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ONLINE HEALTH FORUM AS A SUPPORT FOR PEOPLE WHO PERFORM INTERMITTENT VESICAL CATHETERIZATION

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ABSTRACT

Objective: to evaluate the use of an online forum for people with myelomeningocele and their families and the profile of the users, based on intermittent catheterization.

Method: a quantitative, cross-sectional, descriptive and exploratory study. Data was collected from users of the online forum, based on an *online* questionnaire available from March 20 to April 20, 2015. Sample consisted of 30 users. Descriptive statistical data analyses and chi-square test were performed.

Results: among users, 27% were people with myelomeningocele and 73% were family members. Age, considering the total sample, ranged from 22 to 58 years old. Women represented 67% of the sample. Most users considered the language used in the forum understandable, and also thought the forum had a proper layout and was easy to navigate. It was noted that the mother and the person with myelomeningocele are the main responsible people for intermittent catheterization; 86% use a simple plastic catheter and 14% use a hydrophilic catheter; 81% do not reuse the catheter, 10% use the same catheter for one day and 9% for up to one week. The main place chosen to perform intermittent catheterization was the bed, followed by the toilet and wheelchairs.

Conclusion: the use of the online forum was well evaluated by the users. It can be considered a means to obtain information, create a support network and clarify any doubts, empowering users and contributing to adherence to intermittent catheterization, which is one of the treatments for neurogenic bladder.

DESCRIPTORS: Myelomeningocele. Internet. Rehabilitation. Intermittent urethral catheterization. Health education.

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FÓRUM VIRTUAL DE SAÚDE COMO SUPORTE ÀS PESSOAS QUE REALIZAM CATETERISMO VESICAL INTERMITENTE

RESUMO

Objetivo: avaliar o uso de um fórum virtual para pessoas com mielomeningocele e seus familiares e o perfil dos usuários, de acordo com a realização do cateterismo vesical intermitente.

Método: estudo quantitativo, transversal, descritivo e exploratório. A coleta de dados foi realizada com usuários do fórum virtual, com base em um questionário *online*, disponibilizado de 20 de março a 20 de abril de 2015. A amostra foi composta de 30 usuários. Foram realizadas análises estatísticas descritivas e teste qui-quadrado.

Resultados: dos usuários, 27% eram pessoas com mielomeningocele e 73% familiares. A idade, considerando a amostra total, variou de 22 a 58 anos. O sexo feminino representou 67% da amostra. A maioria dos usuários considerou a linguagem utilizada no fórum compreensível, o visual adequado e a navegação fácil. Foi observado que a mãe e a própria pessoa com mielomeningocele são os principais responsáveis pela realização do cateterismo vesical intermitente; 86% utilizam cateter de plástico simples e 14% o cateter hidrofílico; 81% não reutilizam o cateter, 10% utilizam o mesmo cateter durante um dia e 9% por até uma semana. O principal local de realização do cateterismo vesical intermitente foi a cama, seguida pelo vaso sanitário e cadeira de rodas.

Conclusão: o uso do fórum virtual foi bem avaliado pelos usuários. Ele pode ser considerado um meio para obtenção de informações, formação de rede de apoio e esclarecimento de dúvidas, empoderando os usuários e contribuindo para a adesão ao cateterismo vesical intermitente, que é um dos tratamentos para a bexiga neurogênica.

DESCRIPTORIOS: Mielomeningocele. Internet. Reabilitação. Cateterismo uretral intermitente. Educação em saúde.

FÓRUM VIRTUAL DE LA SALUD COMO SOPORTE A PERSONAS QUE REALIZAN CATETERISMO VESICAL INTERMITENTE

RESUMEN

Objetivo: evaluar el uso de un fórum virtual para personas con mielomeningocele y sus familiares y el perfil de sus usuarios, según la realización del cateterismo vesical intermitente.

Método: estudio cuantitativo, transversal, descriptivo y exploratorio. Se realizó la recolección de datos con usuarios del fórum virtual, en base a una encuesta *online*, disponible desde el 20 de marzo al 20 de abril de 2015. La muestra estuvo compuesta por 30 usuarios. Se realizaron los análisis estadísticos, descriptivos y test chi cuadrado.

Resultados: de los usuarios, 27% eran personas con mielomeningocele y 73% familiares. La edad, considerándose toda la muestra, osciló entre los 22 y 58 años. El sexo femenino representó el 67% de la muestra. La mayoría de los usuarios consideró que el lenguaje utilizado en el fórum es comprensible, la imagen es adecuada y tiene una fácil navegación. Se observó que la madre y la propia persona con mielomeningocele son las principales responsables por la realización del cateterismo vesical intermitente; 86% utilizan catéter de plástico simple y 14% el catéter hidrofílico; 81% no reutilizan el catéter, 10% utilizan el mismo catéter durante un día y el 9% incluso hasta una semana. El principal lugar de realización del cateterismo vesical intermitente fue la cama, seguida de la letrina y la silla de ruedas.

Conclusión: el uso del fórum virtual fue bien evaluado por los usuarios. Se lo puede considerar un medio para obtener informaciones, formación de red de apoyo y aclarar dudas, empoderando a los usuarios y contribuyendo a la adhesión al cateterismo vesical intermitente, que es uno de los tratamientos para la vejiga neurogénica.

