Digital story based on the experience of bladder and bowel symptoms in childhood: a methodological study of technological production*

História digital baseada na experiência de sintomas urinários e intestinais na infância: um estudo metodológico de produção tecnológica

ABSTRACT

Objective: To describe the production of a prototype digital story based on the experience of bladder and bowel symptoms in children. Method: This is an applied research with a multimethod approach, divided into two phases: Phase 1 consisted of a systematic review of mixed methods and a mixed methods study (quantitative phase based on retrospective documentary analysis of medical records, and qualitative phase based on interviews with health professionals, caregivers, and children with bladder and bowel symptoms of school age). Phase 2 consisted of a methodological study of the technological production of the digital story prototype. Results: Based on the triangulation of data obtained in the two phases of the multimethod research, the developed story brought representative characters of the profile of children with the studied symptoms and a narrative with elements of the experience of these symptoms. Conclusion: The story sought to give protagonism and encourage children with such symptoms to treatment and self-care.

Descriptors: Pediatric Nursing; Instructional Film and Video; Lower Urinary Tract Symptoms.

RESUMO


Descritores: Enfermagem Pediátrica; Filme e Vídeo Educativo; Sinto-mas do Trato Urinário Inferior.

INTRODUCTION

Epidemiologically, lower urinary tract symptoms (LUTS) affect 20% to 30% of children, depending on the type of symptom, and may be because of neurological or non-neurological changes. Regarding bowel symptoms, functional constipation (FC) affects 0.7% to 29.6% of children in the same age group, has a multifactorial etiology, and is most often associated with LUTS. One-third of children report having expe-
rrienced FC symptoms, which account for approximately 3% to 5% of pediatric consultations. LUTS are one of the main reasons for pediatric urological consultations, accounting for 40% of cases\(^1\). Involvement of the genitourinary and intestinal systems in childhood is common, with many cases in school-aged children.

A combination of LUTS and FC is referred to as bladder and bowel dysfunction (BBD), an umbrella term that highlights the co-occurrence of bladder and bowel symptoms, explained by the common innervation of these structures and their anatomical proximity (rectum and bladder)\(^1\). The clinical diagnosis of BBD (combination of LUTS and FC) is generally based on history, physical examination, and results of ancillary diagnostic tests (such as ultrasound of the urinary tract), with the recommendation to use voiding diaries and validated scales to assess the severity of bladder and bowel symptoms. Among the scales used is the Bristol Stool Scale, which uses images to assess stool consistency and appearance\(^2\). In all diagnostic examination strategies, it is essential to obtain reliable information, especially from the child with the most accurate perception of his or her bladder and bowel elimination habits. However, in numerous situations, BBD symptoms in children are often neglected and under-diagnosed, either because of late diagnosis by health professionals or because of the difficulty in obtaining this information from the child and their family. Children need to be heard to express their perceptions and opinions; they should be involved in health decision-making, sharing knowledge, and responsibility\(^3\). In addition, it is necessary to promote the child’s self-care, a process by which they adopt behaviors that promote their health and assist in managing their symptoms\(^4\).

An essential right of the child is to receive adequate care, taking into account his or her specificity\(^5\); it is necessary to guarantee the child’s right to be heard, to empower him or her to express his or her point of view on the condition he or she is facing and to place him or her in the position of protagonist of the interventions to be performed in the treatment. In the pediatric context, some interactive tools have been used in the symptom assessment process and are considered innovative strategies that stimulate communication with children, especially when using language appropriate to their developmental level\(^6\). Another approach to stimulate the child’s narrative is storytelling, which allows messages to be conveyed and feelings to be activated through mirror neurons and causes the listener to project themselves into the story empathetically\(^7\). Storytelling can be an essential communication technology in addressing the health-disease process, promoting autonomy, and placing the child as the story's protagonist and the care process\(^8\).

