"De boa com o intestino neurogênico": a report on technological innovation based on design thinking

ABSTRACT

Objective: To describe the processes used to develop the prototype of a program for support and assistance to parents (entitled “De boa com o intestino neurogênico”) applicable to intestinal rehabilitation in the pediatric population using transanal irrigation. Methods: This report on technological innovation uses the design thinking approach to develop a prototype digital educational technology for neurogenic bowel management. This represents a process and a product created as part of a Master’s in Nursing program. Results: The prototype development followed the stages of design thinking: empathy, immersion, ideation, and prototyping. A toolkit was developed to support parents of children with neurogenic bowel dysfunction using transanal irrigation. Conclusion: The design thinking approach and methodology expanded the horizon of care interventions by focusing on families. An innovative solution based on empathy, collaboration, and experimentation was proposed.

Descriptors: User-Centered Design; Neurogenic Bowel; Technological Development and Innovation Projects.

INTRODUCTION

Dealing with complex human health issues is inherent to nursing. To provide quality care, technological innovation has historically been embedded in nursing practice, both as a product and a process. One notable example dates back to the 1950s and 1960s when nurse Bessie Blount Griffin developed an electronic system for people with self-feeding limitations(1).
With the challenges of providing quality care and reducing costs, digital health plays a prominent role in technological innovation. Despite the resistance of some nurses to the digital realm, nursing is urgently needed to play a more significant role in driving technological innovation in healthcare (2).

Within this scenario, design thinking (DT) emerges as a means to foster innovation (3,4). DT involves a process of idea generation to address complex problems through an understanding of user wants and needs. This is achieved through rapid, action-oriented prototyping of solutions (2,5).

The design field originated with conceptualizing and creating material objects and has evolved to encompass crafting experiences. DT has been applied in various healthcare settings and conditions, although its application can vary. It can lead to usable, acceptable, and effective interventions, with an increased focus on the needs of patients and caregivers (4). In healthcare, DT is human-centered (2,5), inspired by humanistic and empathetic values, and aims to ensure the quality of services and products. It affirms respect for the customer profile (6).

Therefore, DT is an approach that can be used to find solutions that promote improved care in the context of advanced practice nursing in uropediatrics. In the current study, the context in which DT will be the tool for technological innovation is managing neurogenic bowel dysfunction in the pediatric population. Neurogenic bowel dysfunction is characterized by gastrointestinal and anorectal dysfunction resulting in varying degrees of constipation and fecal incontinence (FI). In the pediatric population, it is primarily associated with congenital malformations, particularly spina bifida, anorectal malformations, and acquired injuries such as spinal cord trauma. These conditions are associated with gastrointestinal symptoms such as abdominal pain and distention, anorectal complications, and a negative impact on bladder dysfunction (7-9). In addition, regardless of the amount or frequency of fecal loss, incontinence can cause sadness and embarrassment, affecting the child’s social relationships, self-esteem, independence, and overall quality of life (7,8,10,11). The negative impact extends to the family, with half of parents of children with spina bifida citing FI as their primary caregiving concern (7).

Bowel rehabilitation is suggested to treat constipation, achieve social bowel continence, and promote independence to manage neurogenic bowel dysfunction (7,8,12,14). Studies show that a proactive and systematic approach can lead to a more functional lifestyle and that satisfactory bowel management improves the quality of life (7,12,14). Treatment should be approached with interventions ranging from less to more invasive, tailored to the patient’s mobility, cognitive abilities, and social circumstances, focusing on the patient and their family (7,8,12,14). This is a significant challenge for the healthcare team.

For more than 20 years, studies have shown that transanal irrigation (TAI) is a safe and effective method for cases that are refractory to initial bowel management approaches such as dietary management, biofeedback training, anorectal stimulation maneuvers, and the use of laxatives (12-14). TAI allows the primary caregiver to insert a rectal catheter with an inflatable balloon or cone device into the child’s rectum, through which they administer an irrigation solution to promote regular bowel movements (12-15). This is usually done in the home environment daily or on alternate days, depending on the child’s needs (13,14). While various devices are available for TAI, these devices are not approved in Brazil, necessitating treatment with a colostomy irrigation kit (13,15). This kit consists of a flexible cone with an extension tube and a transparent bag with a capacity of 2000 mL, equipped with an integrated thermometer. This system has been mentioned in international (12,13,14,16) articles and national literature (15) as a safe, effective device for TAI.