DESCRIPTORIOS: Mielomeningocele. Internet. Rehabilitación. Cateterismo uretral intermitente. Educación en salud.

INTRODUCTION

Myelomeningocele (MMC) represents 75% of neural tube defects, commonly affecting the lumbosacral segment.¹ Bladder dysfunction characterized by congenital neurogenic bladder (NB) is present in about 95% of patients.² Among the main complications associated with NB are urinary incontinence, urinary tract infection, vesicoureteral reflux, and hydronephrosis. These complications, if not prevented and treated, may lead to kidney deterioration and even death.³ Urological care in children with MMC is often initiated soon after birth and should be maintained for life.

One of the main treatments of NB is intermittent urethral catheterization (IC), performed four to six times a day, which consists in the introduction of a urethral catheter for drainage of urine. Reducing bladder pressure and the incidence of urinary tract infection (UTI), improving urinary incontinence, and preserving kidney function are the goals of this technique.⁴

The need for complex and continuous care, including IC, characterizes MMC as a chronic condition and requires adherence by parents and caregivers to a therapeutic and rehabilitation regimen. Therefore, there is a need for interventions to inform and support IC, aiming at the continuous home care and the success of the therapeutic regimen. In this sense, health education assumes a key position so that the rehabilitation process favors the promotion of autonomy and participation, aiming at the democratization of knowledge and the empowerment of individuals with disabilities.⁵

Information technology topics are being discussed in the media, with a strong influence in the health sector. The use of the internet is increasing in Brazil and in the world, becoming a topic of interest to many researchers.⁶ In online communities, forums are considered to be facilitators of learning. In them, users act autonomously and are able to elaborate their own knowledge based on personal interests.⁷ In these communities shared knowledge supports and answers to daily concerns, experiences and worldviews of those dealing with some kind of illness.⁸

Considering the MMC, NB and IC context, an online forum was created based on the idea and format of a German forum for people with MMC and hydrocephalus. It should be noted that a version identical to the German one was not elaborated, but rather a version for the Brazilian public was created. The coordination of the activities developed in Germany, from the conception, discussion and research, was assigned to a professor and researcher with experience in the area of rehabilitation. There was also collaboration of the coordinators of the German forum in the development phase of MieloFórum, aiming at building a suitable tool for the target audience, improving strategies to encourage users to participate, as well as actions to ensure the quality and security of the information disclosed.

The main purpose of this study was to evaluate the use of an online forum for people with MMC and their families and the profile of their users, based on IC. The goal is to provide an online learning tool where they can exchange experiences, in order to obtain health information and create strategies to support these people and their families in adhering to the treatment indicated for NB.

METHOD

It is a quantitative, cross-sectional, descriptive and exploratory study carried out with the assistance of two universities, one German and the other Brazilian. The place where data was collected was not determined, since it was an online survey conducted at MieloFórum and the participants, Portuguese speakers, contributed from any place with *Internet* access.

The MieloFórum user, in addition to accessing health information and informational texts, could create topics for discussions and talk to other users through messages. The forum manager system adopted was the Personal Home Page – Bulletin Board (phpBB), which was used by the German online forum.

In order to improve MieloFórum's quality and to validate its content, health and computer specialists were invited to perform a general evaluation of the online tool. In addition to this evaluation, the theoretical and informative content was validated by the experts in the health area; and the interface ergonomics content, by information technology specialists. For data analysis and validation of the online forum, the Content Validity Index (CVI) was used.⁹ In addition to the statistical analysis from the CVI, an evaluation of each observation, suggestion or critique made by the experts was performed.

MieloFórum was widely disseminated in the online environment, as *sites* of associations of people with spina bifida and communities. A Facebook page was created in which titles and headlines about texts and contents available in the forum were posted. Another channel of communication was the WhatsApp groups created by people with MMC and their families. A video containing information and explanatory tutorials on the functioning of the forum was developed and disseminated in the online environment. Informational flyers were also distributed in rehabilitation health centers.

After disclosure, users used MieloFórum for five months, from October 2014 to February 2015. Next, an online questionnaire developed on the Survey Monkey platform was sent to all users for evaluation of the forum, through personal emails, Facebook, WhatsApp and private messages in the forum. The questionnaire was composed of closed questions, and the first part was intended to determine the socio-demographic characteristics of the sample. For this, there were questions about gender, age, education and occupation. Specific information about the person with MMC was also requested, such as location of the MMC lesion and information about the IC. The questions in the second part of the questionnaire referred specifically to the evaluation of MieloFórum and some aspects were investigated, such as the language, the layout and the usability of this tool.

All registered users were invited to participate in the survey, which was the inclusion criterion: registration in MieloFórum. It should be noted that a minimum age of 18 years old was required for registration in the forum. Participants who did not complete the entire *online* questionnaire were excluded as these questionnaires were considered an incomplete instrument.

The questionnaire remained open for one month, from March 20 to April 20, 2015. The questionnaires of 30 participants were used. Incomplete questionnaires of participants who abandoned the online questionnaire before the end were excluded.