Therefore, the development of interactive tools using multimedia has also expanded the ability to present and communicate information through images and digital video. Video animation presents a digital story, including narratives that allow for improved communication between the healthcare professional and the child and improved care through a child-centered approach\(^9\). Storytelling allows individuals to narrate their own experiences and explore fundamental elements of their identity. When reading or listening to stories, multiple parts of the brain actively follow the different aspects of the story, as if the individual were experiencing the events firsthand. Mirror neurons play an essential role in this process, allowing us to understand the actions presented and the social meanings and emotions associated with them\(^{7,11}\).

The present study was constructed using a digital story based on the principles of knowledge translation and an arts-based approach. The choice of these principles is based on their sensitivity as methodologies for capturing and conveying information, emotions, history, and culture, thus being appropriate for the target audience of children\(^{12}\).

Therefore, the present study aimed to describe the process of creating a prototype of a digital story based on the experience of bladder and bowel symptoms in children. The authors use the term “prototype” because the video’s preliminary version will undergo the validation process. Therefore, the story may be modified during this process and differ from the prototype version. In addition, it aims to support the communication process of professionals working in pediatric urological health care.

**METHOD**

**Ethical considerations**

The umbrella project for this research was approved by the Research Ethics Committee of the School of Health Sciences, University of Brasilia, under opinion no. 3.133.554. All ethical requirements for research involving human subjects were met throughout the study.
Type of study
The present study is integral to a doctoral dissertation titled “Children’s Experience with bladder and bowel Symptoms: Telling this Story”. It is an applied research study with a multimethod approach, the methodological process of which is divided into two phases following a chronological order. Phase 1 described the production of a systematic review of mixed methods and a mixed methods study in (2). In the quantitative phase, a retrospective cross-sectional study was conducted through the analysis of medical records, while in the qualitative phase, semi-structured interviews were conducted with professionals, caregivers, and school-aged children with bladder and bowel symptoms. Phase 2, to which the present study refers, consisted of a methodological study of technological production (5) (Figure 1).

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**Figure 1** – Stages in the development of the doctoral dissertation, which consisted of applied research with a multi-method approach. Brasilia, DF, Brazil, 2021

Data collection and organization
Phase 1 of the study
Phase 1 of the study consisted of a systematic review of mixed methods (5). This systematic review identified a gap in the literature regarding the experiences of children with BBD and their families. Therefore, a concurrent mixed methods study was conducted in which data were collected simultaneously (quantitative + qualitative). The quantitative phase of this mixed methods study consisted of a retrospective documentary study. Data were obtained through the analysis of medical records. Children aged 6 to 12 years with bladder and/or bowel symptoms treated at the Pediatric Urology Nursing Outpatient Clinic between 2015 and 2019 were included, while those with neurological impairment or congenital malformations of the urinary or gastrointestinal tract were excluded. A total of 238 medical records were reviewed, of which 69 met the research criteria. Data collected included sociodemographic and clinical information (5).

The qualitative phase aimed to understand the experience of bladder and bowel symptoms from the perspective of children, caregivers, and health professionals. A snowball sampling technique was used to select professionals. The children interviewed were seen at the specialized care outpatient clinic and by their respective caregivers, provided they were 18 or older. Semi-structured interviews were conducted, recorded, and later transcribed.

The interviews with children and caregivers were conducted by one of the authors of this study, who has experience in conducting interviews with children. Interviews with children were conducted after appointments at the outpatient clinic, in a private room; the researcher used techniques such as the use of representative dummies for urine and stool to initiate the interview. Interviews with caregivers began after interaction with the child to ensure the appropriateness of communication strategies. A previously trained student researcher conducted interviews with professionals using an interview guide.

For quantitative data analysis, a descriptive approach was used to evaluate frequencies, percentages, means, and medians. Some variables were analyzed using the Pearson chi-square test through the Statistical Package for the Social Sciences (SPSS) version 19.0. The significance level of the tests was set at 5%, with a p-value ≤ 0.05 (5). The analysis of qualitative data from interviews, transcriptions, and images was conducted using NVIVO version 12.0 software, following COREQ recommendations, without further contacting participants to confirm the analyzed content. The researchers conducted the analysis process and later reviewed it with the team of researchers and the supervisor. All participants in the study signed informed consent forms, and chil-
dren signed informed assent forms to ensure the confidentiality and privacy of participants. There were no dropouts during the study\(^5\) (Figure 2).

