Children with urinary incontinence: impact...



INTEGRATIVE REVIEW ARTICLE

CHILDREN WITH URINARY INCONTINENCE: IMPACT ON FAMILY MEMBERS COEXISTENCE

CRIANÇAS COM INCONTINÊNCIA URINÁRIA: IMPACTO NA CONVIVÊNCIA DOS FAMILIARES NIÑOS CON INCONTINENCIA URINARIA: IMPACTO EN LA CONVIVENCIA DE LOS FAMILIARES

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ABSTRACT

Objective: to identify factors that have an impact on the coexistence of family members of children with urinary incontinence. *Method*: bibliographic, descriptive, integrative review type study with search of articles in September 2017, in LILACS, BDENF, MEDLIN, and CINAHL databases. We considered the temporal cut from January 2012 to December 2017, using controlled and uncontrolled Health Science Descriptors (DeCS) in English and Portuguese. Results: we included 11 articles, published between 2012 and 2016, highlighting three categories: 1) The educational level of parents as an impact factor; 2) The impact on the quality of life of family members; and 3) The changes that impact on daily family life. Conclusion: urinary incontinence affects the family routine and can cause psychological disorders, such as stress, anxiety, and depression in children and their family members. There was a shortage of productions that related family members' perceptions of diurnal urinary incontinence and fecal incontinence to the parents' education level. The role of nurses working in pediatric urology was evident with respect to the importance of understanding family coexistence to contribute to the delineation of guidelines aimed at the education and understanding of caregivers' experiences. Descriptors: Urinary Incontinence; Family; Caregivers; Children; Enuresis; Urinary Incontinence Due to Stress.

RESUMO

Objetivo: identificar fatores que impactam na convivência dos familiares de crianças com incontinência urinária. Método: estudo bibliográfico, descritivo, tipo revisão integrativa, com busca de artigos no mês de setembro de 2017, nas bases de dados LILACS, BDENF, MEDLINE e CINAHL. Considerou-se o recorte temporal de janeiro de 2012 a dezembro de 2017, utilizando os Descritores em Ciência da Saúde (DeCS) controlados e não controlados no idioma inglês e português. Resultados: foram incluídos 11 artigos, publicados entre 2012 e 2016, destacando-se três categorias: 1) O nível educacional dos pais como um fator de impacto; 2) O impacto na qualidade de vida dos familiares; e 3) As mudanças que impactam no cotidiano familiar. Conclusão: a incontinência urinária afeta a rotina familiar e pode provocar transtornos psicológicos como estresse, ansiedade e depressão nas crianças e em seus familiares. Houve escassez de produções que relacionassem a percepção do familiar ante a incontinência urinária diurna e fecal com o nível escolar dos pais. Evidencia-se o papel do enfermeiro que atua em uropediatria sobre a importância da compreensão da convivência familiar, a fim de contribuir com o delinear de orientações voltadas para a educação e compreensão das experiências vividas pelos cuidadores. Descritores: Incontinência Urinária; Família; Cuidadores; Crianças; Enurese; Incontinência Urinária por Estresse.

Objetivo: identificar factores que impactan en la convivencia de los familiares de niños con incontinencia urinaria. Método: estudio bibliográfico, descriptivo, tipo revisión integradora, con búsqueda de artículos en el mes de septiembre de 2017, en las bases de datos LILACS, BDENF, MEDLINE y CINAHL. Fue considerado el recorte temporal de enero de 2012 a diciembre de 2017, utilizando los Descriptores en Ciencias de la Salud (DeCS) controlados y no controlados en idioma Inglés y portugués. Resultados: se incluyeron 11 artículos publicados entre 2012 y 2016, destacándose tres categorías: 1) El nivel educativo de los padres como un factor de impacto; 2) El impacto en la calidad de vida de los familiares; y 3) Los cambios que impactan en el cotidiano familiar. *Conclusión*: la incontinencia urinaria afecta la rutina familiar y puede provocar trastornos psicológicos como estrés, ansiedad y depresión en los niños y en sus familiares. Hubo escasez de producciones que relacionaran la percepción de los familiares ante la incontinencia urinaria diurna e incontinencia fecal con el nivel escolar de los padres. Se evidencia el papel del enfermero que actúa en urología pediátrica con respecto a la importancia de la comprensión de la convivencia familiar, a fin de contribuir con el delinear de orientaciones sobre la educación y comprensión de las experiencias vividas por los cuidadores. Descriptores: Incontinencia Urinaria; Familia; Cuidadores; Niños; Enuresis; Incontinencia Urinaria por Estrés.

