DEVELOPMENT OF A VIRTUAL FORUM FOR PEOPLE WITH SPINA BIFIDA AND THEIR FAMILIES:

Collaboration and Exchange of Technology between Brazil and Germany

Presented by

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DEDICATION

I dedicate this work to all the people with spina bifida and their families who will make it real in their daily lives.

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I thank God for giving me this opportunity for qualification.

We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop.

Mother Teresa of Calcutta

ABSTRACT

Spina bifida is a congenital malformation characterized by the incomplete development of the neural tube, which can result in neurological alterations and deformities. Its chronicity requires a complex and continuous process of rehabilitation, associated with health education focused on the empowerment of people with spina bifida and their families. The dissemination of information technologies, such as virtual health forums, promotes the distribution of health content, enables the participation and autonomy of users in elaborating their own knowledge and establishes a network of mutual support, in response to individual and collective demands. In this context, the aim of this study, which was based on a German forum, was to develop, validate, certify, and assess a Brazilian virtual health forum for people with spina bifida and their families. A quantitative, cross-sectional, descriptive, and exploratory study was developed. The MieloForum was developed in four stages: scope definition, planning, production, and implementation. The managing system for forums used to develop the MieloForum was the phpBB (Hypertext Preprocessor Bulletin Board). Seventeen health professionals and eleven informatics professionals participated in the validation of the forum. The MieloForum was certified by the Health on the Net Foundation (HON) with regard to the quality of health information provided, and basic accessibility analysis was performed with Web Accessibility Checker (AChecker). For assessment of the MieloForum from the perspective of users, an online questionnaire was developed and validated. The MieloForum was accessed by people living in all Brazilian regions, with the Southeast region being the most representative (60.21%). It was assessed by 30 users, between 18 and 58 years old; most of them (53%) were the mothers of people with spina bifida. The main reasons that users accessed the MieloForum were to search for information (63.3%) and share experiences (63.3%). As for MieloForum users with spina bifida, most developed some activity (77.8%), like studying or working, and performed urinary self-catheterization (87.5%), suggesting that these people had autonomy and cognitive capacity that favored their participation in the forum. The MieloForum was assessed as good or excellent by 90% of the users; its language was considered understandable by 90%; its appearance was considered adequate by 86.7%; and browsing was considered easy or very easy by 77%. This study showed that the MieloForum was useful and positively assessed by its users, reinforcing the importance of including validation by health and informatics experts, certification of the quality of the information provided and assessment by users in the methodology of the development of virtual tools.

Key words: Virtual forum, Internet, Spina bifida, Myelomeningocele, Health education and rehabilitation

KURZZUSAMMENFASSUNG

Spina bifida (SB) ist eine angeborene Fehlbildung, gekennzeichnet durch die unvollständige Ausbildung des Neuralrohrs, die zu Missbildungen und neurologischen Veränderungen führen kann. Ihr chronischer Zustand erfordert einen komplexen und fortdauernden Prozess der Rehabilitation, verbunden mit einer Gesundheitserziehung, die das Empowerment von Menschen mit SB und ihren Familien fördert. Die Verbreitung von Informationstechnologien, wie beispielsweise virtueller Gesundheitsforen, und von Gesundheitsinhalten ermöglichen die Partizipation und das Empowerment der Nutzer_innen. Sie können eigenes Wissen entwickeln, und es wird ein Netzwerk gegenseitiger Unterstützung nach individuellen und kollektiven Anforderungen aufgebaut. In diesem Sinn war das Ziel dieser Studie, auf Grundlage eines deutschen Forums ein brasilianisches virtuelles Forum für Menschen mit SB und ihre Familien zu entwickeln, zu validieren, zu zertifizieren und zu bewerten. Diese Studie ist eine quantitative, beschreibende und explorative Querschnittsstudie. Das MieloForum wurde in vier Phasen entwickelt: Scoping, Planung, Produktion und Implementierung. Das Manager Forensystem, welches für die Entwicklung von MieloForum verwendet wurde, war das *Hypertext Preprocessor Bulletin Board* (phpBB). An der Validierung des Forums waren siebzehn Personen aus dem Gesundheitsbereich sowie elf Personen aus dem Informatikbereich beteiligt. Das MieloForum wurde vom Team der *Health On the Net Foundation* (HON) hinsichtlich der Qualität der Gesundheitsinformationen zertifiziert, und eine grundlegende Analyse der Zugänglichkeit wurde mithilfe des *Web Accessibility Checker* (Achecker) durchgeführt. Für die Bewertung des MieloForums aus der Perspektive ihrer Nutzer_innen, wurde ein Online-Fragebogen entwickelt und validiert. Das MieloForum wurde von Benutzer_innen genutzt, die ihren Wohnsitz in allen Regionen Brasiliens hatten. In der südöstlichen Region wohnen die meisten Benutzer_innen (60.21 %). Das MieloForum wurde von 30 Benutzer_innen im Alter von 18 bis 58 Jahren bewertet, die Mehrheit (53%) waren Mütter von Menschen mit SB. Die beiden wichtigsten Gründe für die Nutzung des MieloForums waren: Informationen zu suchen (63.3%) und Erfahrungen auszutauschen (63.3%). Insbesondere wurde beobachtet, dass die Mehrheit der Benutzer_innen mit SB einer Aktivität nachgehen (77.8%), wie zum Beispiel studieren oder arbeiten sowie das Durchführen von Selbstblasenkatheterismus (87.5%). Dies lässt annehmen, dass diese Personen autonom sind und über kognitive Kapazitäten verfügen, die die Teilnahme im Forum begünstigt haben. Das MieloForum wurde als gut oder ausgezeichnet von 90% der Benutzer_innen bewertet, die Sprache wurde zu 90% als verständlich angegeben, die visuelle Gestaltung wurde von 86.7% als ansprechend beschrieben und die Navigation wurde von 77% als leicht oder sehr leicht bewertet. Diese Studie zeigt, dass das MieloForum nützlich war und positiv von ihren Benutzer_innen bewertet wurde. Dies bestärkt die Wichtigkeit der Validierung durch Expert_innen aus den Bereichen Gesundheit und Informatik, der Zertifizierung der Qualität der bereitgestellten Informationen und der Bewertung durch Nutzer_innen, in der Methodik der Entwicklung von virtuellen Werkzeugen.

Schlüsselwörter: virtuelles Forum, Internet, Spina bifida, Myelomeningocele, Gesundheit, Erziehung und Rehabilitation

RESUMO

A espinha bífida é uma malformação congênita caracterizada pela formação incompleta do tubo neural podendo resultar em alterações neurológicas e deformidades. A sua cronicidade requer um processo de reabilitação complexo e contínuo associado a uma educação em saúde que fomente o empoderamento dos indivíduos com espinha bífida e de seus familiares. A disseminação de tecnologias da informação, como os fóruns virtuais de saúde, além de promoverem a divulgação de conteúdo de saúde, permitem a participação e autonomia dos usuários parra elaborarem o próprio conhecimento e estabelecerem uma rede de apoio mútuo, de acordo com as demandas individuais e coletivas. Nesta direção, pretendeu este estudo, baseado em um fórum alemão, desenvolver, validar, certificar e avaliar um fórum virtual de saúde brasileiro para indivíduos com espinha bífida e seus familiares. Trata-se de uma pesquisa quantitativa, transversal, descritiva e exploratória. O MieloFórum foi desenvolvido em quatro etapas: definição do escopo, planejamento, produção e implementação. O sistema gerenciador de fóruns utilizado para o desenvolvimento do MieloFórum foi o phpBB (*Hypertext Preprocessor Bulletin Board*). Para a sua validação, contou-se com a participação de dezessete profissionais da área da saúde e onze da informática. O MieloFórum foi certificado pela equipe da *Health on the Net Foundation* (HON) quanto à qualidade das informações de saúde e uma análise básica da acessibilidade foi realizada junto ao *Web Accessibility Checker* (AChecker). Para a avaliação do MieloFórum na perspectiva dos seus usuários, um questionário *online* foi desenvolvido e validado. O MieloFórum foi acessado por pessoas residentes em todas as regiões brasileiras, sendo a região sudeste a mais representativa (60,21%) e foi avaliado por 30 usuários, com idade entre 18 e 58 anos, sendo que a maioria (53%) era mães de pessoas com espinha bífida. Os dois principais motivos que trouxeram os usuários ao MieloFórum foram: buscar informações (63,3%) e compartilhar experiências (63,3%). Especificamente sobre os usuários do MieloFórum com espinha bífida, observou-se que a maioria desenvolve alguma atividade (77,8%), como estudar ou ter um emprego, e realiza o autocateterismo vesical (87,5%), sugerindo que esses indivíduos possuem autonomia e capacidade cognitiva que favoreceram a participação no fórum. O MieloFórum foi avaliado como bom ou excelente por 90% dos usuários, a linguagem foi considerada compreensível por 90%, o visual adequado por 86,7% e a navegação fácil ou muito fácil por 77%. Este estudo mostrou que o MieloFórum foi útil e avaliado positivamente pelos seus usuários, reforçando a importância da inclusão na metodologia, para desenvolvimento de ferramentas virtuais, a validação por profissionais da área da saúde e da informática e da certificação da qualidade das informações divulgadas, além da avaliação da ferramenta pelos seus usuários.

Palavras-chave: Fórum virtual, Internet, Espinha Bífida, Mielomeningocele, Educação em Saúde e Reabilitação

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LIST OF ABBREVIATIONS AND ACRONYMS

AChecker	Web Accessibility Checker
ACP	Administration Control Panel
APA	American Psychological Association
ASBH	Association for Spina Bifida and Hydrocephalus
CAPES	Coordination for the Improvement of Higher Education Personnel
CNS	Central nervous system
CREMESP	Regional Council of Medicine of São Paulo
CSS	Cascading Style Sheets
CVI	Content validity index
EERP	Ribeirão Preto College of Nursing
FAPESP	São Paulo Research Foundation
GNP	Gross National Product
GNU GPL	GNU General Public License
HC	Hydrocephalus
HON	Health on the Net Foundation
HONcode	Health on the Net Code
HTML	Hyper Text Markup Language
IBGE	Brazilian Institute of Geography and Statistics
IC	Intermittent catheterization
KAAD	Catholic Academic Exchange Service
LILACS	Latin American and Caribbean Center on Health Sciences Information
M	Mean

Mdn	Median
MMC	Myelomeningocele
NB	Neurogenic bladder
NGO	Non-governmental organization
NTD	Neural tube defects
p	Statistical significance
PHP	Hypertext Preprocessor
phpBB	Hypertext Preprocessor Bulletin Board
PubMed	United States National Library of Medicine
PVPI	Povidone-iodine
REC	Research Ethics Committee
SB	Spina bifida
SciELO	Scientific Electronic Library Online
SD	Standard deviation
SPSS	Statistical Package for the Social Sciences
SUS	Brazilian Unified Health System
TU	University of Dortmund
UFSCar	Federal University of São Carlos
URAC	Utilization Review Accreditation Commission
US	Ultrasonography
USP	University of São Paulo
UTI	Urinary tract infection
VHL	Virtual Health Library
VPSV	Ventriculoperitoneal shunt valve

WHO	World Health Organization
WWW	World Wide Web
W3C	World Wide Web Consortium

SUMMARY

PHASE 1

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1. INTRODUCTION

Spina bifida (SB) is one of the most common congenital malformations worldwide. It represents about 75% of neural tube defects (Nadel, Green, Holmes, Frigoletto & Benacerraf, 1990; Yen, Khoury, Erickson, James, Waters & Berry, R. J., 1992) and myelomeningocele is its most severe form (Fernandes, 2009).

SB consists of incomplete development of the spinal cord with the involvement of the tissue overlying the spinal cord, vertebral arch, spine muscles and skin and structures that protect the spine, resulting in several levels of neurological alterations and deformities (Nadel et al., 1990; Yen et al., 1992). In addition, there may be sensory deficits in the lower limbs and changes in bladder and bowel function (Soares, Moreira & Monteiro, 2008).

Regarding changes in bladder function, neurogenic bladder is the name given to urinary dysfunction that is secondary to nervous system impairment (Furlan, Ferriani & Gomes, 2003). Despite being considered an important complication as regards spina bifida, neurogenic bladder is not often seen by patients, families and even professionals as a priority during treatment, as families initially worry mainly about the patient’s motor deficits (Faleiros-Castro, 2012).

Urinary tract infections (UTIs) are the most common complication resulting from neurogenic bladder, whereas renal deterioration is the most severe (Furlan et al., 2003; SBU, 2006). Renal deterioration currently represents the main cause of death and morbidity among young adults with myelomeningocele (Hunt & Oakeshott, 2003).

Intermittent catheterization (IC) is one of the main methods for treating neurogenic bladder. This procedure consists of the introduction of a urethral catheter for emptying the bladder. The main objectives of this technique include reduced intravesical pressure, decreased incidence of UTIs, improved urinary continence, prevention of vesicoureteral reflux and renal deterioration, and maintenance of skin integrity (Cole, Mark, Brock & Pope, 2003).

The chronicity of this malformation requires adherence to a complex and continuous therapeutic and rehabilitation regimen. Adaptations, care and coping on the part of patients, their families, society, and health services and systems are essential, and the latter must offer support for the continuous and prolonged care of these subjects (Gaiva, Neves & Siqueira, 2009).

In this context, health education plays a fundamental role in making the rehabilitation process effective and favors the promotion of autonomy, participation and quality of life for these patients, in both their family settings and the communities where they live. It is important to articulate technical and popular knowledge, institutional and community resources, and public and private initiatives so that health education includes all spheres and is aimed at the democratization of knowledge and empowerment of subjects with this deficiency (L. Sousa, Torres, Pinheiro & Pinheiro, 2010).

The dissemination of information technologies is occurring in several population strata and various sectors of society. In light of this informatics revolution, modern society is undergoing changes in many activities, such as work, education, health, art and culture (Fonseca, 2007). These technological advances must be considered in the planning and development of health education.

The ever-growing use of the Internet in Brazil and around the world has made the virtual environment a subject of interest for many researchers (Dal Pai & Lautert, 2007). In virtual communities, forums are considered to be learning facilitators, as users act autonomously in these environments, while having the opportunity to create their own knowledge based on personal interests (Chorbev, Sotirovska & Mihajlov, 2011). Some conditions are desirable in virtual learning environments, such as common objectives among participants, a focus on the results pursued by the group, agreement as regards community behaviors, rules and values, teamwork, the presence of community counselors, collaborative learning, permanent interaction, equal rights, and participation of all members (Pallof & Pratt, 2002).

An example of a virtual forum is the Sternchen-Forum, a German forum used by subjects with spina bifida and their families. Moderators and trained users work in this forum, supervising the content of the discussions with themes suggested by the users (Faleiros-Castro, 2012).

The aim of this study, which was based on the Sternchen-Forum, was to develop, validate and evaluate a virtual health forum adapted to the Brazilian population. The initial focus of the forum was to approach the subjects of neurogenic bladder and intermittent catheterization with the aim of contributing to teaching-learning strategies and encouraging mutual support among the participants. However, throughout the development of this study, and in response to the demands of forum users, other subjects besides spina bifida were approached.

The challenge of this study was to develop a virtual forum that was adequate to the Brazilian reality, where individuals with spina bifida and their family members could find information and exchange experiences, aiming at rehabilitation by promoting autonomy, empowerment and participation. This virtual tool was built with international and interdisciplinary cooperation, the transfer and exchange of technologies, and the experience of researchers in Brazil and in Germany. It is noteworthy that the development of a virtual health forum covering Brazilian territory, in the face of the complexity, diversity and size of the country, was at the same time an objective and a challenge.

It is believed that the development of studies to broaden scientific knowledge of spina bifida and strategies for encouraging support networks and virtual learning contribute to the rehabilitation and quality of life of people with spina bifida and their families.

2. LITERATURE REVIEW

In this chapter, the subjects of rehabilitation, autonomy, participation, spina bifida, neurogenic bladder, health information on the internet, virtual forums, usability and accessibility to the internet in spina bifida will be approached with the aim of contextualizing the subject and universe of this study.

2.1. REHABILITATION

In the context of spina bifida, autonomy and participation in society must be considered as the target of rehabilitation programs. This subject is complex and involves individuals and collective expectations and needs, in families and society. The word “rehabilitation” derives from the Latin *habilitare*, which is a verb that means to become able or apt. The inclusion of the prefix re- adds the meaning of again acquiring a lost or diminished ability (Greve, 2007).

In the context of rehabilitation, a transformation must take place from the perspective of education, making patients involved. The focus on persons as citizens who are participative and conscious of their life condition must be seen as the objective to be achieved by health professionals (I. Couto, Marins, Espírito-Santo & Neves, 2013).

Health education and information for the population allows broadened discussions and knowledge, which helps overcome difficulties and encourage the acquisition of greater autonomy by patients (Cipriano et al., 2012).

The definition of autonomy varies among subjects and cultures. Autonomy can be divided into two different categories: decision, which is the ability to make decisions without external restriction; and execution, consisting of the ability to act as desired.

Autonomy of both execution and decision are considered a prerequisite for social participation (Cardol, De Jong & Ward, 2002). The process of building and developing autonomy are central themes of studies on the quality of life of people with deficiencies or chronic diseases (Soares et al., 2008).

Participation is mentioned as a parameter in the formulation of policies and actions targeted at people with deficiencies. It is important to recognize that participation is a result of the interaction between people with deficiencies and the attitudinal and environmental barriers they face. The full and effective participation of these people in society, in terms of equality of opportunities, is impaired (Diniz, Barbosa, & Santos, 2009).

One of the strategies for rehabilitation of people with disabling chronic conditions is to increase their individual autonomy and participation in society. Autonomy must be considered the key element of participation, which is regarded as the final outcome of rehabilitation (Cardol et al., 2002). Although autonomy and participation are the main issues in rehabilitation programs for individuals with spina bifida, accessibility difficulties, emotional barriers, lack of adequate social support, and possible neurological impairment can all interfere negatively in the rehabilitation of these people. Hence, strategies must be developed with a focus on health education to promote the autonomy and consequent social participation of this population.

2.2. HEALTH INFORMATION ON THE INTERNET

Current changes in information technologies have led to a new model, which is characterized by globalization of economy and culture, establishment of new sectors of work, and interactivity and interdependence among technologies (S. Silva, 2012). The recent revolution in informatics has been remarkable (Godoy, Gont revolution in info &

Wolff, 2012). In addition, especially as of the 1980s, its dissemination in several sectors has led to a transformation of society (J. Oliveira, 1994).

With the evolution of informatics and the population’s growing access to the Internet, communication through the Internet has become an important tool and strategy for distributing information. The fact that every individual has the freedom to post and share content in the form of texts, videos, or audio recordings explains this diffusion of information (Mendonça, 2013).

Health is one of the areas in which information is increasingly available in the virtual network, and the number of people interested in it also keeps growing. This may be confirmed by the fact that subjects related to health represent one of the main concerns of humans (Garbin, Pereira-Neto & Guilam, 2008). Thus, the search for information about health on the Internet is constantly growing.

In this sense, it is fundamental that the Internet be considered a tool for facilitating contact and support for patients and families. On the other hand, it is important to consider that the Internet may also provide inconsistent, divergent information that lacks scientific evidence as regards certain pathologies and treatments (Balbani, Miyake, Melo-Junior & Butugan, 2000).

The distribution of such information may result in hazardous effects on users. Hence, ensuring information quality and making it accessible to all is a great challenge (Mendonça, 2013).

The Health on the Net Foundation was created in 1995, after a conference on health and the Internet that was held in Geneva, in Switzerland, with the aims of encouraging the distribution of quality health information for patients, professionals and the public in general, and facilitating access to health data through the Internet. A code to establish an ethical standard, providing for issuance of certification for health websites, was created by this foundation and named the HONcode (HON, 2013). The HONcode guides administrators of websites as to the creation of a minimum set of mechanisms aiming at quality, objective, and transparent information. By receiving a HONcode seal, a website demonstrates its intention to contribute to quality medical information (HON, 2013; Silveira, Costa & Lima, 2012).