### Phase 2 of the study

The current phase is a methodological study for technological production aimed at developing a prototype of a digital story. The results were based on the profile of children with such symptoms\(^13\) so that the characters in the digital story created were inspired by the aspects identified in the qualitative and quantitative portions of the mixed methods research conducted in Phase 1. Phase 2 consisted of three stages: script writing, storyboard development, and video animation.

### Creation of the script

The digital story prototype’s production phase began with the storyline, which was constructed based on the triangulation of the quantitative and qualitative data obtained in the mixed-methods study. The quantitative portion of the mixed methods study contributed to creating the characters, looking for elements that could reflect the identified profile and represent the target audience of the digital story. These data converged on a girl as the main character, considering that the symptoms are more prevalent in women (60%, \(n = 24\)). However, although this difference is not as significant, it was also important to represent boys (as supporting characters). In addition to gender, the most common age group, children aged 6 and 7, was represented (55%, \(n = 22\)). Finally, the most common bladder symptoms were also depicted in the figure, including urgency (80%, \(n = 32\)), holding maneuvers (70%, \(n = 28\)), daytime urinary incontinence (60%, \(n = 24\)), enuresis (urinary incontinence during sleep) (47.5%, \(n = 19\)), and polyuria (increased urinary frequency) (37.5%, \(n = 15\))\(^13\).

In the qualitative portion of the mixed-methods study, themes were identified so that there was convergence and divergence among the interviewees to bring contextual elements into the creation of the story’s plot. This allowed the children and their families to identify with the scenes in the story.

### Creating the storyboard

Once the story was created, a storyboard was developed detailing the scenes that made up the video. For the graphic representation of the story, the application “Storyboard That”\(^14\) was used, which consists of different panels with illustrations or photos describing what happens in the scene and what was programmed in the script. The storyboard was created based on scientific studies of digital storytelling, and the scene representations were defined according to the created script. The characters of the story, the main dialogues, facial expressions, and the most important and decisive comic scenes for the plot were characterized\(^9\). Thus, the storyboard represents the preliminary version of the video before the final format\(^15\).

### Creating the video animation

To create the video animation, the authors used the “Animaker” application in its premium version\(^16\). It allows the editing of animated videos with flexibility in the composition of scenes, characters, soundtrack, narration, and inclusion of text or images, among other functionalities. It is a user-friendly tool with explanatory tutorials that allows authors to use the application autonomously, eliminating the need to hire a professional for this prototyping phase. Video animation can be used as an educational or interactive resource based on text, sound, images, and interactive dialog, making learning more accessible and more effective\(^17\) (Figure 2).

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<th>Phases</th>
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<td>Definition and creation of characters</td>
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<td>Creating the scenes by selecting the scenery and objects</td>
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<td>3</td>
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Thus, professional to adolescents due to bullying and anxiety be considered a stressful place for children and environment to represent the important role of the school and/or FC.

In the treatment process of a child with BBD (Dona Júlia) symbolizes the role of caregivers as a support network for Malu. Malu’s mother presented the same symptoms in males and acts accordingly. A boy named Roberto was chosen to represent the findings, a 7-year-old girl named Malu was chosen as the main character, and Nurse Juliana. We chose the characters’ names to help explore their personalities, make them easily identifiable to the reader, and avoid distractions. Malu is the main character:

Maria Luiza, better known as Malu, is a 7-year-old girl with blond hair, slim, short, very happy, and shy. She lives with bladder and bowel symptoms but is afraid that her friends and schoolmates will find out about her problem (narrator of the story).

Her best friend was Roberto, who also suffered from these symptoms, and they studied together in the same classroom:

Roberto is a short, outgoing 7-year-old with bladder weakness (narrator of the story).

To represent the findings, a 7-year-old girl named Malu was chosen as the main character, who had BBD and FC, representing the main symptoms identified in the study in girls. Similarly, a boy named Roberto was chosen to represent the same symptoms in males and act as a support network for Malu. Malu’s mother (Dona Júlia) symbolizes the role of caregivers in the treatment process of a child with BBD and/or FC.