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INTRODUCTION

epidemiological

30 and 40%.1-2

It is known that the etiology of urinary incontinence is multifactorial. This is a common condition in childhood, especially in the context of uropediatric care. Urinary incontinence is defined by the International Children's Continence Society (ICCS) as an involuntary loss of urine. It is subdivided into incontinence intermittent diurnal and intermittent nocturnal incontinence; the known latter is also as enuresis.

terms,

incontinence/enuresis affects between 20 and

30% of children with behavioral disorders, and

diurnal urinary incontinence affects between

nocturnal urinary

Nocturnal urinary incontinence is considered to be involuntary urination during sleep, not associated with comorbidity, and problematic when it affects children aged five years or older. According to the Diagnostic and Statistical Manual of Mental Disorders, urinary incontinence is considered among the behavioral and emotional disorders associated with internalization disorders, including depression and anxiety.¹⁻²

In this context, caregivers—individuals responsible for children's health—perceive that the children are vulnerable, which is a conviction that increases the levels of anxiety and depression in family members.³ Anxiety can be influenced by behaviors learned and by observation and interaction with close family members, which may increase the risk of psychological stress in family members.³

It is recognized that psychological stress influences the way in which caregivers behave and treat children with urinary incontinence. It has been observed that the most common of involuntary psychological affective aggression are fights, constraints, and even verbal and physical aggressions as a form of punishment. Such behaviors were discussed in a study conducted in Brazil with 132 children diagnosed with nocturnal urinary incontinence. It was found that 89% of the participants had suffered some type of aggression and there were forms of verbal aggression in 100% of the cases analyzed by the study, pointing the mothers (caregivers) as the main responsible individuals for the actions.4

It is observed that the aggressive behavior of the caregivers may aggravate a preexisting mental health condition of the children, which is explained by the exacerbated release of cortisol (stress hormone), triggering even a mechanism of higher urinary output. This fact may also lead to behavioral problems, either

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emotional or affecting socialization among peers.⁵ There are other risk factors strongly discussed in the literature, such as the association between large families and the low educational and socioeconomic levels of the caregivers, given that the search for help in health services is reduced and this fact may influence the permanence of nocturnal incontinence until adulthood.^{6,7,8}

Faced with this general panorama of the subject studied, the adoption of coping and behavioral strategies to deal with the psychosocial stress of caregivers is suggested by addressing the bases for the prevention of risks related to children's mental health. Therefore, behavioral and emotional disorders should be treated simultaneously with the therapeutic regimen for urinary incontinence.

In order to overcome the challenges posed by the children's condition to their families, caregivers are expected to incorporate the therapeutic regime into their daily lives and, therefore, successfully coordinate treatment requirements. To that end, the family routine changes and it is hoped that the children will accept the new standards of the treatments.⁹

In addition, there is a shortage of interventions in the family perspective that involves the psychosocial nature of urinary incontinence in the family context in order to understand the family roles and relationships in the environment in which the therapeutic regimen is managed. Health professionals should make decisions with the purpose of improving the engagement of family members, seeking to understand how family involvement contributes to better control children's urinary condition.9

In view of the above mentioned, it is relevant to identify the factors that may interfere in the family management and in the therapeutic interventions applied to the children with urinary incontinence.

OBJECTIVE

• To identify factors that have an impact on the coexistence of family members of children with urinary incontinence.

METHOD

This is a bibliographical, descriptive and integrative review study conducted in September 2017, using databases by means of a survey of the scientific productions about the impact and behavior of the family members of children affected with any type of urinary incontinence. The integrative review is a research method that allows synthesizing the literature on a certain topic, allowing the

inclusion of multiple studies with different methodological approaches. The aim is to obtain a more general conclusion and provide guidelines for further studies.¹⁰

The following steps were performed for the conduction of the present study: Identification of the topic and selection of the question: 2) Establishment of research inclusion and exclusion criteria for the study; 3) Identification of pre-selected and selected studies; 4) Categorization of selected studies; 5) Analysis and interpretation of results; and Presentation of the knowledge review/synthesis.¹⁰

The guiding question of this research was: Which is the available evidence in the literature on the factors that have an impact on the coexistence and behavior of family members of children with urinary incontinence?

The search for the studies was carried out in the following electronic databases: Latin American and Caribbean Health Sciences Literature database (LILACS); Specialized Bibliographic Database in the Nursing Area Children with urinary incontinence: impact...

