

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

## "De boa com o intestino neurogênico": um relato de inovação tecnológica baseado no *design thinking*

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### 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.

### RESUMO

**Objetivo:** Descrever os processos usados para desenvolver o protótipo de um programa para suporte e apoio aos pais (denominado "*De boa com o intestino neurogênico*") com aplicabilidade na reabilitação intestinal na população pediátrica em uso de irrigação transanal. **Método:** Trata-se de um relato de inovação tecnológica no qual a abordagem *design thinking* foi usada para desenvolvimento do protótipo de tecnologia educativa digital para manejo do intestino neurogênico, como um processo e produto desenvolvido em um curso de Mestrado em Enfermagem. **Resultados:** O desenvolvimento do protótipo seguiu as etapas do *design thinking*: empatia, imersão, ideação e prototipagem. Foi criado o kit de ferramentas que apoiará pais de crianças com disfunção intestinal neurogênica em uso da irrigação transanal. **Conclusão:** O *design thinking* como abordagem e metodologia permitiu ampliar o horizonte das intervenções de enfermagem, focando nas famílias, propondo uma solução inovadora com base na empatia, colaboração e experimentação.

**Descritores:** Design Centrado no Usuário; Intestino Neurogênico; Projetos de Desenvolvimento Tecnológico e Inovação.

### 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<sup>(1)</sup>.

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<sup>(2)</sup>.

Within this scenario, design thinking (DT) emerges as a means to foster innovation<sup>(3,4)</sup>. 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<sup>(2,5)</sup>.

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<sup>(4)</sup>. In healthcare, DT is human-centered<sup>(2,5)</sup>, inspired by humanistic and empathetic values, and aims to ensure the quality of services and products. It affirms respect for the customer profile<sup>(6)</sup>.

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 that can result 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<sup>(7-9)</sup>. 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<sup>(7,8,10,11)</sup>. The negative impact extends to the family, with half of pa-

rents of children with spina bifida citing FI as their primary caregiving concern<sup>(7)</sup>.

Bowel rehabilitation is suggested to treat constipation, achieve social bowel continence, and promote independence to manage neurogenic bowel dysfunction<sup>(7,8,12,14)</sup>.

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<sup>(7,12,14)</sup>. 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<sup>(7,8,12,14)</sup>. 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<sup>(12-14)</sup>. 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<sup>(12-15)</sup>. This is usually done in the home environment daily or on alternate days, depending on the child's needs<sup>(13,14)</sup>. While various devices are available for TAI, these devices are not approved in Brazil, necessitating treatment with a colostomy irrigation kit<sup>(13,15)</sup>. 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<sup>(12,13,14,16)</sup> articles and national literature<sup>(15)</sup> 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<sup>(13,17)</sup>.

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<sup>(3,5,6)</sup>, 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<sup>(3,5)</sup>.

## 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<sup>(3)</sup>. During the initial empathy stage, one must consider the solution's end user and their core values and perspectives<sup>(5)</sup>. 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<sup>(18)</sup> (Figure 1) was chosen to operationalize this stage, and the gaps were filled based on a qualitative study of parents' perceptions of TAI<sup>(17)</sup>. 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.

**Figure 1** – Empathy Map based on parents' perceptions of children with spina bifida. Brasília, DF, Brazil, 2022

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<sup>(3)</sup>.

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<sup>(17)</sup>.

The four main findings from the study by Sanders and Brays<sup>(17)</sup> regarding parent and professional perceptions of TAI emphasized the need for a comprehensive assessment before initiating TAI, followed by an initial, comprehensive education<sup>(17)</sup>. 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<sup>(17)</sup>. Proper training in the procedure and ongoing

support were also identified as critical to adherence and success with the technique, even without face-to-face support<sup>(19,14)</sup>. Using the problem definition matrix tool (Figure

2), it was possible to narrow down the problem to be addressed<sup>(18)</sup>, considering the skills and fundamental principles that will structure the work ahead<sup>(5)</sup>.

