Continuing Education Course

This author has created and beta trialed a continuing education course on the connection between sensory integration theory and toileting dysfunction. This will be a way to educate and train more therapists in using the SM-BBQ as well as better meeting the needs of children with these connected challenges. Within a year of the completion of this study, this course will be submitted to the American Occupational Therapy

Association (AOTA) and the American Physical Therapy Association (APTA) in order for therapists to get continuing education credit for the course. The author may also find out if Herman & Wallace want to host this course.

Budget

The majority of the dissemination activities require an investment of time by the author, but minimal financial resources. The proposed larger budget for this study is noted in Chapter 7, Table 7.1 and includes details surrounding the above-mentioned website. Additional expenses are listed in Table 6.1 and include creation and office supplies for mailing brochures as well as submissions of articles for publication.

Table 6.1 Budget for Dissemination

Item	Justification	Year 1	Year 2–3
Brochure creation and dissemination	Creation and dissemination of a brochure will be helpful in getting the word out about the SM-BBQ.	$0	$500–1000 for supplies and mailing
Article submissions	Submission of articles are free with the exception of *The Journal of Urology* which has a fee of $250.	$0	Up $250
Total			Approx. $1000

Evaluation

The dissemination will be successful if the different activities noted previously are completed in a meaningful manner.

- **Written information:** Having a published journal article in a peer-reviewed journal will indicate successful dissemination. Additionally, tracking the metrics of the traffic driven to the website by a brochure will help determine if that method is effective.

- **Electronic media:** Analyzing the overall metrics of the website will provide information as to how it is being used. A quick popup form on the website could also help with gathering details as to what types of individuals are visiting the site and for what purpose.
- **Continuing Education Course:** Gaining continuing education units (CEU) approval through AOTA and APTA for a course in the sensory underpinnings of toileting dysfunction will increase the reach of the SM-BBQ and improve the likelihood of having occupational and physical therapists trained in the tool and the treatment approaches that will be most successful and holistic for sensory based bowel and bladder dysfunction.

Conclusion

The dissemination of this study's results and the SM-BBQ will target two groups: primarily healthcare professionals and secondarily parents/caregivers of children with toileting issues. Dissemination will occur through journal articles, a website, brochures, and a continuing education course provided by this author. The total expenses of dissemination will require approximately $1000 of total budget for the program of $20,800 as noted in Table 7.1. This whole process will occur over 2–3 years and will result in more accurate diagnoses, better foundational knowledge by healthcare professionals and families, as well as an improved path to treatment. In the long-run children and families will have better outcomes with improved quality of life and more independence with activities of daily living.

CHAPTER SEVEN

Funding Plan

Introduction

After identifying a problem and better understanding the gap through a literature review, this author created and piloted a tool for improved understanding of sensory under-responsiveness that impacts bowel or bladder function for children. This chapter will discuss the longer-term funding plan for the completion of norm referencing/standardizing of the Sensory Modulation - Bowel and Bladder Questionnaire (SM-BBQ), as well as the eventual dissemination of this new diagnostic tool. Financial capital is expected to come from a few different sources and can be expanded or reduced depending on the amount of financial support attained.

Fortunately, the creation and piloting phase of the SM-BBQ required minimal funding and were performed as part of this author's doctoral program. The information gained in the initial period was an informative baseline but requires further data collection and analysis to be certain the tool meets the intended goal with meaningful results. The continued work will require many more participants and likely more complex data analysis.

While the costs associated with this program could be reduced to save funds, this chapter will provide a robust proposal for a three-year plan that addresses all potential needs. The author's hope is for the SM-BBQ to be a useful and efficient instrument in the pediatric healthcare community. The intended end goal is for the SM-BBQ to be easily accessible online, with a simple set of training videos, straightforward scoring, and

information for appropriate next steps. Table 7.1 provides a budget for this project. It is broken down into years 1 and 2–3 as that is the dividing line between different types of expenses.

Table 7.1: Budget for Project

Item	Justification	Year 1	Year 2–3
Non-profit incorporation	If the SM-BBQ is being provided free of charge it would make sense to become incorporated as a non-profit entity. This tax-exempt status will allow for benefits such as an unpaid volunteer research assistant.	$800	
Research assistant	Unpaid volunteer or paid assistant ($20/hr., 10 hrs./wk for 48 weeks per year) to help with recruitment and dissemination of the tool.	Up to $9,600	Up to $19,200
Statistician	Hired in the 2nd or 3rd year once data has been collected to analyze the results ($30/hr., 15 hours).	$0	$450
Domain purchase	Easily memorable and individualized website for project will help with professionalism and dissemination.	$300	$0
Website hosting	To have a website requires hosting.	$75	$150
Website creation	An easy to navigate, clean, and professional website will help with recruiting participation in the study as well as dissemination.	$1,500	$0
Dissemination Plan	Creation and dissemination of a brochure will be helpful in disseminating information about the SM-BBQ. Submitting a journal article for review and publication.	$0	$1000
Total		$12,275	$20,800