(BDENF); Medical Literature Analysis and Retrieval System Online (MEDLINE); Cumulative Index to Nursing and Allied Health Literature (CINAHL), through the Virtual Health Library (VHL). We used the following controlled and uncontrolled Health Science Descriptors (DeCS) in English and Portuguese: urinary incontinence; urinary incontinence due to stress; urge urinary incontinence; nocturnal enuresis; diurnal incontinence; family; caregivers; caregiver; family member; experience; child; incontinência urinária; por incontinência urinária estresse; incontinência urinária de urgência; enurese incontinência urinária noturna; diurna; família; membro familiar; cuidadores; cuidador; vivência; and criança, by means of different forms of combination, using the Boolean searching strategy, i.e., the terms associated among them with AND and the joining of similar terms with OR, in order to achieve better results during the research (Figure 1).

SEARCH STRATEGY	MEDLINE	BDENF	LILACS	CINAHL
(urinary incontinence) OR (urinary incontinence due to				
stress) OR (urge urinary incontinence) OR (nocturnal				
enuresis) OR (diurnal incontinence) AND (family) OR				
(caregivers) OR (caregiver) OR (family member) OR	141	27	14	22
(experience) AND child				

Figure 1. Combination of descriptors according to selected databases. Brasília, DF, Brazil, 2017.

The inclusion criteria were articles in English, Portuguese, and Spanish, made available in full and published from January 2012 to December 2017 in the aforementioned databases, which were relevant to the object of study and the guiding question of the review. Duplicate publications, studies on relatives of children with neurological impairment or congenital malformation of the genitourinary and intestinal dissertations, books, theses, case studies, papers presented at conferences, informative studies, literature reviews, and studies that did not correspond to the delimited search period in the databases and that did not address the topic of the present study were excluded. 10

This way, the selection of the literature was performed by means of meticulous reading of the titles and abstracts of the original articles, available in full and online, that met the inclusion criteria mentioned. Still, they were submitted to the classification criteria of the Critical Appraisal Skills Program (CASP) to evaluate the quality of the selected articles.¹¹

The process was carried out in three phases in order to choose the selected studies, namely: A) Selection of articles according to the combination of the descriptors associated with Boolean search (AND/OR) in the selected databases (Figure 1); B) Reading of the titles and abstracts of 204 articles corresponding to 141 in MEDLINE, 14 in LILACS, 27 in BDENF, and 22 in CINAHL (Figure 1), which resulted in a total of 13 articles selected for the study according to the inclusion criteria; and C) Reading of the 13 articles selected in full. Two articles that did not address the topic of the study were excluded. 10 The selection process of the articles is illustrated in Figure 2.

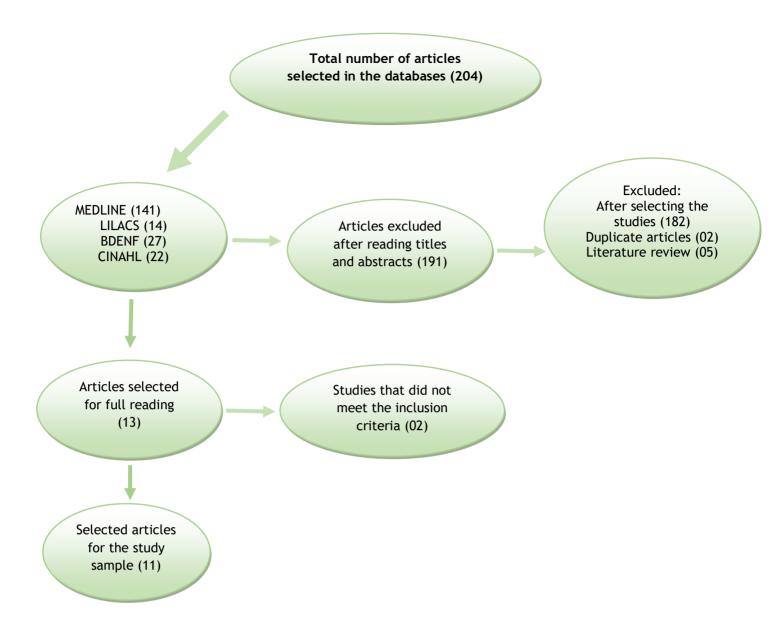


Figure 2. Flowchart of the selection and inclusion of studies for the review conducted in September 2017. Brasília, DF, Brazil, 2017.

The extraction of data and synthesis of the studies included in the review were carried out using a descriptive tool elaborated in the Microsoft Word® program, which included year of publication, country of origin, authors, titles, level of evidence/methodology of the studies, and main results of the included studies (Figure 3).