Adherence to the HON quality code is considered a gold standard by international experts (I. Lopes, 2006). Compliance with the eight principles is required for the acquisition of the HONcode certification. These are the HONcode principles (HON, 2013).

Principle 1. Authority: Any medical or health advice provided and hosted on the site will be provided only by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organization.

Principle 2. Complementarity: The information provided on the site is designed to support, not replace, existing relationships between patients/site visitors and their existing doctors.

Principle 3. Privacy: Confidentiality of data relating to users, including their identity, is respected by the website. The website owners undertake to honor or exceed the legal requirements for medical/health information privacy that apply in the country and state where the website is located.

Principle 4. Attribution: Where appropriate, information contained on the site will be supported by clear references to source data and, where possible, specific HTML links to that data will be provided. The date when a page was last modified will be clearly displayed.

Principle 5. Justifiability: Any claims relating to the benefits and performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

Principle 6. Transparency: The designers of the website will seek to provide information in the clearest possible manner and provide contact addresses for visitors who seek further information or support. The webmaster will display an e-mail address clearly throughout the website.

Principle 7. Financial disclosure: Support for the website will be clearly identified, including the identities of commercial and non-commercial organizations that have contributed funding, services or material for the site.

Principle 8. Advertising policy: If advertising is a source of funding, it will be clearly stated. A brief description of the advertising policy adopted by the website owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

In addition to these eight principles for online collaborative platforms such as virtual forums, privacy and messages were also assessed.

There are currently initiatives that deal with the subject of the quality of health information available on the Internet. Some of them are the Health on the Net Foundation (HON), the American Accreditation Healthcare Commission (URAC - Utilization Review Accreditation Commission), Agencia de Calidad Sanitaria de Andalucia (Web Sanitary Pages) and the São Paulo Regional Medical Council (CREMESP), which developed the “Ethics Manual for Medicine and Health Sites on the Internet” (Mendonça, 2013).

The success of some initiatives, such as the HONcode, which has international repercussions, demonstrates the awareness of health professionals and institutions concerning the distribution of quality health information (I. Lopes, 2006).

2.3. VIRTUAL FORUM

As emphasized in the previously, the Internet has become an instrument of communication, and the use of this tool allows greater access to information and the expansion of knowledge. Software, websites, virtual environments, and other technological resources have been produced with the aim of favoring the work of professionals and the provision of health care to the population (Cavalcante, Ferreira, Silva & Silva, 2011).

When information is digitalized, it can be reproduced, modified and updated in different interfaces. The interface of a virtual forum allows the distribution and reception of information that is fed by all participants. In this context, there is the development of a virtual community that enables dialogue among people who are geographically distant (Santos, 2003). A characteristic of virtual forums is the possibility of both asynchronous communication, that is, communication that is not developed in real time, and synchronous communication, which is developed in real time, for instance in chats (Rodrigues, Capellini, & Nascimento, 2012). In addition to allowing the participation of users and the exchange of information and experiences either in real time or not, the virtual forum enables the storage of content, which will be available for later access, preserving the published and shared information.

In the light of technology innovation, new virtual tools are being used in the context of access to information in the health area. In this direction, a literature search was performed with the descriptor Virtual Forum, in English and in Portuguese.

In the Virtual Health Library (VHL) and Latin-American and Caribbean Center on Health Sciences Information (LILACS) (Table 1), ten articles were found, five in Portuguese, three in Spanish and two in English. Of these, nine complete articles were available, but only five addressed the subjects of learning, virtual environments and health. Another similar search was performed in the United States National Library of Medicine (Pubmed) (Table 2), which yielded 91 articles, of which 21 complete articles were available. The studies were analyzed and selected according to the same criteria, resulting in two articles in Spanish, one in German and seven in English. This bibliographic search resulted in a total of 15 articles.

Table 1

Articles selected from the Virtual Health Library (LILACs), according to their year of publication, author, title and journal

Year	Authors	Title	Journal
2014	Alves, E. & Cogo, A.	[Nursing students' perception of the learning process in a hospital setting] Percepção de estudantes de enfermagem sobre o processo de aprendizagem em ambiente hospitalar	Rev Gaúcha Enferm, v.35, n.1
2013	Chaparro-Díaz, L.	ICT as a social support mechanism for family caregivers of people with chronic illness: a case study	Aquichán, v.13, n.1
2012	Portella, V. et al.	[Virtual environment forum in trust relationship between the heath professional and the person being cared for] Fórum em ambiente virtual na relação de confiança entre o profissional	Rev Gaúcha Enferm, v.33, n.4

		e o indivíduo cuidado	
2011	Ventura, F. et al.	[Satisfaction of students of dentistry in the development of the virtual support for the course General Anatomy and Stomatology] Grado de satisfacción de estudiantes de estomatología en el desarrollo del curso de Anatomía General y Estomatológica con apoyo virtual	Rev Estomatol Herediana, v.21, n.3
2011	Torriente, L. et al.	[Instrument and informatics tool for guiding, controlling and evaluating the interactions among students in the virtual forum] Instrumento y herramienta informática para guiar, controlar y evaluar las interacciones de los estudiantes en foros virtuales	Educación Médica Superior, v.25, n.2

Table 2

Articles selected from the United States National Library of Medicine (Pubmed), according to their year of publication, author, title and journal

Year	Authors	Title	Journal
2014	Ho, K. & Wall, Peter.	Harnessing the social web for health and wellness: issues for research and knowledge translation	J Med Internet Res 2014; v.16, n.2
2013	Santiago, M. et al.	[Discourse on violence against women in a virtual forum: the view from the gender framework] Discurso sobre la violencia hacia la mujer en un foro virtual: presencias del marco de género	Gac Sanit, v.27, n.2

2013	Lacroix, V. et al.	Evaluating the efficacy of a web-based program (Diapason) for informal caregivers of patients with Alzheimer’s disease: protocol for a randomized clinical trial	JMIR Research Protoc, v.2, n.2
2012	Espie, C. et al.	A randomized, placebo-controlled trial of online cognitive behavioral therapy for chronic insomnia disorder delivered via an automated media-rich web application	Sleep, v.35, n.6
2012	Wu, V. et al.	Evaluation of the progress and challenges facing the Ponseti method program in Vietnam	The Iowa Orthopaedic Journal, v.32, n.1
2011	Jayawardena, A. et al.	Diffusion of innovation enhancing the dissemination of the Ponseti method in Latin America through virtual forums	The Iowa Orthopaedic Journal, v.31, n.1
2011	Salzmann-Erikson, M. & Eriksson, H.	Torrenting values, feelings, and thoughts: cyber nursing and virtual self-care in a breast augmentation forum	Int J Qual Stud Health Well-being, v.6, n.4
2010	Freudenberg, L. et al.	[Problem oriented learning in virtual rooms: first experiences in nuclear medicine] Problem-orientiertes lernen im virtuellen raum: erste erfahrungen in der nuklearmedizin	GMS Zeitschrift für Medizinische Ausbildung, v.27, n.5
2009	Agudelo, C. et al.	[Health research priorities in Colombia from the researchers' point of view] Prioridades de investigación en salud em colombia: perspectiva de	Rev. Salud Pública, v.11, n.2

		los investigadores	
2007	Baillargeon, J. et al.	Integrated obesity care management system: implementation and research protocol	BMC Health Services Research, v. 163, n.7

The analysis of the selected studies revealed that virtual environments, especially virtual forums, are present in various segments related to learning and the health area.

In Colombia, an online forum was used as an auxiliary tool in the identification of priorities for investigation in health and contributed to the formulation of health policies (Agudelo et al., 2009).

The authors of a study developed in Cuba stated that the use of information and communication technologies based on the teaching-learning process, and a virtual forum, helped professors supervise, guide and evaluate the learning process for medical undergraduates (Torriente, Senti, Hernández & Ortega, 2011).

The use of web conferences and virtual forums in Vietnam presented positive results in the continuing education of orthopedists, facilitating distribution of technical knowledge among professionals (Wu et al., 2012). In a similar context, another study developed in Latin America found that web conferences can be an important vehicle for promoting and updating professional practices (Jayawardena, Boardman, Cook, Oprescu & Morcuende, 2011).

The use of a learning virtual platform with German medical students had a high level of acceptance and was positively assessed by the participants (Freudenberg, Bockisch & Beyer, 2010). In Brazil, nursing students used a virtual forum to report experiences in the hospital environment, and the authors of this study highlighted that the use of a forum must be encouraged by professors as a place for interaction that contributes to professional education (Alves & Cogo, 2014).

A study developed in Peru with participants in a general anatomy and stomatology program who used virtual forums concluded that the use of virtual methods helps students through learning and promotes the exchange of educational experiences (Ventura, Guillén & Parra, 2011).

In Bogotá, online social networks (blogs) were used to support the care of people with chronic diseases. Four categories were found involving the use of this tool: care, interaction, experience, and technology, which can be considered for theoretical perspective analyses in online social support (Chaparro-Díaz, 2013).

Other authors used social networks to develop a study on violence against women, through a virtual journal from Latin America. Data analysis of this study considered the publications of the participants in a virtual forum (Santiago, Peregrín & Gonçalves, 2013).

Web-based interventions were also found to be effective in a French study with people with Alzheimer’s disease. The authors stated that this facilitated the acquisition of information and support by the caregivers and families of these patients (Cristancho-Lacroix et al., 2013).

A study developed in the United Kingdom found that adults with sleep disorders also benefitted from the use of a virtual forum and cognitive-behavioral therapy through the Web (Espie et al., 2012).

Another study developed with virtual forums available on the Internet presented positive results. In this study, women who had received cosmetic breast surgeries shared values, feelings, and thoughts, and offered support to each other (Salzmann-Erikson & Eriksson, 2011).

Aimed at developing subsidies for the treatment of obesity, a group of Canadian researchers used a discussion forum and monthly virtual meetings as tools for data collection (Baillargeon et al., 2007).

The control and prevention of musculoskeletal pain through Brazilian virtual forums contributed to the creation of relationships of trust between professionals and patients (Portella, Crossetti, Baron, Mendes & Crippa, 2012).

An interdisciplinary assessment of the terms of use of social media to support health and well-being by Canadian researchers raised fundamental points that must be reflected, such as the construction of trust and credibility in relationships between professionals and patients in social media (Ho & Wall, 2014).

In the light of this, it is possible to see that virtual tools are increasingly present in several health area segments and in many places in the world, be professional education, support of research in the area, or creation of information and support networks for the population, patients, and caregivers.

2.4. ASSESSMENT OF A VIRTUAL FORUM

The search for health information in the virtual environment enables not only acquisition of information, but also exchange of experiences and the promotion of autonomy and interaction among users, which is pointed out as a teaching strategy (Murray, Burns, See, Lai & Nazareth, 2005). These virtual environments must be assessed in an attempt to ensure the efficacy and validity of the content they distribute (P. Oliveira & Pagliuca, 2013).

The assessment of a health virtual environment must consider the selection of an appropriate and accurate instrument for data collection, which depends on the study design and must provide reliable indicators (Alexandre & Coluci, 2011). Validity, reliability, feasibility, sensitivity and responsiveness are important characteristics to be considered in these instruments (Fayers & Machin, 2013). Validity and reliability, in particular, must be considered as essential attributes when choosing an instrument for data collection (Fitzner, 2007).

A valid instrument must really assess its objective and measure the phenomenon to be studied with precision (Pilatti, Pedroso & Gutierrez, 2010). Some of the methods that can be used to assess validity include content validity, criterion-related validity and construct validity (Alexandre & Coluci, 2011). If the reproduction of results precisely measures a phenomenon, the instrument used for data collection can be considered reliable (Pilatti et al., 2010). Validity and reliability are criteria that reflect the quality of an instrument, and must be demonstrated before an instrument is used to measure a variable of specific interest (S. Couto, Coelho, Souza, Marin & Lanzillotti, 2009).

Some authors state that when defining a study’s methodology, researchers often have to opt for the use of an existing instrument or build a new one that suits their project proposal. When choosing the second alternative, researchers must consider the need for a previous study to ensure the validity and reliability of this instrument (Pilatti et al., 2010). Since the present study is recent research, there are few instruments available in the literature for the assessment of virtual forums. We decided to build a new instrument for the assessment of the virtual forum in question.

2.5. SPINA BIFIDA

2.5.1. ORIGIN AND DEFINITION

The human nervous system originates from the primitive ectoderm. The ectoderm, the endoderm and the mesoderm form the three primary germ layers. The endoderm, especially the notochord plate and the intra-embryonic mesoderm, induces the overlying ectoderm to develop the neural plate in the third week of development. Failures in this normal induction result in most neural tube defects (NTBs) (Kliegman, Behrman, Jenson & Stanton, 2009).

Neural tube defects, also known as dysraphism, occur when the neural tube does not close completely between the 3rd and the 4th weeks of intrauterine development. They are responsible for most congenital abnormalities of the central nervous system (CNS). The main NTBs are: spina bifida occulta, meningocele, myelomeningocele, encephalocele, anencephaly, dermal sinus, tethered spinal cord, syringomyelia, diastematomyelia, and lipoma involving the conus medullaris or the filum terminale, or both (Kliegman et al., 2009).

The term “spina bifida” refers to a defect in neural tube closing and the posterior vertebral arches (Umphred, 2004) and spinal dysraphism concerns neural tube defects (Kliegman et al., 2009).

2.5.2. CLASSIFICATION

Spina bifida can be classified as open or closed (Melo-Souza, 2000). Spina bifida occulta consists of a defect in the midline of the vertebrae, generally without any harm to the spinal cord and the meninges. Most patients affected by this malformation do not present symptoms or neurological impairment (Kliegman et al., 2009). Open spina bifida results from incomplete closing of the neural and superposed vertebral arches. Cystic protrusion of the spinal cord and the meninges occurs through the defective vertebral arches (Umphred, 2004).

Meningocele is the moderate form of open spina bifida. It occurs when the meninges herniate through a defect in the posterior vertebral arches. A floating mass can be observed in the midline, throughout the spine, generally in the lumbar area. The spinal cord remains in the spinal canal; however, tethered spinal cord, syringomyelia or diastomyelia may occur (Kliegman et al., 2009).

Myelomeningocele is the most common and severe form of spina bifida. It can occur at any level of the spinal cord, but is found most commonly in the thoracic and lumbar-sacral areas. In this case, both the spinal cord and the meninges are contained in a cystic bag. In the case of open myelomeningocele, the spinal cord and the associated neural tissue are exposed (Umphred, 2004).

Figure 1 shows a sequence of images that illustrate a normal spinal cord (A), spina bifida occulta (B), meningocele (C) and myelomeningocele (D).

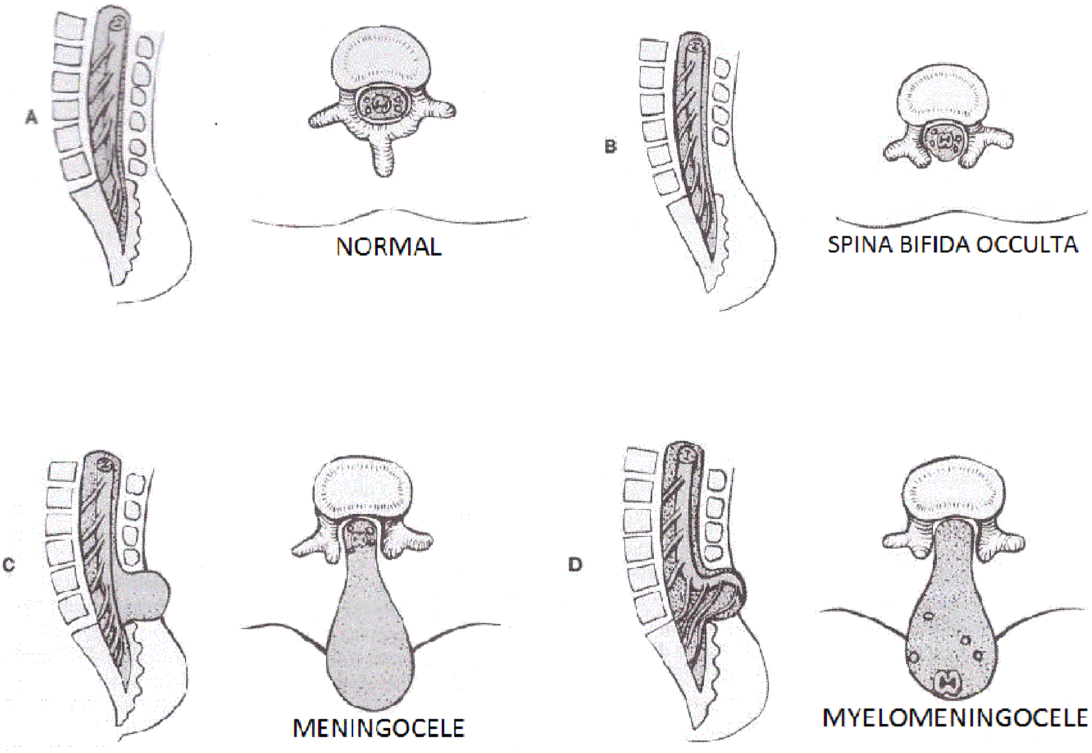


Figure 1. Midline spinal defects with variable degrees of neural herniation. Adapted (Wong, 1999)

2.5.3. EPIDEMIOLOGY

The overall incidence of neural tube defects varies between 0.1 and 10 cases in every 1,000 live births (Bizzi & Machado, 2012). In countries in Central Europe, this incidence varies between 1 and 2 cases in every 1,000 live births (Bartsch, Schneider-Rätzke, & Theile, 2009). The incidence of spinal bifida found in Latin America is 1.5 in every 1,000 live births (Nazer, López-Camelo & Castilla, 2001). In a study developed by the World Health Organization in 2003, Brazil was mentioned as being the country with the fourth highest incidence of spina bifida among the 41 countries studied, with a rate of 1.139 in every 1,000 live births (WHO, 2003). Another study developed in the city of Campinas (São Paulo, Brazil) found a myelomeningocele incidence rate of 2.28 in every 1,000 live births (Sbragia et al., 2004).

In a study developed with 126 Brazilian newborns with congenital malformations, 31.8% of the defects were found in the central nervous system. The most prevalent malformation was hydrocephalus (HC), followed by myelomeningocele, agenesis of the corpus callosum, anencephaly and encephaloceles (Barros et al., 2012).

Spina bifida is more frequent among Caucasians and less frequent among Blacks. It is slightly more frequent among women and in lower social classes (Fernandes, 2009; Henriques & Pianetti, 2011). If a person already has a child with spinal dysraphism, the second child’s risk of having the same condition is 5% and, if the person already has two children with this condition, the risk increases to 15% (Melo-Souza, 2000). The risk for second-degree relatives of a person with myelomeningocele is estimated at between 1% and 2% (Bizzi & Machado, 2012).

As of 1970, a decrease in the prevalence of spina bifida was observed, mainly due to instructional programs on the use of folic acid in the prevention of neural tube defects and improvements in diagnosis during prenatal care by means of ultrasonography, enabling elective pregnancy termination in countries where legislation allows for such practices (Hisaba et al., 2003).

2.5.4. ETIOLOGY

The etiology of spina bifida is still not completely known and is considered to be multifactorial (Bizzi & Machado, 2012). It is believed to stem from multiple factors, including folic acid deficiency, maternal diabetes, use of some drugs by the mother (such as valproic acid and carbamazepine), and genetic and environmental factors (Segal, Deatrick & Hagelgans, 1995). Maternal age under 19 years and over 40 years, Hispanic origin and exposure to hyperthermia in the beginning of pregnancy have also been reported as factors that may favor the development of spinal bifida (Au, Ashley-Koch & Northrup, 2010). Nonetheless, folic acid deficiency is considered the most important risk factor for neural tube closing defects (Aguiar et al., 2003).