Data collected in Survey Monkey was migrated to the statistical *software Statistical Package for Social Sciences (SPSS)*, version 22.0 for the descriptive statistical analysis of the numerical data. Absolute and percentage frequencies were used for the categorical data. Pearson's chi-square test and Fisher's exact test were used for advanced statistical analysis.

RESULTS

The sample consisted of 30 users of the online health network; among them, 27% were people with MMC and 73% were family members of people with MMC. Of these, 16 were mothers and six were other family members (father and siblings). With respect to gender, 20 (67%) were female and ten (33%) were male. Age ranged from 22 to 58 years old, with an average of 35. Most participants who evaluated MieloFórum had a higher education, 18 (60%), followed by complete high school, eight (27%) and complete elementary and middle school, four (13%). As current occupation, 12 (40%) had a job and 11 (36%) did not perform any activity. The others in the sample attend school – two (7%) – or attend college – two (7%) – or are engaged in another activity – three (10%) – such as volunteer work or language courses; there was a person who was retired and another on leave.

It is noteworthy that the family members answered the questions with data regarding the person with MMC when she was younger than 18 years old, since it was required to be of legal age to register in the online forum.

Considering the answers of the 30 participants regarding the person with MMC (n=30), it was verified that age ranged from zero to 38 years old, with an average of 12 years old. Of these, 14 (47%) were female and 16 (53%) were male. It was observed that elementary education was the predominant level of education, representing 30% of the sample. Regarding current occupation, it was found that 13 (43%) of the participants with MMC did not perform any activities, of which 11 had passed school age; therefore, it was considered that two participants did not have any occupation. Among the rest of the sample, four (13%) had a job, 11 (37%) studied and attended school or college and two (7%) participated in a preparatory course for public sector recruitment examination, swimming or language courses.

The main reasons why users sought MieloFórum were searching for information – 19 (63%) – and sharing of experiences – 19 (63%) –, followed by making new friends – six (20%) – and curiosity – five (16%).

It was verified that MieloFórum was positively evaluated as “excellent” or “good” by 27 (90%) users, and one (3%) user rated it negatively, as “poor” or “very poor”.

According to the degree of difficulty found by the user to navigate MieloFórum, 23 (77%) considered it easy or very easy, four (13%) considered it difficult or very difficult and three (10%) considered it neither easy nor difficult.

It is important to note that, among the 30 (100%) users, 25 (83%) would indicate MieloFórum to another person and five (17%) might indicate.

The evaluation of MieloFórum’s language and layout by the users is represented in Table 1.

Table 1 – Distribution of the language and layout evaluation of MieloFórum by the users , 2015 (n=30)

Evaluation	Understandable language		Proper layout	
	n	%	n	%
Agree and strongly agree	27	90.0	26	86.7
Neither agree nor disagree	3	10.0	1	3.3
Disagree and strongly disagree	0	0.0	3	10.0
Total	30	100.0	30	100.0

As to the interest in MieloFórum’s informational texts, 27 (90%) MieloFórum users expressed an interest, while three (10%) did not express their opinions as they did not read the texts. Specifically on the IC theme, 24 (80%) participants reported that texts and discussions about the topic helped them to clarify doubts about IC, whereas for three (10%) the texts did not help them to clarify their doubts. It is noticed that three (10%) users chose not to answer this question, because they did not perform IC.

No statistical significance was found when the variable “performs intermittent catheterization” was correlated to “helped to clarify doubts about intermittent catheterization” (Fisher’s exact test, $p=1.000$).

When the variables “level of education of the user who participated in the evaluation of MieloFórum” and “reason that led the user to search for MieloFórum” were correlated, no statistical significance was found. Pearson’s chi-square test was used for this analysis, and the respective p values are described below: “searching for information ($p=0.214$)”, “making friends ($p=0.855$)”, “sharing experiences ($p=0.821$)” and “curiosity ($p=0.861$)”.

The predominant location of the MMC lesion was in the lumbar and sacral regions, representing 24 (80%) of the sample, followed by the cervical region – two (7%) – and the thoracic region – one (3%). It is highlighted that three users (10%) could not tell where the MMC was located.

IC was reported by 21 (70%) individuals with NB and nine (30%) did not undergo this procedure. According to the type of catheterization, ten (47.6%) performed self-catheterization while 11 (52.4%) had assistance in the process. Catheterization performed by a caregiver or family member is also related to the fact that the mother takes care of the child due to his/her dependence.

Table 2 presents data related to the number of times participants performed IC per day (daily frequency of the procedure). It is noted that 95.3% of individuals with MMC who underwent IC performed this procedure four or five times a day.

Table 2 – Distribution of participants with myelomeningocele who perform intermittent catheterization according to the daily frequency of the procedure, 2015. (n=21)

Daily frequency of catheterization	n	%	% accumulative
5 times a day	13	61.9	61.9%
4 times a day	07	33.4	95.3%
Once a day	01	4.7	100.0%
Total	21	100.0	

According to the primary responsible individual for performing catheterization, the sample was distributed according to Table 3.