For the analysis of the level of evidence of the selected sample, we used the parameters that classify six levels of scientific evidence, namely: Level 1: evidence resulting from the meta-analysis of multiple controlled and randomized clinical studies; Level 2: evidence individual obtained in studies experimental designs; Level 3: evidence of quasi-experimental studies; Level 4: evidence in descriptive studies (non-experimental) or with qualitative approach; Level 5: evidence in case or experience reports; Level 6: evidence based on experts' opinions.¹⁰

RESULTS

From the articles selected for this study, we obtained a final sample of 11 articles.

Regarding the year of publication, the period of greatest production of the studies occurred in 2015, with 36% (n = 4). There was one article published in 2012 and another in 2016, representing the smallest production of articles. Most of the studies were published in English (n = 10), and only one in Portuguese. Turkey was the country with the highest number of publications (n = 3), followed by the United Kingdom and the United States (n = 2 each). The other publications were from Japan, Sweden, Germany, and Brazil (n = 1 each). With respect to the methodological outline, it was observed that 10 articles had a quantitative approach and one article a qualitative approach, six articles descriptive studies, three articles were casecontrol studies, and two articles were cohort studies. A summary of the studies selected for this review and their main results are presented in Figure 3.

There is a need of methodological quality of studies to support clinical practice, given that the use of more robust scientific ISSN: 1981-8963

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evidence can reduce risks and uncertainties in nurses' clinical decision making. 12

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No.	Year / Country	Author(s)	Title	Level of evidence/ Method	Main results
1	2012 Japan	Naitoh, Y. et al. ¹³	Health Related Quality of Life for Monosymptomatic Enuretic Children and Their Mothers	III - Quantitative case-control study	Anxiety state was lower in mothers of healthy volunteers than in mothers of enuretic children.
2	2013 Sweden	Cederblad, M. et al. ¹⁴	Nobody Asked Us if We Needed Help - Swedish parents experiences of enuresis	IV - Qualitative descriptive study	The findings indicated that nocturnal urinary incontinence is stigmatizing and life- threatening for parents.
3	2013 United States	Schlomer, B. et al. ¹⁵	Parental beliefs about nocturnal enuresis causes, treatments, and the need to seek professional medical care	IV - Quantitative descriptive study	Most parents associated nocturnal urinary incontinence with deep sleep, laziness to wake up, or they thought the bladder was small. In addition, parents were not aware of the causes of nocturnal urinary incontinence.
4	2013 Turkey	Karaman, M. I. et al. ¹⁶	Methods and Rates of Punishment Implemented by Families to Enuretic Children in Turkey	IV - Quantitative descriptive study	Most of the children suffered a severe punishment method. The most used were condemnation, deprivation of desires, reprimand, threat, and sleep deprivation.
5	2014 Germany	Equit, M. et al. ¹⁷	Health-related quality of life and treatment effects on children with functional incontinence, and their parents	IV - Quantitative descriptive study	Mothers of children with nocturnal urinary incontinence exhibited reduced capacity in psychological mastery in comparison to the parents of children without this comorbidity.
6	2014 Turkey	Kilicoglu, A. G. et al. ¹⁸	Impact of nocturnal enuresis on health-related quality of life in children and their mothers	III - Quantitative case-control study	The mothers reported feelings of anger, intolerance and disrespect, and considered that the quality of life of their children was low in relation to that of the control group.
7	2015 Brazil	Ferrari, R. A. et al. ¹⁹	Incontinência urinária noturna: associações entre gênero, impacto, intolerância materna e problemas de comportamento	IV - Cohort study	The average of behavioral problems associated with nocturnal urinary incontinence reached a clinical level. In the sample assessed, more intolerant mothers had more impacted children.
8	2015 Turkey	Sarich, H. et al. ²⁰	Prevalence of nocturnal enuresis and its influence on quality of life in school-aged children	IV - Quantitative descriptive study	Factors such as large family, family history of nocturnal urinary incontinence, low educational level, unemployed parents, and single mothers were regarded as predispositions for nocturnal urinary incontinence.
9	2015 United Kingdom	Joinson, C. et al. ²¹	Early childhood psychological factors and risk for bedwetting at school age in a UK cohort	IV - Quantitative cohort study	Stress of mothers during early childhood may be a predisposing factor for increased levels of emotional and behavioral symptoms of the children with nocturnal urinary incontinence at school age.
10	2015 United Kingdom	Tai, T. T. et al. ²²	Parents have different perceptions of bed-wetting than children from six to 15 years of age	III - Quantitative case-control study	Children with severe nocturnal urinary incontinence and advanced age reported greater difficulty in dealing with their condition which, associated with low maternal education, became a risk factor for the permanence of the disorder.
11	2016 United States	Sá, C. A. et al. ²³	Increased Risk of Physical Punishment among Enuretic Children with Family History of Enuresis	IV - Quantitative descriptive study	The family history of nocturnal urinary incontinence was a condition for the children to suffer more physical than verbal punishments.