Available Local Resources

The author is the co-owner of an interdisciplinary sensory integration based pediatric therapy clinic, Development is Child's Play in Cupertino, California. This role provides the author significant resources to help meet the aims of this project. Since this study is in line with the mission, vision, and values of Development is Child's Play,

some of the incurred costs could be assumed by the company. A research assistant will not be challenging to hire as Development is Child's Play has an exceptional reputation and many interested in the therapy professions apply to work at the clinic in an aide role while they pursue relevant higher education. Part of their time could be spent assisting with this research. Additionally, if the larger project surrounding this tool is incorporated as a non-profit entity, an unpaid volunteer could be recruited. Many other small costs could be covered by Development is Child's Play. Items such as office supplies, computer software, and HIPAA compliant storage could easily be provided by the company without the author incurring additional expenses for this project.

The use of a website would be beneficial both as a recruitment tool and for eventual ongoing dissemination. The web content could either be a page on the existing Development is Child's Play website or linked to the clinic's website. If the webpage is part of the Development is Child's Play website, then content could be designed by the company's current designer as part of an existing annual fee. Whereas if a new website were necessary or desirable there would be costs associated with both purchasing the domain and creation of the site.

Additional Costs

Once data is collected, in the second or third year of this plan, a statistician (likely a college or university student) will be hired for up to 15 hours to assist with analyzing the data. It seems possible that a few iterations of data analysis (discussion of results and re-running of data) might occur during this process. Because this person would be a student with specialized skills, it seems likely that pay would be around $30 per hour. If

such an individual were hired for 15 hours the total cost would be $450.

Other Potential Funding Sources

Other opportunities for funding exist in grants. This author found a variety of grants to apply for as either a sole researcher or in association with a couple of other professionals involved in the pediatric pelvic health and/or sensory integration fields. The Intervention Research Grant Program (an AOTF scholarship) would provide a one year, $50,000 grant for research that improves occupational therapy intervention. Similarly, the American Physical Therapy Association's Academy of Pelvic Health Physical Therapy's Research Grant awards $10,000 for research in the field of pelvic heath. A less specifically occupational therapy related funding source is the Robert Wood Johnson Foundation (https://www.rwjf.org/en/grants/active-funding-opportunities.html?o=1&us=1) which provides numerous grant opportunities in the area of children and healthcare. Table 7.2 provides information on the evaluated potential funding sources.

Table 7.2: Potential Funding Sources

Grants	Amount	Funding Source
The Intervention Research Grant Program	$50,000	AOTF
Academy of Pelvic Health Physical Therapy's Research Grant	$10,000	APTA
Healthcare related grants	Various amounts	Robert Wood Johnson Foundation

Conclusion

This program, over the course of three years will bring to fruition a tool and improved knowledge to help families of children with bowel and/or bladder dysfunction related to sensory under-responsiveness. While this is quite a large undertaking for a 26-item parent questionnaire, the hope is that not only will parents be able to better able to find an underlying cause for their child's toileting challenges, but efficiency will be improved with regard to referrals for appropriate treatment if needed and healthcare professionals will have more knowledge and expertise in an area of everyday function.

CHAPTER EIGHT

Conclusion

Using the toilet for bowel and bladder elimination seems so simple when everything goes right. It is a daily occupation that when successfully performed allows for dignity and independence. At the same time, it is typically something about which most humans use very little conscious thought. But toileting, like many other basic human processes or activities of daily living relies on a variety of underlying systems to be working well.

This doctoral project fits in the broader context of occupational therapy and its aim for occupational justice and improving wellbeing. According to Tatlow-Golden et al. (2017) who studied kindergarteners gaining independence with the occupation of toileting

> "avoiding incontinence and being able to use the toilet when needed is important for bladder and bowel health and is influenced not only by the physiology of their individual bodily control but also by a range of individual, social, and contextual factors…toileting and continence is likely to be affected by their immersion in school and play activities, desire for personal privacy and social anxiety, ability to negotiate physical and social environments, teachers' classroom management practices, and the quality of toilet facilities including cleanliness and toilet accessibility" (p. 215).

The implications of these successes or failures can last a lifetime. It is both unjust and troubling that factors outside a child's control can play such a central role in toileting.

Many individuals spend large portions of their childhood in environments where the conditions surrounding toileting are not optimal, and at times highly stressful. The result is that only narrow band children are being well accommodated in situations where toileting is at the discretion of adults in the children's lives and occurs in bathrooms that can increase anxiety and sensory overload.

In utilizing ASI as the theoretical lens for this doctoral project, the author has chosen a framework that fits with toileting being an interplay between environmental/social expectations and the individual's sensorimotor integration/modulation. As Ayres (1979) stated "when the flow of sensations is disorganized, life can be like a rush hour traffic jam" (Ayres and Robbins p.5). The goal of this project is to help healthcare professionals and families to better understand how sensory input that is inaccurately or not perceived, disorganized, or poorly modulated can impact toileting and what can be done to help. The recent, more complex appreciation of interoception as the "8th sense" also provides more nuance to understanding and addressing bowel and bladder dysfunction.