Table 3 – Distribution of the primary responsible individual for performing clean intermittent catheterization, 2015. (n=21)

Primary responsible individual for catheterization	N	%
Mother	9	42.9
Person with spina bifida	9	42.9
More than one responsible individual	2	9.5
Health professional or caregiver	1	4.7
Total	21	100.0

It was noticed that the mother and the person with MMC are the primary responsible individuals for the IC. Mothers were also mentioned in cases where more than one person is considered responsible for the IC, such as, for example, the mother and the individual with MMC assume the same level of responsibility for the IC.

For the IC, two types of catheters were used, the simple plastic catheter mentioned by 18 (86%) users and the hydrophilic or pre-lubricated catheter, mentioned by three (14%) users.

It was found that 17 (81%) participants who performed IC did not reuse the catheter, disposing of it after each procedure. The use of the same catheter over a one-day period was mentioned by two (10%) individuals, and two (10%) used the same catheter for up to one week.

The main place where the individuals performed IC was the bed (62%), followed by the toilet (24%) and the wheelchair (5%); one participant mentioned performing the technique while standing and another in bed or in the wheelchair. IC was performed outside the home by 95% of the participants and 5% reported that they performed the procedure only at home.

It was verified that 18 people did not report difficulties during IC, two reported sphincter resistance and pain/sensitivity.

For evaluating the acquired urinary continence after IC, two categories were established: total continence (the person has no urine leakages) and incontinence (the person has urine leakages, regardless of the amount of urine, and needs to constantly use pads, diapers or urine collector), as shown in Table 4.

Table 4 – Distribution of individuals with spina bifida according to urinary continence after intermittent catheterization, 2015. (n=21)

Acquired continence after intermittent catheterization	N	%
Yes (total continence)	7	33.3
No (incontinence)	14	66.7
Total	21	100.0

Regarding the interest in the informational texts available in the online health network, 27 (90%) users of the online health network showed interest, while three (10%) reported not having read the content. Specifically on the IC theme, 24 (80%) participants acknowledge that the texts and discussions helped to clarify their doubts about the IC.

With respect to the professional responsible for explaining the methods regarding catheterization, nurses – ten (47%) – and physicians – ten (47%) – were mentioned by participants in the same proportion. Only one participant mentioned having received guidance from both professionals.

The reported age of individuals with MMC ranged from less than 1 year old to 38 years old. It is important to note that these data refer to individuals with MMC, and not necessarily to the person who answered the questionnaire.

DISCUSSION

The use of the internet is an increasingly accessible alternative for exchanging experiences and knowledge. Development of researches involving health and information technology has been growing in recent years, as well as the concern in the dissemination of accessible and reliable online information. This work intends to collaborate with this line of research with the creation of an online forum for people with MMC and their families.

It is worth emphasizing that MieloFórum is not an identical version to the German forum, but one based on the German version for the Brazilian population. With this experience, it was verified that the cultural and social differences directly influenced the creation of MieloFórum; however, the preexistence of a tool similar to the one that this study proposed to create contributed to its idealization and development.

The development of an online health tool intended to be accessible and adequate, both to people with MMC and their families, favors access to information about malformation and the exchange of experience among users, adding knowledge and creating a network of mutual support. In this context, it is important to consider that, in addition to encouraging population and professionals to use technologies, it is worth considering family members/caregivers and including their participation.¹⁰

The link to access the online questionnaire, provided by the Survey Monkey platform, was disclosed to MieloFórum users through Facebook, personal emails, WhatsApp groups and private messages in MieloFórum. The fact that 57% of the participants had access to the data collection instrument through Facebook reinforces the potential of this social media as a way to disseminate information. Facebook was important in the process of disclosing MieloFórum, attracting new users

and sharing discussion topics. These activities were developed among the MMC groups that already existed in this social media. The links disclosed in the social media connected users to the MieloFórum page. With this, the statement that social medias facilitate the exchange of information, interaction and collaboration between users proved to be true, and Facebook, in addition to these functions, enables the development of heterogeneous and collaborative activities.¹¹

Regarding the characterization of the users who evaluated MieloFórum, it was verified that the age of MieloFórum users ranged from 18 to 58 years old. In an American study, which sought online forums on the use of electronic cigarettes, participants were between 18 and 71 years old and the majority were between 26 and 35 years old.¹²

The predominance of women was evaluated. According to the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística* - IBGE), from 2005 to 2011, the growth in Internet access by women was higher than that observed among men; however, the percentage of men accessing the Internet is still higher than the percentage of women.¹³ To justify female predominance among the participants in this research, two aspects must be considered: first, the growth of this public in the online environment; and second, the significant involvement of mothers of children with disabilities in the context of rehabilitation, care and search for health information, also reflecting in the online environment. This corroborates the traditional relationship of the female gender, mothers, with the habit of caring for their children.¹⁴

Almost 40% of MieloFórum users who evaluated it did not perform any type of activity. According to the IBGE, 39.9% of the Brazilian population without jobs access the Internet.¹³ Also, since MieloFórum users are mostly family members of people with MMC, it must be considered that, in the Brazilian reality, as described by other authors, most family caregivers of children with disabilities do not work as they need to spend most of their time taking care of their children.⁵

Regarding the characterization of users with MMC, regarding the gender of the individuals with MMC, there was a reduced difference between male and female. Data similar to those found in this study were described by other authors. A US study conducted with 50 adolescents with MMC revealed that 48% of the sample were female and 52% male.¹⁵ Another study conducted with 200 Brazilian individuals with MMC, found that 43% of the sample were female and 57% male, while 65% of the German sample were female and 35% male.¹⁶

When discussing the level of education of individuals with MMC in this study, part of the sample was below school age and 30% had completed elementary school. The latter result may be related to the age of these individuals, since the average of 12 years old refers theoretically to the first school years.