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

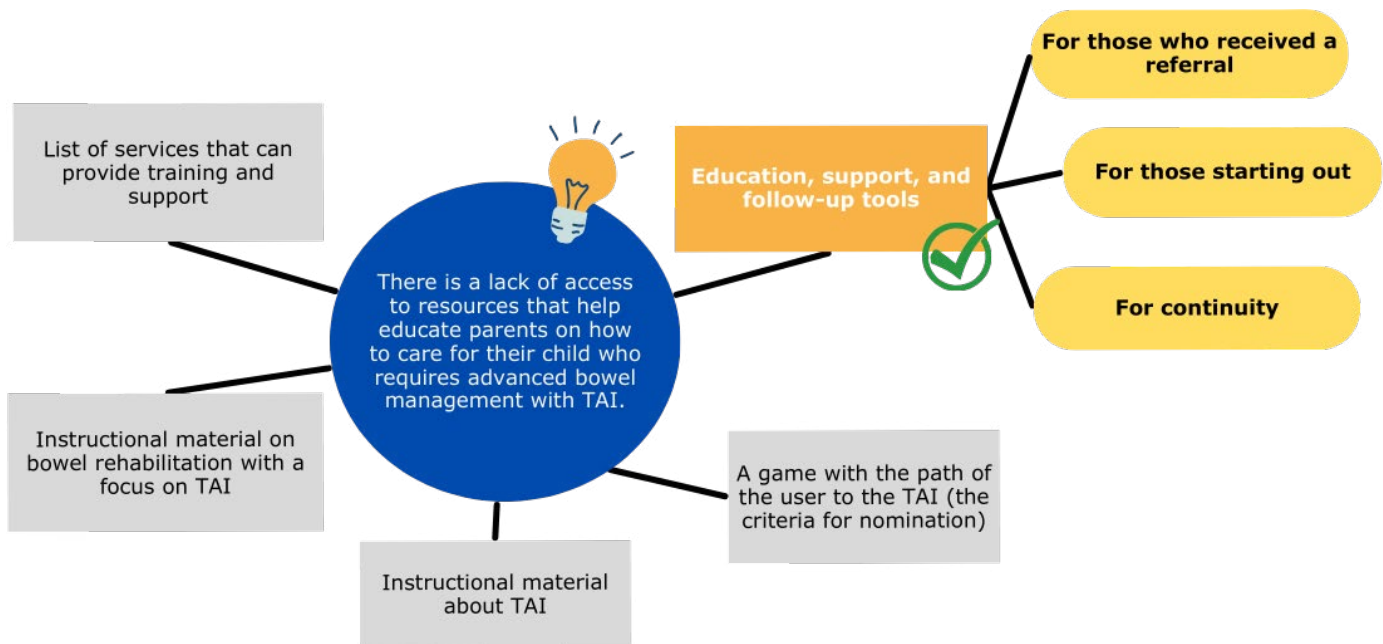
Key questions	Answers
<i>What is the main issue and why is it important?</i>	Parents are key players in the continuity of care and can have negative feelings about FI and managing TAI, especially if they do not have the necessary educational support and follow-up. If they do not feel confident, they may not adhere, or they may have difficulties that could lead to further suffering for themselves and their child.
<i>For whom is that a problem?</i>	For parents, children, and professionals.
<i>What are the consequences of this problem that affect people the most?</i>	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 <sup>(17,10)</sup> .
<i>Can you think of this problem differently?</i>	The problem can be greatly minimized with family involvement, empowerment, and ongoing support <sup>(17,19)</sup> .
<i>What social and cultural factors affect this problem?</i>	It is socially unacceptable to defecate in public; there are beliefs associated with procedures in the anal region (“being invasive or abusive”) (17).
<i>Can you define the problem in one sentence?</i>	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.

### 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<sup>(18)</sup>. In this initial phase, ideas were generated from all actors involved in the pro-

blem – professionals, children/youth, health services, and families.