The teacher of the story, Lucia, was introduced to represent the important role of the school environment in these symptoms. School can be considered a stressful place for children and adolescents due to bullying and anxiety. In addition, a nurse (i.e., Juliana) is represented to show the important role of this health professional in dealing with these events.

Thus, the digital story featured five characters: Maria Luiza (Malu), Roberto, Lúcia, Dona Júlia, and Nurse Juliana. Their teacher was Lucia, a brown-haired woman who always smiled, loved to teach and participated in Malu and Roberto’s experiences in the classroom. Malu’s mother, Dona Júlia, a blonde woman of medium height, always showed great concern for her daughter, representing paternal authoritarianism and not understanding the symptoms her daughter presented before starting treatment. On the other hand, Juliana was the nurse who accompanied Malu and Roberto throughout their treatment. With black hair, Juliana was known for her competence and professionalism and worked in a pediatric urology outpatient clinic (Figure 3). The decision to include these characters was based on the qualitative study, which highlighted the importance of school, family, and specialized services in the experience of children with bladder and bowel symptoms.

RESULTS
In the quantitative phase of the mixed-methods study in phase 1 of the study, of the 238 medical records analyzed, 69 (29%) met the inclusion criteria and formed a sample of school-aged children (6 to 12 years) with bladder and/or bowel symptoms. Within these 69 cases, 40 children (57%) had BBD, which is characterized by the presence of both bladder and bowel symptoms. Of the remaining 29 cases in the sample, 24 had LUTS only, and 5 had FC only. A predominance of girls aged 6 and 7 with BBD and FC symptoms—urgency, straining, and incontinence—was observed. The profile identified in the data was crucial in selecting the clinical characteristics of the characters in the story, ensuring the representativeness of the profile of children seen in pediatric urology outpatient clinics.

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The qualitative phase of the mixed methods study involved 32 participants, including 14 healthcare professionals, 11 caregivers, and 7 children. The healthcare professionals included 4 nurses, 5 physicians, and 5 physiotherapists. The caregivers consisted of 9 mothers of patients, 1 grandmother, and 1 father, aged between 33 and 60 years. From the perspective of the three groups interviewed (parents, children, and health professionals), the aim was to identify points of convergence and divergence between the groups (Figure 4). Finally, the analysis allowed the synthesis and creation of the constituent elements of the video animation produced.

Point “A” of the image includes unanimous perceptions among children, guardians, and specialist professionals, while point “B” contains statements expressed only by professionals and guardians. From this perspective (A), some conclusions were unanimous:

- Pain is a significantly relevant symptom and is often reported as a nuisance, especially when evacuating and from diaper rash.
- Feelings of sadness and shame are common in children with bladder or bowel symptoms.
- The inability to sleep at friends’ and family members’ houses is perceived as a negative aspect of some children.
- In some cases, children have the behavior of postponing urination to continue performing other activities.
- Some children report not being bothered by their bladder or bowel problems.
- The words “pee” and “poop” are widely used by children when referring to their eliminations.

On the other hand, from the perspective of managers and professionals (B), there was convergence on the following topics:

- Parents/guardians are irritated and upset by the children’s symptoms.
- Health professionals often question children about the occurrence of bullying. While some guardians report cases of bullying even in the family environment, others claim that their children’s symptoms are a family secret.
- In addition to the unanimous feelings, they reported the presence of irritation, guilt, fear, and anxiety.
- Children hide their episodes of urinary incontinence by changing clothes or blaming others (such as pets), which may be behavior related to fear or shame.

The children who participated in the study also spoke in unique ways about their experience of symptoms:

- Prohibition on using the toilet at school.
- A traumatic episode of urinary incontinence at school.

Based on the script, a storyboard consisting of 24 illustrations of the story was created. These illustrations served as a reference for the production of the video animation. The prototype of the digital story in the form of a video animation was called “Malu Tells Her Story” and went through 9 stages, from the definition and creation of the characters to the download for posting on YouTube.