Similar findings were obtained by researchers in a study with Brazilian individuals with MMC, which found that 41% of the sample were not in school age or early childhood, 5% attended "special schools", 26% had between one and five years of education and 28% had between six and 12 years of education.⁵ In a study conducted exclusively with adult patients with MMC in the city of Chicago, 36% had completed school education and 49% had completed university education.¹⁷

A study conducted with people with MMC in Germany found that 45% of the sample attended school or university, 24% had a job, 19% were newborns or attended kindergarten, 10% had no occupation and 2% were pensioners.⁵ It is noted in the current research that, although more than 40% of individuals with MMC do not perform any activity, it should be considered that almost 37% are children below school age. When analyzing the rest of the sample, it is noticed that most perform some type of activity, whether going to school or to college or having a job.

The two main reasons that brought users to MieloFórum were to search for information and to share experiences. The search for health information on the Internet is significantly related to some chronic illness or to an acute health impairment. People with disabilities or chronic diseases are

more likely to use the Internet to access *sites* with health information.¹⁸ In addition to the search for information, people searching for information want to share their fears and experiences.¹⁹ It was noted that the level of education did not interfere in the reasons why users searched MieloFórum, showing that the search for information and the sharing of experiences are independent from this factor.

The clarification of doubts about IC, through informational texts and discussions in MieloFórum, was reported by most of the participants, including a portion that did not perform IC. This result confirms that the informational texts on IC have been useful not only for those who already perform IC, but also for those who search for more information about this technique, reinforcing the potential of this online tool as a means of disseminating health information.

Most users of MieloFórum considered the language used in MieloFórum to be understandable. This result is likely to be directly related to the fact that the theoretical texts were prepared by health professionals with experience in rehabilitation of individuals with MMC. In addition, the validation of MieloForum's content by health specialists, among them nurses, physicians, psychologists and physiotherapists, resulted on a review of this content, contributing to adaptations and improvements in the grammatical and contextual area.

The use of MieloFórum was considered "very easy" or "easy" by the majority. Improvements based on the suggestions of the computer specialists were considered as the main factor for this result. The search for quality of the interfaces of the online programs is reflected in the concern to promote satisfaction of the user when using this tool.²⁰

Formal and regular evaluation of an online health tool by the users is essential for improvements in the resources and information available in them.²¹ The fact that MieloFórum was positively evaluated by its users and that they inform that they would indicate the forum to another person shows that the online tool responded positively to the expectations of the users.

Regarding data on MMC and IC, there was predominance of MMC at the lumbar and sacral levels, in line with the results of other studies. A study reports that the most frequent location of the MMC lesion was the lumbosacral.³ The lumbosacral region accounted for 84% of the sample of a Brazilian study performed with 108 patients with MMC.²² It was verified that 10% of the sample did not know the location of the malformation, showing a possible deficit of information about their own health condition.

A comparative study between Brazil and Germany described that 31% of the Brazilian sample performed self-catheterization, 63% did not perform self-catheterization and 6% did not perform this procedure at all.³ In this study, the difference between self-catheterization, catheterization and non-performance of catheterization was not considered significant. However, when considering only the eight users who had MMC and personally answered the questionnaire, there was a frequency of intermittent self-catheterization of almost 90%, suggesting that these individuals have autonomy and cognitive ability that favored participation in the online health network and self-catheterization.

Performing IC four or five times a day was the frequency most mentioned by the participants in this study. Similar data was also found by other authors.³ It is usually recommended to perform IC four to six times a day, which should be adjusted considering individual aspects such as bladder capacity, fluid intake, post-voiding residual urine and urodynamic parameters.²³

The increased use of the uncoated plastic catheter when compared to the hydrophilic or pre-lubricated catheter may be justified because it is less expensive. There is no consensus in the literature regarding the use of the plastic catheter and the pre-lubricated or hydrophilic catheter. The first is a less expensive alternative, while the second brings the advantages of practicality and comfort of its use.³ Other authors state that there are no significant differences in complications from the use of one or other type of catheter, such as urinary tract infection. And others reinforce the decrease in the

frequency of complications with the use of the hydrophilic catheter, in addition to reducing the rate of long-term urethral complications such as urethral stricture.^{24–25}

The predominance of the use of the plastic catheter reflects the difficulties in Brazilian economic condition. The cost of the hydrophilic catheter may be a better option; however, according to the Brazilian reality and as a rule, it is not available through the Unified Health System (SUS), which makes its use significantly smaller. On the other hand, the plastic catheter, in addition to being less costly, can be distributed by the government free of charge.³