Studies often evaluate clinical outcomes and their impact on quality of life. However, only some studies focus on the patient and family experience and how to improve it (13,17). This work aims to describe the processes used in developing the prototype of a program to support and assist parents with applicability in the intestinal rehabilitation of the pediatric population with TAI using the principles of DT. The name of this tool is "De boa com o intestino neurogênico."
METHODS
This is a technology innovation report detailing the development of a prototype toolkit to support and assist parents of children and adolescents with neurogenic bowel disease using TAI. The DT approach was used in the development of the prototype, which served as both a process and a product within the framework of the Urological Care in Lifecycles in Clinical Practice and Research course in the Master's in Nursing program at the University of Brasilia during the first semester of 2022. DT is an approach that describes principles and strategies through which innovations are developed in an iterative and creative process. Because of its iterative and collaborative nature(3,5,6), the process was often revisited and modified after reflections following meetings with the professor and graduate students. This approach includes five stages: empathizing with the end users of innovations, the Empathy/Discovery phase; defining the basic principles that will guide the work, the Immersion/Definition phase; conceptualizing all possible solutions, the Ideation phase; Prototyping/Experimentation, where prototypes are created to make ideas tangible; and the rapid solution Testing phase, also known as Experimentation(3,5).

RESULTS
The results correspond to the prototype development process and are presented according to the DT phases:

Step 1 - Empathy/Immersion
This stage is about understanding the wants and needs of the people involved in the problem(3). During the initial empathy stage, one must consider the solution’s end user and their core values and perspectives (5). Stakeholders in this process include children/youth, primary parents or caregivers, and healthcare professionals involved in bowel rehabilitation. Considering that parents play a central role in the decision-making process to initiate and maintain treatment until their child becomes independent and that neurogenic bowel dysfunction is a chronic condition that requires most care to be provided outside of healthcare facilities, the decision was made to consider them as the end users of the solution. The Empathy Map tool(18) (Figure 1) was chosen to operationalize this stage, and the gaps were filled based on a qualitative study of parents’ perceptions of TAI(17). In addition, the author’s experience working in a rehabilitation center where she follows children with neurogenic bladder and bowel dysfunction was incorporated into the process.
The four main findings from the study by Sanders and Bray's(17) regarding parent and professional perceptions of TAI emphasized the need for a comprehensive assessment before initiating TAI, followed by an initial, comprehensive education(17). Ongoing support positively impacted the family's ability to adopt, persist, and confidently manage irrigation with their child.

In this study, parents and professionals identified the need for access to resources to improve their problem-solving skills(17).

Proper training in the procedure and ongoing support positively influenced parents' thinking and built their confidence to ask their child's doctor if they could try irrigation(17).

Weaknesses
- Little access to reliable information (through sharing of experiences in mothers' groups or even from unprepared professionals) and the risk of starting the procedure without training;
- Distance from reference centers for bowel rehabilitation;
- There are few Brazilian publications on this subject, and they do not suggest how to proceed with longitudinal follow-up (15);
- Promotion of independence vs. concern for the child's ability.

Gains
- TAI is a valuable option in the management of FI: safe, effective, and associated with child-family satisfaction.
- Telemedicine allows access to patients from different regions of the country and can contribute to continuity of care and greater family confidence;
- Parents seek information about the procedure; Importance of nurse support.

The user context for those who will benefit from the desired solutions in this work is that of parents/caregivers of children with neurogenic bowel dysfunction in Brazil.

**Step 2 – Problem Definition**

At this stage, it is time to interpret the information and define the problem(3).

Although TAI is a safe, effective strategy for improving fecal incontinence, some parents may be uncomfortable with the procedure, leading to a lack of confidence(17).

![Empathy Map based on parents' perceptions of children with spina bifida. Brasília, DF, Brazil, 2022](https://example.com/empathy_map.png)
support were also identified as critical to adherence and success with the technique, even without face-to-face support\(^{19,14}\). Using the problem definition matrix tool (Figure 2), it was possible to narrow down the problem to be addressed\(^{18}\), considering the skills and fundamental principles that will structure the work ahead\(^{5}\).

**Figure 2** – Problem definition matrix for parents of children with neurogenic bowel dysfunction. Brasília, DF, Brazil, 2022

<table>
<thead>
<tr>
<th>Key questions</th>
<th>Answers</th>
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<tbody>
<tr>
<td><strong>What is the main issue and why is it important?</strong></td>
<td>Parents are key players in the continuity of care and can have negative feelings about FI and managing TAI, especially if they do not have the necessary educational support and follow-up. If they do not feel confident, they may not adhere, or they may have difficulties that could lead to further suffering for themselves and their child.</td>
</tr>
<tr>
<td><strong>For whom is that a problem?</strong></td>
<td>For parents, children, and professionals.</td>
</tr>
<tr>
<td><strong>What are the consequences of this problem that affect people the most?</strong></td>
<td>Suffering associated with the maintenance of FI due to failure of the therapeutic regimen (due to nonadherence or improper implementation) and suffering associated with treatment(^{17,10}).</td>
</tr>
<tr>
<td><strong>Can you think of this problem differently?</strong></td>
<td>The problem can be greatly minimized with family involvement, empowerment, and ongoing support(^{17,19}).</td>
</tr>
<tr>
<td><strong>What social and cultural factors affect this problem?</strong></td>
<td>It is socially unacceptable to defecate in public; there are beliefs associated with procedures in the anal region (“being invasive or abusive”) (^{17}).</td>
</tr>
<tr>
<td><strong>Can you define the problem in one sentence?</strong></td>
<td>There is a lack of access to tools to help educate parents in the process of caring for their child who requires advanced bowel management with TAI.</td>
</tr>
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**Step 3 – Ideation**