Risk factors seem to converge at a common point: the metabolic pathways of folic acid and glucose, where external or environmental agents can interact with genetic factors. The development of the neural tube requires intense metabolic activity, with the synchronized participation of its components. Abnormal action of a gene or cofactor of this pathway affects the metabolic processes and results in a neural tube closing defect. Low socioeconomic conditions can be associated with an insufficient intake of folic acid. Genetic differences among ethnic groups could predispose subjects to the occurrence of spina bifida. Maternal exposure to hyperthermia could cause the reduction or deactivation of metabolic components involved in the developmental process of the nervous system. Some metabolic disorders, such as hyperglycemia and diabetes, could cause gene expression of harmful proteins in the developing neural tube. Oxidative stress and failure in cell death control are related to cellular age and exposure to harmful environmental agents, which are factors that favor the occurrence of neural tube closing defects. The search for the gene responsible for neural tube closing defects has been intense and frustrating, due to the presence of multiple variables and the complexity of the metabolic pathways (Bizzi & Machado, 2012).

2.5.5. DIAGNOSIS

Spina bifida can be diagnosed as of the 11th week of pregnancy by ultrasonography. This exam can detect the condition in around 75% of cases (Henriques & Pianetti, 2011). The sensitivity of ultrasonography depends on the professional qualifications of the examiner and the quality of the equipment used in the fetal evaluation (Hisaba et al., 2003).

Maternal serum alpha-fetoprotein was more commonly used as to diagnose neural tube closing defects in the past. This is explained by the fact that high levels of alpha-fetoprotein are present in countless other fetal clinical conditions, besides the possibility of a false positive. When this method is used, the mother’s serum level of alpha-fetoprotein must ideally be determined between 16 and 18 weeks, but it can also be determined between 14 and 21 weeks to diagnose NTDs (Bizzi & Machado, 2012).

Magnetic resonance has been increasingly used for this purpose, as it is not invasive and provides fetal images with good resolution. It is considered an excellent alternative for cases in which high-resolution ultrasonography is not diagnostic or provides data that require further study with complementary images (Saleem et al., 2009).

Morphological ultrasonography is used with the aim of evaluating fetal anatomy to verify the existence of malformations or congenital defects in the second trimester. It is ideally performed between 20 and 22 weeks. This exam can detect two cranial alterations that may occur in association with spina bifida. The first is known as the “lemon sign” and consists of an indentation of the frontal bone in the biparietal view; the second is the “banana sign” and consists of a brain stem deformity in which the cerebellum is curved and elongated (Bizzi & Machado, 2012).

Amniocentesis is useful in the confirmation of syndromic malformation diagnoses, which include spina bifida in its phenotype. It is considered to be the only method that provides information regarding biochemical and cytogenetic conditions; however, its indication for the diagnosis of neural tube closing defects has been reduced because the ideal period for its application is between 15 and 20 weeks, obtaining results and interpretation takes time, there are risks inherent to the procedure, and it is an invasive technique (Bizzi & Machado, 2012).

When diagnosis is performed only at birth, it hampers medical conduct and guidance for the parents, who are duly informed about the several aspects of the child’s malformation (Henriques & Pianetti, 2011). The evolution of prenatal diagnostic techniques for spina bifida, allowing for early knowledge of its gestational occurrence, allows for provision of information and counseling of parents concerning their baby’s pathology (Bizzi & Machado, 2012).

2.5.6. PREVENTION

The etiology of spina bifida is considered to be multifactorial, and a deficiency of folic acid is deemed the most important risk factor for neural tube defects (Aguiar et al., 2003). Studies point out that appropriate supplementation with folic acid can reduce the risk of incidence of NTDs in up to 70% of cases (Au et al., 2010). It is recommended that pregnant women take between 0.4 and 1 mg of folic acid a day for at least three months before pregnancy and during the first trimester. Its use after diagnosis is considered ineffective for this purpose, since NTDs occur in the first three weeks after ovulation (Bizzi & Machado, 2012).

Many women do not carry out supplementation with folic acid as recommended because they do not know when they will get pregnant, and the use of folic acid only after the pregnancy is confirmed to have a lower protective effect. A more effective recommendation would be that women who want to get pregnant take folic acid right after the interruption of contraceptive methods, or that women of reproductive age make regular use of folic acid (Pietrzik, 2009).

In order to reduce the incidence of NTDs, several countries recommend the addition of folic acid in foods that are consumed in great quantities. In the United States, this action led to a decline of approximately 19% in the incidence of NTDs (Honein, Paulozzi, Mathews, Erickson & Wong, 2001). Chile was the first country in South America to add folic acid to foods (Nazer et al., 2001). In Brazil, the fortification of wheat and maize flour with folic acid was implemented in 2002 (Brasil, 2002). It is a measure that has already been adopted in 40 other countries around the world (Santos & Pereira, 2007).

Care directed towards maternal diet, supplementation with folic acid, and appropriate professional follow-up before and during pregnancy are important factors in the prevention of NTDs (Cunha, Fontana, Garcias, & Martino-Roth, 2005).

2.5.7. TREATMENT

In cases of closed spina bifida, such as simple spina bifida occulta, most patients do not present symptoms or neurological signs, and it often does not have consequences. It is occasionally associated with more significant abnormalities in spinal cord development, such as syringomyelia, diastematomyelia and tethered cord (Kliegman et al., 2009).

Regarding open spina bifida (myelomeningocele), prenatal diagnosis allows for anticipation of a series of care measures, such as providing information on the delivery, instructions to parents regarding the morbidity associated with the condition, measures to be taken immediately after birth, and the availability of professionals involved in the care of the child (Bizzi & Machado, 2012).

No prospective and randomized studies have been developed on the best mode of delivery for this type of congenital malformation (Hisaba et al., 2003). Elective Cesarean section has been recommended, however, as the mode of delivery for babies with prenatal diagnosis of myelomeningocele, since it enables the synchronization and optimization of neonatal care (Bizzi & Machado, 2012). Another reason for the use of Cesarean section is that since it is performed before obstetric labor, when uterine contractions initiate, it prevents the mechanical trauma of the exposed intrauterine nervous tissue and the pelvic trajectory that occurs during vaginal birth (Hisaba et al., 2003).

Regarding surgical treatment of myelomeningocele , closing must occur as early as possible, ideally in the first 48 hours after birth. The ability to treat the condition is not related to the possibility of reversing existing neurological impairments, since these are mostly permanent and irreversible. The fundamental objectives of surgical repair are the preservation of viable nervous tissue, anatomic reconstitution and a decrease in the risk of infection of the central nervous system (Bizzi & Machado, 2012; Bulbul, Can, Bulbul, Cömert & Nuhoglu, 2010).

Prenatal diagnostic methods have gained even more importance, given the possibility of correcting the malformation in the intrauterine period (Bizzi & Machado, 2012). Fetal correction in humans is performed between 20 and 25 weeks of pregnancy, since repair in this period minimizes the time interval in which neuronal damage to the exposed cord can occur (Walsh, Adzick, Sutton & Johnson, 2001). The disadvantages of fetal surgery include the risk of premature birth, the risks of the surgical procedure for the mother, and a greater risk of fetal death in the perioperative period (Henriques & Pianetti, 2011). It is noteworthy that the prospects for fetal surgery are constantly improving due to refinements in technology and the efforts of those who believe in a therapeutic answer for these patients (Hisaba et al., 2003).

Complications resulting from hydrocephalus are among the main causes of death in patients with myelomeningocele (Bizzi & Machado, 2012). In the 1950s, the ventriculoperitoneal shunt valve (VPSV) was introduced in the treatment of hydrocephalus, which represented a great advance in the survival of patients with myelomeningocele (Boockvar, Loudon & Sutton, 2001).

Patients with spina bifida require treatment and follow-up throughout their lives, which characterizes myelomeningocele as a chronic condition. It is the health team's role to intervene in advance in the events and complications that can be expected to occur, so as to give these people's lives more dignity. The defense of rights already achieved and their extension must be a cause defended by healthcare professionals, together with people with spina bifida and their families (Gaiva et al., 2009).

2.5.8. COMPLICATIONS

The gravity of the complications that may be associated with spina bifida depends on the level of the lesion, the degree to which the nerve roots have been compromised, and other associated malformations (J. Costa, Silva, Carvalho & Almeida, 2009). Complications of hydrocephalus may include Arnold-Chiari malformation, latex allergy, tethered cord, syringomyelia (Bizzi & Machado, 2012), urological alterations, intestinal alterations (Martín, Fernández Vila, & Estévez, 1999), difficulty of locomotion, deformities, alteration in cutaneous sensitivity, obesity/overweight (Bronzeri, Coimbra, Faria, Frangella & Silva, 2011) and cognitive alterations (Mendes, Torres, Lopes & Evangelista, 2012).

Hydrocephalus is characterized by an accumulation of fluid inside the cerebral ventricles, with consequent dilatation, which generates an imbalance between the production and absorption of this fluid (Sawyer & Macnee, 2010). Ventricular system dilatation is observed in all children with myelomeningocele. Hydrocephalus with intracranial hypertension and progressive ventricular dilatation requiring a ventriculoperitoneal shunt valve, which decreases fluid pressure, is present in approximately 80% of these children. The development of hydrocephalus can also occur after a surgical procedure for myelomeningocele closing (Bizzi & Machado, 2012).

Type II Arnold-Chiari malformation is a structural and morphological alteration of the rhombencephalon that is almost always associated with myelomeningocele. Despite its relatively low clinical manifestation (only 20% to 30%), when symptomatic, this malformation is responsible for the mortality of around one-third of the people who manifest it (Bizzi & Machado, 2012). A study developed with 72 cases of myelomeningocele treated in a pediatric hospital found that the signs and symptoms of the Arnold-Chiari malformation were directly or indirectly responsible for the absolute majority of deaths observed during the first year of life (Salomão et al., 1995). The symptomatology includes strabismus, noisy breathing, apnea crises, sleep disorders, dysphagia and alterations in the function of the upper limbs. These symptoms can also be caused or aggravated by poor operation of the ventricular shunt valve (Wagner, Schwarz & Perneczky, 2002).

Patients with myelomeningocele present a greater risk for latex allergy or sensitivity (Majed et al., 2009). These subjects are exposed to latex starting at birth; the factors associated with greater prevalence of this allergy include multiple surgeries for placing and revising the ventricular shunt, urological surgeries, vesical catheterizations, and orthopedic procedures (Bizzi & Machado, 2012). A study developed with 80 children with spina bifida showed that around 40% presented some sensitivity to latex with specific immunoglobulin, and 37% had clinical reactions when exposed to latex, such as urticaria, conjunctivitis, angioedema, rhinitis, and bronchial hyperreactivity (Ausili et al., 2007).

Tethered cord occurs as a consequence of mechanical traction of the cord with progressive neurological deterioration (Könü-Leblebicioglu & Yonekawa, 2008). It is believed that cord distension resulting from anchoring develops from the first year up to around 20 years of age, the period when one must be attentive to its development. Since virtually all children with repaired myelomeningocele have cords with low implantation, demonstrated through imaging exams, tethered cord is diagnosed based on clinical criteria. Clinical manifestations include progressive weakness, gait deterioration, scoliosis, pain, urinary alterations, and orthopedic deformity. In most cases, early diagnosis and tethered cord surgical release result in stabilization or improvement of the symptoms (Bizzi & Machado, 2012).

The development of syringomyelia results from a fluid circulation block at the craniovertebral junction level, due to a Type II Arnold-Chiari malformation. Associated symptoms are dissociated sensory loss, segmental muscle atrophy, spasticity, scoliosis, reduced strength, urinary dysfunction, and pain (Bizzi & Machado, 2012).

Neurogenic bladder is one of the main complications of myelomeningocele, as a consequence of the lesion in the central nervous system. Patients with this dysfunction can present important urinary-sphincter alterations, such as urinary incontinence, incomplete bladder emptying and increased intravesical pressure (Hopps & Kropp, 2003). This subject will be approached in the next sections.

Most children with spinal cord alterations present bowel dysfunction. Despite the existence of several methods for managing neurogenic bowel, none has been universally indicated to date (Eire, Cives, & Gago, 1998). Neurogenic bowel causes social, physical and psychological impacts (Thomé, Borgui, Berardi Moser, & Assis, 2012). Fecal incontinence is present in 75% of people with myelomeningocele (Martín et al., 1999) and constipation is also very frequent. Both fecal incontinence and constipation must be treated with dietary control and bowel training (J. Costa et al., 2009).

Most patients with myelomeningocele present muscle strength alterations in the lower limbs, and the greater the extent of cord lesion, the greater the motor difficulty. Other authors state that in investigating the acquisition of gait in children with myelomeningocele, in addition to the level of neurological impairment, other factors such as the strength of the lower limbs and the presence of articular deformities must be considered (Collange et al., 2006). The authors of a literature review on the factors that influence the ambulatory prognosis of people with myelomeningocele concluded that orthopedic alterations and lesion levels had received more attention than family motivation and socialization, which were not always present in the studies (Ramos, Macedo, Scarlato & Herrera, 2005). The need for a wheelchair for locomotion by people with myelomeningocele occurs in 90%, 45% and 17% of patients with lesions in the thoracic-lumbar, lumbar and sacral areas, respectively. Ambulation without locomotion assistance is possible in 57% of patients with sacral lesions and 7% of patients with lumbar lesions, and is not seen in patients with thoracic-lumbar lesions (Cochrane et al., 1996).

Deformities can be present at birth or appear with growth. They occur mainly in the spine, hips and lower limbs (Sharrard, 1993). Hip luxation frequently occurs, but it does not always require treatment (Karol, 1995). Deformities can interfere negatively in activities of self-care and daily living.

Cutaneous sensitivity alterations are characterized by perception deficits for pain, touch, temperature or position of body segments. It may lead to the development of skin lesions, such as burns, excoriations and pressure ulcers; the latter can also be generated due to the prolonged use of a wheelchair and lower limb orthosis, among others (Ekmark, 2009). Given these sensitivity alterations, professionals must instruct patients with spina bifida concerning daily care, for instance, regarding bath water temperature, clothing adjustments, changing positions and relieving pressure points.

A literature review showed that several factors influence the nutritional deviations of children with myelomeningocele. Height deficits associated with loss of function of lower muscle groups (loss of mobility), genetic and environmental factors, and excessive food ingestion favor the development of overweight or obesity (Bronzeri et al., 2011). A study developed with 24 children with myelomeningocele observed that approximately 50% of the sample, including both boys and girls, presented overweight or risk for overweight (Coelho, Egashira, Silva & Ribeiro, 2009).

In many cases, patients with myelomeningocele can present deficits in gross and fine motility, motor perception, and cognitive function (Mendes et al., 2012). A study developed with 165 children, 91 with spina bifida and 74 without this malformation, showed that the first group presented slower developmental rates in the cognition and language areas (Lomax-Bream, Barnes, Copeland, Taylor & Landry, 2007). As a consequence of alterations in cognitive function, with memory and learning impairment, these children can present problems in school development (Vachha & Adams, 2005).

2.6. NEUROGENIC BLADDER

Neurogenic bladder in children is generally congenital and may result from neural tube defects or spinal cord abnormalities such as myelomeningocele (Kliegman et al., 2009).

Physiologically, urination refers to the process in which a full bladder empties, involving two stages. In the first stage, the bladder progressively fills up, until the tension in its walls reaches a limit that triggers the next stage. In the second stage, a nervous reflex (micturition reflex) takes place, which generates bladder emptying or, if that does not happen, at least produces the conscious desire to urinate. The micturition reflex is an autonomic reflex of the spinal cord, but it can be repressed by centers in the cerebral cortex or the brain stem (Guyton & Hall, 1998). The function of retaining urine is totally passive, but urination is active and requires perfect integration between the corticospinal tract and the autonomic system to produce a coordinated activity (Lianza, 2001).

Pelvic nerves provide the main nerve supply to the bladder, and they connect to the spinal cord through the sacral plexus at the S-2 and S-3 cord segments. Sensory and motor nerve fibers follow the pathway of these nerves. The degree of distension of the bladder wall is detected by the sensory fibers that are responsible for the reflexes that trigger bladder emptying. Motor nerves consist of parasympathetic fibers ending in ganglion cells located on the bladder wall. In addition to pelvic nerves, skeletal motor fibers are transmitted through the pudendal nerve to the urinary external sphincter, which are somatic nerve fibers that innervate and control the voluntary skeletal muscle of the sphincter (Figure 2) (Guyton & Hall, 1998).

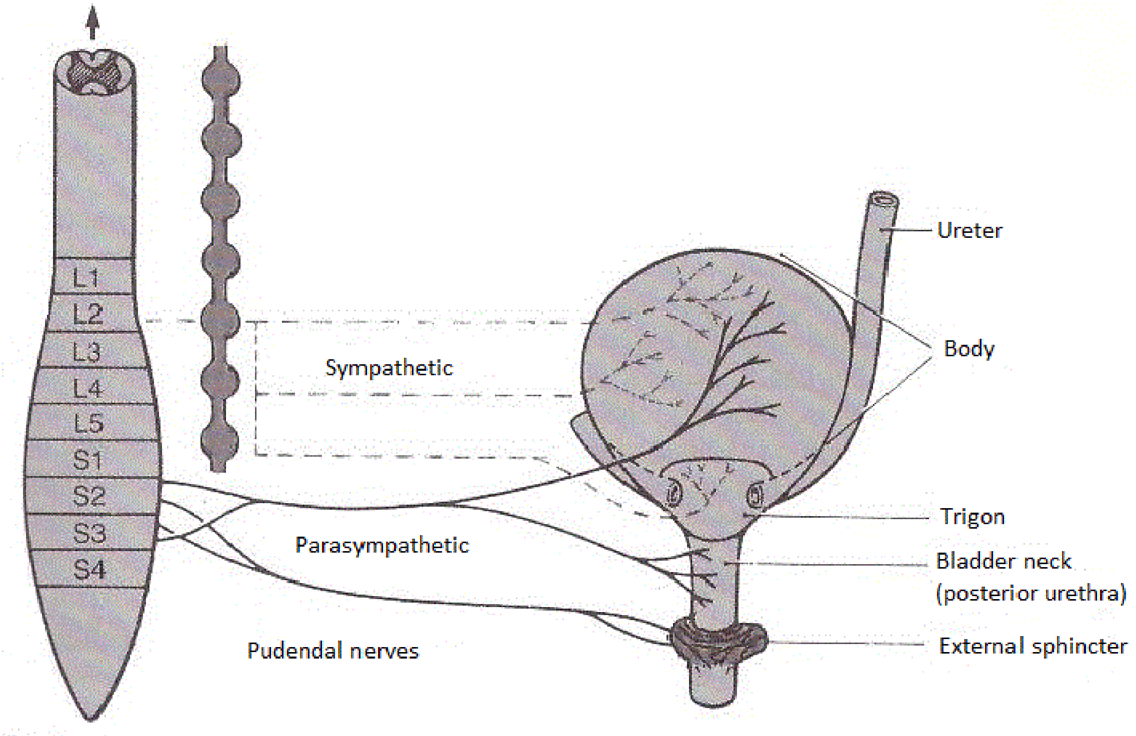


Figure 2. Urinary bladder and its innervation. Adapted (Guyton & Hall, 1998)

Neurogenic bladder is characterized by interference in the normal conduction of nerve impulses in one or more nerve bundles related to urination, and it produces urinary dysfunction (Lapides, 1979). The dynamics of bladder retention and emptying occur in an altered fashion (Henriques & Pianetti, 2011).

The classification of neurogenic bladder can be spastic (hyperreflexic) or flaccid (areflexic). The spastic type occurs at the suprasacral level and is characterized by trabeculated, thick walls, with a radiologic image that resembles a Christmas tree. The flaccid type occurs when the lesion is located in the sacral center or in motor or sensory pathways that compose the micturition reflex arc (Lianza, 2001). The great majority of patients with myelomeningocele present urinary dysfunction according to the level of the lesion, which varies from the thoracic to the sacral region, being more common in the lumbar region (D'Ancona & Silva Jr, 2008). Table 3 shows the relationship between risk of renal complications and characteristics of detrusor, sphincter and bladder emptying disorders.