Explaining the many factors within and outside of a child that could possibly result in their "adaptive response" to bowel and bladder emptying being dysfunctional helps takes the blame for any challenges off the child. These challenges are then more appropriately placed into a space where brain/body/environment can be analyzed, comprehended, and addressed for improved function. Ayres (1972) stated that an adaptive response "is the action or reaction of the organism to the environment acting upon the organism" (p. 126). With homeostasis as the underlying driver for human

survival, it is clear why leakage of urine and or stool would eventually be necessary if urges are not felt or addressed. Reducing blame and shame while increasing understanding and treatment are the objectives of this doctoral work.

APPENDIX

Appendix A: Sensory Modulation–Bowel and Bladder Questionnaire (SM-BBQ)

Bowel and Bladder Sensory Questionnaire
Sahana Baker-Malone, MA, OTR/L

	Always	Most of the time	Half of the time	Occasionally	Never
1) My child poops in their clothes without noticing					
2) My child urinates in their clothes without noticing					
3) My child does not make it to the toilet in time					
4) My child does not want to stop what they are doing to get to the potty					
5) My child does not seem aware of when they are doing the "potty dance"					
6) My child does not seem to notice when they have to use the potty					
7) My child sits on the potty for a long time when pooping					
8) My child is not aware of when they are done pooping					
9) My child takes a long time to initiate pooping after sitting down on the potty					
10) My child is surprised when pee or poop comes out					
11) My child does not cry when they are injured					
12) My child does not notice when they are hungry, or does not notice until they are "hangry"					
13) My child prefers spicy foods/strong flavors					
14) My child does not know when they are messy (food on face, runny nose, clothing twisted)					
15) My child melts into surfaces and/or people					
16) My child bumps into people and/or objects					
17) My child prefers sedentary play					
18) My child "w-sits" on the floor most of the time (knees together feet to sides)					

	Always	Most of the time	Half of the time	Occasionally	Never
19) My child has a dampened awareness to sound (does not respond right away to their name being called, less aware of loud noises, or talks with a loud voice)					
20) My child observes play but does not participate right away					
21) My child takes longer than normal to learn new motor skills					
22) My child has difficulty imitating others					
23) My child uses too much or too little force when doing things					
24) My child has vomited without warning					
25) My child is less aware of temperature (tolerates or seems oblivious of more extreme temperatures)					
26) My child can spin for a long time without getting nauseous or dizzy					

Appendix B: Sensory Processing Measure-2 (SPM-2) Hypo-Responsive Items

Preschool Home Form **3–5 year-old study participants**	**Child Home Form** **5–12 year-old study participants**
VISION	VISION
#2	#2
#5	
	HEARING
HEARING	#13
#18	#14
TOUCH	TOUCH
#24	#26
#28	#28
#29	#29
TASTE AND SMELL	TASTE AND SMELL
#32	#33
	#40
BODY AWARENESS	
#41	BODY AWARENESS
#42	#41
#43	#43
#44	#45
#45	#46
#48	#49
#49	
#50	BALANCE AND MOTION
	#53
BALANCE AND MOTION	#54
#53	#59
#54	
#55	

Appendix C: Correlation coefficients for the SPM-2 subtest scores and SM-BBQ and THPQ-R

SM-BBQ and SPM-2 3-5 yr:

Vision:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.64506574	-0.7277429

Hearing:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.55565345	-0.6003499

Touch:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.71053284	-0.6563954

Taste and Smell:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.88418427	-0.8271702

Body Awareness:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.57076325	-0.9161588

Balance and Motion:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.90414153	-0.7886933

Planning and Ideas:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.84581506	-0.955929

Social Participation:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.21370549	-0.3957797

SM-BBQ and SPM-2 5 yr+:

Vision:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.57950267	-0.0398654

Hearing:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.42859584	-0.0268912

Touch:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.40855142	0.039813

Taste and Smell:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.27154261	-0.1698974

Body Awareness:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.67181736	-0.2045999

Balance and Motion:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.72914897	-0.2920042

Planning and Ideas:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.87336841	-0.188071

Social Participation:

SM-BBQ And SPM-2	THPQ-R And SPM-2
0.7382206	0.10552266

Appendix D: Consent Form for Participation in Study

Study Title: Sensory Integration and Bowel and Bladder Dysfunction

Please note that this study is part of a doctoral research project performed by Sahana Baker- Malone, MA, OTR/L as part of the Occupational Therapy department of Boston University's Sargent College.

You are being asked to take part in this voluntary research study because you have indicated that your child has bowel and/or bladder dysfunction.

In this study, the researcher is utilizing survey data to learn more about the role that sensory processing challenges play in bowel and bladder/pelvic floor dysfunction.

What will happen if I take part in this study?

If you agree to be in this study, you will complete a set of surveys/questionnaires. It will take you about *30 minutes* to complete the main portion of the study. There is an additional questionnaire to be filled out by you with regard to your child's bowel habits for 1 week.

