

Bladder and bowel dysfunction in childhood: multi-method approach

Disfunção vesical e intestinal na infância: abordagem multi-metodológica

Disfunción vésico-intestinal en la infancia: enfoque multimetodológico

Nayara dos Santos Rodrigues¹  <https://orcid.org/0000-0003-4797-0832>Gisele Martins¹  <https://orcid.org/0000-0002-4656-6195>Aline Oliveira Silveira¹  <https://orcid.org/0000-0003-4470-7529>

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Corresponding author

Nayara dos Santos Rodrigues
E-mail: nsrodrigues94@gmail.com

Associate Editor (Peer review process):

Denise Myuki Kusahara
(<https://orcid.org/0000-0002-9498-0868>)
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil

Abstract

Objective: To describe the sociodemographic profile, access and interest in receiving online information about bladder and bowel dysfunction as well as understand the experience of families of children and adolescents affected by this dysfunction.

Methods: This is a multi-methodological study carried out in an outpatient clinic of Advanced Nursing Practice in uropediatrics of a teaching hospital in midwestern Brazil.

Results: The experience of families of children with bladder and bowel dysfunction points to a negative impact on everyday life, which may be related to sociodemographic conditions, lack of knowledge of families about the symptoms and stigmas associated with its manifestation. To this end, access to online information is a potential support tool to improve the experience of children's families with the symptoms.

Conclusion: The results express children's sociodemographic characterization and their family and the access and interest in receiving information on the internet about bladder and bowel dysfunction, which may be important for compliance and perception of improvement in symptoms, reflecting on family experience. Therefore, nurses who work in the context of uropediatrics care need to innovate in their approach and implement new care modalities or health interventions, mainly through the incorporation of internet-based technologies, aimed at improving the quality of life of both the families and children with bladder and bowel dysfunction.

Resumo

Objetivo: Descrever o perfil sociodemográfico, o acesso e interesse em receber informações on-line sobre a disfunção vesical e intestinal, bem como compreender a vivência da família de crianças e adolescentes acometidos por essa disfunção.

Métodos: Trata-se de estudo multi-metodológico realizado em um ambulatório de Prática Avançada de Enfermagem em Uropediatria de um hospital de ensino da região centro-oeste do país.

Resultados: A vivência da família da criança com disfunção vesical e intestinal aponta para um impacto negativo no cotidiano podendo estar relacionado às condições sociodemográficas, a falta de conhecimento das famílias sobre os sintomas e aos estigmas associados à sua manifestação. Para tanto, o acesso a informações on-line apresenta-se como potencial ferramenta de apoio para melhorar a experiência da família da criança com os sintomas.

Conclusão: Os resultados expressam a caracterização sociodemográfica da criança e sua família e o acesso e interesse em receber informações pela internet sobre a disfunção vesical e intestinal, que podem ser importantes para a adesão e percepção de melhora nos sintomas refletindo na vivência familiar. Portanto,

¹Universidade de Brasília, Brasília, DF, Brazil.

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o enfermeiro que atua no contexto de cuidado em uropediatria precisa inovar em sua abordagem e implementar novas modalidades de assistência ou intervenções em saúde, principalmente por meio da incorporação de tecnologias baseadas na internet, visando à melhora da qualidade de vida tanto da família quanto da criança com disfunção vesical e intestinal.

Resumen

Objetivo: Describir el perfil sociodemográfico, el acceso y el interés en recibir información digital sobre la disfunción vésico-intestinal, así como comprender la vivencia de la familia de niños y adolescentes acometidos por esta disfunción.

Métodos: Se trata de un estudio multimetodológico realizado en consultorios externos de Práctica Avanzada de Enfermería en Urología Pediátrica de un hospital universitario de la región Centro-Oeste del país.

Resultados: La vivencia de la familia de niños con disfunción vésico-intestinal indica un impacto negativo en la cotidianidad, lo que puede estar relacionado con las condiciones sociodemográficas, la falta de conocimiento de las familias sobre los síntomas y los estigmas asociados a su manifestación. Para eso, el acceso a la información digital se presenta como una potencial herramienta de apoyo para mejorar la experiencia de la familia de niños con los síntomas.