After group reflection and using the “desk research” tool<sup>(18)</sup>, 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

To select the project, factors such as desirability and feasibility were weighed, along with time and resources.

#### Step 4 – Prototyping

This stage aims to transform the best ideas from the previous stage into a concrete solution, materialized in a prototype. The tool used to carry out this phase was the infographic.

The idea is to create a toolkit that will serve as a guide for parents of children with an indication of TAI or who are already performing TAI. The name will be "*De boa com o intestino neurogênico!*" with three aspects or sections that will accompany the user's journey, from their decision before starting TAI, providing information to support this decision, instructing on the initial phase of using TAI for bowel management, to longitudinal follow-up with support and monitoring for those already performing TAI (Figure 4). The three sections are as follows:

1. About TAI: This session aims to clarify bowel rehabilitation and management strategies leading to the indication of TAI. It will explain the procedure, the requirements to begin using TAI to manage constipation and FI, and the potential complications associated with TAI.

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<sup>(20)</sup>. 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.

**Figure 4** - Infographic of the parent support toolkit prototype, summarizing the educational dimensions that will be covered. Brasília, DF, Brazil, 2022



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/saY6O3F1t-zJ1EuI62cAffg/edit?utm\\_content=DAFfthi1ZOU&utm\\_campaign=designshare&utm\\_medium=link2&utm\\_source=sharebutton](https://www.canva.com/design/DAFfthi1ZOU/saY6O3F1t-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<sup>(2,4,5)</sup>. 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)<sup>(10,11)</sup>, the strategy of TAI is considered a minimally invasive, safe, effective solution associated with satisfaction and improvement of fecal incontinence and constipation<sup>(12,13,14,19)</sup>. There still needs to be more publications for solutions in this context that are directed towards the family experience<sup>(13,17)</sup>, 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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## CONFLICT OF INTERESTS

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

## REFERENCES

- Dreisbach C, Wright ML, Walker RK, DoByon H, Keim-Malpass J. Nursing science as a federally-recognized STEM degree: A call to action for the United States with global implications. *Int J Nurs Studies Advances*. 2022;4:100084. <https://doi.org/10.1016/j.ijnsa.2022.100084>
- Risling TL, Derek ER. Advancing nursing participation in user-centred design. *J Res Nurs*. 2020;25(3):226-238. <https://doi.org/10.1177/1744987120913590>.
- Coelho TPB, Fracolli LA, Chiesa AM, Silva FSC, Junior HMFS, Silva LA. A abordagem Design Thinking como proposta de inovação social em um programa de visitaç o domiciliar na primeira inf ncia. *Re Sa d Digi Tec Edu*. 2019;4(2):8-19. <https://doi.org/10.36517/resdite.v4.n2.2019.a1>
- Altman M, Huang TT, Breland JY. Design Thinking in Health Care. *Prev Chronic Dis* 2018;15:180128. <https://doi.org/10.5888/pcd15.180128>
- Lewis BJ, Brady SS, Sutcliffe S, Smith LA, Mueller RE, Rudser K ... & Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium. Converging on Bladder Health through Design Thinking: From an Ecology of Influence to a Focused Set of Research Questions. *Int J Environ Res Public Health*. 2020;17(12):4340. <https://doi.org/10.3390/ijerph17124340>.
- Paiva ED, Zanchetta MS, Londono C. Inovando no pensar e no agir cient fico: o m todo de Design Thinking para a enfermagem. *Esc Anna Nery (Rio de Janeiro)*. 2020;24(4). <https://doi.org/10.1590/2177-9465-ean-2019-0304>.
- Beirerwaltes P, Church P, Gordon T, Ambartsumyan L. Bowel function and care: Guidelines for the care of people with spina bifida. *J Ped Rehab Med: An Interd Approach*. 2020;13(4):491-498. <https://doi.org/10.3233/PRM-200724>
- Ambartsumyan L, Rodrigues L. Bowel management in children with spina bifida. *J Ped Rehab Med*. 2018;11(4):293-301. <https://doi.org/10.3233/PRM-170533>
- Milivojevic S, Milic N, Lazovic JM, Radojicic Z. The influence of bowel management on urodynamic findings in spina bifida children with detrusor overactivity and detrusor sphincter dyssynergia. *J Ped Urol*. 2020;16(5):556.e1-556.e7. <https://doi.org/10.1016/j.jpuro.2020.04.013>
- Gibbons C, Coyle D, White C, Aldridge E, Doyle M, Cascio S. Assessment of neurogenic bowel symptoms with the bowel dysfunction score in children with spina bifida: a prospective case-control study. *Ped Surg Inter*. 2020;36(7):773-777. <https://doi.org/10.1007/s00383-020-04670-8>
- Szymanski K, Cain MP, Whittam B, Kaefer M, Rink RC, Misseri R. Incontinence affects health-related quality of life in children and adolescents with spina bifida. *J Ped Urol*. 2018;14(3):279.e1-279.e8. <https://doi.org/10.1016/j.jpuro.2018.02.021>.
- Mosiello G, Safder S, Marshall D, Rolle U, Benninga MA. Neurogenic bowel dysfunction in children and adolescents. *J Clin*