Figure 3. Grouping of studies selected for the sample according to year of publication, country, author(s), title, level of evidence, and main results. Brasília, DF, Brazil, 2017.

We used the concept of categorization of the topics according to the criteria for organizing the data collected in order to construct a set of categories (Figure 4).¹² In the selected sample, the object of the studies was nocturnal urinary incontinence mostly in children and adolescents (90.9% = 10). The goal of using the published studies was to assess parental¹⁵ and family members'^{13,14,15,16,17,18,20,22,23} beliefs, the quality

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of life of family members, children, and adolescents, 13,17,18 psychological and behavioral factors, 19,21,22 and the methods of punishment used by the caregivers. 16,23 It is worth noting that only one article addressed diurnal and nocturnal urinary incontinence in conjunction with fecal incontinence in children, 17 which indicates the scarcity of publications in this area.

Tanian addressed in the studies	Sequence of Authors (legend)										
Topics addressed in the studies	1	2	3	4	5	6	7	8	9	10	11
Educational level of parents:											
Illiterate ^{16,20,21,22}	N	Ν	Ν	R	Ν	Ν	Ν	R	R	R	Ν
Primary ^{16,18,20,21,22,23}	N	Ν	Ν	R	Ν	R	Ν	R	R	R	R
Secondary ^{14,15,16,18,20,21,22,23}	N	R	R	R	Ν	R	Ν	R	R	R	R
Higher ^{14,15,16,18,20,21,22,23}	N	R	R	R	Ν	R	N	R	R	R	R
Quality of life of parents:											
Anxiety ^{13,14,17,18,22}	S	R	Ν	Ν	R	R	Ν	Ν	Ν	R	N
Stress ^{13,14,21}	S	R	Ν	Ν	Ν	Ν	Ν	Ν	R	N	N
Depression ^{13,17,21}	S	Ν	N	Ν	R	Ν	N	Ν	R	N	N
Changes in daily family life:											
Social isolation ^{14,17,18,22}	N	R	N	Ν	R	R	N	N	N	R	N
Financial impact ^{13,20,21,23}	S	Ν	Ν	Ν	Ν	Ν	Ν	R	R	N	R
Social protection ¹⁴	N	R	N	Ν	Ν	Ν	N	Ν	Ν	N	N
Changes in parents' behavior:											
Intolerance ^{13,14,16,19,23}	S	R	Ν	R	N	N	R	N	Ν	N	R
Anger ^{13,16,18}	S	Ν	Ν	R	Ν	R	Ν	Ν	Ν	N	N
Fear ¹⁵	N	Ν	R	N	N	N	N	Ν	N	N	N

Figure 4. Categorization of the sample of articles based on the topics addressed. Brasília, DF, Brazil, 2017.

Legend: 1 - Naitoh, Y. et al.; **2** - Cederblad, M. et al.; **3** - Schlomer, B. et al.; **4** - Karaman, M. I. et al.; **5** - Equit, M. et al.; **6** - Kilicoglu, A. G. et al.; **7** - Ferrari, R. A. et al.; **8** - Sarich, H. et al.; **9** - Joinson, C. et al.; **10** - Tai, T. T. et al.; **11** - Sá, C. A. et al.; **R** = reported in the study; and **N** = non-reported in the study.

After the construction of the categories, according to the publications selected, three thematic units were identified, namely: 1) Parents' educational level as an impact factor; 2) Changes that impacted on daily family life; and 3) Impact on the quality of life of family members/caregivers, which are discussed below.