Conclusión: Los resultados expresan la caracterización sociodemográfica de los niños y su familia y el acceso e interés en recibir información por internet sobre la disfunción vésico-intestinal, que puede ser importante para la adhesión y percepción de mejora de los síntomas y puede reflejarse en la vivencia familiar. Por lo tanto, los enfermeros que actúan en el contexto de cuidado en urología pediátrica necesitan innovar su enfoque e implementar nuevas modalidades de atención o intervenciones en salud, principalmente mediante la incorporación de tecnologías basadas en internet, con el objetivo de mejorar la calidad de vida tanto de la familia como de los niños con disfunción vésico-intestinal.

Introduction

The coexistence of urinary and intestinal symptoms is recognized in the clinical practice of pediatric urology, and this condition is known by the term bladder and bowel dysfunction (BBD). This updated nomenclature covers lower urinary tract dysfunction (LUTD) in combination with bowel dysfunction. Examples of these symptoms are urinary and bowel incontinence, changes in urinary frequency, changes in voiding pattern such as urgency, nocturia, hesitation, straining, weak or intermittent stream, dysuria, holding maneuvers, feeling of incomplete emptying and urinary retention associated with functional constipation (FC) and/or encopresis.⁽¹⁾

BBD is a prevalent condition in the pediatric population with significant impacts on children's health, in order to interfere with their quality of life and emotional and psychosocial development, especially related to self-esteem and social interaction, in addition to impacts on family functioning.^(2,3) The need for changes in activities of daily living and limitation to the home environment is significant, with a decrease in social interaction, as an adaptive response to the symptoms presented by children.⁽⁴⁾

The use of standard urotherapy (SU) practices as the first line of care for BBD has been recommended.⁽⁵⁾ In this way, the therapeutic management based on SU interventions is based on guidelines on the demystification of urinary and/or intestinal

symptoms through educational strategies, associated with regular follow-up with an approach to changes in behavior and lifestyle habits, which can be combined, in some cases, with drug treatment.⁽³⁻⁵⁾ Thus, for the resolution of symptoms, a patient- and family-centered approach is necessary so that the understanding of BBD can generate positive influences on therapeutic adherence and coping strategies, in addition to reducing health costs.^(3,6)

Given the need for long-term follow-up for the proper management of BBD symptoms, patients and families face multiple challenges and difficulties in coping with the symptoms, mainly in terms of adherence to SU interventions, a fact that impacts the outcomes expected by patients/family and health professionals.⁽⁷⁾ In this context, the importance of nurses in specialized pediatric urology services is emphasized, as its performance is recognized for its high resolution rate, low cost and high quality of care provided.^(4,8-10) An example is the existing nursing service in a university hospital in the Federal District that operates in the area of uropediatrics in the Advanced Nursing Practice (ANP) model.⁽¹¹⁾ This service promotes children's urological health through empowerment and an informed decision-making process shared between patients and their families.⁽¹¹⁾

At the same time, the rise of the use of the internet and, more specifically, social networks for accessing information related to health in the context of pediatric urology has been highlighted.⁽¹²⁾ The lit-

erature indicates that parents or family members access the internet to obtain information about health problems of different specialties, including urology.^(13,14) Therefore, the internet can be considered a tool with great potential to be used by nurses for therapeutic purposes in the sense of sharing information and generating positive results in adherence and management of BBD symptoms.

Thus, the importance of a broader understanding of the context and family experience in living with childhood BBD is verified, as well as exploring the interest and access to the internet by this population, in order to enable the development and assessment of innovative interventions that are sensitive to the specificities of children and their families. Therefore, this study aimed to describe the sociodemographic profile, access and interest in receiving online information about BBD as well as understand the family experience of children and adolescents with BBD.

Methods

This is a cross-sectional multi-methodological study developed in two stages: quantitative and qualitative. Thus, an independent study was carried out with a quantitative approach first and then a study with a qualitative approach was carried out, for a broader understanding and analysis of new perspectives on the investigated phenomenon as well as to support the development and implementation of complex interventions in health services.⁽¹⁵⁾

For the qualitative stage, the phenomenology approach was used based on the framework of interpretive phenomenology, which aims to understand the worlds experienced by the participants in the different contexts they belong to.⁽¹⁶⁾ In this way, the researcher can access what really matters to participants from their voices that express the concerns and desires of their contexts.⁽¹⁶⁾

The study was carried out at the ANP outpatient clinic in uropediatrics of a teaching hospital in the Midwest region, with a convenience sample composed of families of children and adolescents with symptoms of BBD, of both genders, aged between

5 and 18 years old and who were being followed up at the service during the data collection period. Children or adolescents who had neurological or cognitive disorders, with malformations of the genitourinary and/or intestinal tract, were excluded, because such comorbidities require different therapies for symptom management, differing from the pattern of response to exclusive treatment with SU interventions directed at BBD symptoms.