Regarding the reuse of the urinary catheter, it has been found that single use of the catheter, not re-using it, is an increasingly common practice. Re-using the catheter for IC is a controversial topic in the literature. Some authors state that the use of the sterile catheter does not reduce the incidence of urinary tract infection when compared to the use of the catheter cleaned by many catheterizations.²⁵ Other authors state that although several investigations show that catheter re-use does not increase the risk of urinary infection, mothers of children with MMC are uncertain about catheter re-use and prefer not to reuse except when the amount is not enough to make one single use.³

It is considered that single use of the catheter stimulates autonomy, encourages self-catheterization and adherence to the procedure, as it facilitates the accomplishment of the technique, eliminating the steps of cleaning and storage of the catheter.

With respect to the primary responsible individual for IC, it is emphasized that the mother and the person with MMC are the primary responsible people for performing this procedure. The group of mothers was the most representative one, in line with literature.³ Other Brazilian authors defend that the responsibility for IC generally stays with the mother, who assumes the role of caregiver of children with disabilities.⁵

The most commonly used places in the house for IC, recorded in this survey, were the bed, followed by the toilet. Such results may be justified by the fact that the bedroom is considered to be one of the most private places in the residences, and the use of the toilet, in addition to the seated position favoring the passage of urine, if it coincides with the bath time, enables economy of material, since during the bath the technique does not require the use of gauze for the hygiene of the genitalia.

Performing IC outside the home represents a factor that favors social inclusion of people who perform this procedure. In this study, 95% of the individuals also performed IC in a place other than their homes. This result reinforces the hypothesis that users of the online health network have autonomy, which favors their participation.

Regarding the difficulties during IC, urethral resistance, pain and sensitivity were mentioned. These difficulties were also reported in other studies. The difficulties related to the IC technique, whether technical, domiciliary, emotional or financial, may lead to the interruption of this procedure.³

In this study, total urinary continence was reported in a smaller percentage than incontinence among individuals who perform IC. It is known that urinary incontinence can be considered one of the main problems that compromise the quality of life of people with neurogenic bladder, as it interferes negatively in their independence and social participation.²⁶ The performance of IC and the increased frequency of this procedure are factors that may increase the chances of acquiring urinary continence.¹⁹ In addition, it is also necessary to consider that, in order to achieve urinary continence, factors such as detrusor overactivity, sphincter deficiency, decreased bladder compliance or combinations thereof, and a combination of treatments such as catheterization, medications and surgeries may be required.²⁷

Clarification of doubts about IC, through informational texts and discussions in an online health network, reinforces the potential of this tool as a means of disseminating health information, contributing to health education and the empowerment of its users.

The professionals mentioned as responsible individuals for the orientation of the IC procedure were the nurse and the physician in the same proportion. In health education, nurses, through their

educational activities, can facilitate understanding of neurogenic bladder and of the technique of catheterization. Added to this, the bond created between the nurse, the patient and his/her family collaborates for the adherence to the IC technique.

A research on the learning of intermittent self-catheterization performed with children between seven and 12 years old showed that the approach in groups and by a multi-professional team favored the process of learning IC by the children. It is emphasized that good or excellent understanding of IC can positively influence adherence and the decrease in the interruption rates of this procedure.⁵

CONCLUSION

The use of the Internet, whether to search for health information or to share experiences, can be considered as a good option for the empowerment of the disabled population and their families. In this sense, an online health forum presents itself as a potential strategy to reduce the obstacles for the treatment of neurogenic bladder.

The advancement of technology and the diffusion of the Internet revolutionized the dissemination and access to information. With this, searching for information in the online environment involving several areas such as security, health, education and entertainment is ever increasingly present in people's daily lives.

The creation of MieloFórum was encouraged by the desire to favor the empowerment of people with MMC. This term is directly related to the definition of autonomy, with which individuals can decide on the issues that concern them, whether regarding politics, education, health and culture.

The creation of an online forum for the Brazilian population with MMC and their families, based on a German model in which people could find correct information and form a network of mutual support, was one of the main guiding principles of these researchers. For this, it was fundamental to validate the tool developed by experts both in the areas of health and of information technology, aiming at the usability of the computer aspects, as well as the quality of health information available at MieloFórum.

It is believed that the evaluation of MieloFórum, from the perspective of the users, has unique importance, considering the opinion of the users, which enabled to improve the tool.

With the characterization of MieloFórum users, it was observed that most users who have MMC perform self-catheterization, study or work. These characteristics allowed to assume that MieloFórum users with MMC are people with autonomy and cognitive capacity that favored the participation in MieloFórum.

The fact that MieloFórum has been well evaluated, both in the general aspect and in terms of its language, layout and utility by the users, regardless of whether they are people with MMC or family members, their age and level of education, reinforces the fact that the forum was considered suitable by its public, despite their heterogeneity.

Considering Internet access and the use of computers, as well as mobile devices, there is a growing demand for the use of the Internet as a means of disseminating health information and tools that collaborate with online health education. The development of studies with online learning tools that address chronic diseases such as MMC, and topics such as rehabilitation, social inclusion and empowerment, is a current public need that needs to be addressed, aiming at the accessibility and democratization of health information.