The digital story features several important events developed based on the qualitative study’s collected data from the interviews. One example is the scene where Malu experiences urinary incontinence at school, which brings up...
feelings of sadness and shame about her symptoms\(^5\). The animation also depicts the pain Malu feels in her “little tummy” related to FIC, as well as her mother’s irritability in response to her daughter’s urinary incontinence at school and Malu’s unhealthy eating habits (Figure 5).

![Figure 5 – Dona Júlia (Malu’s mother) is annoyed by her daughter’s urinary incontinence at school. Brasília, DF, Brazil, 2021](image)

The plot also emphasizes the importance of the support network composed of significant people, the relevance of self-care, and the search for specialized health services, a process strongly mediated by Roberto, a great encourager of Malu and one of the protagonists of the support network. Living with symptoms similar to those of his friend, he pointed out the specialized service he was looking for, the Outpatient Clinic for Advanced Practice Nursing in Uropediatrics, as well as encouraging therapeutic adherence to standard urotherapeutic interventions and Malu’s self-care journey, during which she actively participated in the management of her bladder and bowel symptoms. With her friend’s encouragement and positive experience with urologic care, Malu also seeks out health services and is seen by Nurse Juliana (Figure 6).

![Figure 6 – Malu begins treatment for her bladder and bowel symptoms at the specialized outpatient nursing clinic. Brasília, DF, Brazil, 2021](image)

Another significant episode was bullying at school when Malu’s classmates laughed at her because she had an episode of enuresis after visiting a friend’s house. Although the teacher was in the classroom during the incident, it proved traumatic for the protagonist. The statements from the qualitative study also represented this situation and stand out as an opportunity for interdisciplinary action between health and education. After 7 months of treatment, the story shows Malu’s clinical outcome. The scene shows her discharge from the health service due to the improvement of her bladder and bowel symptoms. This moment is marked by emotion and the sharing of the success with her mother, Dona Julia, Nurse Juliana, and Roberto (Figure 7). This scene was depicted to demonstrate that conservative treatment (standard urotherapy) is successful in most clinical cases of BBD and involves the participation of both the child and the family.

![Figure 7 – End of Malu’s treatment. Brasilia, DF, Brazil, 2021](image)

The prototype of the digital story in video animation format has been made available on YouTube and can be accessed via the following link: https://www.youtube.com/watch?v=Uyxfj8H9PiU&feature=emb_imp_woyt\(^18\).

**DISCUSSION**

The methodological path to creating the digital story prototype was based on the experience of bladder and bowel symptoms in children between 6 and 12. This research highlighted a fundamental right of the child — the responsibility of the health professional to create an environment conducive to the qualified and comprehensive listening and active participation of the child and his/her family in the therapeutic process. In the context of urological care, especially for children dealing with bladder and bowel symp-
tom, the production of the digital story prototype highlights the importance of a communication channel that allows for a more precise understanding of the symptoms and issues that affect the child’s life, such as bullying, academic performance, and social relationships\(^2\). The power to represent the experience of symptoms lived by the child is crucial to make them active in the treatment process and to understand better the symptoms they face, thus expanding care strategies and placing them at the center of the assistance provided \(^6\).

Digital storytelling is emerging as a powerful technological tool for knowledge transfer and empowerment, as children absorb and construct knowledge through the stories they hear and participate in\(^11\), especially when the story is aligned with the cognitive maturity and narrative skills of school-age children. An arts and storytelling approach has the potential to illustrate the experiences of the target audience in a meaningful way, integrating photographs, voices, drawings, and music. The arts play a fundamental role in developing the mind by addressing non-linguistic issues by expanding reasoning and ways of expressing what has been experienced during the inquiry process \(^19\). In the developed prototype, images, voices, and music were adopted that were representative of the experiences lived by the main characters. The use of digitally produced video stories can be implemented during outpatient visits, both in the anamnesis phase to identify symptoms and related problems and in stimulating or promoting therapeutic adherence interventions (e.g., in standard urotherapy protocols)\(^2\) to improve the urologic care provided. In the first case, the video can encourage the child to share his or her own story, recounting experiences with the symptoms or even mentioning episodes similar to those depicted in the digital story, reflecting the identification in the narrative stemming from mirror neurons\(^7\). The software SISOM, developed for children with cancer and actively involving them in its creation, has similarities with the digitally created video story, aiming at a comprehensive understanding of symptoms based on the perspective of children living with bladder and bowel symptoms\(^6\).