For the purposes of this study, a family was considered the “group of individuals united by strong emotional bonds, with a sense of belonging and inclination to participate in each other’s lives”.⁽¹⁷⁾ Based on this conception, one or more family members were considered for the invitation to participate in the study.

Data collection was conducted from October 2018 to March 2019, and began with the quantitative design through the application of a questionnaire (prepared by the researchers) consisting of two axes: sociodemographic characterization of children/adolescents and family, and data on internet use to access information about children’s/adolescents’ problem. Subsequently, a qualitative design was performed. In this study, some families were invited to participate in an in-depth open-ended, audio-recorded interview conducted by the first author of this article. The interviews lasted an average of 30 minutes, starting with the guiding question: What is it like to live with the condition of your child/adolescent diagnosed with BBD? Intermediate questions were inserted, according to the need to deepen the understanding. The number of families participating in this stage was guided by the concept of theoretical saturation.⁽¹⁸⁾ In this sense, the qualitative sample reflects, in quantity and intensity, the multiple dimensions of the phenomenon in terms of understanding the object of study.

Quantitative data were stored in a database and descriptive analysis was performed. Qualitative data were analyzed by the thematic analysis method, based on the theoretical framework of interpretive phenomenology.⁽¹⁶⁾ For the presentation of results, it was decided to standardize the term “child” for children and adolescents in the study, since most interviewees (69%) were younger than twelve years old.

The research was submitted to the Research Ethics Committee and was approved under Opinions 2,839,520, 3,033,085 and 3,224,020 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 90434518.5.0000.0030. Participants signed the Informed Consent Form (ICF) and had their secrecy assured so that the identification in the study was carried out by the letter F, followed by the number representing the order in which the interview was carried out.

Results

The study had the total participation of 23 families. Of these, 11 also participated in the qualitative study. In the research with a quantitative approach, the information collected corresponding to the characterization of children and families are arranged in tables 1 and 2, respectively.

Table 1. Percentage distribution of children according to sociodemographic characteristics

Variables	n(%)
Gender	
Female	10(43)
Male	13(57)
Age	
5 to 10 years	14(61)
11 to 19 years	9(39)
Temperament	
Calm	10(43)
Nervous	5(22)
Hyperactive	8(35)
Type of school	
Public	14(61)
Private	9(39)
Problems at school	
Yes	10(43)
No	13(57)

n – Number of participants; % - Percentage; *Temperament assessed by family report

As for information on internet use by families, it appears that 87% of them have access, 55% only access via cell phone and 35% use Facebook and WhatsApp (Table 3).

Table 2. Percentage distribution of families according to sociodemographic characteristics

Variables	n(%)
Maternal age	
≤ 40	14(61)
> 40	9(39)
Paternal age	
≤ 40	13(57)
> 40	10(43)
Divorced parents	
Yes	6(26)
No	17(74)
Education	
Complete higher education	12(26)
Incomplete higher education	1(2)
Complete high school	18(39)
Incomplete high school	4(9)
Complete elementary school	2(4)
Incomplete elementary school	9(20)
Family income	
Less than 1 minimum wage	4(17)
From 1 to 2 minimum wages	10(43)
From 3 to 5 minimum wages	5(22)
More than 5 minimum wages	4(17)
Number of children	
1	4(17)
2	11(48)
3	7(30)
4 or more	1(4)

n – Number of participants; % - Percentage

Table 3. Percent distribution of families according to internet use

Variables	n(%)
Access to the Internet	
Yes	20(87)
No	3(13)
Device for access	
Cellphone only	11(55)
Mobile and computer	9(45)
Social media	
Yes	20(87)
No	3(13)
Which social media	
Only WhatsApp	6(26)
Facebook and WhatsApp	8(35)
Instagram and WhatsApp	2(9)
Facebook, Instagram and WhatsApp	4(17)
Used the internet to access information about BBD	
Yes	14(61)
No	9(39)
Would like to have access to information about BBD on the internet	
Yes	22(96)
No	1(4)