How will my information be used?

Researchers will use your information to conduct this study. Once the study is done using your information, we may share it with other researchers so they can use it for other studies in the future. We will not share any personal or identifiable information that would let the researchers know who you or your child are. We will not ask you for additional permission to share this de-identified information.

Are there any risks to me or my child's privacy?

The main risk of allowing us to use and store the information you provide us for research is a potential loss of privacy. We will do our best to protect the information we collect from you. Information that could potentially identify you will be kept secure. The survey itself will not include details that directly identify you or your child, such as your name or address. Please do not put this information on your surveys. Only researchers on this study will have direct access to study documents. If this study is published or presented at scientific meetings, names and other information that might identify you or your child will not be used.

The following people or groups may review your study records for purposes such as quality control or safety: the Institutional Review Board (IRB) at Boston University, any

potential sponsor or funding agency for the study, federal and state agencies that oversee or review research, Central University Offices.

Are there any benefits?

There is no direct benefit to you. The survey results will be used for research.

Can I say "No"?

Yes, you do not have to complete a survey. If you choose not to be in this study you will not lose any of your regular benefits.

Are there any payments or costs?

You will not be paid for completing the survey. There are no costs to you.

Who can answer my questions about the study?

You can talk with the study researcher about any questions, concerns, or complaints you have about this study. Contact the study researcher: Sahana Baker-Malone at [redacted]. Kevin Berner, the academic advisor for this study can also be contacted at [redacted].

If you have questions or concerns, you may also contact: Boston University Charles River Campus IRB at 617-358-6115. The IRB Office webpage has information where you can learn more about being a participant in research, and you can also complete a Participant Feedback Survey.

Statement of Consent

I have read the information in this consent form including risks and possible benefits. I have been given the chance to ask questions. My questions have been answered to my satisfaction, and I agree to participate in the study.

Appendix E: Demographic Questionnaire

Demographic Questionnaire
Child's Age in years and months (i.e., 7years, 4 months): _____

Child's gender: ☐ Male ☐ Female ☐ Gender non-binary ☐ Gender fluid Type of bowel and/or bladder dysfunction (list all that apply):

☐ Constipation
☐ Encopresis/poop leaks/accidents
☐ Loose stool/diarrhea
☐ Incomplete emptying of bowels
☐ Withholding of bowel movements ☐ Pain before/with bowel movements ☐ Rectal prolapse

☐ Urine leaks/accidents
☐ Urinary urgency
☐ Urinary frequency
☐ Stress incontinence
☐ Giggle incontinence
☐ Incomplete emptying of bladder ☐ Withholding of urine

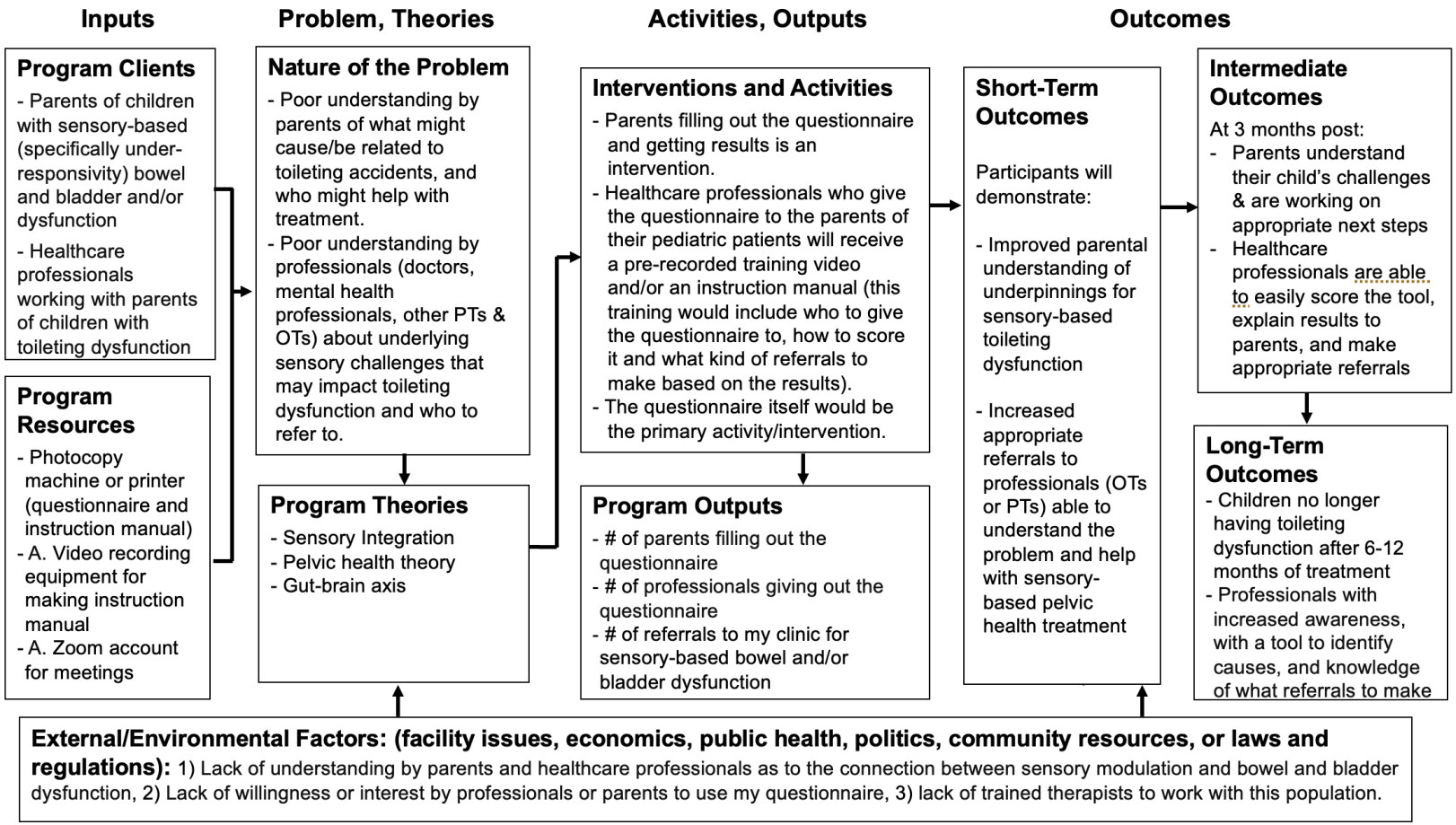
For how long have these problems occurred: _____