Concerning the use of educational videos, the study by Pinto et al.\(^17\) developed an animation on the care of premature infants using resources such as graphic animation, text, sounds, images, and interactive dialogues. These educational materials are essential for promoting healthcare education. In the case of this research, the value of narratives as a means of disseminating evidence-based information to the pediatric audience is also highlighted, especially for children with bladder and bowel symptoms, demonstrating the possibility of use as a knowledge translation tool targeted to the pediatric population. In addition, the use of video animation proves to be an important tool for the development of supported self-care skills, as demonstrated in the developed prototype, which showed Malu’s participation and development of autonomy in her treatment.

Another example of video animation for educational purposes is the study by Pinheiro et al.\(^20\), which describes a technological development involving the creation of a digital animation of the pediatric chemotherapy treatment process. The result of the production was a 12-minute, 22-second film that could serve as a health education tool. Like the present study, this product is a prototype to be validated, with potential positive effects in the context of health education through animation.

Another potential use of digital stories is to reduce procedural anxiety and make children more comfortable. One example is an animated video developed to prepare children for magnetic resonance imaging (MRI) scans. Results showed that children who watched the animation understood the procedure to be performed and showed reduced anxiety levels. This study demonstrated the effectiveness of animation as an accessible educational tool and support in preparing children for MRI procedures\(^21\).

The developed digital story has the potential to influence changes in children’s behavior, both through the narrative presented and the characteristics of the characters, which can promote the development of individual decision-making skills and health promotion, especially self-care\(^4,6\).

The concept of self-care encompasses the ability of individuals, families, and communities to maintain and promote health by managing illness with or without professional support. Therefore, self-care is essential to managing children with chronic conditions by promoting symptom self-management through patient and family education and empowerment\(^5\).

The construction of the digital story followed the elements that constitute a knowledge translation tool as a theoretical framework, as shown in a previous literature review\(^10\), to provide robustness to the scientific data representative of
the experience of children living with bladder and bowel symptoms. The stages of reviewing existing knowledge and synthesis of knowledge preceded the phase described in the present study, which focused on presenting the phase of creating tools or knowledge products. As a limitation, the prototype of the digital story still needs to undergo the validation process by judges composed of professionals and clinical validation based on the perspectives of caregivers and children. These research phases are currently underway.

CONCLUSION
The development process of the digital story prototype, based on the experience of children with bladder and bowel symptoms, has the potential to be a knowledge translation tool specifically targeted to the pediatric audience. In addition, it aims to encourage children with such symptoms to feel like protagonists in their self-care journey and empower them to manage their symptoms. Inspired by the protagonist Malu, who overcomes challenges throughout the story, the narrative conveys that there is treatment for these symptoms and that feelings of shame and fear can be overcome.

REFERENCES

This study has enabled the dissemination of evidence-based knowledge derived from the characters’ experiences so that other children can identify their symptoms and feel encouraged to share them. In addition, the digital story can facilitate communication between healthcare professionals and patients in pediatric urology consultations. The next step outlined by the authors is to evaluate the effectiveness of the prototype as a mediator of information and facilitator of narratives from children with bladder and bowel symptoms. This will include validating the content and appearance of the digital story. It is also proposed that future studies be conducted to validate the digital story and assess its impact on the process of supported self-care in children aged 6 to 12 with such symptoms, empowering them to be protagonists of their care.

*Paper extracted from the PhD thesis “Children’s experience with urinary and bowel symptoms: telling this story”, presented to the Universidade de Brasília, Brasília, DF, Brazil.

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


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Data analysis and interpretation: Fonseca LCF da, Salviano CF, Gisele Martins G

Writing and/or critical review of the intellectual content: Fonseca LCF da, Salviano CF, Gisele Martins G

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