n – Number of participants; % - Percentage

It is noteworthy that although 43% of families have a monthly income of 1-2 minimum wages and 39% report incomplete high school education, 87% have internet access, 61% use the internet to access

information about their children's BBD, and the majority, 96%, state that they would like to have access to information about their children's BBD via the internet. In qualitative research, a deeper understanding of the family context was sought in order to explore the implications that sociodemographic characteristics and access, use and interest in information provided by the internet could have on family experiences with BBD. From the analysis, two major categories emerged from the narratives: *Family understanding about BBD*; and *Living with the children's BBD*.

Family understanding about BBD

Initially, it was observed that some families had prior knowledge arising from the experience with the eldest child.

As the eldest already has this nervous bladder problem, you know, that talks, so his was easier because there was already follow-up, I had guidance, so everything was easier. (F2)

However, many families still had doubts or gaps in information about BBD, especially related to treatment and expected prognosis. In addition to the behavior of not associating BBD with a problem or illness, but attributing its occurrence to emotional or behavioral aspects.

[...] know what the result will be. To find out what's going on? Why did that happen. We are also curious to know why that happens. (F4)

[...] bladder and bowel dysfunction, what is it like, is there a treatment? [...] I asked if there was a cure, if there is a treatment, how does it work. (F11)

[...] From the psychological treatment, it is neither like this nor the physical illness or disease itself. [...] when he manages to control his anxieties, he can take it normally. (F2)

I don't see it as a disease, I see that we just have to police ourselves more in this area, right? (F3)

This for me is not a disease, for me it's a bit of a problem [...] I don't think so because for me disease is other things, it's something more serious. (F5)

I don't see it as a disease. (F6)

In this sense, the importance of access to information for understanding the symptoms and proper management of BBD is highlighted. In the narratives, families pointed to access to information through specialist nurses' work during the consultation performed, configuring it as social support for coping, handling or better living with the child's BBD symptoms.

There are a lot of things that I learned in the last consultation, three months ago, that we have already put into practice and improved. (F1)

Before, we didn't have any concerns, but now we have, we know, we are getting more information. (F8)

After I had the knowledge, you know, about urope-diatrics, I thought it was better, this treatment she is doing now has improved a lot, right? (F6)

Family living with the children's BBD

For some families, discovering the children's BBD is marked by emotions such as sadness, discouragement, fear and frustration at different times of living with BBD.

It was bad, it was bad to know, I didn't like it. [...] I would like her to stop wetting the bed, because it's annoying. (F4)

It was a fright, right, because we wouldn't expect that. (F5)

I thought it was a malformation of the intestine, for his gallbladder, of the bladder. (F8)

I was surprised, I was surprised by that and I was scared too [...] I thought it had been a problem, that she had a low bladder, then I was already

terrified and so was she [...] more serious [...] we discovered that it was not what we were thinking. (F9)

Ah, I thought she could have a more serious problem too, because I think this thing of trapping urine, you know, like it could bring something more serious. (F10)

We are sad to see him having these difficulties peeing or holding the urine and having difficulty going to the bathroom, we get worried, we know that it is not good [...] we get frustrated, we want to help and many times can't, can't see the result. (F11)

The statements of some families reveal the denial of the impact of BBD on daily life and, on the other hand, other families highlighted the repercussions on children's lives, thus showing a different scenario for identifying the impacts caused by BBD, disregarding even the previously mentioned emotional impacts.

Affecting only his health even so for us didn't mean anything. (F2)

It had no impact on him. (F5)

It had no impact on her life, she is calm. (F8)

It does not affect the routine [...]. (F9)

No, I don't think it affected anything in the family's life. This affected his life more [...] Health and emotional [...] Because, if he doesn't do it, he gets anxious. (F11)

However, when detailing the family's daily life, it was observed that the families had to make adjustments in their parenting style or in their routine due to the presence of BBD in the children, observing in these aspects the impacts that the symptoms cause.