Table 3

Relationship between risk of renal complications and characteristics of detrusor, sphincter and bladder emptying disorders

Characteristics	Bladder emptying disorders	Risk for renal complication
Underactive detrusor and sphincter	Low pressure inside the bladder Overflow incontinence	Very high
Underactive detrusor Overactive sphincter	Bladder retains large urine volume Bladder does not empty properly Risk for vesicoureteral reflux	Possible
Overactive detrusor Underactive sphincter	Bladder with low capacity to retain urine Detrusor contracts constantly	Possible
Overactive detrusor and sphincter	Bladder with low capacity to retain urine High pressure inside the bladder	Very low

Note: Adapted (Beetz & Stein, 2009)

The most important urologic consequences of neurogenic bladder are urinary incontinence, urinary tract infections, hydronephrosis with vesicoureteral reflux and detrusor-sphincter dyssynergia. Pyelonephritis and loss of renal function are considered to be potential causes of premature death in patients affected by this condition (Kliegman et al., 2009).

People with neurogenic bladder are subject to various emotional and social repercussions: a greater number of hospital visits; special care measures that force them to have different life habits from those of their peers; and social embarrassment that may occur due to involuntary urine leakage, which makes their integration into social life difficult and negatively impacts their self-esteem, modifying their day-to-day life (Furlan et al., 2003).

2.6.1. DIAGNOSIS AND TREATMENT OF NEUROGENIC BLADDER

The diagnosis and treatment of neurogenic bladder positively influence the evolution of patients with myelomeningocele when performed early, since they favor the prevention of urologic complications (J. Costa et al., 2009).

Clinical anamnesis in association with urological and laboratory examinations are fundamental for the evaluation of neurogenic bladder (Guys, Hery, Haddad & Borrionne, 2011). To make the diagnosis, professionals must consider performing ultrasonography, evaluating residual urine volumes, and performing voiding cystourethrography and urodynamic study, after surgical closure of the myelomeningocele. The use of urodynamics consists of filling the bladder with saline solution, measuring urinary pressure and volume, and evaluating the tonus of the sphincter (Kliegman et al., 2009); this is considered to be the gold standard procedure for the evaluation of neurogenic bladder (Sá, Orsini, Abelheira & Sohler, 2010).

It is recommended that people with myelomeningocele be systematically evaluated from the urologic point of view starting in their first weeks of life (J. Costa et al., 2009). In a study analyzing the medical records of children with myelomeningocele, the authors observed that 100% of the sample presented neurogenic bladder and said that this result reinforces the importance of early urologic evaluation and intervention and their relationship to the prognosis of these patients (Sá et al., 2010).

Treatment of neurogenic bladder aims mainly at preserving renal function, improving continence and favoring a better quality of life (SBU, 2006).

Drug therapy

Anticholinergic agents are drugs commonly used to improve bladder capacity, of which oxybutynin chloride is the most frequently used. Tolterodine and diazepam are also used, latter being for the relaxant effect it may have on the detrusor muscle (Guys et al., 2011). A study developed with 55 children with myelomeningocele observed that 94.5% used some type of bladder medication, oxybutynin chloride being the most common (J. Costa et al., 2009). The antimuscarinic action of this medication is responsible for most of its side effects, the main one being dry mouth (Arruda et al., 2007; Wolosker et al., 2012). As a result of these effects, around 25% of patients stop using the drug (Andersson & Chapple, 2001) or use subtherapeutic doses (Barroso, Macedo, & Srougi, 2000).

In addition to oral administration, oxybutynin chloride can be used via the intravesical route. The direct action of the drug in the vesical mucus, the absence of liver first-pass metabolism, and prolonged time of action may be responsible for the reduction of side effects and more effective action (Barroso et al., 2000).

The use of smooth muscle relaxants and alpha-adrenergic blockers can also be indicated for drug therapy with the purpose of favoring bladder emptying, especially in cases with hypertonia (Guys et al., 2011).

Botulinum toxin has been used in the treatment of neurogenic bladder since 2000. Unlike other injectable drugs, it only acts on the points where it is applied, rather than in the bloodstream. Its action consists of inhibiting the release of acetylcholine neurotransmitter, which results in a local anticholinergic effect (Vidigal et al., 2009). Some researchers have reported that successive repetition of botulinum toxin injections in the detrusor, at intervals of six months, is an effective therapy for treating neurogenic bladder overactivity (Chenet et al., 2007).

Intermittent catheterization

Intermittent catheterization allows for periodic emptying of the bladder, or a surgically created urinary reservoir, by means of the introduction of a catheter through the urethra or a stoma. Its main objective is to preserve the urinary tract. This procedure can be temporarily indicated for patients with transitory urinary dysfunctions, such as postoperative urinary retention, or as a long-term treatment, especially for persistent urinary dysfunction, as is the case with neurogenic bladder. If the urethra cannot be catheterized safely, as in cases of urethral stenosis, this procedure is contraindicated. Obesity and spasticity may also be limiting factors for performing catheterization (SBU, 2008). Despite the recognized benefits of intermittent catheterization, there are complications associated with this technique, such as urethral stenosis and traumatisms, urinary tract infections and false urethral pathways (Carvalho, Damasceno, & Barbosa, 2006).

Intermittent catheterization is one of the main methods of treating neurogenic bladder (Bauer, 2008; Segal et al., 1995). In these cases, the sterile technique or the clean technique are the two methods used. The main difference is that, in the first, sterile materials are used and handled with sterile gloves, whereas in the second, the procedure is not sterile, it is just clean. The clean technique is most commonly used, because not only is there no statistically significant difference in the frequency of bacteriuria and urinary infection between the two methods, but also because the cost is lower when compared to that of the sterile technique (SBU, 2008). The clean technique is encouraged by authors who defend the idea that the natural resistance of the organism prevents the development of urinary infections due to the introduction of bacteria into the urinary tract during intermittent catheterization, and that this procedure prevents bacterial multiplication, since it allows the bladder to be periodically emptied (Lapides, Diokno, Silber & Lowe, 2002).

The clean technique basically consists of rigorous hygiene of the hands and genitalia using water and neutral soap before the introduction of the catheter, which must be handled as little as possible so as to reduce the risk of contamination (J. Costa et al., 2009). The catheter must be lubricated and introduced through the urethra until urine is released. It must be kept in position until urine stops flowing and then carefully removed. The Valsalva or Credée maneuvers may be performed at this time for complete bladder emptying. Urine can be drained into a clean container or directly into the toilet. The catheter caliber can vary between 4 and 14 Fr, and must be chosen based on the patient’s characteristics. Both sterile disposable and reused catheters can be used; the latter must be washed, dried and stored in a clean location after every use. The procedure can be performed with the patient sitting, lying down or standing. The use of a mirror can make it easier for women to see the urethral meatus. Catheterization frequency depends on bladder capacity, hydric intake, post-urination residue, bladder compliance, and detrusor pressure, but it is generally recommended that it be performed every four or six hours (SBU, 2008).

Intermittent catheterization can be classified into one of three categories: self-catheterization when the procedure is performed by the patient; intermittent catheterization when a caregiver or relative is responsible for the technique; or intermittent catheterization performed by health professionals, namely doctors or nurses (Advide, 2003). Self-catheterization should be preferentially encouraged. Children aged five years or older can learn this technique, unless psychomotor deficits interfere; however, they require supervision for dependability purposes (Christopher & Gans, 2002).

Asymptomatic bacteriuria is frequent in patients who perform intermittent catheterization. Urine culture is indicated only if there is clinical suspicion of urinary infection through signs and symptoms, such as fever, abdominal discomfort, and increased urinary leakage. There is no evidence of benefits resulting from performing this exam periodically. In general, asymptomatic bacteriuria should not be treated with antimicrobials, unless the patient may have to undergo any surgical or endoscopic procedures (SBU, 2008).

It is known that people who present urinary incontinence are at greater risk for reduced self-esteem and social isolation, depriving themselves of participation in social activities out of fear of suffering urinary leakage (“accidents”) (J. Costa et al., 2009). Hydric balance, quantity of residual urine, follow-up with professionals, and intermittent catheterization procedure and frequency are aspects that should be discussed with neurogenic bladder patients and their families or caregivers, with the aim of promoting urinary continence (Cipriano et al., 2012).

The combination of anticholinergics and intermittent catheterization is common in cases of overactive bladder, since oxybutynin inhibits involuntary contractions of the detrusor, promoting relaxation of this muscle and decreasing intravesical pressure. In addition, promoting this relaxation also improves bladder compliance and, indirectly, urinary leakage (McMonnies, 2002).

Improvement of urinary continence and reduction in the number of urinary infections and costs related to the number of diapers used favor the acceptance of intermittent catheterization. The main difficulties that in practice lead patients to abandon this procedure or perform it inadequately include costs of the materials, patient resistance, and lack of time to perform the technique (J. Costa et al., 2009).

Intermittent catheterization represents a psychosocial act that requires time availability, space preparation and psychosocial control, so that the technique will be performed and accepted (G. Araújo, 2000). Adequate orientation and training, a minimally traumatic technique, and adherence to treatment are factors that contribute to the good evolution of these patients (SBU, 2008).

Surgical treatment

Bladder augmentation using tissue from the gastrointestinal tract is indicated if there is low bladder compliance and capacity; if it does not respond well, anticholinergics or intermittent catheterization are used (SBU, 2006).

In cases with external urethral sphincter deficiency, a surgical procedure that uses an artificial sphincter with the aim of increasing urethral resistance is indicated. In this context, a surgical technique with the aim of reconstructing the bladder neck in order to achieve continence is also used. Intermittent catheterization must be frequently performed for bladder emptying in this case (SBU, 2006).

Intermittent catheterization is usually performed via the urethra. However, if this route is unavailable, for instance, due to urethral stenosis, quadriplegic disability or unfeasibility, as is the case with obese girls who use a wheelchair, the procedure can be performed via a continent bladder-skin conduit; this is known as the Mitrofanoff procedure (Mitrofanoff, 1980).

2.7. REHABILITATION, AUTONOMY AND PARTICIPATION IN SPINA BIFIDA

Congenital malformations, such as spina bifida, are a chronic condition, since people with this condition need prolonged and continuing professional care (Gaiva et al., 2009). The World Health Organization (WHO) states that the term “chronic condition” describes health problems that persist over time and require some type of management. A partnership among patients, families, healthcare teams and people who support the community is important for the successful management of chronic conditions (OMS, 2003).

Developing children have not yet acquired certain skills before becoming disabled (Greve, 2007; Peres, 2007). With the clarity of specific parameters that can either enable or hinder the opportunity for singular interventions, appropriate strategies can be chosen for children only through careful interpretation of the results and long-term consequences of the condition in adulthood. Planning for the transition to adult age must begin as early as possible and be based on children’s development. In addition, subjects must be approached in a timely manner starting in childhood, continuing through all the developmental stages up to adulthood (Christopher & Gans, 2002).

The families of children with spina bifida must not only readapt their routines, but also learn how to manage intermittent catheterization, administer medications, and administer skin care, among other tasks. Besides this readaptation and new learning, the families also have to learn how to deal with difficulties in children's social life, emotional and physical burdens, and complications that often result in the need for permanent follow-up in health services (Gaiva et al., 2009). Given the multiplicity of the presentation of comorbidities associated with spina bifida, interdisciplinary care by a team that is capable of dealing with these various aspects is recommended (Sá et al., 2010).

The chronic condition of myelomeningocele may also cause reduction or even loss of autonomy and ability for self-care, and patients may become dependent on others. Hence, the establishment of a supportive relationship between patients and caregivers, caregiver understanding that people with deficiencies have individual needs, respect for limitations, and encouragement of strengths and autonomy are all inherent in the care process (Gaiva et al., 2009).

People with myelomeningocele have to deal with physical, cognitive, and social limitations throughout their lives. Independence, employment, and social acceptance are important factors in adulthood. In this context, educational programs with an emphasis on following children with spina bifida up to adulthood can significantly improve the quality of life of these people (Roach, Short & Saltzman, 2011).

A study developed with seven adolescents with spina bifida between 12 and 18 years old and their parents and caregivers found that the young adults related the concept of autonomy to that of independence, whereas for parents and caregivers, independence and autonomy were directly related to the degree of responsibility of their children for proposed activities. In this study, the achievement of autonomy was considered to be essential for self-esteem and motivation to perform tasks, whereas overprotective attitudes were considered to be a factor that hindered the acquisition of autonomy (Caseiro, Gonçalves & Malheiro, 2013).

In Brazilian culture, stigmas are established subtly, masked by family, school and social overprotection. Thus, people with spina bifida are discriminated against by means of limitations imposed on them that also limit their life experiences. To change this reality, the laws must be followed, which must be ensured by means of an intense campaign for information and behavioral change, making society sensitive to the issue and strengthening the self-esteem and civil rights of people with physical deficiencies (Soares et al., 2008).

2.8. USABILITY AND ACCESSIBILITY OF THE INTERNET REGARDING SPINA BIFIDA

The criteria fort usability and accessibility ensure that websites are easy to use and accessible to all users. Usability refers to the visual aspects of websites, for example, browsing, speed, and compatibility with other browsers. Accessibility refers to ease of access to websites for people with deficiencies (Brasil, 2010).

The main objectives of usability are ease of use, learning, and memorizing tasks, productivity in the execution of tasks, prevention of errors and user satisfaction. Some guidelines are suggested for meeting these objectives:

- Context and browsing: Users must find that the website identity, context and options are clearly available.
- Information load: This is the sum of interface elements (texts, links, icons, functionalities, colors, backgrounds, and menus). It is recommended that it be reduced to facilitate user links, icons, functionalities, colors, backgrounds

clearly Autonomy: Users must have autonomy during use of the website. Procedures and functions cannot be changed to meet page requirements.

- Errors: Information and clarification of failures and unavailability events expected on the website must be provided to users. Any errors made by users must have the possibility of being corrected.
- Design: Design and visual programming have an impact on website credibility and usability. The design must work in the service of information.
- Composition: Texts must be written considering the target public of the website, which must be diagrammed to facilitate the understanding of information.
- Consistency and familiarity: The provision of an interactive system is favored when the necessary procedures for executing a task are compatible with the psychological, cultural and technical characteristics of users (Brasil, 2010).

Accessibility of web tools refers to the proper conception, development and editing of websites favor equal access to their information and functionalities. Accessibility means users can easily move from one page to another within a virtual tool. Interaction among users is related to the ability to provide effective social interaction within a virtual forum (Achecker, 2013). Users of a virtual tool can present different skills and demands. Hence, in an attempt to ensure accessibility to all users, different tools are proposed for the assessment of accessibility and which confront the tools with guidelines with the aim of obtaining results that locate problems in the codes and specific errors of the virtual page (Amaral, 2014).

Computer use and access represent the promotion of autonomy and independence for people with deficiencies. This population may need technological resources to assist them during the task of using computers, be it through larger keys, adapted mouses or more sophisticated and specific software. Some limitations, such as those related to memory, problem-solving and comprehension, must be considered so that a virtual tool is accessible (Brasil, 2014).

The Internet creates a new form of interpersonal relationship and must be used as an element of inclusion, which requires that it be accessible and usable by people with deficiencies (digital accessibility in virtual environments) (S. Silva, 2012). It is an important component in social networks, overcoming geographical barriers and providing social support (Barnfather, Stewart, Magill-Evans, Ray & Letourneau, 2011). A study developed with people with spina bifida in the United States found that 92% of the sample used the Internet. The Internet was accessed from home (87%), school (59%), someone else’s house (28%), a public library (28%), or other locations (7%) (Betz, Smith, Macias & Bui, 2014).

Children with myelomeningocele have a higher probability of presenting intelligence below the average standards, attention deficit, and hyperactivity (Liptak, 2002). Hydrocephalus is known to be strongly associated with myelomeningocele and is related to cognitive alterations, and consequently, to learning disadvantages among this population (Lindquist, Carlsson, Persson, & Uvebran, 2005; Vachha & Adams, 2005).

A study developed with two Brazilian siblings with myelomeningocele found important alterations in their psycholinguistic skills, which affected their performance in reading, writing and arithmetic, and negatively impacted the learning process of both siblings (Lamônica, Ferreira, Prado & Crenitte, 2012).

The results of a Brazilian study with the aim of assessing the psycholinguistic and school skills of children with myelomeningocele reported difficulties that did not match the grade level and were related to both decoding of graphic symbols and understanding of the content read. This finding corroborates the complaints of parents about difficulties in the literacy and learning process presented by their children (Lamônica, Maximino, Silva, Yacubian-Fernandes & Crenitte, 2011).

A study developed in Canada with young adults with cerebral palsy and spina bifida, using an online environment, observed that typing speed, cognitive skills, and perception of need for additional support were factors that influenced the use of this virtual tool. In this study, adolescents stated that the interactions with people with the same deficiency favored the creation of interpersonal bonds and the exchange of information (Barnfather et al., 2011).

To be accessible on a website or in a virtual community, discussion forum, newspaper, magazine or self-help group, information must be provided on pages that are developed and adapted for the potential public, making access effective for all users (Brasil, 2014).

In the light of this, usability of and accessibility to the Internet are found to be important factors to be considered when a tool is built for people with spina bifida. Hence, it is necessary to consider possible limitations related to spina bifida and promotion of autonomy and independence in this population.

3. OBJECTIVES

3.1. GENERAL OBJECTIVE

To develop, validate, certify, and assess a virtual forum for Brazilian individuals with spina bifida and their families.

3.2. SPECIFIC OBJECTIVES

- Develop a virtual forum to support subjects with spina bifida and their families
- Validate the virtual forum with informatics and health experts
- Check forum accessibility by means of Web Accessibility Checker (AChecker)
- Certify health information from the forum according to the Ethical Code (HONcode) of the Health on the Net Foundation (HON)
- Create and validate an online questionnaire to assess the forum from the perspective of users
- Distribute information about the virtual forum among subjects with spina bifida and their families
- Assess the forum from the perspective of users by using the previously validated online questionnaire

4. METHODOLOGY

4.1. TYPE OF STUDY

This quantitative research is characterized by the use of statistical techniques for data collection and analysis (Baptista, 2007). It is cross-sectional, since it describes a situation at a certain time (Aragão, 2011); descriptive, because its main objective is to describe the characteristics of a certain population; and exploratory, as it provides a close and global perspective on a certain topic (Gil, 2008).

The challenge of this project was to create and assess a virtual forum, adjusted to the Brazilian reality, in which subjects with spina bifida and their families could find information and share experiences, aiming for rehabilitation and autonomy, empowerment and participation.

The study was developed with the collaboration of two institutions, one in Germany (Faculty of Rehabilitation Sciences, University of Dortmund) and the other in Brazil (Ribeirão Preto College of Nursing, University of São Paulo). However, the location of data collection was not determined, since the research was carried out in a virtual environment, and the Portuguese-speaking participants contributed from anywhere as long as they had Internet access.

The guidelines of the *Publication Manual of the American Psychological Association* (APA), 6th edition, were used for the presentation of tables, figures, and references. EndNote software was used to manage the bibliographic references.

4.2. PROCEDURES FOR THE DEVELOPMENT, VALIDATION, CERTIFICATION AND ASSESSMENT OF THE VIRTUAL FORUM

The methodology was divided into two phases. The first phase consisted mainly of the construction and validation of the virtual forum and the instrument used for assessment of the forum. In the second phase, the virtual forum was assessed from the perspective of users.

Phase 1

1. Bibliographic update and literature review.
2. Submission and approval of the research proposal by the Research Ethics Committee of the University of São Paulo at the Ribeirão Preto College of Nursing (EERP/USP) - Protocol: 18774213.9.0000.5393.
3. Selection of the team that developed and moderated the virtual forum.
4. Selection of national and international collaborators.
5. Development of the virtual forum.
6. Meetings with German collaborators.
7. Validation of the virtual forum by health and informatics experts.
8. Virtual forum accessibility check with Web Accessibility Checker.
9. Certification of the virtual forum with the Health on the Net Foundation (HON).
10. Creation, validation and pretest of an online questionnaire to assess the virtual forum from the perspective of its users.