- Med. 2021;10(8). <https://doi.org/10.3390/jcm10081669>
13. Xavier TS, Duarte LM, Martins G. Transanal irrigation to manage neurogenic bowel in the pediatric population with spina bifida: a scoping review. *J Ped.* 2023. <https://doi.org/10.1016/j.jpmed.2023.02.001>
  14. Caponcelli E, Meroni M, Brisighelli G, Rendeli C, Ausili E, Gamba P, et al. Transanal irrigation (TAI) in the paediatric population: literature review and consensus of an Italian multicentre working group. *La Ped Med Chirurg.* 2021;43(1):250-255. <http://dx.doi.org/10.4081/pmc.2021.250>.
  15. Rodrigues BDS, Buzatti KCLR, Durço VN, Sousa PHM, Souza TGS, Morais TG. Abordagens terapêuticas nos pacientes portadores de incontinência anal, com enfoque na irrigação transanal. *Brazilian J Health Rev.* 2020;3(1):325-341. <https://doi.org/10.34119/bjhrv3n1-024>.
  16. Van Renterghem K, Sladkov M, Matthysens L, Van de Putte D, Pattyn P, Van Bieveliet S, et al. Prospective switch study comparing two irrigation systems for transanal irrigation in children. *Acta Gastro Enterol Belgica.* 2021;84(2):295-298. <https://doi.org/10.51821/84.2.295>.
  17. Sanders C, Bray L, Driver C, Harris V. Parents of children with neurogenic bowel dysfunction: their experiences of using transanal irrigation with their child. *Child Care Health Dev.* 2014;40:863-869. <https://doi.org/10.1111/cch.12117>
  18. Hohemberger DA, Rossi FD. Guia Didático Do Design Thinking: uma metodologia ativa para estimular a criatividade, a inovação e o empreendedorismo em sala de aula [Internet]. Jaguari (RS): [editora desconhecido]; 2020 [cited 2022 Jul 20]. Available from: <https://educapes.capes.gov.br/handle/capes/572344>
  19. Patel S, Hopson P, Bornstein J, Safder S. Impact of transanal irrigation device in the management of children with fecal incontinence and constipation. *J Ped Gastr and Nut.* 2020;71(3):292-297. <https://doi.org/10.1097/MPG.0000000000002785>
  20. Jozala DR, Oliveira ISDF, Ortolan EVP, Oliveira WED, Comes GT, Cassettari VMG, et al. Brazilian Portuguese translation, cross-cultural adaptation and reproducibility assessment of the modified Bristol Stool Form Scale for children. *J Ped.* 2019;95:321-327. <https://doi.org/10.1016/j.jpmed.2018.01.006>

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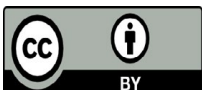
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