I always had this concern to look for some fruit, something to loosen her intestines. [...] I try to go

out, come back quickly because she can't defecate, you know... without being at home, so I always plan to go out one day and come back at the latest the next day. (F1)

If he was going somewhere, he had to stop, stop in the middle of the street for him to do it, because he can't hold it. (F2)

I tend to stay at home more, I don't like going to other people's houses to spend a lot of time with her there. (F3)

[...] she changed some habits, now she is more used to drinking water, she has a separate bottle for her to drink water. (F6)

And start with food to see if it improves [...] my husband started buying more fruit [...] he started eating more fruit, and juices and water. (F7)

It is this care with food [...]. (F11)

Discussion

Data from this study with a multi-methodological approach demonstrate that the greatest differences observed in quantitative results were in socio-demographic characteristics of children aged 5 to 10 years. Characteristic that is similar to the study conducted with children with BBD with an average age of 8 years.⁽¹⁹⁾ With regard to gender, a slightly larger sample of male children was noted, a fact that disagrees with some studies that report the prevalence of BBD symptoms in girls.^(20,21) However, the literature shows a higher prevalence of isolated symptoms in boys, such as enuresis.⁽²¹⁾ Due to the sampling technique being of convenience and based on the occurrence of BBD, it was not possible to perform the stratification by symptoms.

With regard to children's temperament, most parents reported it as "calm"; however, it is noteworthy that 35% referred to it as "hyperactive". This fact is similar to the study carried out on the same theme, which reports a high prevalence of urinary

symptoms and, to a lesser extent, intestinal symptoms, in children and adolescents diagnosed with attention deficit hyperactivity disorder (ADHD).⁽²⁰⁾ However, it should be noted that in the present study, the assessment of children's temperament was strictly based on family reports, without the use of clinical diagnostic tests.

Another factor that requires attention is the fact that 43% of families report the occurrence of school problems. In this sense, the importance of a multidisciplinary assessment in children and adolescents with urinary and/or intestinal symptoms is highlighted, since the presence of problems with school performance and impaired social interactions in this population is reported in the literature.^(19,22,23)

Still regarding the school environment, the type of school that most children attend in the present study was public school, similar to that found in the literature in a study conducted with a sample of schoolchildren with BBD.⁽¹⁹⁾ It is noteworthy that in Brazilian basic education, especially small schools that correspond to the equivalent of 46% of schools for this age group, a pattern of precarious infrastructure is mentioned.⁽²⁴⁾ Moreover, the school has been seen as a relevant contextual variable, highlighting the relationship between the bathrooms' physical structure, the organizational model and the low knowledge of teachers about the condition, with the development of BBD in students.⁽²⁾

Regarding paternal and maternal age, there was a predominance of age equal to or less than 40 years and the majority had two children, the latter factor being similar to the study conducted with 53 children diagnosed with BBD and their caregivers.⁽¹⁹⁾ Most families reported a family income of 1 to 2 minimum wages. Although the stratification of symptoms by family income was not performed, it is possible to observe in the literature the occurrence of urinary and/or intestinal symptoms related to the lowest socioeconomic level.^(21,22)

As for internet use, most families have access (87%), many (67%) had already used this tool to access information about BBD and almost all respondents (96%) reported an interest in having access to information about BBD on the internet. In the literature, it is observed that internet use by

parents and caregivers to access information about their children's health problems has contributed to overcome challenges and lack of knowledge, being reported as the main source for clarifying doubts.^(13,14,25) The internet is also referred to as a tool used to provide content related to the context of care in pediatric urology, and can be linked as a means of disseminating high quality information.⁽¹²⁾

In the narratives of families, the lack of knowledge about the symptoms was revealed, in addition to their devaluation, thus exposing the phenomena from the point of view of the studied subjects.⁽¹⁶⁾ In this regard, it is attributed to the non-detection of many cases of intestinal symptoms due to the lack of knowledge of families, in addition to the embarrassment and fear of receiving a negative response when approaching a health professional.⁽²⁴⁾ Additionally, surveys addressing isolated urinary and/or intestinal symptoms point to the lack of knowledge of families about symptoms and treatment, in addition to the difficulty in accessing this information.^(3,28)

On the other hand, some families expressed the impacts caused by BBD in the emotional scope and in the daily life of both the child and the family. The impacts of symptoms on children's lives can be seen in terms of children's difficulty in dealing with urinary and/or intestinal symptoms and seeing it as a problem for social interaction, leading to social isolation.^(27,29) The symptoms of incontinence are covered with stigmas and enuresis is sometimes seen by the family as a symptom that children are to blame for its occurrence.^(6,30)

Furthermore, the relevance of SU interventions based on demystifying and reducing stigmas associated with symptoms is pointed out, as well as the adoption of behavioral changes related to regular trips to the bathroom and healthy lifestyle habits, including with regard to adequate intake of fluids throughout the day.⁽³⁻⁵⁾ This finding was also observed in the families' narratives related to SU interventions.