Phase 2

1. Distribution of information about the virtual forum.
2. Implementation, update and maintenance of the virtual forum.

3. Assessment of the virtual forum from the perspective of its users using the previously validated online questionnaire.
4. Statistical data analysis.

PHASE 1: Construction and validation of the virtual forum and the instrument for assessing the forum from the perspective of users

4.2.1. BIBLIOGRAPHIC UPDATE AND LITERATURE REVIEW

The main databases used for the literature review developed in this study were PubMed (United States National Library of Medicine), LILACS (Latin American and Caribbean Center on Health Sciences Information) and SciELO (Scientific Electronic Library Online), of the VHL (Virtual Health Library). The descriptors used were Spina Bifida, Spinal Dysraphism, Myelomeningocele, Intermittent Catheterization, Rehabilitation, Health Education, Education Technology, Virtual Forum and Online Forum. In this line of research, the databases of the library of the Technical University of Dortmund (TU- Dortmund/Germany) and the Federal University of São Carlos (UFSCar/Brazil) were also searched.

4.2.2. ETHICAL ASPECTS

This research project was reviewed and approved by the Research Ethics Committee of the Ribeirão Preto College of Nursing (CEP-EERP/USP), under Protocol No. 18774213.9.0000.5395 and Opinion No. 447.980, on November 6, 2013 (Annex 1). The project complied with all ethical guidelines on research involving human subjects, as established by Resolution No. 196/96 of the National Health Council (Brasil, 1996).

Initially, the virtual forum was created and assessed by health informatics professionals, called “experts.” Before assessing this tool, the participants signed a Free and Informed Consent Form (Appedix 3). Since the data collection instruments were different for each group, two consent forms were created, one for health experts (Appendix 1) and another for informatics experts (Appendix 2). Later, a group of health experts participated in the validation of the online questionnaire and a pretest was applied to people who used the virtual forum. To participate in this stage, the health professionals agreed to sign a Free and Informed Consent Form (Appendix 3), as did the users of the virtual forum (Appendix 4), prior to data collection. A consent form (Appendix 5) was inserted at the beginning of the online data collection instrument, so that each user of the virtual forum could agree to participate before answering the questionnaire and assessing the tool.

It is noteworthy that to participate in the virtual forum, the users had to be 18 years of age or older. This condition is clearly stated in the document “Terms of Use” presented in the virtual forum.

4.2.3. SELECTION OF THE TEAM TO DEVELOP AND MODERATE THE VIRTUAL FORUM

The team was made up of two undergraduate students (nursing and biomedical informatics), one master’s student (fundamental nursing, University of São Paulo at the Ribeirão Preto College of Nursing – EERP-USP), one doctoral student (TU-Dortmund), one professor of the EERP and one professor of TU-Dortmund. In Brazil, the researchers also counted on the support of the Informatics Department of the Ribeirão Preto College of Nursing, which provided the necessary technical support for developing the virtual forum.

4.2.4. SELECTION OF NATIONAL AND INTERNATIONAL COLLABORATORS

The present study was developed with the collaboration of Brazilian and German institutions.

Project coordination was assigned to PhD Prof. Fabiana Faleiros, a professor at the Ribeirão Preto College of Nursing. The EERP-USP offers a nursing undergraduate course that is recognized by the State Education Council and has received the highest rank (5 stars) in the Student's Guide since its inclusion. The EERP has four graduate nursing programs: fundamental nursing, psychiatric nursing, public health nursing and professional master's in nursing technology and innovation, besides offering the opportunity for a postdoctoral program. The EERP is responsible for editing the *Latin American Journal of Nursing* and publishing the *Electronic Journal of Mental Health, Alcohol and Drugs*. It is also a World Health Organization collaborating center due to its activity in teaching, research, and university extension. In 2002 it became the first chapter of the Sigma Theta Tau International Honor Society of Nursing in Brazil (USP, 2014).

PhD Prof. Christoph Käppler was assigned the coordination of the activities developed in Germany. He is a full professor at the TU-Dortmund, located in Dortmund (Germany) in the Ruhr region. It is highly rated in terms of research performance, offering 65 possibilities for undergraduate courses. The Faculty of Rehabilitation Sciences of Dortmund is one of the largest research and teaching centers for qualification in special education and rehabilitation in Europe (Faleiros-Castro, 2012; TU-Dortmund, 2014).

In Brazil, the researchers also collaborated with PhD Prof. Evandro Eduardo Seron Ruiz (biomedical informatics at USP - Ribeirão Preto, with experience in analysis of virtual social networks) and PhD Fernanda dos Santos N. Góes (EERP-USP, with experience in teaching in virtual environments). The Informatics Department of the EERP-USP provided the necessary technical support for developing the virtual forum.

The development of this study had the support of the German virtual forum Sternchen-Forum (http://sternchenforum.de/) and the German Spina Bifida and Hydrocephalus Association.

The Sternchen-Forum, founded in 2004 in Germany, is an independent and private virtual forum to provide mutual support for patients with spina bifida or hydrocephalus, or both, and their families. The team of moderators for the forum is made up of professionals and trained users who supervise the content of discussions. The themes to be discussed are proposed by the users, according to their individual difficulties and experiences. Users participate in the forum for free; however, subscription with a photo is needed, and their involvement is also expected in financial issues on the forum. Publications are only accessible to registered users. Disclosure of professionals' names is not allowed during discussions, and members must take responsibility for their own publications. An emergency telephone number is available for families, especially pregnant women who have recently learned that they are pregnant with a child with spina bifida or hydrocephalus, offering the possibility of receiving support from people who have already faced a similar situation (Faleiros-Castro, 2012; Sternchen-Forum, 2014).

The Spina Bifida and Hydrocephalus Association, founded in 1966 in Germany, is a national organization for mutual support, whose objectives are to inform, guide, and foster cooperation among people with spina bifida or hydrocephalus, or both, and their families. The association is headquartered in the city of Dortmund and has the support of approximately 75 regional associations and groups made up of subjects with spina bifida or hydrocephalus, or both, their families, and volunteers. It has around 1,300 members all over Germany (ASBH, 2014; Faleiros-Castro, 2012).

4.2.5. DEVELOPMENT OF THE VIRTUAL FORUM

The development of the Brazilian virtual forum was based on the idea and format of the Sternchen-Forum (www.sternschenforum.de). It is noteworthy that a Brazilian version was developed, rather than a version identical to the German forum, based on the experience of Brazilian and German researchers and a study developed by Faleiros-Castro (2012).

For the construction of the virtual forum, the researchers used the model proposed by Bernardo (1996) and cited by Góes (2010), which presents four steps for software development: scope definition, planning, production, and implementation, as illustrated in Figure 3.

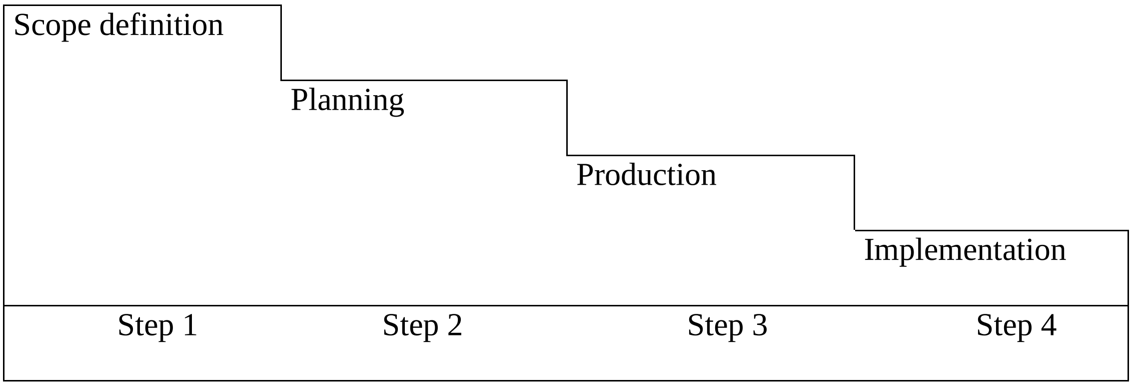


Figure 3. Scheme of the methodology used for developing the virtual forum (Goes, 2010)

The activities in each step are as follows.

The first step (scope definition) involved research and brainstorming, definition of the content and scope, user characterization, analysis of resource availability (hardware and software), interface development, gathering of media resources, creation of the project folder, and approval of the step.

The second step (planning) included content organization, construction of presentation flowcharts, interface design, chronological planning, verification of financial support and necessary or additional computational resources, prototyping, and approval of the step.

The development of the third step (production) required gathering of drafts, creation of a database, authorship and programming (scripting), analysis of errors in the programming, and approval of the step.

The fourth and last step (implementation) consisted of critical analysis of the application, analysis of the authorship and editing tools, test of acceptance by users, final review of the project, implementation, post-implementation review, and distribution.

Step 1. Scope definition

A literature search was carried out on the theme and in virtual forums like the Sternchen-Forum, to guide the definition of the project scope and content, with the aim of reviewing, updating, and reorienting the material to allow definitive elaboration.

The theme of spina bifida includes a multiplicity of potential subthemes to be worked into a virtual forum, such as prevention, treatment, urological alterations, intestinal alterations, difficulty of locomotion, deformities, pressure ulcers, sexuality, rehabilitation, accessibility, and legislation. Given the broad diversity of subjects, the initial focus for this project was to approach neurogenic bladder and intermittent urinary catheterization, with the clear aim of continuing the project and developing further work with other subjects of interest for the users of this tool.

For outlining the theoretical content to be included in the virtual forum, the researchers carried out literature searches on the themes spina bifida, neurogenic bladder, and intermittent catheterization. They also reviewed contributions based on the professional experiences of the team in charge of developing this project and subjects discussed in the virtual environments visited, which resulted in the following topics: what spina bifida/myelomeningocele is; what neurogenic bladder is; intermittent catheterization; and urinary infection.

As for characterization of the users, the focus on working with patients with spina bifida and their families was defined and determined during the realization of this project.

Regarding the virtual tool, the software phpBB (Hypertext Preprocessor Bulletin Board) was used, as it is also used by the Sternchen-Forum. It allows for the creation of environments where people can contact each other, be it through small groups or a large variety of virtual communities. The administration panel of the phpBB allows users to customize even the most complex characteristics without the need to edit the code directly. It has an extensive database and packages for style and images to customize the interface, which makes it simpler for users to change or add resources. The phpBB is open under the GNU GPL (General Public License) and accepts alterations in code without the need for permission from the phpBB Group, besides being completely free (phpBB, 2014).

After finishing the content to be developed, defining the potential users and determining the virtual tool, the team responsible for this project reassessed and approved this set of actions.

Step 2. Planning

In this step, the functionality of the chosen virtual tool and the most appropriate formatting for organizing the theoretical content were studied.

With the aim of offering the best possible dynamics between theoretical content and users, the content was adjusted so that it was both compatible with the tool and instructive to users. Hence, a presentation flowchart and a draft of the interface were designed.

Since the researchers used a tool that had been previously created and already used in other virtual forums, prototyping was performed by pre-analyzing the interface presentation and defining practical aspects, as described below, regarding the functionality of the virtual forum.

Users of the virtual forum will be subjects with spina bifida or their families, or both, who accept the terms of agreement and sign up for the forum. Certain information will be required: login, password, e-mail and verification code. Registered members can have three levels of permission: users, moderators, and administrators. Members with user status will be able post messages in open threads for discussion and answer, regardless of who posted them. Members with moderator status will be able to edit and delete posted threads if they are considered inappropriate, and send alerts to users through messages. The activities of members with administrator status will include administering and configuring the forum, creating new content, granting permission to send mass e-mails, and blocking, suspending, or banning members.

Students from the University of São Paulo in Ribeirão Preto, Brazil and the Technical University of Dortmund in Germany were trained to act as moderators, together with the project team, in the discussions that took place in the virtual forum and updating the tool.

Once the planning step was analyzed and approved by the project team, the production step was initiated.

Step 3. Production

The first version of the virtual forum was created by means of media processing through specific programs, such as MS Word and Paint Shop.

In this step, a database and a script for filing all the content worked on during the steps for scope definition, planning and production were developed.

After programming, a search for programming errors was conducted so as to ensure the proper operation of the virtual forum.

Messages sent by fictitious users were simulated, aiming at promoting discussions and exchange of experiences on the theme. These messages were displayed by date, in decreasing order, and the threads were arranged by the date of the last post. In addition, the forum provided photos, videos, and texts of interest to the target public.

In order to approve this step, the simulations with fictitious users were assessed and the virtual tool was systematically tested by the members of the project team.

Step 4. Implementation

The implementation step included critical analysis of the tool, editing by the project team, development of the first functional tests, and meetings carried out with the German collaborators, who contributed valuable suggestions for the practical functionality of the Brazilian forum.

Assessment of the virtual forum from the perspective of users, post-implementation review, and distribution will be carried out in the second phase of the project.

4.2.6. MEETINGS WITH GERMAN COLLABORATORS

During the process of development of the virtual forum, meetings were carried out between the project developing team and the German collaborators with the aim of collecting suggestions and contributions to improve the tool. Meetings occurred as follows: Three meetings in Dortmund, Germany (April, October and November 2014); one in Weide, Germany; three at the Ribeirão Preto College of Nursing in Brazil (May, August and September 2014); and weekly virtual meetings between the Brazilian and German teams.

4.2.7. VALIDATION OF THE VIRTUAL FORUM BY HEALTH AN INFORMATICS EXPERTS

Aiming at improving the quality and validating the content of the virtual forum, the tool was submitted to analysis by experts in the health and informatics areas.

4.2.7.1. EXPERTS WHO PARTICIPATED IN VALIDATION OF THE VIRTUAL FORUM

Health experts were asked to perform a general assessment of the virtual tool and its theoretical content. Informatics experts were asked to provide a general assessment and look at the interface ergonomics. Analysis of the theoretical content and interface by qualified experts is believed to favor a more perceptive assessment of better quality.

Initially, the sample of experts who participated in the validation process was determined following the criteria established by Rubio et al. (2003). These authors suggested between 3 and 10 experts for each group, which generates a sample of 6 to 20 experts (Rubio, Weger-Berg, Tebb, Lee & Rauch, 2003).

The only inclusion criteria completion of an undergraduate degree in health or informatics. The search for experts with experience in rehabilitation, software/system/website development and distance education was the rule during preselection; however, it was not considered a criterion for sample inclusion.

One exclusion criterion was failure to finish filling in the questionnaires, since these were considered incomplete assessment instruments. Those who did not agree to participate or did not sign a Free and Informed Consent Form were also excluded.

4.2.7.2. DATA COLLECTION INSTRUMENTS FOR THE VALIDATION OF THE VIRTUAL FORUM

The following data were requested to characterize the sample for health (Appendix 6) and informatics (Appendix 7) experts: gender, age, academic degree, area of professional activity, participation in scientific events in the last two years, and experience in rehabilitation or development of software, systems or websites, or in distance education.

The data collection instruments for assessment of the general impression of the forum (Appendix 8), content assessment (Appendix 9), and assessment of the interface ergonomics (Appendix 10) were created based on an adaptation of the instruments used by a collaborator in this project, Ph.D. Prof. Fernanda Góes, in her doctoral thesis (Goes, 2010). It is noteworthy that the author provided prior consent to the adaptation of these instruments, and reviewed and approved them once they were finished.

4.2.7.3. DATA ANALYSIS FOR THE VALIDATION OF THE VIRTUAL FORUM

For descriptive quantitative analysis, the data collected were organized and entered in Microsoft Excel 2010 and in databases for the statistical software SPSS (Statistical Package for the Social Sciences), version 19.0.

Content validity is determined by the analysis of the extent to which the items selected to measure a theoretical construction represent all the important aspects of the measured concept (Pilatti et al., 2010). Rubio et al. (2003) define content validity as a measure that represents the domain of interest and extension of each item within that which it is proposed to investigate. Data analysis and validation of the virtual forum were carried out using the content validity index (CVI), which has been used and studied by health researchers (Alexandre & Coluci, 2011; McGilton, 2003; Polit & Beck, 2006; Wynd & Schaefer, 2002). The decision to use the CVI to analyze data in this study was made after an analysis and instructions provided by a statistics professional.

A Likert scale with a score between one and four was used (Alexandre & Coluci, 2011). In this study, the score was established as: 1= strongly disagree, 2= disagree, 3= agree, and 4= strongly agree.

The content validity index was calculated as follows: For each criterion, the number of answers 3 or 4 was summed and this value was divided by the total number of answers, as suggested by Berk (1990) and cited by Alexandre and Colucci (2011). A minimum CVI of 0.80 (80% agreement) was set as desirable, since it represents a high index of agreement among the experts (Martins et al., 2012; Vituri & Matsuda, 2009). All criteria that obtained CVI below 0.80 were reviewed.

In addition to the statistical analysis performed by means of the CVI, each observation, suggestion or critique described by the experts was evaluated, regardless of the CVI achieved by the criterion assessed.

4.2.8. VIRTUAL FORUM ACCESSIBILITY CHECK WITH WEB ACCESSIBILITY CHECKER (ACHECKER)

The accessibility of the virtual forum was checked using Web Accessibility Checker (AChecker), by scanning the source code, page by page, and verifying real and potential problems. This tool uses standard norms detailed by the World Wide Web Consortium, which is the main international organization for regulation of the World Wide Web (www) and helps developers evaluate the source code of their websites (AChecker, 2013).

In the analysis, the data were organized and analyzed with the aid of PHP programming language (Hypertext Preprocessor) and Microsoft Excel 2010.

4.2.9. CERTIFICATION OF THE VIRTUAL FORUM BY THE HEALTH ON THE NET FOUNDATION (HON)

In order to obtain the reliability certification seal, the virtual forum was submitted to analysis by the Health on the Net Foundation team (HON, 2013).

It was necessary to show compliance with all eight principles of HONcode certification: authority, complementarity, confidentiality, attribution, justifiability, transparency, financial disclosure, and advertising. In addition to these general principles, principles for privacy and messages were also abided with, as required by the HONcode Health 2.0, as this was a collaborative platform (virtual forum).

4.2.10. DATA COLLECTION INSTRUMENT USED IN THE SECOND PHASE

This phase involved the creation, validation, and pretest of an online questionnaire to assess the virtual forum form the perspective of users. This assessment constitutes an important stage for improving this tool and assessing the fulfillment of the objectives proposed at its creation. First, the questionnaire was developed and later submitted to an assessment by experts with experience in the rehabilitation of people with spina bifida, aiming at validating its content. After these stages, a pretest was applied to users of the virtual forum.

First step: elaboration of the online questionnaire

Initially, a literature search was performed in the databases of the Virtual Health Library (VHL) and the United States National Library of Medicine (PubMed) for articles that addressed the use of health virtual forums. However, no studies were found on the use of virtual forums as a tool for teaching and mutual support for people with spina bifida and their families. Therefore, a new questionnaire was developed by a team of health professionals: two nurses with experience in rehabilitation and one nursing undergraduate student. After design, the questionnaire was transferred to an online version on the Survey Monkey platform.

The questionnaire was divided into two parts: The first aimed at characterizing the sample, and the second at assessing the virtual forum.

The sample was characterized using a questionnaire that was previously designed and validated by a team of one psychologist, two nurses and two pediatricians, all with experience in rehabilitation of patients with spina bifida (Faleiros-Castro, 2012).

The construction of the questions for the assessment of the virtual forum from the perspective of users was based on previous studies (Chorbev et al., 2011; Faleiros-Castro, 2012; Vasconcelos, Góes, Fonseca, Ribeiro & Scochi, 2013) and on suggestions of the Survey Monkey platform. A Likert scale was used in some of the questions to verify whether the subject agreed, was in doubt or disagreed with the items. Other questions did not allow the application of this type of scale; however, the multiple-choice standard was maintained.

Second step: validation of the online questionnaire

An instrument must present reliability and validity before being used to measure a variable. One of ways to validate a data collection instrument is submitting it to the opinion of experts, taking those opinions into consideration for each item evaluated (Alexandre & Coluci, 2011). Hence, the online questionnaire to assess the virtual health forum was submitted to the evaluation of experts in the health area.