DISCUSSION

◆ Parents' educational level as an impact factor

The parents' low educational level was discussed in the sample studies as a factor for a greater predisposition of difficulty in dealing with urinary incontinence. 14,18 The mothers were the main caregivers, due to the fact that they experience in a more intensive way the daily life of their children and, in general terms, had a lower educational level in comparison to the fathers.²⁰ These factors increase the risk for persistent urinary incontinence throughout the children's lives, combine especially for those that psychological factors and nocturnal urinary incontinence. 20,21 It was observed that the educational level of the caregivers could also influence the way of dealing with the children, and verbal and physical punishment were common.¹⁶

In the present review, there was an evident relationship between caregivers' educational level and psychosocial factors, such as behavioral problems, hyperactivity, emotional difficulties, and peer relationship problems. Such behavioral findings were more frequently observed in children living with mothers of low educational level in comparison to children living with mothers with higher educational levels.6 Therefore, it can be suggested that low maternal education is a risk factor for adequate management of children with nocturnal urinary incontinence, given that the disorder is influenced by and behavioral factors that emotional promote the difficulty in cosidering and seeking healthcare.6

The late search for healthcare services⁴ can be explained by the fact that the parents of children with nocturnal urinary incontinence do not regard this condition as a disease. This finding is similar to that found in studies that affirm the relationship between low educational level and reduced demand for medical care.⁹ In addition to the low educational level, the socioeconomic status of

the family explains the reduced search for healthcare.⁸ However, this finding should be better investigated in further studies, given that this issue may not be related to education or social level, but to restricted access to healthcare, or even to the caregivers' work characteristics.⁵

In a study on parents' beliefs in the treatment of nocturnal urinary incontinence conducted with 216 subjects, 55% reported the search for medical care for their children with nocturnal urinary incontinence, and 36% believed in treatment efficacy.¹⁵ Also, in that study, it was observed that women with postgraduate level were more likely to seek medical nocturnal care for urinary incontinence in comparison to women with a low educational level. This was a direct impact factor in the early decision for the treatment of this morbidity. 15

prevalence of nocturnal urinary incontinence in countries such as Nigeria, Democratic Republic of Congo, Yemen, and Iran, considered to be in development, was about two to three times greater than the rates of developed countries with similar socioeconomic inequity. In comparison to developed countries, the rate of nocturnal urinary incontinence was higher and more severe. Youngest age, men, family history of nocturnal urinary incontinence, large families, ineffective prior treatment, as well as financial situation, individuals' role in the culture, beliefs and community resources are variables that will also contribute to the permanence of urinary incontinence.8,24

The literature points to nocturnal urinary incontinence as a condition that was more in children accompanied prevalent caregivers of low educational and socioeconomic level, evidencing an important variation between social levels. 6,25 It can be mentioned that this is an important variable to be investigated. It is suggested that the population affected by nocturnal urinary incontinence should be clarified and oriented in order to achieve better results of treatments.

In order to maximize patients' compliance with the treatment and education regarding the clinical management of the symptoms of urinary incontinence in the urological scope, nursing should be capable of offering holistic care to the patients, from the stage of user embracement in the specialized service to the meticulous evaluation of biological, psychological, social, and emotional risk factors. In addition, the nurses should explain the procedures necessary for diagnosis,

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discuss the concerns, and assist in care provided to the patients.²⁶

♦ Impact on the quality of life of family members/caregivers

Quality of life is measured as the way in which the individuals perceive their state of psychological, mental, emotional well-being, and socio-cultural values, i.e., how the impact of a disease and/or treatment is perceived. Urinary incontinence is a common disorder in childhood and significantly affects the daily family life, leading to a decreased quality of life of the caregivers with regard to the family psychosocial dimension. 13,17-8

A cohort study conducted in the United assessed influence Kingdom the psychological factors during early childhood on the risk of nocturnal urinary incontinence at school age. Through the application of two questionnaires, the Postnatal Depression Scale (EPDS) in Edinburg and the Emotionality Activity Sociability (EAS), the study found that mothers of children with nocturnal urinary incontinence had a probable diagnosis of depression.²¹ maternal Another conducted with 139 children with nocturnal urinary incontinence assessed their mothers' quality of life using the following three scales: SF-36® Quality of Life Questionnaire; Self-Rating Depression Scale; and State-Trait Anxiety Inventory. It was found that the reduced vitality of the mothers for the management of nocturnal incontinence, the greater burden of time and additional efforts, physical pain, pessimism were associated with a possible higher masked depression and levels. 13,18

Caregivers' stress was pointed out as a predisposing factor that potentiates children's behavioral and emotional problems, such as low self-esteem and diminished self-image, and promotes a reduced family coexistence.²¹-² In the sample of the present study, there was only one article that addressed diurnal urinary incontinence, fecal incontinence, and nocturnal urinary incontinence associated with each other or individually. Among the study population, 34% had incontinence in a combined manner, with significant impairment in the psychological domain of the parents, who had increased anxiety and depression levels.¹⁷ Anxiety is an impact factor that causes impairment to parents and jeopardize their skills in parental practices, as well as the quality of family relationships. 14,22