Have the problems changed over time? ☐Yes ☐No

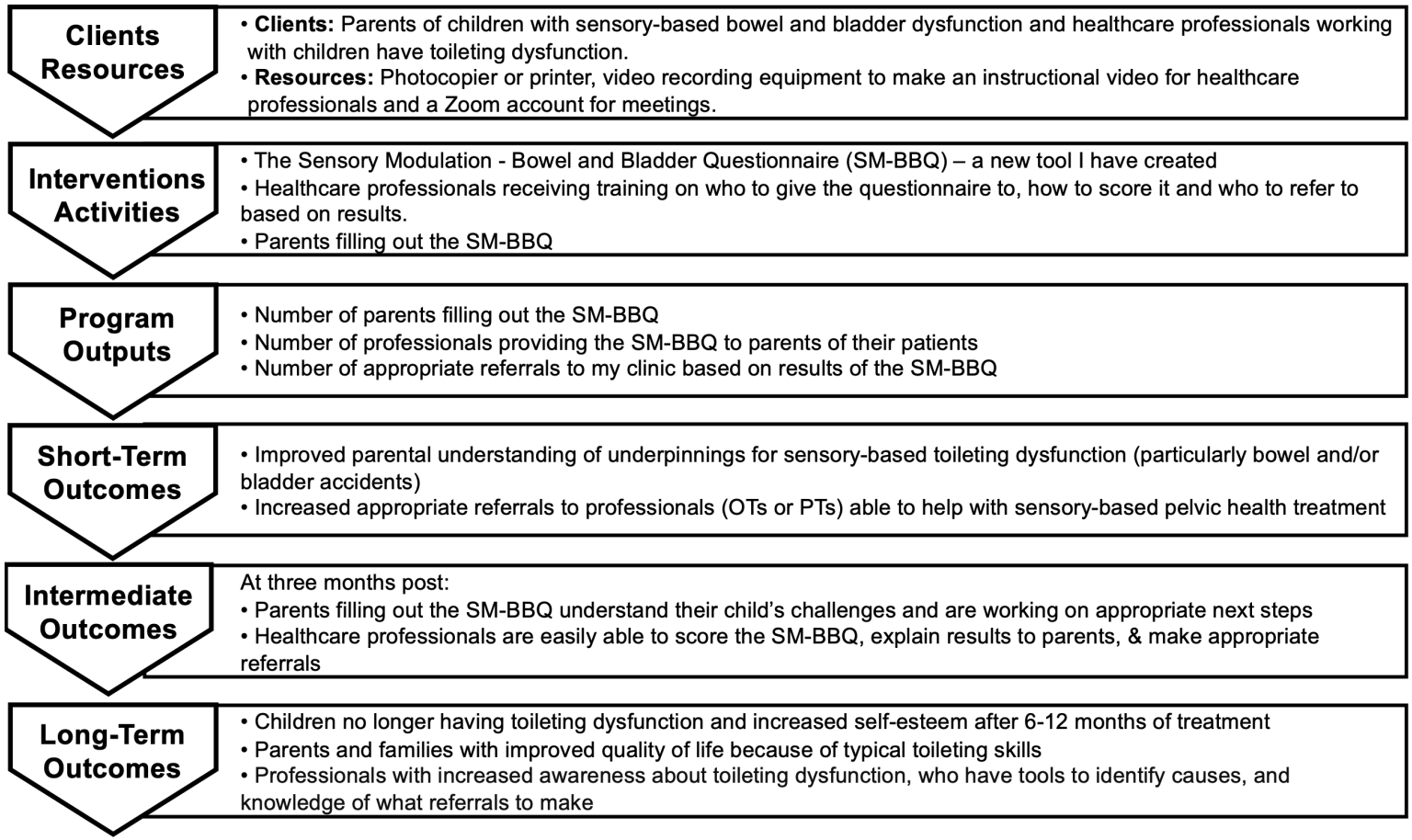
If yes, how:
_____
_____
_____

Please list previous treatments/medications:
_____
_____
_____
_____
_____
_____

Appendix F: Logic model for The SM-BBQ: Pilot Dissemination Program



Appendix G: Simplified Logic model for The Sensory Modulation - Bowel and Bladder Questionnaire (SM-BBQ): Pilot Dissemination Program



Appendix H: Stakeholder Program Evaluation Research Questions

Stakeholder or Stakeholder Group	**Types of Program Evaluation Research Questions**
The author/ primary researcher	***Formative:*** • Are healthcare providers aware of the SM-BBQ? • What does broad dissemination look like for the SM-BBQ? ***Summative:*** • Does data show improved quality of life for those who use the SM-BBQ? • Has giving the tool improved patient care for the healthcare providers?
Primary intended users: Parents of children with toileting challenges	***Summative:*** • Did you understand and easily complete the questionnaire? • How long did the questionnaire take to complete? • Were the questions relevant to your child's challenges? • Did the SM-BBQ provide you with a better understanding of your child's toileting difficulties? • What services was your child referred to following filling out the SM-BBQ? • How fast was your child referred to appropriate professionals? • Has your and/or your child's quality of life improved after using the SM-BBQ? • Have your child's toileting challenges improved 3 months or 6 months after using the SM-BBQ and being referred to services? Which improvements?
Healthcare providers: physicians, psychologists, therapists	***Summative:*** • Were you aware of toileting dysfunction for children and its potential causes and effects? Do you feel more informed now? • What tools are you currently using to diagnose toileting dysfunction? • Was the information in the training prior to giving the SM-BBQ relevant? • Was the information presented too easy or too complicated? • Was teaching delivered at an optimal pace for learning? • Was the instruction sufficient for you to feel comfortable knowing when to give the SM-BBQ?

	• Was the instruction sufficient for you to feel comfortable scoring the SM-BBQ? • Was the instruction sufficient for you to feel comfortable explaining the results of the SM-BBQ? • Did you feel adequately equipped to make an appropriate referral? • Do you feel able to identify children with toileting challenges? • Have you created a procedure for building the SM-BBQ and other toileting dysfunction diagnostic tools into your practice? • Did the parents of your patients seem to understand their children's toileting difficulties?