In order to characterize the sample of experts who participated in the process of validation of the online questionnaire, the following data were requested: gender, age, academic degree, area and length of professional practice, experience in rehabilitation and participation in scientific events in the last two years (Appendix 11). A sample size of between 3 and 10 experts was determined (Rubio et al., 2003).

To validate the online questionnaire, the experts evaluated all questions for clarity, comprehension, language, and relevance. The scores for the questions were: 0 = inadequate; 1 = adequate with many alterations; 2 = adequate with a few alterations; and 3 = adequate with no alterations. Each question provided a space for comments and suggestions.

The experts were sent an e-mail inviting them participate in the study, which included the Free and Informed Consent Form, a direct link to the online questionnaire, and a script for evaluating it, with instructions for completion (Appendix 12). Once the questionnaire was completed, the experts were instructed to return it by e-mail, along with the signed FICF.

For descriptive quantitative analysis, data were organized and entered in Microsoft Excel 2010 and databases of the statistical software SPSS, version 19.0.

The content validity index (CVI) was used; it is determined through the proportion of opinions on the evaluated items (Pilatti et al., 2010). The percentages of the responses “adequate with no alterations” and “adequate with a few alterations” on each item for clarity, comprehension, language, and relevance were totaled to calculate the CVI. The total sum was divided by the total number of answers, as instructed by Berk (1990) and cited by Alexandre and Coluci (2011). A minimum CVI of 0.80 (80% of agreement) was adopted as desirable, as it represents a high index of agreement among the experts (Martins et al., 2012; Vituri & Matsuda, 2009). The questions that did not reach the minimum CVI were reviewed. In addition to statistical analysis by means of the CVI, each observation, suggestion or critique presented by the experts was evaluated, regardless of the CVI reached by the item.

Third step: pretest with users of the virtual forum

The researchers included laypeople in the development of the pretest as representatives of the study population. The pretest was aimed at verifying the understanding of the instrument by the target population, by asking them about their understanding of the questions and encouraging them to report any doubts related to the questionnaire (Nakano, 2007). The inclusion of these people was also aimed at ensuring the correction of unclear statements and terms, improving the quality of the instrument (Alexandre & Coluci, 2011).

The sample of laypeople was selected by means of forum; a sample size of between 3 and 10 participants was preestablished (Rubio et al., 2003).

Each participant received an e-mail with the invitation to participate in the study, the Free and Informed Consent Form, a direct link with to the online questionnaire provided by Survey Monkey, and a script for assessment of the questionnaire (Appendix 14). The following data were requested to characterize the sample of laypeople: gender, age, education level, and relationship to the person with myelomeningocele (Appendix 13). The pretest was the instrument used, and it was made up of multiple-choice questions regarding clarity, comprehension, language used, relevance of the questions presented in the online questionnaire, and the how difficult they were to answer. The participants were also questioned regarding their suitability for assessing the virtual forum. After completion of the questionnaire, the participants were instructed to return them by e-mail along with the signed Free and Informed Consent Form (Appendix 4).

In the descriptive quantitative analysis, the data were organized and entered in Microsoft Excel 2010 and in an SPSS database, version 19.0.

Phase 2: Assessment of the virtual forum from the perspective of users

4.2.11. DISTRIBUTION OF INFORMATION ABOUT THE VIRTUAL FORUM

The distribution of information about the virtual forum was initiated five months prior to data collection, that is, before the assessment of the virtual tool by users through the online questionnaire.

Information on the forum was broadly distributed in the virtual environment, such as on websites of spina bifida associations, virtual communities and non-governmental organizations (NGOs). A Facebook page was created, in which posts about texts and contents available in the forum were published. Another means of information distribution was WhatsApp groups formed by people with spina bifida and their families. A video with information and tutorials on forum operation was developed and distributed in the virtual environment.

In addition to the virtual environment, informational brochures were distributed in rehabilitation centers.

4.2.12. IMPLEMENTATION, UPDATE AND MAINTENANCE OF THE VIRTUAL FORUM

During this step, the aforementioned strategies for information distribution were continued, with the aim of gathering users for the virtual forum and participants for the research. Concomitant with the process of distributing information, content updates were made, including publication of new texts, creation of discussion threads, and maintenance of the forum. The content published in the forum was reviewed on a daily basis by trained moderators so as to ensure the quality and suitability of the information.

4.2.13. ASSESSMENT OF THE VIRTUAL FORUM FROM THE PERSPECTIVE OF USERS OF THE ONLINE QUESTIONNAIRE

After the virtual forum was promoted, people with myelomeningocele and their family members used this tool for five months. In the sequence, the online questionnaire that was created and validated in the first phase of this study was made available on Survey Monkey to all users of the virtual forum. Messages providing the direct link to the online questionnaire were sent to the users' personal e-mail, Facebook and WhatsApp accounts, and by private messages in the MieloForum.

The sample consisted of users of the virtual forum. Convenience sampling was used, where subjects who have access to the research and who, somehow, represent a certain population are selected (Gil, 2008).

The inclusion criterion for the sample was being a user who participated in the virtual forum. All users who were registered in the forum received an invitation to participate in the study.

Exclusion criterion: Participants who did not fill in the entire online questionnaire were excluded, since these instruments were considered incomplete.

In order to characterize the sample of users who participated in the assessment of the virtual forum, the following data were requested: gender, age, education level, family income, and occupation. In addition to general data, specific information was also collected from people with myelomeningocele, such as the location of the myelomeningocele and information regarding the intermittent catheterization procedure. The questions in the second part of this questionnaire referred specifically to the assessment of the virtual forum, addressing language, appearance, usability, and interaction among users (Appendix 15).

4.2.13.1. STATISTICAL DATA ANALYSIS

For descriptive statistical analysis, the data collected for the assessment of the virtual forum from the perspective of users were stored in Microsoft Excel 2010 and in SPSS statistical software, version 22.0.

Google Analytics and who's.amung.us were used to analyze the visits to the MieloForum.

Mean (M), median (Mdn), standard deviation (SD), and minimum and maximum values were used for descriptive statistical analysis of the numerical data. The mean and median values were exhibited with their respective standard deviation and interquartile range, the former as defined by Tukey's hinges. The median was considered, in relation to the mean value, for ordinal data and where the coefficient of variation (SD ÷ M) was greater than 0.5. The confidence interval of 95% was established, and a significance level (p-value) equal to or lower than 0.05 was chosen. Percentages and absolute frequencies were used for categorical data.

The following tests were used in the advanced statistical analysis: Pearson’s chi-square, Kruskal-Wallis H, Mann-Whitney U and Fisher’s exact.

Pearson’s chi-square test was used to verify the association between two nominal variables, as in the associations described below:

- Level of education” x “Person who assessed the MieloForum”
- “Current occupation” x “Person who assessed the MieloForum”
- “General assessment of the MieloForum” x “Person who assessed the MieloForum”
- “Education level” x “Reason for visiting the MieloForum”
- “Monthly family income” x “Reason for visiting the MieloForum”
- “Education level” x “What was it like to use the MieloForum?”
- “Person who assessed the MieloForum” x “What was it like to use the MieloForum?”
- “User’s origin” x “Means of access to the MieloForum”
- “Monthly family income” x “Means of access to the MieloForum”

The Kruskal-Wallis nonparametric H test was used to compare the means of several groups. This test was used in the statistical crossings that involved the age of the respondents of the online questionnaire with other questions. The Mann-Whitney U test is a particular case of the Kruskal-Wallis; it was used in the comparison of the mean age between the variables “by which means the MieloForum was accessed” and “the age of the respondent of the online questionnaire.”

Fisher’s exact test is an alternative to Pearson’s chi-square test for small samples. It was used in the association between the variables: “Type of urinary catheterization” x “Who answered the online questionnaire”; “Type of urinary catheterization” x “Person who assessed the MieloForum”; and “The person with spina bifida undergoes catheterization” x “The MieloForum helped in discussion or clarification of questions regarding urinary catheterization.”

4.3. STUDY FUNDING

In Germany, the study depended on the collaboration of the Catholic Academic Exchange Service (KAAD), which financed the doctoral scholarship of this study’s researcher.

In Brazil, the development team of the project depended on the support of the São Paulo Research Foundation (FAPESP).

5. RESULTS

For didactic purposes, the results were organized in two phases, following the same pattern used in the methodology. The first phase consisted of the construction and validation of the virtual forum and the instrument used for assessment of the forum. In the second phase, the virtual forum was assessed from the perspective of users.

PHASE 1: Construction and validation of the virtual forum and the instrument for assessing the forum from the perspective of users

During this phase, the MieloForum and the online questionnaire were created and validated for assessment of the forum from the perspective of users. Both tools can be accessed through their respective links:

http://mieloforum.eerp.usp.br/

https://pt.surveymonkey.com/s/mieloforum4

5.1. DEVELOPMENT OF THE VIRTUAL FORUM

The virtual forum, which is called the MieloForum, was developed in strict compliance with the aforementioned methodology, using a model that presents four stages of software development: scope definition, planning, production, and implementation.

5.2. VALIDATION OF THE VIRTUAL FORUM BY EXPERTS

After development, the MieloForum was submitted to analysis by health and informatics experts, aiming at its validation.

A total of 37 health experts were invited to participate in the study, of whom 17 accepted. Sample characterization is described in Table 4.

Table 4

Characteristics of the health experts who participated in the MieloForum validation (n=17)

Characteristics	n	Mean (SD)
Age	17	38 (7.521)
Years of professional activity	17	8 (6.550)
Length of activity in rehabilitation (years)	13	8 (5.747)

	Categories	Frequency (%)
Gender	Female	15 (88.24)
	Male	2 (11.76)
Total		17 (100.00)
Experience in rehabilitation	Yes	13 (76.70)
	No	4 (23.53)
Total		17 (100.00)
Participation in scientific events in the last two years	Yes	14 (82.35)
	No	3 (17.65)
Total		17 (100.00)

Academic degree	Undergraduate	3 (17.65)
	Specialization	2 (11.76)
	Master	8 (47.06)
	Doctorate	2 (11.76)
	Post doctorate	2 (11.76)
Total		17 (100.00)
Professional area	Nursing	14 (82.35)
	Physical Therapy	1 (5.88)
	Psychology	2 (11.76)
Total		17 (100.00)
Current area of professional practice	Rehabilitation	9 (52.94)
	Higher education teaching	4 (23.53)
	Doctoral student	1 (5.88)
	Fundamental/pediatric nursing	1 (5.88)
	Intensive therapy unit	1 (5.88)
	Epidemiological surveillance	1 (5.88)
Total		17 (100.00)

A total of 22 informatics experts were invited to participate in the study, and 11 agreed. The characteristics of this sample are described in Table 5.

Table 5

Characteristics of the informatics experts who participated in the validation of the MieloForum (n=11)

Characteristics	n	Mean (SD)
Age	11	38.273 (8.833)
Years of professional activity	11	10.727 (6.101)
Length of activity in software/systems/website (years)	8	10.375 (5.630)
Characteristics	Categories	Frequency (%)
Gender	Female	1 (9.09)
	Male	10 (90.91)
Total		11 (100.00)
Experience in development of software/systems/websites	No	3 (27.27)
	Yes	8 (72.73)
Total		11 (100.00)
Participation in scientific events in the last two years	No	4 (36.36)
	Yes	7 (63.64)
Total		11 (100.00)
Academic degree	Doctorate	3 (27.27)
	Specialization	3 (27.27)
	Undergraduate	5 (45.45)
Total		11 (100.00)

Professional area	Systems analysis	2 (18.18)
	Computer sciences	4 (36.36)
	Computer graphics	1 (9.09)
	Social communication	1 (9.09)
	Physics applied to medicine and biology	1 (9.09)
	Information technology	1 (9.09)
	Technical - Data analysis	1 (9.09)
Total		11 (100.00)
Current area of professional practice	Support analyst	1 (9.09)
	Social communication	1 (9.09)
	Development and maintenance of web applications	1 (9.09)
	Distance education	1 (9.09)
	Information systems	2 (18.18)
	Research/management – Informatics systems	1 (9.09)
	Informatics technician	4 (36.36)
Total		11 (100.00)

Assessment of the general impression of the MieloForum by health and informatics experts

To assess the general impression of the MieloForum, both informatics and health experts participated and analyzed the criteria described in Table 6. The total number of assessments was 28 (11 informatics experts and 17 health experts). Table 6 presents the content validity index and the respective percentage of agreement for each criterion.

Table 6

Content validity index figures for the assessment of the general impression of the MieloForum by informatics and health experts

Criteria	Content validity index	Agreement (in %) among the experts
1. The interface favors user participation in the forum.	**0.79**	**78.6**
2. Content presentation favors user participation in the forum.	0.85	85.2
3. The figures and photos help in understanding the Forum theme.	**0.78**	**77.7**
4. The forum is also shown to be an educational tool.	0.88	8.4
5. The limitations of the forum do not overshadow its usefulness as a tool for information and mutual support to users.	0.88	88.4
6. The name of the forum (MieloForum) is adequate.	0.92	92.2
7. I would recommend the forum to subjects with spina bifida and their families	0.96	96.4

Note: Figures in bold font did not reach minimum CVI of 0.80 (80% of agreement)

In the assessment of the general impression of the MieloForum, two criteria on the questionnaire did not reach the minimum content validity index: Criterion 1 (“The interface favors user participation in the forum”) and Criterion 3 (“The figures and photos help in understanding the Forum theme”), with CVI of 0.79 and 0.78, respectively.

Free access to reading the theoretical content of the MieloForum was provided to all visitors for the adjustment of Criterion 1 (“The interface favors user participation in the forum”) in agreement with the assessments of the experts, that is, registration was no longer mandatory for this activity. The color of the buttons to reply, mention or create a new thread was changed from grey to green, aiming to emphasize these functions. The main logo was redesigned and we removed the logo of the collaborating universities from the main page, based on the following observation from Expert 17H: *"... the logos could be removed from the front of the photos, it is information overload, it is cluttered..."*. The new version of the logo can be seen in Figure 4.

Figure 4. Presentation of the MieloForum logo after being redesigned according to experts' suggestions.

After analyzing the suggestions for Criterion 3 regarding the figures, it was observed that some experts said they were small and did not help in understanding the forum theme. In response, access to the figures and photos was changed and users were able to see the original enlarged images by clicking on them. In addition to modifications to improve visualization of photographs, an illustrative video regarding myelomeningocele was included.

At the end of the assessment of the general impression of the MieloForum, the 28 experts answered questions 8 and 9 on the data collection instrument: "Would you like to change anything in the forum?" and "Would you like to include anything in the forum?" The responses showed that 67.9% of the experts would like to change something and 50% would like to add something. Table 7 shows the observations of the experts in response to those questions and the resulting alterations performed on the MieloForum.

Table 7

Distribution of the observations of the informatics and health experts, according to the alterations performed in the MieloForum

Observations	Actions
The content must be reinforced with illustrations. (Expert 03I).	One illustrative video about spina bifida was included.
Better customization of the template... (Expert 04I).	We improved the customization of the template and worked to make the forum look more attractive.
"*Why do I automatically enter the forum?" I believe the doubt should refer to someone who asks "Why CAN'T I automatically enter the forum?"* (Expert 07I).	This contextual flaw was corrected, changing it from "*Why do I automatically enter the forum?*" to "*Why can't I automatically enter the forum?*"
I think the visual is cluttered, especially the site header, and I understand it can be improved, with a better logo and a cleaner and more interesting visual. (Expert 07I).	The MieloForum logo was redesigned.
The icons of the developers are twisted. (Expert 07I).	The photos of the project developers, present in the icon *"Who we are,"* were changed.
The link to Facebook in the upper menu could open a new browser tab" (Expert 08I)	Access to Facebook was changed. Instead of opening Facebook directly in the MieloForum page, it now gives access to a new window so the user does not have to leave the forum page to access it.
The links "Forum" in the upper menu	The "*Forum*" link was deleted. Only

and "MieloForum" in the intermediate menu lead to the same page" (Expert 08I)	"*MieloForum*" remains.
The links "X new messages" and "View your messages" could be combined into one..." (Expert 08I)	The links were combined into "View your messages."
The time on the website is incorrect. (Expert 08I)	The time on the MieloForum was configured according to the time zone of Brasília (DF/Brazil).
Unregistered users should have "reading" access to the threads. (Expert 09I)	Access for reading the theoretical content was provided to all visitors.
...letters are too close to one another, which affects reading. (Expert 10I)	The font of the content was changed to *"Verdana."*
Registration should be completed automatically, without the need for confirmation by an administrator or activation e-mail (Expert 10I)	It was decided to set up registration to be completed automatically, without the need for confirmation by an administrator or activation e-mail.
Any participation in the forum is non-mandatory. I suggest you change this sentence... (Expert 01H)	In the "*MieloForum Terms of Use*" the sentence "*Any participation in the forum is non-mandatory*" was corrected to "*Any participation in the forum is not mandatory*".
"*What is spina bifida?" There are some spacing errors in this part, and the use of specific terminology. I suggest using more simplified language, so laypeople can understand it.* (Expert 01H)	In the topic *"What is spina bifida /myelomeningocele?"* some spacing errors were corrected and specific terms were explained, such as cerebrospinal fluid (sterile fluid present in the brain and the spinal cord), cystic lesion (forming a "sac"), and epithelial fistula (connection).
In "*What is neurogenic bladder?" I would start talking about urinary*	The introductory paragraph of the topic "*What is neurogenic bladder?*" which

alterations... (Expert 01H)	approached spina bifida complications, was removed. The theoretical content now begins with the theme “*Urinary System*.”
I missed an explanation on the anatomy of the urinary tract, including an image including the organs involved in this system: the bladder, ureter, kidneys, and urethra. (Expert 12H)	An illustrative figure was included, showing the anatomy of the urinary system.
...at first I had some difficulty finding out how to participate in the forum. (Expert 13H)	Aiming at helping users find out how to participate in or start a discussion, “*MieloForum/Discussions*” was added to the main page as a title on the topic of access to participation in discussions in the MieloForum.
Bibliographic references take too much space. I would reduce the font size of the title and increase the font size of the content. (Expert 14H)	The font size of “*Bibliographic References*” was reduced and that of the theoretical text was increased.
The figure about bladder disorders in the neurogenic bladder topic is not very clear. I think it may hamper understanding. (Expert 08H)	The figure in “*Bladder Disorders*”, was reformatted.

Some observations could not be followed, due to limitations of the virtual tool or because the team decided so after discussing them, which will be explained in the discussion section. These are some of those observations:

- Replacing the name “*MieloForum*” with “*Spina Bifida Virtual Forum.*”
- Including qualified areas for institutions, professionals, researchers, and related organizations.
- Creating a link to make scientific content available.

- Including the possibility of sharing the MieloForum content.
- In the topic "*Intermittent catheterization,*" experts suggested the inclusion of chlorhexidine (2%) and topical povidone-iodine (10%) for genital hygiene in the text.
- Transferring the divisions of "*Learn more about spina bifida*" to the main page.
- Adding illustrative material to the topic "*Intermittent catheterization.*"
- Adding a space dedicated for reporting experiences.
- Remodeling the graphic project and making the interface more dynamic.
- Replacing the characters which are required for confirming registration.

Assessment of the theoretical content of the MieloForum by health experts

Only the health experts participated in the assessment of the theoretical content of the MieloForum. A total of 17 assessments were made, and Table 8 presents the CVI and percentages of agreement for each assessment.

Table 8

Assessment of the content of the virtual forum by health experts, using the content validity index

	Criteria	CVI	Agreement in % among the experts
1.	The objectives of the forum are clearly defined.	1.00	100.0
2.	The forum is consistent with the objectives proposed.	0.88	88.2
3.	Content is up-to-date.	0.94	94.1

4. The content presents logical organization.	1.00	100.0
5. Content is consistent with the target public.	0.82	82.3
6. Information is clear and concise.	0.82	82.3
7. Texts are easy to read.	0.87	86.6
8. The presentation of figures and photos is relevant to the information in the texts.	1.00	100.0
9. Grammar is properly used.	0.82	82.4
10. Terms are properly used.	1.00	100.0
11. The presentation of contents draws the attention of users.	1.00	100.0
12. The forum encourages user participation.	1.00	100.0
13. Interaction among users is effective.	1.00	100.0
14. The forum enables learning by means of the exchange of experiences among users.	1.00	100.0
15. The forum encourages mutual support.	1.00	100.0

In the assessment of the theoretical content of the MieloForum, all criteria of the questionnaire reached the minimum CVI of 0.80 (80% of agreement).