According to a cohort study conducted in Lithuania to assess the impact of maternal stress on the emotional and behavioral difficulties of children aged between four and

investigated in this area.6

six years, the family environment during early childhood can influence health and wellbeing, and may also generate emotional and behavioral difficulties during the future life. Exposure to family stressors also leads to the release of stress hormone (cortisol), which triggers epigenetic changes, such as chromatin and DNA modifications, thus leading to changes in the metabolic pathways involved in the etiology of diseases.⁷ It is still unclear whether the presence of epigenetic triggers (stress) is related to the control of urination. This way, there is still a gap to be

A case study assessed 93 children with nocturnal urinary incontinence and found that the family members' perceptions regarding the children's emotional behavior did not match their own perceptions, because the children did not consider themselves different from their peers who did not suffer from nocturnal urinary incontinence. It is possible to consider lack of knowledge, given that the discrepancy in the children's perception of their condition indicates the existence of family isolation. The inefficient approach to the topic can interfere with children's well-being.²²

Clarification on nocturnal urinary incontinence is essential, presenting it as a common childhood condition. Also, it should be stressed to the parents that with the advancement of the child's age, in most cases, the problem has a spontaneous resolution; however, comorbid conditions, such as psychological disorders, should be taken into consideration, because they can contribute to the permanence of urinary incontinence.^{7,27}

A study on quality of life conducted with 87 children with nocturnal urinary incontinence and their mothers, assessed using the German version of the World Health Organization's WHOQOL-BREF quality of life assessment, which attributes a score to the factors influencing the quality of life, found that children and mothers scored their perceptions about quality of life differently. The same instrument was applied in a another study to a similar group and the mothers obtained a higher score for social relations. That study also pointed out greater social impairment for caregivers of children with nocturnal urinary incontinence. The same instrument was applied in a social impairment for caregivers of children with nocturnal urinary incontinence.

Social isolation is a worrying factor for parents who deal with their children's nocturnal urinary incontinence. They feel lonely and fail to participate in community activities, because they consider urinary incontinence a taboo, and deprive their children of social interaction. Parents argue that protecting their children from family

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members, neighbors, and friends is an obligation, because it is a very personal matter and, this way, they avoid exposing their children.¹⁴

Social exclusion can be harmful both to the children and their caregivers, and can aggravate the psychological factor during the maintenance of the incontinence condition. It is important to show that parents deprive their children of social life, because they feel they are protecting them embarrassment at school, among friends, and in the family. Such a protective attitude of the parents occurs due to the fear of discovering that their children have urinated in bed. They begin to hide these accidents by all possible means.²⁸ This social impact is evidenced by the fact that children with severe nocturnal urinary incontinence exhibit difficulties in interacting with their peers, resulting in emotional isolation and difficult family relationships.²⁶

Considering urinary incontinence dysfunction that affects the quality of life of the family members and the children, health professionals should establish new healthcare in their practice, approach involving the relationship with the family members, as well as the perception of the disease of the children and the quality of care provided. Therefore, professional training in the field of pediatrics becomes necessary. Health professionals should be aware of the risks inherent to the health condition and to the physical and psychological suffering of the children and their caregivers.²⁹

3. Changes that impact on daily family life

In the selected literature, nocturnal urinary incontinence was the topic further investigated. This condition exhibits a gradual reduction as the children's age increases. 15,18,20 Parents believe that involuntary nocturnal urination is uncontrollable and try understand the etiology of this condition, experiencing feelings of helplessness, concern, and annoyance. In addition, family social relationships are hampered by the fact that their children urinate in bed during the night; therefore, they avoid overnight visits.

It is common for parents to conceal the truth by keeping diapers as a strategy to deal with their children's condition, in addition to sharing management of tasks, such as performing hygiene and changing the sheets after their children have urinated in bed in an attempt to keep it dry.¹⁴

From the perspective of the Dyadic Adjustment Scale (DAS), it was observed that the scores relating to affection were reduced in parents of children with nocturnal urinary

incontinence.³⁰ The studies assessed indicated the parents' difficulty in coping with family agreement in basic situations, which promotes less empathy between the fathers and the mothers and makes the family management difficult. The relationship between peers was seen as a risk factor for monitoring, supervision, and involvement with children.²⁷ If these relationships are negative, they can lead to children's suffering due to the lack of caregivers' control. This fact demonstrates the lack of other approaches in studies aimed at analyzing family coexistence in children with urinary incontinence, and the abilities of the families to manage the disease condition.