***** The questions noted for the author are just that, questions and not to be evaluated in a formal manner.

Appendix I: Executive Summary for Toileting Dysfunction in Children with Sensory Under-responsiveness: the Sensory Modulation Bowel and Bladder Questionnaire (SM-BBQ)

Introduction

The current gold standard for addressing bowel and bladder dysfunction is urotherapy and medication. Urotherapy encompasses education regarding the anatomy and function of the lower urinary tract (LUT), behavior modifications including fluid intake, removing or managing bladder irritants, diet changes, timed or scheduled voids, toilet postures and avoidance of holding maneuvers, manual therapy and biofeedback. For bowel challenges, similar methods to urotherapy are typically employed. These forms of treatment have shown a roughly 50% success rate six months to several years after treatment is concluded (Pijpers et al., 2010 and Noordhoff et al., 2018). Bongers et al., 2010 showed that 25% of children with chronic constipation continued to experience symptoms into adulthood, even after treatment. While the previously mentioned treatment methods are often necessary and appropriate, they fail to address the central role that sensory processing, sensory integration, and emotional regulation play in basic biological functions and homeostasis.

Theoretical Foundations

Sensory integration is defined as “the organization of sensory input for use” (Spitzer and Smith Roley, p. 5). There are eight sensory systems: vision, auditory, tactile, olfactory, gustatory, vestibular, proprioceptive, and interoceptive. These are systems that take in and process information from within and outside of the body. Sensory integration

disorders can be classified as Sensory Modulation Disorders, Sensory Discrimination Disorders and Sensory-Based Motor Disorders (Bundy & Murray 2002 & Miller et al., 2007). Individuals with modulation disorders tend to experience sensations as too intense to tolerate or too mild to provide an accurate picture, while those with discrimination disorders tend to have difficulty with interpreting the meanings of sensations. People with sensory-based motor dysfunction have a form of dyspraxia, or difficulty with ideation, motor planning and execution of novel tasks often involving coordination (Bundy & Murray, 2002). Ayres Sensory Integration is a meaningful and appropriate framework with which to better understand bowel and bladder dysfunction that often appears untreatable and becomes chronic and impacts daily occupational success.