Similar to the process followed in the analysis of the general impression of the MieloForum, all critiques, suggestions, and comments made by the health experts were analyzed and the resultant changes were as follows:

- The order of presentation of the medications in the topic "*Neurogenic bladder treatment"* was changed.
- Theoretical texts were reviewed with the aim of making the language easier to understand.
- Theoretical texts were reviewed and standardized, and grammar and agreement mistakes were corrected.
- The use of water and neutral soap for performing clean intermittent catheterization was mentioned in the text.
- A paragraph regarding the caliber of the catheter for performing clean intermittent catheterization was added in the body of the theoretical text.
- The link in the topic "*Intermittent catheterization*" was directing users to a blank page; this error was solved.

Some observations regarding the content could not be followed, due to limitations of the virtual tool or because the team decided so after discussing them, which will be explained in the discussion section. These are the observations:

- "The figures could be colored, instead of black and white" (Expert 12S).
- Regarding the objectives of the MieloForum, Expert 12H mentioned "(...) I believe the presentation of the forum, where the objective is stated, should appear in the first page".
- Expert 11H stated "(...) the titles and subtitles could have a larger font… and fewer words (...)".
- "Something *cleaner and more dynamic should be worked out*." (Expert 17H).

Interface ergonomics assessment by informatics experts

Informatics experts participated in the interface ergonomics assessment of the MieloForum. A total of 11 assessments were made. Table 9 presents the content validity index and the respective percentage of agreement for each criterion.

Table 9

Interface ergonomics assessment of the virtual forum by informatics experts using the content validity index

	Criteria	CVI	Agreement (%) among the experts
1.	Menu pages have titles and headers.	0.80	80.0
2.	Menu panels are formed based on a logical criterion for grouping options.	0.91	90.9
3.	The names of the menu options are concise.	0.82	81.8
4.	The menu structure is designed so as to reduce the steps necessary for selecting an option.	0.91	90.9
5.	The use of abbreviations is minimized in the menus.	0.82	81.8
6.	Icons are legible.	**0.64**	**63.7**
7.	Icons are different from one another and always have the same meaning on different pages.	**0.73**	**72.7**
8.	Icons are economic as regards the space on the pages.	**0.55**	**54.6**
9.	The user always controls system browsing.	0.91	90.9
10.	The user can interrupt a dialogue and resume it at any time.	1.00	100.0

11. The user can move quickly from one part of the system to another.	**0.73**	**72.8**
12. Error messages are concise and objective.	1.00	100.0
13. Data to be read are presented continuously.	0.82	81.8
14. The forum adopts codes that are significant or familiar to users.	0.88	87.5
15. The usual meaning of colors is respected in the color codes defined.	0.86	85.7
16. The presentation of texts and style resources (italic, bold, underline or different fonts) is properly employed.	**0.64**	**63.7**
17. Visual codes are employed to associate different categories of data spread on the pages.	**0.78**	**77.8**
18. Items selected for alteration, update or activation are distinguished from others.	**0.73**	**72.8**
19. Any change in the current status of control objects is presented in a clear fashion to users.	**0.75**	**75.1**
20. 20. Controls and commands are visually differentiated from the information presented in the pages.	0.82	81.8
21. Pages present only information that is necessary and essential to users for their tasks.	0.91	90.9
22. The density of information on the windows/pages is reduced.	0.82	81.8

23. System design does not cause memory overload.	0.89	88.9
24. The presentation space is diagrammed into small functional zones.	0.90	90.0
25. The arrangement of the interaction objects of a dialogue box follows a logical order.	0.82	81.8
26. Links work properly.	1.00	100.0
27. System optimization is adequate to different bandwidths.	1.00	100.0
28. The system works properly in different browsers.	1.00	100.0

Note: Figures in bold font did not reach minimum CVI of 0.80 (80% agreement)

In the interface ergonomics assessment, as seen in Table 9, eight criteria on the questionnaire did not reach the minimum CVI.

Criteria 6, 7 and 8 refer to the icons. In order to respond to the observations *"I found the images of the icons were not very intuitive."*(Expert 11I) and *"The 'My Profile' and 'Members' icons are visually similar, but they lead to different contents, and so are the 'Sign in' and 'Sign out' icons* (...)" (Expert 09I), the image of the "*Members*" icon was replaced with a figure with multiple faces, and the lamp from the "*Sign in*" and "*Sign out*" icons was replaced with the image of a partially open door (Figure 5).

Figure 5. Illustration of the icons from the main page of the MieloForum

For Criterion 11, the following observation was offered: “*This layout, which looks like an old information system, does not help browsing.*” (Expert 05I). Some changes in the presentation of the MieloForum were made and the link “*How to use the MieloForum*” was created with explanatory content on the operation of the virtual tool (Figure 6).

TÓPICOS	RESPOSTAS	EXIBIÇÕES	ÚLTIMA MENSAGEM
☐ Vídeo- Tutorial de utilização do MieloFórum por **equipemielo** » Sáb Fev 21, 2015 04:44	0	34	por **equipemielo** Sáb Fev 21, 2015 04:44
☐ Como criar Tópicos no MieloFórum (Tutorial) por **equipemielo** » Seg Nov 24, 2014 04:23	0	85	por **equipemielo** Seg Nov 24, 2014 04:23
☐ Como participar das "Discussões" no MieloFórum (Tutorial) por **equipemielo** » Sex Out 17, 2014 01:11	0	79	por **equipemielo** Sex Out 17, 2014 01:11

Figure 6**.** Illustration of the topic “*How to use the MieloForum*”

Criterion 16 refers to the presentation of the texts and style resources, and elicited the comment, “*In different texts at ‘Learn more about spina bifida,’ the titles or topics of the texts are either underlined and blue or not underlined and green.*” (Expert 09I). Considering this observation, all theoretical texts for the MieloForum were reformatted and standardized.

As regards Criterion 17, Expert 10I mentioned, “*The codes are identical in all pages.*” And in the assessment of Item 19, which refers to the change in the current status of the control objects, the same expert stated, “*I didn’t obtain any information.*” No changes were proposed for these two criteria.

In the opinion of Expert 10I, “*For laypeople, access to the changes can be complicated,*” and in an attempt to improve Criterion 18, the items selected for changes, update or activation were distinguished from others, being given the color green instead of gray.

In addition to the criteria that did not reach the minimum the CVI established for this study, all critiques, suggestions and comments made by the informatics experts were analyzed.

The following changes were made based on the comments of the informatics experts:

- The color of error messages was changed to red, as per the suggestion of Expert 08I, *“Present the error message in red, if possible, like an alert.”*
- Expert 11I found an error on the *“Members”* page, when clicking on a letter in the option *“Search for a user.”* This error was corrected.
- There was a link that did not work properly during the assessment by Expert 1I; the link was in the topic *“Urinary infection and intermittent catheterization,”* and it directed the user to a blank page. The error was corrected.

Some observations could not be followed, due to limitations of the virtual tool or because the team so decided after discussing them, which will be explained in the discussion section. These observations are listed below:

- Expert 10I commented, *“Submenus inside the options demand more clicks, delaying content reading.”*
- Expert 08I mentioned, *“On any page (except the link to the home page), you always have to roll down to see the content (below the main menu), and using screens with lower resolution (in notebooks, for instance) facilitates visualization by users, who are browsing for posts and replies. Another alternative would be to slightly reduce the height of the upper menu,”* Along the same line of thought, Expert 10I suggested, *“Information should appear on the screen without the aid of the mouse scroll.”*

5.3. VIRTUAL FORUM ACCESSIBILITY CHECK WITH WEB ACCESSIBILITY CHECKER (ACHECKER)

After accessibility analysis using Web Accessibility Checker, a report was issued with the identification of real and potential problems found. A total of 28 problems were found in the code of the MieloForum, which are listed in Table 10. These data were organized and analyzed with the aid of PHP programming language and Microsoft Excel software.

Table 10

Distribution of the MieloForum pages according to the number of problems identified in the AChecker analysis

	Number and name of the page	Number of problems found
1.	Forum index	7
2.	Sign in	0
3.	Registration	0
4.	Frequently asked questions	5
5.	Welcome to the “MieloForum”	0
6.	MieloForum/Discussions	0
7.	Information about the MieloForum	8
8.	Terms of use of the MieloForum	0
9.	Who we are	0
10.	Contact	0
11.	Learn more about spina bifida/myelomeningocele	8
12.	What is Spina Bifida?	0
13.	What is Neurogenic Bladder?	0
14.	Intermittent catheterization	0
15.	Urinary infection and intermittent catheterization	0
Total	15 pages	28 problems found

The problems identified on each page are described as follows.

On Page 1, seven problems were found in the code of the MieloForum. The first six problems were related to the code ***<b>*** (bold in HTML). The seventh problem was related to the code *<h1>* (heading in HTML), claiming it was empty.

On Page 4, five problems were found in the code of the MieloForum. All five problems referred to the code *<i>* (italic in HTML).

Eight problems in the code of the MieloForum were found on Page 7. All eight problems were related to the code ***<b>*** (bold in HTML). Exactly the same number and type of problem were found on Page 11.

Pages 2, 3, 5, 6, 8, 9, 10, 12, 13, 14 and 15 did not present any problems in the AChecker analysis.

The AChecker analysis also pointed out a possible problem with the names of our objects in the Cascading Style Sheets (CSS – a style sheet language that is used to define the presentation of written documents in a markup language, such as HTML), claiming that the objects had irrelevant titles.

5.4. CERTIFICATION OF THE VIRTUAL FORUM WITH THE HEALTH ON THE NET FOUNDATION (HON)

The certification of the MieloForum by the Health on the Net Foundation (HON) was achieved after the forum was submitted to the Health on The Net Code, in the HON website, which initiated the process of obtaining the certification seal. The certification process is illustrated in Figure 7.

Figure 7. Illustration of the HON Certification Process. Adapted (HON, 2013)

The website was reviewed and assessed with regard to compliance with the eight principles of the HONcode, in addition to principles of privacy and messages. Modifications made to the website that were based on the suggestions from the HON assessment are described as follows. It is worth highlighting that all corrections suggested by the HON certifiers were made.

For the purpose of compliance with Principle 3 (confidentiality), a page containing the privacy policy for information collected on the website was created. This page was called “Terms of use of MieloForum,” and it provides information on the confidentiality policy and use of the forum.

Aiming at disclosing the funding sources for the MieloForum, regarding Principle 7 (financial disclosure), a page called “Partners” was created, in which the institutions that provided financial support for project development are mentioned.

Principle 8, regarding honesty in editorial policy and advertisement, was also addressed on the “Partners” page, which explains that the MieloForum currently has no form of advertisement, advertising links or banners.

In order to take the Health 2.0 principles into account, two items were added to the “Terms of use of the MieloForum,” providing clarification to users regarding privacy and messages.

5.5. ILLUSTRATIONS OF THE FINAL VERSION OF THE VIRTUAL FORUM

The main pages of the MieloForum are shown below. This is the version that was presented to users after making the changes suggested by the experts and the HONcode team.

Figure 8 shows the main page, which appears to users as soon they access the MieloForum. This page presents access tabs for “Who We Are,” “Facebook,” “Contact” (e-mail of the MieloForum team for contact with users), “Frequently Asked Questions,” “Partners” (organizations that are partners of the MieloForum), “HONcode Certification,” “Information about the MieloForum,” “Profile and Participation of Users,” a “List of All Users,” “Informational Texts about Spina Bifida,” and “Discussions about Various Topics.”

Índice do fórum

Bem-vindo: Seg Mai 11, 2015 05:43
[Painel de Controle do Moderador]

A sua última visita foi em Dom Mai 10, 2015 02:23

Ler mensagens sem resposta • Ver mensagens não lidas • Ver mensagens novas • Pesquisar por tópicos ativos

Assinalar todos os fóruns como lidos

FÓRUM	TÓPICOS	MENSAGENS	ÚLTIMA MENSAGEM
Bem-Vindo!	1	1	por equipemielo Sáb Jun 28, 2014 10:31
Informações sobre o MieloFórum	5	5	por equipemielo

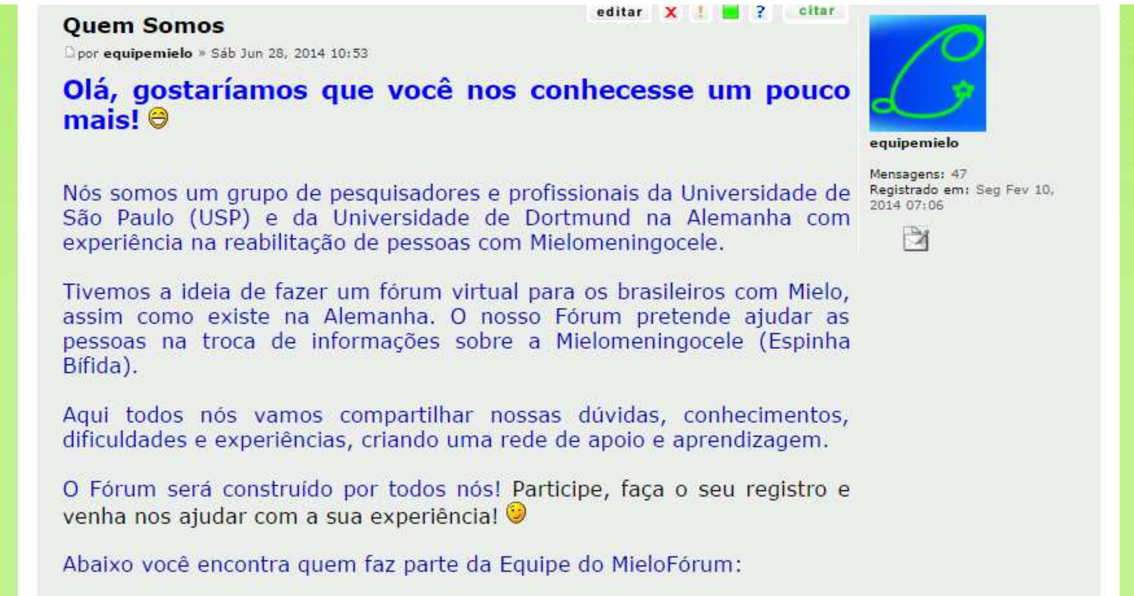
Figure 8. Illustration of the main page of the MieloForum (to be continued)

MIELOFÓRUM/DISCUSSÕES	TÓPICOS	MENSAGENS	ÚLTIMA MENSAGEM
Apresente-se para a comunidade	15	42	por equipemielo Qua Abr 08, 2015 04:17
Dúvidas sobre a técnica do cateterismo	1	6	por naira Qua Mar 18, 2015 07:52
Problemas para conseguir o material do cateterismo	1	5	por Simone Dos Santos Sáb Fev 28, 2015 01:57
Moda Inclusiva	1	4	por Joaolucas.costa Ter Mar 17, 2015 07:45
Esfincter urinário artificial	1	1	por equipemielo Sex Abr 10, 2015 03:53
Violência contra as pessoas com deficiência	1	1	por equipemielo Seg Abr 27, 2015 09:59

CURIOSIDADES/TEXTOS SOBRE MIELOMENINGOCELE	TÓPICOS	MENSAGENS	ÚLTIMA MENSAGEM
Ácido Fólico e prevenção da Mielo	1	2	por sat Sáb Mar 21, 2015 07:24
Reparo intraútero (cirurgia antes do nascimento)	1	7	por Laura G tavares Qui Mar 26, 2015 09:51

Figure 8. Illustration of the main page of the MieloForum

Figure 9 illustrates the tab “Who We Are.” This section discloses the objectives of the MieloForum and the members of the team, with their resumes, and the institutions involved in this project.



Quem Somos

por **equipemielo** » Sáb Jun 28, 2014 10:53

Olá, gostaríamos que você nos conhecesse um pouco mais!

Nós somos um grupo de pesquisadores e profissionais da Universidade de São Paulo (USP) e da Universidade de Dortmund na Alemanha com experiência na reabilitação de pessoas com Mielomeningocele.

Tivemos a ideia de fazer um fórum virtual para os brasileiros com Mielo, assim como existe na Alemanha. O nosso Fórum pretende ajudar as pessoas na troca de informações sobre a Mielomeningocele (Espinha Bífida).

Aqui todos nós vamos compartilhar nossas dúvidas, conhecimentos, dificuldades e experiências, criando uma rede de apoio e aprendizagem.

O Fórum será construído por todos nós! Participe, faça o seu registro e venha nos ajudar com a sua experiência!

Abaixo você encontra quem faz parte da Equipe do MieloFórum:

equipemielo

Mensagens: 47
Registrado em: Seg Fev 10, 2014 07:06

Figure 9. Illustration of the tab “Who We Are” (to be continued)

Fabiana Faleiros Santana Castro
Enfermeira, Professora Doutora da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP/USP);
Currículo Lattes

Karl Christoph de Oliveira Käppler
Psicólogo, Professor Doutor da Faculdade de Ciências da Reabilitação da Universidade de Dortmund (Alemanha);
Currículo Lattes

Figure 9. Illustration of the tab “Who We Are” (to be continued)

Naira Beatriz Favoretto
Enfermeira, doutoranda da Faculdade de Ciências da Reabilitação da Universidade de Dortmund (Alemanha)
Currículo Lattes

Figure 9. Illustration of the tab “Who We Are” (to be continued)

Alef Janguas da Costa
Graduando da Informática Biomédica da Universidade de São Paulo (USP);
Currículo Lattes

Figure 9. Illustration of the tab “Who We Are”

Figure 10 presents the information provided about the MieloForum, which includes the terms of use, HONcode certification seal, partners, who we are and contact information.

TÓPICOS	RESPOSTAS	EXIBIÇÕES	ÚLTIMA MENSAGEM
SELO DE CERTIFICAÇÃO DO HONcode por **equipemielo** » Sáb Mai 02, 2015 10:45	0	3	por **equipemielo** Sáb Mai 02, 2015 10:45
Parceiros por **equipemielo** » Qua Out 15, 2014 12:04	0	481	por **equipemielo** Qua Out 15, 2014 12:04
Termos de uso MieloFórum por **equipemielo** » Sáb Jun 28, 2014 11:00	0	209	por **equipemielo** Sáb Jun 28, 2014 11:00
Quem Somos por **equipemielo** » Sáb Jun 28, 2014 10:53	0	699	por **equipemielo** Sáb Jun 28, 2014 10:53
Contato por **equipemielo** » Sáb Jun 28, 2014 10:24	0	488	por **equipemielo** Sáb Jun 28, 2014 10:24

Figure 10. Illustration of the threads for access to information about the MieloForum

Figure 11 shows the HON certification seal and a brief description of the Health On the Net Foundation (HON).

SELO DE CERTIFICAÇÃO DO HONcode

HON @ CODE CERTIFIED 03/2015

equipemielo

Mensagens: 47
Registrado em: Seg Fev 10, 2014 07:06

O nosso trabalho para construir uma ferramenta virtual confiável e de qualidade foi reconhecido pela **Fundação Health On the Net (HON)**. Essa fundação avalia sites da área da saúde e certifica a qualidade e a transparência das informações.

Para a aquisição da certificação **HONcode** é necessário o cumprimento de **8 princípios**:

Autoridade, Complementariedade, Confiabilidade, Atribuição, Justificativas, Transparências, Divulgação Financeira e Publicidade.

A adesão ao selo de qualidade da HON é considerada como **"padrão-ouro"** por especialistas internacionais!!!

Equipe MieloFórum

Figure 11. Illustration of the HON certification seal

Figure 12 illustrates the first step of a tutorial about how the MieloForum operates. In addition to tutorials on how to create new threads and participate in discussions, there is also an instructional video in this section about the MieloForum and its operation.