In view of the foregoing and considering the perspectives, it is suggested to develop studies on the use of the Internet and its use in the health area, involving the rehabilitation topic. This work is expected to contribute to the incentive and improvement in health as a way to obtain clear and qualified information, as well as to establish strategies for the adherence of people with MMC to the indicated

treatments for NB, such as IC. The huge potential of this context and its benefits are believed to help the population with respect to health education, rehabilitation and social participation.

REFERENCES

1. Ramsundhar N, Donald K. An approach to the developmental and cognitive profile of the child with spina bifida. *S Afr Med* [Internet]. 2014 Feb [cited 2018 Jun 29]; 104(3):5-7. Available from: <https://dx.doi.org/10.7196/SAMJ.8048>
2. Lee B, Featherstone N, Nagappam P, McCarthy L, O'Toole S. British Association of Paediatric Urologists consensus statement on the management of the neuropathic bladder. *J Pediatr Urolog* [Internet]. 2016 [cited 2018 Oct 12]; 12(2):76-87. Available from: <https://dx.doi.org/10.1016/j.jpuro.2013.09.018>
3. Faleiros F, Cordeiro A, Favoretto N, Kappler C, Murray C, Tate D. Patients with spina bifida and their caregivers feelings about intermittent bladder catheterization in Brazil and Germany: a correlational study. *Rehabil Nurs* [Internet]. 2015 Aug. [cited 2018 Jun 29]; 42(4):175-9. Available from: <https://dx.doi.org/10.1002/rnj.223>
4. Lopes MAL, Lima EDRP. Continuous use of intermittent bladder catheterization – can social support contribute? *Rev Lat Am Enfermagem* [Internet]. 2014 Jun. [cited 2018 Jun 29]; 22(3):461-6. Available from: <https://dx.doi.org/10.1590/0104-1169.3268.2438>
5. Freitas GL de, Sena RR de, Silva JCF, Castro, FFS. Rehabilitation of children and adolescents with myelomeningocele: the daile life of mothers-caregivers. *Rev Gaúcha Enferm* [Internet]. 2017 Feb. [cited 2018 Jun 29]; 37(4):e60310. Available from: <http://dx.doi.org/10.1590/1983-1447.2016.04.60310>
6. Reis C, Mattos MM, Lenzi FC, Santos T. Tecnologias de Informação em Saúde: Desafios e Perspectivas a partir da avaliação dos usuários de Rede Pública de Blumenau (SC). *Rev Gest Sist Saúde* [Internet]. 2015 [cited 2018 Oct 11]; 4(1):71-82. Available from: <https://dx.doi.org/10.5585/rgss.v4i1.115>
7. Faleiros F, K  ppler C, Pontes FAR, Silva SSC, Goes FN, Cucick CD. Use of virtual questionnaire and dissemination as a data collection strategy in scientific studie. *Texto Contexto Enferm* [Internet]. 2016 [cited 2018 Oct 11]; 25(4):2-6. Available from: <https://dx.doi.org/10.1590/0104-07072016003880014>
8. Ortega F, Zorzanell R, Meierhoffer LK, Ros  rio CA, Almeida CF, Andrada BFCC, et al. A constru  o do diagn  stico do autismo em uma rede virtual brasileira. *Interface- Comunic, Sa  de, Educ* [Internet]. 2013 Mar [cited 2018 Oct 12]; 17(44):119-32. Available from: <https://dx.doi.org/10.1590/S1414-32832013000100010>
9. Pedreira RBS, Rocha SV, Santos CA, Vasconcelos LRC, Reis MC. Content validity of the Geriatric Health Assessment Instrument. *Einstein* [Internet]. 2016 [cited 2018 Oct 12]; 14(2): 158-77. Available from: <https://dx.doi.org/10.1590/S1679-45082016AO3455>
10. Varela RCB, Oliver FC. A utiliza  o da tecnologia assistiva na vida de crian  as com defici  ncias. *Cien Sa  de Coletiva* [Internet]. 2013 [cited 2018 Oct 12]; 18(6):1773-84. Available from: <https://dx.doi.org/10.1590/S1413-81232013000600028>
11. Veale HJ, Sacks-Davis R, Weaver ER, Pedrana AE, Stoov   MA, Hellard ME. The use of social networking plataforms for sexual health promotion: identifying key strategies for successful user engagement. *BMC Public Health* [Internet]. 2015 Feb [cited 2018 Oct 12]; 15(85):2-11. Available from: <https://doi.org/10.1186/s12889-015-1396-z>
12. Hua M, Alfi M, Talbot P. Health-related effects reported by electronic cigarette users in online forums. *J Med Health Int Res* [Internet]. 2013 Apr [cited 2018 Oct 12]; 15(4):e59. Available from: <https://dx.doi.org/10.2196/jmir.2324>