Project Overview

This doctoral project is an attempt to create and pilot a questionnaire to help identify children who have bowel and/or bladder dysfunction related to sensory under-responsivity. The author has created the Sensory Modulation Bowel and Bladder Questionnaire (SM-BBQ) to meet these diagnostic needs.

This pilot study involved recruitment of participants with the use of fliers and emails to healthcare and community members. Participants were the parents of children identified as being between the ages of three and 13 years of age, who seemed physiologically be able to use the toilet, but demonstrated bowel or bladder dysfunction. These individuals filled out three questionnaires, a general information form (which not contain the name or other identifying information), and some, but not all of them also filled out a daily Stool Questionnaire adapted from the MCRI-Barts-London Stool Sheet

by Adeline Foo for her doctoral project regarding hypo-responsiveness and defecation (Foo, 2016).

Twenty participants took part in this pilot study between June 2022 and March 2023. The study compared scores on the author's Sensory Modulation-Bowel and Bladder Questionnaire (SM-BBQ) with 2 existing reliable and valid measures. The Toileting Habits Profile Questionnaire (THPQ) is a parent questionnaire that helps identify children who have hyper-responsiveness to sensory input that impacts toileting, and The Sensory Processing Measure-2 (SPM-2) is a parent questionnaire used to understand how sensory processing challenges in different areas impact function. The SM-BBQ is attempting to fill a gap in understanding of bowel and bladder dysfunction by demonstrating a link between toileting dysfunction and sensory hypo-responsivity. A seven-day sensory-based bowel movement questionnaire was also provided to gain additional understanding but was only completed by half of the participants.

Key Findings

The results of this pilot study focused on a few specific areas. Since the purpose of the study was to create and pilot a tool that could help identify children who have bowel or bladder dysfunction due to sensory under-responsivity a current tool that could help determine hypo-responsivity was needed. Questions from the SPM-2 were analyzed by the author and a panel of experts in Sensory Integration. Eighteen questions in the 3–5-year-old SPM-2 and 16 questions in the 5–12-year-old SPM-2 were determined to be indictive of hypo-responsivity in various sensory systems.

Hypo-responsiveness on the SPM-2 and SM-BBQ score:

- A correlation coefficient was calculated to determine the correlation between the children who demonstrated hypo-responsiveness on the SPM-2 and their SM-BBQ score. **The correlation coefficient is 0.60.** While some of the hypo-responsive children fell below a score of 59 on the SM-BBQ, which is what the author believes to be a likely significance score, all participants above the line are hypo-responsive.

- **Children leaking both urine and stool and demonstrated hypo-responsiveness on the SPM-2, and SM-BBQ score:**
  - A correlation coefficient was calculated to determine the correlation between the children who leaked both urine and stool and demonstrated hypo-responsiveness on the SPM-2 and their SM-BBQ score. **The correlation coefficient is 0.84.** All the hypo-responsive children who leaked both urine and stool had an SM-BBQ of 59 or higher.
- **Link between the SPM-2 scale scores and the scores on both the SM-BBQ and the THPQ-R:** A higher score on the SPM-2 scales indicates more challenges but does not break down the challenges into hypo- or hyper- responsivity. For this reason, this author did not have a hypothesis about how the data on the SM-BBQ or the THPQ-R and the SPM-2 scale scores would correlate. Also, a higher score on the SM-BBQ appears to indicate more challenges and a lower score on the THPQ-R is indictive of more challenges.

- **3–5-year-old SPM-2 group - five most significant correlation coefficients for the SPM-2 scale scores and the SM-BBQ:**
  - Balance and Motion (Vestibular) 0.90
  - Taste and Smell 0.88
  - Planning and Ideas (Praxis) 0.85,
  - Touch 0.71
  - Vision 0.65.
- **5–12-year-old SPM-2 group - five most significant correlation coefficients for the SPM-2 scale scores and the SM-BBQ:**
  - Planning and Ideas (Praxis) 0.87
  - *Social Participation 0.74
  - Balance and Motion (Vestibular) 0.73
  - Body Awareness (Proprioception) 0.6
  - Vision 0.58.

  *One important note is that for Social Participation a higher score indicates more social aptitude, not social challenges. A positive correlation thus indicates that children with more toileting challenges likely have more social challenges as well.
- **3–5-year-old SPM-2 group - five most significant correlation coefficients for the SPM-2 scale scores and the THPQ-R:**
  - Planning and Ideas (Praxis) -0.96
  - Body Awareness -0.92
  - Taste and Smell -0.83
  - Balance and Motion (Vestibular)-0.79
  - Vision -0.73.
- **In the 5–12-year-old SPM-2 group no significant correlation coefficients were found between the SPM-2 scale scores and the THPQ-R.**

Interpretation

In contemplating how these findings fit in with Ayres Sensory Integration theory, it is important to note that perception and threshold may be more relevant than responsivity. Several of the same participants were noted to be both hypo- and hyper-responsive, scoring in the significant range on both the SM-BBQ and THPQ-R, and on the SPM-2 items that denote hypo- and hyper-responsivity. This can be explained in two meaningful ways: 1) children with toileting dysfunction appear to have a narrow window of "just right awareness." These children do not feel sensations until they rise to an almost "boiling point" at which time they are felt very intensely and often becomes painful, uncomfortable, or otherwise noxious. At this point the sensations are often both unbearable and need to be dealt with immediately. If the sensations relate to toileting and are not felt until that boiling point is reached, urine or stool may be leaking out before the situation is remedied by cognitively driven action; and 2) the internal sensory signals (interoception) are competing with signals from the proprioceptive system related to the pull of gravity on one's body, and also sensory signals from outside one's body. If attention is pulled outward such as in cases of hyper-sensitivity to visual or auditory input, perception as a limited commodity may not be used for homeostatic functions until after the child leaks urine and/or stool.