Parents wake their children up at night as a strategy to deal with nocturnal urinary incontinence. This procedure causes fatigue, both in the parents and the children, generating stress, irritability, conflicts, and frustrations. This fact even happens when using positive psychological reinforcement methods, such as rewards, which have no effect, causing feelings of anger and, consequently, threats toward the children. The observation of this behavior indicated parents' increased feelings of guilt related to their children's condition. 14-5

In addition, it is inferred that parents are more susceptible to psychiatric problems in the face of this reality, because they are disappointed by the lack of success in therapeutic interventions with the threats or rewards and, also, by the consequent obligation of maintaining the daily hygiene of the place, such as washing the sheets and removing odors from the rooms. Moreover, several interruptions of sleep at night may result in intolerant caregivers. ^{18,23}

The level of parents' intolerance has a significant impact on children with nocturnal urinary incontinence. As the children's age advances, this level of intolerance tends to increase. 19 The level of caregivers' tolerance is considered to be a factor that causes child abuse, because it is believed that the children are guilty for bedwetting.²³ Parents are extremely vigilant, but, due to the feeling of anger, they may choose punishments classified (condemnation, threatening, mild deprivation of desires, humiliating children in front of others) and severe (tapping softly, leaving the children wet, locking the children inside the house, tapping with the hands or a stick) as a treatment for nocturnal urinary incontinence.16

Studies conducted in the United States and France have found that most families used at least one method of punishment to manage

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their children's nocturnal urinary incontinence, and that this situation occurred repeatedly. Another important fact reported in the studies refers to the parents' experience regarding the diagnosis and family history of nocturnal urinary incontinence. This experience occurred concomitantly with verbal and/or physical punishment, thus increasing the incidence and repetition of these practices with their children. 18,23

The literature shows that nocturnal urinary incontinence causes changes in daily family life and may give rise to maltreatment and punishment. In addition, inconsistence has a greater relationship with recurrent lower urinary tract infections and psychological changes. Parents and caregivers regard the condition of the children as normal and blame them for their urine losses and dirty clothing. This fact can lead to verbal and physical punishment and expose children to embarrassments.^{4,9}

To treat the children, it was observed that parents use simple behavioral practices, such as restricting the intake of liquid before going to bed, disruption of sleep at night to go to the bathroom, and giving rewards that stimulate the children to stay dried. Such methods are considered satisfactory for the management of nocturnal urinary incontinence, but they become more effective when used concomitantly with the enuresis alarm therapy.⁸

According to a study on children and perceptions, adolescents' positive negative situations, which induce actions to adapt them to their condition, may influence the care and treatment process.²⁹ Proactive actions are collaborative attitudes of family members, such as health routine, communication, and treatment plan, which are associated with the lifestyle, the problem, collaboration, and mental support. Reactive actions are a significant change to achieve an established goal. Health professionals intervene to improve the management of the disease using the promotion and education of patients and their caregivers.²⁴

The way in which the parents deal with these interventions is fundamental for the management of the children's condition. Recent studies have shown that interventions involving the family improve the capacity to administer the treatment. Although parents are involved in the interventions, there is a deficiency in the family context, emphasizing the need for further studies centered on families and the psychosocial content of the intervention to involve roles and family

relationships and achieve a better and more effective therapeutic regimen.⁹

The literature points out other factors related to socioeconomic status and the presence of adversities, such as unemployed parents, financial difficulties, large families, and inadequate housing. This factors are regarded as having an impact on family life and as contributors to the permanence of nocturnal urinary incontinence, because there is a large increase in household expenses due to the multiple clothes washing and constant changing of bed sheets and mattresses. 13,15,21,30

CONCLUSION

Urinary incontinence involves more than one physical disorder. It affects the family routine and can cause psychological disorders such as stress, anxiety, and depression in children and their caregivers. In general terms, caregivers feel powerless, worried, guilty, irritated, and intolerant when they have to manage urinary incontinence.

The low educational level of the parents was considered a risk factor, given that such a variable can lead children to suffer verbal and physical punishment. This fact poses a challenge to the practice of health professionals, especially nurses of pediatric urology. They should recognize the family members' ability to learn and guide the family as a whole to be engaged in specific actions for their children's educational condition and respect the particularities of each family member.

A gap to be filled is the need for scientific productions that relate the family members' perceptions of diurnal urinary incontinence and fecal incontinence to the parents' educational level, given that the primary role of nurses working in pediatric urology lies in the expanded understanding of the family context in which the children are inserted.

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Submission: 2018/02/18 Accepted: 2018/06/08 Publishing: 2018/07/01

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