This phase aims to find a solution to the problem by generating creative ideas using specific tools. The first tool used was brainstorming\(^{18}\). In this initial phase, ideas were generated from all actors involved in the problem – professionals, children/youth, health services, and families. After group reflection and using the “desk research” tool\(^{18}\), which involves seeking additional information from different sources, new ideas were generated, as shown in Figure 3.
Figure 3 - Brainstorming solutions. Brasília, DF, Brazil, 2022

2. "Golden Tips" and "Problem-Solving": This session summarizes guidelines for strategies that promote better outcomes, the major problems that can occur during and after the TAI procedure, and suggested solutions for each problem.

3. Support/Monitoring: This session is designed to assist families in implementing TAI care and achieving success with this strategy through tools that can guide treatment adjustments, such as an evacuation diary. The evacuation diary includes procedural details, such as the amount and type of irrigation used, bowel movements, and descriptions based on the pediatric Bristol Stool Scale. Although not specific to neurogenic disorders, this scale visually represents stool consistency and is essential for therapeutic monitoring and research. A version was created over a decade ago and was translated and validated for Brazilian Portuguese in 2019(20). This section will also include information on the devices used for TAI, care instructions, and alerts for system replacement. In addition, there will be a designated space for communication with healthcare professionals to report complications, questions, or concerns and to record the details of the next appointment with their reference team.
This educational toolkit will be digital and can be inserted into a website or, ideally, an app. Each session can also be printed according to each patient’s needs to personalize the user experience. Prototype Link: https://www.canva.com/design/DAFfthi1ZOU/saY6O3FI1t-zJ1EuI62cAffg/edit?utm_content=DAFfthi1ZOU&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton

Step 5 – Test/Experiment
The fifth stage of the DT will be carried out in future research after approval by the Ethics Committee, with families of children treated at the Neurogenic Bowel Outpatient Clinic in a rehabilitation center. These families will receive this digital or printed material as support and education.

DISCUSSION
DT is an approach derived from entrepreneurship, and its pillars of collaboration, empathy, experimentation, and user-centeredness make it timely for the healthcare context, providing a methodology for innovative solutions to complex problems\(^2,4,5\). Adapting to the era of digital health and becoming familiar with other transdisciplinary approaches and methods is a challenge and necessary for the evolution of the nursing profession. Faced with a potentially devastating problem in the lives of children, adolescents, and their families, such as neurogenic bowel dysfunction (particularly FI)\(^10,11\), the strategy of TAI is considered a minimally invasive, safe, effective solution associated with satisfaction and improvement of fecal incontinence and constipation\(^12,13,14,19\). There still needs to be more publications for solutions in this context that are directed towards the family experience\(^13,17\), which plays a central role in the continuity of care and is crucial for adherence to FI management with TAI.

We propose that the developed prototype serves as a support for the healthcare team and families, intending to improve the experience of parents and children in managing neurogenic bowel dysfunction. The interaction and bond between the team, family, and child should guide the management of neurogenic bowel dysfunction, with the educational toolkit proposed in this study serving as a facilitator and important care resource throughout the process. The limitations of this study relate to the fact that the toolkit created did not undergo the testing or experimentation phase; however, the
account of the creative process is valuable, aiming to share experiences and working models to propose the construction of innovative solutions.

CONCLUSION
Using DT as an approach and methodology has made it possible to broaden the horizon of care interventions, focusing on families and seeking an innovative solution based on empathy, collaboration, and experimentation. Through TAI, it was possible to develop a prototype of a toolkit to support and strengthen the role of parents/caregivers in the intestinal management of FI in children with neurogenic bowel dysfunction, which could consequently lead to better outcomes and satisfaction for the children and adolescents involved.

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We thank the postgraduate nurses who contributed to the collaborative, creative and iterative process, pillars of DT, to develop the prototype “De boa com o intestino neurogênico!”.

CONFLICT OF INTERESTS
The authors have declared that there is no conflict of interests.

REFERENCES


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