13. Instituto Brasileiro de Geografia e Estatística. Acesso à internet e à televisão e posse de telefone móvel celular para uso pessoal [Internet]. 2015 [cited 2018 Oct 12]; Available from: <https://biblioteca.ibge.gov.br/visualizacao/livros/liv99054.pdf>
14. Muylaert CJ, Delfini PS, Reis AOA. Relações de gênero entre familiares cuidadores de crianças e adolescentes de serviços de saúde mental. *Rev Saúde Coletiva* [Internet]. 2015 Apr [cited 2018 Oct 12]. Available from: <https://dx.doi.org/10.1590/S0103-73312015000100004>
15. Betz CL, Smith KA, Macias K, Bui K. Exploration of internet use: profile and preferences of transition-aged adolescents with spina bifida. *Pediatric nursing* [Internet]. 2014 Aug. [cited 2018 Jun 2]; 40(4):173-8. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25269357>
16. Faleiros F, Pelosi G, Warschausky S, Tate D, K  ppler C, Thomas E. Factors influencing the use of intermittent bladder catheterization by individuals with spina bifida in Brazil and Germany. *Rehabil Nurs* [Internet]. 2018 Feb. [cited 2018 Jun 2]; 43(1):46-51. Available from: <https://dx.doi.org/10.1002/rnj.302>
17. Freitas GL, Sena RR, Silva JCF, Faleiros F. The reality of children and adolescents with meningomyelocele and their families, in the city of Belo Horizonte and Its Metropolitan Area, Brazil. *Health* [Internet]. 2016 Apr. [cited 2018 Oct 9]; 8(1):559-66. Available from: <https://dx.doi.org/10.4236/health.2016.86059>
18. Oh YS, Cho Y. Examining the relationships between resources and online health information seeking among patients with chronic diseases and healthy people. *Soc Work Health Care* [Internet]. 2015 Feb. [cited 2018 Oct 12]; 54(2):83-100. Available from: <https://doi.org/10.1080/00981389.2014.987940>
19. Mendonça APB, Pereira-Neto A. Crit  rios de avalia  o da qualidade da informa  o em sites de sa  de: uma proposta. *Rev Eletr Comun Inf Inov Sa  de* [Internet]. 2015 Mar. [cited 2018 Oct 12]; 9(1):1-15. Available from: <https://dx.doi.org/10.29397/reciis.v9i1.930>
20. Sousa P, Fonseca H, Gaspar P, Gaspar F. Usability of an internet-based platform for adolescent weight management. *J Pediatr* [Internet]. 2015 Feb. [cited 2018 Oct 12]; 91(1):1-7. Available from: <https://dx.doi.org/10.1016/j.jpeds.2014.05.010>
21. Rosenfeld L, Shepherd a, Agunwamba AA, McCray AT. Iterative evaluation of a web-based health information resource. *J Health Commn* [Internet]. 2013 Aug. [cited 2018 Oct 12]; 18(8):974-990. Available from: <https://dx.doi.org/10.1080/10810730.2012.757395>
22. Melo TM, Duarte OHM, Pereira HCB, Pereira NFM, Silva RMC, Maciel NFB. Avalia  o postural de crian  as com mielomeningocele: um estudo de revis  o. *Arch Health Invest.* [Internet]. 2018. [cited 2018 Oct 9]; 7(2):77-81. Available from: <https://dx.doi.org/10.21270/archi.v7i2.2406>
23. Truzzi JC, Canalini AF, Prezotti JA, Resplante J. Recomenda  es SBU: cateterismo vesical intermitente. *Sociedade Brasileira de Urologia* [Internet]. 2016 [cited 2018 Jun 2]. Available from: http://portaldaurologia.org.br/medicos/wp-content/uploads/2016/11/Recomenda  es_Cateterismo-Vesical-SBU-2016_final.pdf
24. Kiddoo D, Sawatzky B, Bascu CD, Dharamsi N, Afshar K, Moore KN. Randomized Crossover trial of single use hydrophilic coated vs multiple use polyvinylchloride catheters for intermittent catheterization to determine incidence of urinary infection. *J Urol* [Internet]. 2015 Jul. [cited 2018 Jun 2]; 194(1):174-9. Available from: <https://dx.doi.org/10.1016/j.juro.2014.12.096>
25. Ercole FF, Macieira TG, Wenceslau LC, Martins AR, Campos CC, Chianca TC. Integrative review: evidences on the practice of intermittent/indwelling urinary catheterization. *Rev Lat Am Enfermagem* [Internet]. 2013 Feb. [cited 2018 Jun 2]; 21(1):459-68. Available from: <https://dx.doi.org/10.1590/S0104-11692013000100023>

26. Fischer N, Church P, Lyons J, McPherson AC. A qualitative exploration of the experiences of children with spina bifida and their parents around incontinence and social participation. *Child: Care, Health and Develop* [Internet]. 2015 May [cited 2018 Jun 2]; 41(6):954-62. Available from: <https://dx.doi.org/10.1111/cch.12257>
27. Vieira CENK, Coura AS, Frazão CMFQ, Enders BC, Andrade PS, Lira ANBC. Autocuidado para bexiga neurogênica em pessoas com lesão medular. *Revisão Integrativa. Rev enferm UFPE* [Internet]. 2014 Jan [cited 2018 Oct 12]; 8(1):128-36. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/9615>

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No any conflict of interest

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