Recommendations

While 20 participants are a meaningful number for a pilot study, a larger scale follow-up study will need to be conducted to ensure that the SM-BBQ is a reliable and valid measure for identifying children with toileting dysfunction related to sensory

perception and helping those families to then seek appropriate services.

General Conclusions

When envisioning the role of occupational therapy, it is vital to note that it is a profession tasked with understanding, identifying, and addressing activities of daily living. When specifically looking at a toileting questionnaire, Beaudry-Bellefeuille et al. (2016) noted that while "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…these tools do not include items related to toileting, a crucial childhood occupation" (pp. 172). This lack of caregiver questionnaires for such a vital daily occupation means that understanding, diagnosis, and treatment of sensory-based toileting dysfunction leaves many families with no idea of where to turn for help and most occupational and physical therapists under-trained for the task.

Appendix J: Factsheet for Doctoral Presentation

BOSTON UNIVERSITY

Toileting Dysfunction in Children with Sensory Under-responsiveness: the Sensory Modulation - Bowel and Bladder Questionnaire (SM-BBQ)

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https://www.nicepng.com/

Sensory Modulation - Bowel and Badder Questionnaire (SM-BBQ) is an evidence-based parent questionnaire/diagnostic tool, created to help identify and determine the best treatment for pediatric bowel and bladder dysfuction related to sensory under-responsiveness.

Bowel and Bladder Dysfunction

Traditional forms of treatment for bowel and bladder dysfunction have shown a roughly 50% success rate six months to several years after treatment is concluded (Pijpers et al., 2010 and Noordhoff et al., 2018). Bongers et al., 2010 showed that 25% of children with chronic constipation continued to experience symptoms into adulthood, even after treatment.

A Lens for Understanding What is Missing

Sensory integration is defined as "the organization of sensory input for use" (Spitzer and Smith Roley, p. 5). Sensory integration disorders can be classified as Sensory Modulation Disorders, Sensory Discrimination Disorders and Sensory-Based Motor Disorders (Bundy et al., 2002 & Miller et al., 2007). Individuals with modulation disorders tend to experience sensations as too intense to tolerate or too mild to provide an accurate picture, while those with discrimination disorders tend to have difficulty with interpreting the meanings of sensations. (Bundy & Murray, 2002).

Gaps in Current Tools and Treatment

Sensory over-responsiveness and sensory sensitivities, both result from input feeling too intense and are common in children with chronic constipation and/or retentive fecal incontinence (Beaudry-Bellefeuille, & Lane, 2017; Little et al., 2019, & Mazurek et al., 2013).

Under-responsiveness may lead to leaks of urine or feces if the individual is unaware of its presense. Beaudry-Bellefeuille et al. (2019) noted that while her tool The Toielting Habits Profile Questionnaire (THPQ-R) was able to identify children with bowel dysfunction related to sensory over-responsivity, "the THPQ-R cannot be used to clearly identify sensory under-reactivity and/or poor perception and its relationship with challenging defecation behavior. This is something to consider for future work" (pp. 244).

Results and next steps

Results of this pilot study show a statistically significant correlations in the following areas:

- A **strong positive correlation of 0.84** between the children who leaked both urine and stool and demonstrated hypo-responsiveness on the SPM-2 and their **SM-BBQ score.**
- A **postitive correlation of 0.60** between children who demonstrated hypo-responsiveness on the SPM-2 and their SM-BBQ score.
- Most significant correlation coefficients in the 3-5 year old age group for the SPM-2 scale scores and the SM-BBQ were in:
  - **Balance and Motion (Vestibular) 0.90**, **Taste and Smell 0.88**, and **Planning and Ideas (Praxis) 0.85**
- Most significant correlation coefficients in the 5-12 age group were in:
  - **Planning and Ideas (Praxis) 0.87**, **Social Participation 0.74**, and **Balance and Motion (Vestibular) 0.73**

The next steps will be to revise the SM-BBQ and perform a largescale study across demographics and countries. The hope is that after this next phase the SM-BBQ will be ready for dissemination and use by healthcare professionals. This tool should help improve diagnosis, treatment, and outcomes.

https://depositphotos.com/

"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…these tools do not include items related to toileting, a crucial childhood occupation"

- Beaudry-Bellefeuille et al. (2016)

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