Furthermore, in the present study, some families reported acquiring information through specialist nurses and that the information received had a positive effect on the understanding, acceptance or adequate management of BBD symptoms. The spe-

cialist nurses role in addressing and managing urinary and/or intestinal symptoms becomes evident, as these symptoms are sometimes not addressed and diagnosed by non-specialist professionals, in addition to the privileged position of these professionals in the early detection of dysfunctions and in carrying out an approach aimed at understanding family life and their experiences with symptoms.^(26,27,31,32)

Finally, some narratives reflected the importance of providing adequate information for the acquisition of knowledge about BBD by the family, a factor that enabled understanding and adherence to the proposed treatment. It is known that the early identification and treatment of BBD are essential factors to avoid social and clinical repercussions with negative impacts.⁽²⁾ Therefore, it reinforces the need to disseminate knowledge of existing evidence in the area of care in pediatric urology, as well as to remedy the lack of information with a language that is accessible to the receiver, either through the training of health professionals or even by providing information to families using the internet.^(6,28,33)

In this sense, it is observed that although 50% of families have low economic power with up to two minimum wages, most have internet access (87%) and would like to have access to information about BBD (96%) through this means. Reflecting the importance of using this tool for therapeutic purposes to be able to access patients and their families in different contexts.⁽²⁵⁾

By contrasting with the narratives, these data bring a reality of doubts and knowledge gaps presented by the families as well as the impact of the occurrence of symptoms in their daily lives. It is questioned if these families had access to information about BBD through the internet, because it is in their interest and access is more convenient, the experience with BBD symptoms of children would be different. The use of online information has the potential to play the role of social support for families of children living with chronic conditions, contributing greatly to maintaining health, managing and better living with the disease.⁽³⁴⁾

Thus, the use of social networks as a source of clinical information in pediatric urology for families presents itself as a promising health interven-

tion, since the literature already indicates the use of social networks such as Facebook to propose educational interventions in conditions chronic in this population.^(33,35) Additionally, it is noteworthy that the families reported the importance of specialist nurses' work during consultation for a better understanding of symptoms and therapeutic management. Therefore, for nurses' clinical practice, the therapeutic use of groups on the internet is suggested as an extension of their work process, in order to support families of children with BBD.

The limitation of this study is related to small sample size, which made inferential statistical analyzes unfeasible. It is suggested that future studies be carried out with a more representative sample, as well as studies that link the internet as a tool to reach families of children with BBD by providing adequate information, identifying determining factors for a better understanding of BBD and the experience with the symptoms.

Still in this context of future research, it is questioned whether child characteristics such as gender, age and temperament could be modulating factors of families' experience. It is also suggested to investigate the therapeutic effects of monitoring through social networks as a support system and exchange of experiences among families, as well as a platform for the dissemination of information by uropediatric nurses, aiming to improve the quality of life of both the families and children with BBD.

Conclusion

The coexistence of children's family with BBD is presented in different ways with a negative impact on daily life, which may be related to sociodemographic conditions. It is highlighted the lack of knowledge of families about the symptoms and the stigmas associated with their manifestation. To this end, access to online information becomes a potential ally to support the family of a child with BBD. Moreover, it is considered that although the families participating in our study have a sociodemographic profile that places them in a position of social vulnerability, it is possible to identify a po-

tential in terms of internet access and the behavior of searching for health information on the internet, including the interest in receiving information regarding the condition of BBD. Therefore, specialist nurses who work in the context of uropediatrics care need to advance in their professional practice and innovate in their approach by implementing new health care modalities, mainly through the incorporation of internet-based technologies.

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Collaborations

Rodrigues NS, Martins G and Silveira AO contributed to study design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

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