MIELOFÓRUM/DISCUSSÕES	TÓPICOS	MENSAGENS	ÚLTIMA MENSAGEM
☐ Dúvidas sobre a técn do cateterismo	1	2	por **Monica** Seg Ago 25, 2014 08:02
☐ Dificuldade para realizar o cateterismo	1	2	por **José** Sex Ago 22, 2014 02:35
☐ Problemas para conseguir o material do cateterismo	1	3	por **José** Seg Ago 25, 2014 07:53

Figure 12. Illustration of the first step of the tutorial on how to participate in discussions in the MieloForum

Figure 13 shows the threads for access to the informational texts about spina bifida/myelomeningocele, namely: “What is spina bifida/myelomeningocele?” “What is neurogenic bladder?” “Intermittent catheterization and urinary infection.”

O que é Espinha Bífida/Mielomeningocele? por **equipemielo** » Ter Jul 22, 2014 10:47	0	1084	por **equipemielo** Ter Jul 22, 2014 10:47
O que é Bexiga Neurogênica? por **equipemielo** » Ter Jul 22, 2014 10:46	0	953	por **equipemielo** Ter Jul 22, 2014 10:46
Cateterismo Vesical Intermitente por **equipemielo** » Ter Jul 22, 2014 10:45	0	989	por **equipemielo** Ter Jul 22, 2014 10:45
Infecção urinária e cateterismo vesical intermitente por **equipemielo** » Qui Jun 26, 2014 05:44	0	697	por **equipemielo** Qui Jun 26, 2014 05:44

Figure 13. Illustration of the threads for access to the informational texts about spina bifida/myelomeningocele

Figure 14 illustrates an extract of one of the informational texts about spina bifida/ myelomeningocele available in the MieloForum. This text describes aspects such as the definition and classification of the malformation in question, in the form of both text and with figures.

ESPINHA BÍFIDA

A Espinha Bífida, também conhecida como Disrafismo Espinhal, é uma malformação congênita (presente ao nascimento), caracterizada por um fechamento incompleto do tubo neural (é o que dá origem a coluna vertebral).

Pode ser classificada como **Espinha Bífida Aberta** ou **Fechada**.

A **Espinha Bífida Aberta** pode ser dividida em:

- **Mielomeningocele (MMC)**: lesão da linha média contendo líquor (líquido estéril presente no cérebro e medula espinhal), meninges (camadas que protegem o sistema nervoso central) e elementos da medula. Tecido nervoso exposto (não coberto por pele).

- **Meningocele**: lesão cística (forma uma "bolsa" que é composta por líquor, meninges e pele).

- **Lipomielomeningocele**: massa de gordura, geralmente coberta por pele, que se estende para a medula.

Legenda de cores: **Vermelho:** Medula Espinhal; **Verde:** Meninges; **Cinza:** Estruturas Ósseas; **Preto:** Discos Vertebrais.

Legenda numérica: (1) Coluna normal; (2) Meningocele; (3) Mielomeningocele

equipemielo

Mensagens: 47

Registrado em: Seg Fev 10, 2014 07:06

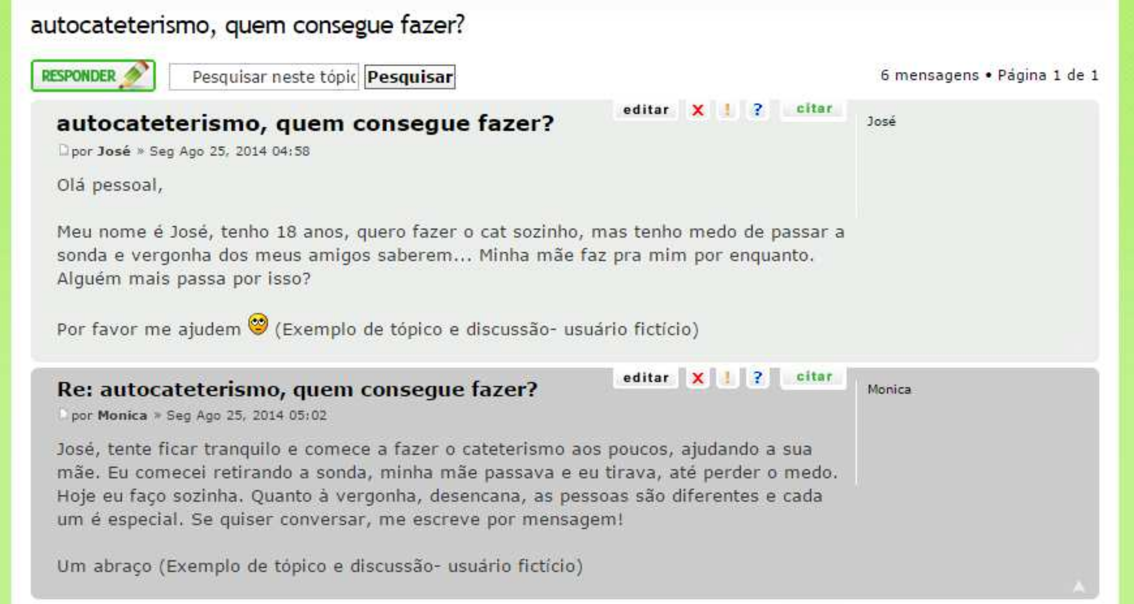
Figure 14. Illustration of the informational texts about spina bifida/myelomeningocele

Figure 15 shows some discussion threads that are open to users to report their experiences, ask questions, and participate in the discussion of a predetermined subject.

MIELOFÓRUM/DISCUSSÕES	TÓPICOS	MENSAGENS	ÚLTIMA MENSAGEM
☐ Apresente-se para a comunidade	15	42	por **equipemielo** Qua Abr 08, 2015 04:17
☐ Dúvidas sobre a técnica do cateterismo	1	6	por **naira** Qua Mar 18, 2015 07:52
☐ Problemas para conseguir o material do cateterismo	1	5	por **Simone Dos Santos** Sáb Fev 28, 2015 01:57
☐ Moda Inclusiva	1	4	por **Joaolucas.costa** Ter Mar 17, 2015 07:45
☐ Esfincter urinário artificial	1	1	por **equipemielo** Sex Abr 10, 2015 03:53
■ Violência contra as pessoas com deficiência	1	1	por **equipemielo** Seg Abr 27, 2015 09:59

Figure 15. Illustration of the discussion threads that are open for participation of users of the MieloForum

Figure 16 presents an example of participation in the discussion threads illustrated in the previous illustration.



autocateterismo, quem consegue fazer?

autocateterismo, quem consegue fazer?

por **José** » Seg Ago 25, 2014 04:58

Olá pessoal,

Meu nome é José, tenho 18 anos, quero fazer o cat sozinho, mas tenho medo de passar a sonda e vergonha dos meus amigos saberem... Minha mãe faz pra mim por enquanto. Alguém mais passa por isso?

Por favor me ajudem (Exemplo de tópico e discussão- usuário fictício)

Re: autocateterismo, quem consegue fazer?

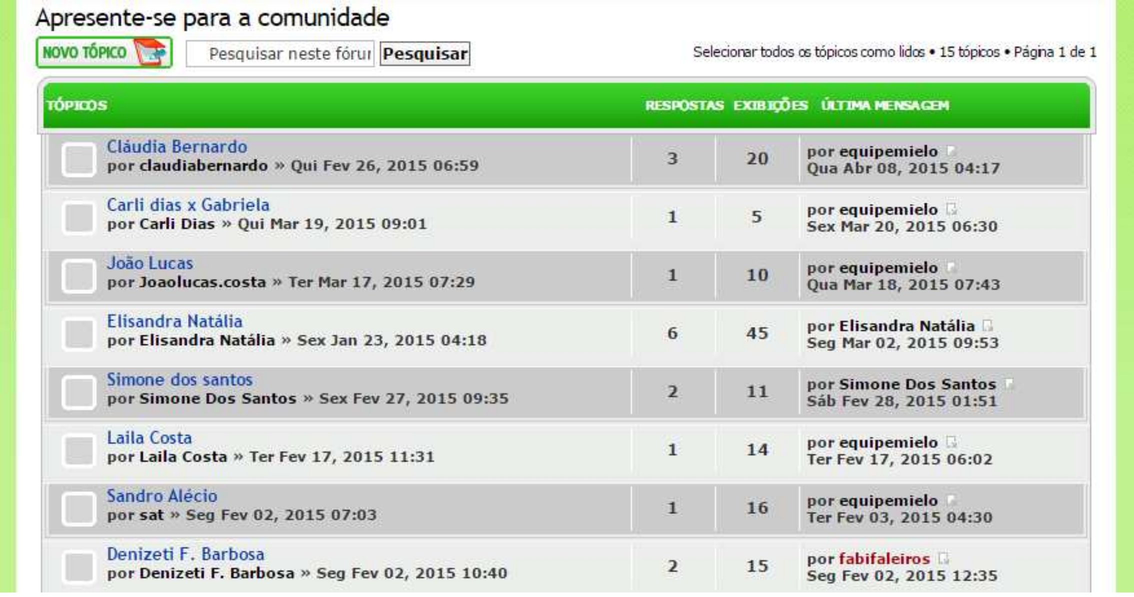
por **Monica** » Seg Ago 25, 2014 05:02

José, tente ficar tranquilo e comece a fazer o cateterismo aos poucos, ajudando a sua mãe. Eu comecei retirando a sonda, minha mãe passava e eu tirava, até perder o medo. Hoje eu faço sozinha. Quanto à vergonha, desencana, as pessoas são diferentes e cada um é especial. Se quiser conversar, me escreve por mensagem!

Um abraço (Exemplo de tópico e discussão- usuário fictício)

Figure 16. Illustration of an example of participation in discussion threads on the MieloForum

Figure 17 illustrates the thread “Introduce yourself to the community.” In this section, the users briefly introduce themselves after registering in the MieloForum. The aim of this thread is for users to get to know each other, and to encourage their participation in the MieloForum.



TÓPICOS	RESPOSTAS	EXIBIÇÕES	ÚLTIMA MENSAGEM
Cláudia Bernardo por claudiabernardo » Qui Fev 26, 2015 06:59	3	20	por equipemielo Qua Abr 08, 2015 04:17
Carli dias x Gabriela por Carli Dias » Qui Mar 19, 2015 09:01	1	5	por equipemielo Sex Mar 20, 2015 06:30
João Lucas por Joaolucas.costa » Ter Mar 17, 2015 07:29	1	10	por equipemielo Qua Mar 18, 2015 07:43
Elisandra Natália por Elisandra Natália » Sex Jan 23, 2015 04:18	6	45	por Elisandra Natália Seg Mar 02, 2015 09:53
Simone dos santos por Simone Dos Santos » Sex Fev 27, 2015 09:35	2	11	por Simone Dos Santos Sáb Fev 28, 2015 01:51
Laila Costa por Laila Costa » Ter Fev 17, 2015 11:31	1	14	por equipemielo Ter Fev 17, 2015 06:02
Sandro Alécio por sat » Seg Fev 02, 2015 07:03	1	16	por equipemielo Ter Fev 03, 2015 04:30
Denizeti F. Barbosa por Denizeti F. Barbosa » Seg Fev 02, 2015 10:40	2	15	por fabifaleiros Seg Fev 02, 2015 12:35

Figure 17. Illustration of the thread “Introduce yourself to the community”

Figure 18 presents the titles of the threads where users can find scientific texts and up-to-date content, items of interest, and texts about spina bifida/myelomeningocele, for reading and discussion.

CURIOSIDADES/TEXTOS SOBRE MIELOMENINGOCELE	TÓPICOS	MENSAGENS	ÚLTIMA MENSAGEM
Ácido Fólico e prevenção da Mielo	1	3	por Suellem Vieira Ter Jun 09, 2015 06:08
Cat (cateterismo urinário)	3	11	por oscar miranda Ter Abr 14, 2015 07:45
Úlcera por Pressão	1	10	por Fernanda07 Seg Jun 08, 2015 09:37
Cirurgias	3	13	por vitorhugo Sex Jul 31, 2015 01:52
Sexualidade	1	4	por Joaolucas.costa Sáb Mai 02, 2015 12:51
Mielomeningocele e Alergias	2	5	por Simone Dos Santos Qui Fev 26, 2015 06:40
Cuidado da criança com Espinha Bífida pela família no domicílio	1	7	por Fernanda Araújo Dom Fev 15, 2015 09:38
Acessibilidade domiciliar	1	8	por Joaolucas.costa Qua Mar 18, 2015 08:51
Inclusão escolar			por Laura G tavares

Figure18. Illustration of the thread “Items of interest and texts about spina bifida/myelomeningocele”

5.6. CREATION, VALIDATION AND PRETEST OF AN ONLINE QUESTIONNAIRE TO ASSESS THE VIRTUAL FORUM FROM THE PERSPECTIVE OF USERS

First step: creation of the online questionnaire

An online questionnaire with 40 questions, 38 multiple-choice and 2 open-ended, was created. It was divided into two parts. The first section had the aim of characterizing the sample, and included questions related to user characteristics, such as name, age, gender, academic degree and spina bifida location. The second section was aimed at assessing the interface of the MieloForum and eliciting the suggestions and comments of users regarding the use of the forum. In addition, there were questions related to the contribution of the MieloForum to the promotion of autonomy, exchange of information and experiences, learning, and interaction among users (Appendix 15).

Second step: validation of the online questionnaire

Fifteen health experts were invited to participate in the validation of the online questionnaire. In the end, the sample totaled eight experts, because even though ten agreed to participate, two did not return the completed data collection instrument and were therefore excluded. The characteristics of this sample are represented in Table 11.

Table 11

Characteristics of the health experts who validated the online questionnaire for the assessment of the MieloForum by users (n=8)

Characteristics	n	Mean (SD)
Age	8	36 (5.397)
Years of activity in rehabilitation	8	8 (6.655)
Characteristics	Categories	Frequency (%)
Gender	Female	7 (87.50)
	Male	1 (12.50)
Total		8 (100.00)
Experience in rehabilitation	No	0 (0.00)
	Yes	8 (100.00)
Total		8 (100.00)
Participation in scientific events in the last two years	No	1 (12.50)
	Yes	7 (87.50)
Total		8 (100.00)
Academic degree	Undergraduate	2 (25.00)
	Specialization	1 (12.50)
	Master	5 (62.50)
Total		8 (100.00)
Professional area	Nursing	8 (100.00)
Total		8 (100.00)
Current area of professional practice	Doctoral students	2 (25.00)
	Nursing/Rehabilitation	6 (75.00)
Total		8 (100.00)

Table 12 shows the content validity index (CVI) and the respective percentage of agreement for each question of the online questionnaire as for principles of clarity, understanding, language, and relevance.

Table 12

Distribution of the questions according to the content validity index and the percentage of agreement among the experts in relation to the principles assessed

Questions	Principles assessed							
	Content validity index				Agreement among the experts			
	Clarity		Understanding		Language		Relevance	
1	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
2	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
3	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
4	0.86	87.5%	1.00	100.0%	1.00	100.0%	1.00	100.0%
5	1.00	100.0%	1.00	100.0%	1.00	100.0%	0.86	87.5%
6	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
7	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
8	0.86	87.5%	1.00	100.0%	1.00	100.0%	1.00	100.0%
9	**0.75**	**75.0%**	0.86	87.5%	0.86	87.5%	0.86	87.5%
10	0.86	87.5%	1.00	100.0%	1.00	100.0%	1.00	100.0%
11	0.86	87.5%	0.86	87.5%	0.86	87.5%	0,86	87.5%
12	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
13	0.86	87.5%	1.00	100.0%	1.00	100.0%	1.00	100.0%
14	0.86	87.5%	0.86	87.5%	0.86	87.5%	0.86	87.5%
15	1.00	100.0%	1.00	100.0%	1.00	100.0%	0.86	87.5%
16	0.86	87.5%	0.86	87.5%	0.86	87.5%	1.00	100.0%
17	1.00	100.0%	1.00	100.0%	0.86	87.5%	1.00	100.0%
18	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
19	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%

20	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
21	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
22	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
23	1.00	100.0%	1.00	100.0%	**0.75**	**75.0%**	1.00	100.0%
24	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
25	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
26	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
27	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
28	1.00	100.0%	1.00	100.0%	0.86	87.5%	1.00	100.0%
29	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
30	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%
31	1.00	100.0%	1.00	100.0%	1.00	100.0%	0.86	87.5%
32	1.00	100.0%	1.00	100.0%	1.00	100.0%	1.00	100.0%

Note: Figures in bold font did not reach minimum CVI of 0.80 (80% agreement)

Thirty questions had a CVI greater than or equal to 0.86; however, two questions (10 and 23) had a CVI of 0.75. Hence, Question 10 was modified as to its clarity and Question 23 regarding its language. Suggestions and comments made by the experts regarding the online questionnaire led to the reformulation of some questions (4, 5, 7, 10, 13, 16, 17 and 28) and the addition of a question regarding the type of catheter used for urinary catheterization.

Third step: pretest with users of the virtual forum

Ten users of the MieloForum were invited to participate in the pretest. The sample was made up of three people who agreed to participate in the study, signed the Free and Informed Consent Form, and answered the entire data collection instrument. The characteristics of this sample are presented in Table 13.

Table 13

Characteristics of the MieloForum users who participated in the pretest of the online questionnaire (n=3)

Characteristics	n	Mean (SD)
Age	3	38 (7.363)
	Categories	Frequency (%)
Gender	Female	2 (66.33)
	Male	1 (33.33)
Total		3 (100.00)
Relationship to the person with spina bifida	The participant has spina bifida	2 (66.33)
	The participant is a relative of someone with myelomeningocele	1(33.33)
Total		3 (100.00)
Level of education	Complete high school	1 (33.33)
	Incomplete undergraduate degree	1 (33.33)
	Complete undergraduate degree	1 (33.33)
Total		3 (100.00)

Filling in the online questionnaire was considered easy by one participant and very easy by two participants. A participant reported having difficulty answering the question: “What is the current occupation of the person with myelomeningocele/spina bifida?” due to the impossibility of providing more than one alternative. Regarding clarity, comprehension, language, and relevance, the questions of the online questionnaire were considered adequate. As suggested by a participant, questions regarding hydrocephalus were included. All participants considered the online questionnaire adequate to assess the MieloForum.

The final version of the online questionnaire was made available on Survey Monkey through the link: https://pt.surveymonkey.com/s/mieloforum4

Phase 2: Assessment of the virtual forum from the perspective of users

This section will present the results of the assessment of the MieloForum from the perspective of users. Data were collected using an online questionnaire, which was created and validated in the first phase of this research. The sample was made up of MieloForum users.

5.7. ASSESSMENT OF THE VIRTUAL FORUM FROM THE PERSPECTIVE OF USERS

All 72 MieloForum users were invited to participate in the forum assessment. Of these, 35 agreed to participate; however, only 30 answered all the questions in the online questionnaire, yielding a total sample of n=30.

The data collected were organized into five parts for presentation of the results of the second phase:

1) Descriptive statistical analysis of the sociodemographic variables of all 72 MieloForum users (people with spina bifida and family members).
2) Descriptive statistical analysis of the sociodemographic variables of the 30 MieloForum users (people with spina bifida and family members) who participated in the assessment of the forum.
3) Descriptive statistical analysis of the sociodemographic and health variables of the people with spina bifida who participated in the study.

4) Descriptive statistical analysis of the variables used for the MieloForum assessment from the perspective of users.
5) Advanced statistical analysis.

1) Descriptive statistical analysis of the sociodemographic variables of all 72 MieloForum users (people with spina bifida and family members)

This section will present the descriptive statistical analysis of the variables available in the profile filled in by the MieloForum users, with the aim of characterizing the individuals who use the forum. Therefore, this section presents data from all 72 MieloForum users who registered in the forum between November 28, 2014 and April 28, 2015.

Brazil is divided into five regions (North, Northeast, Center-West, Southeast, and South). The percentages of visits to the MieloForum by region are represented in Figure 19.

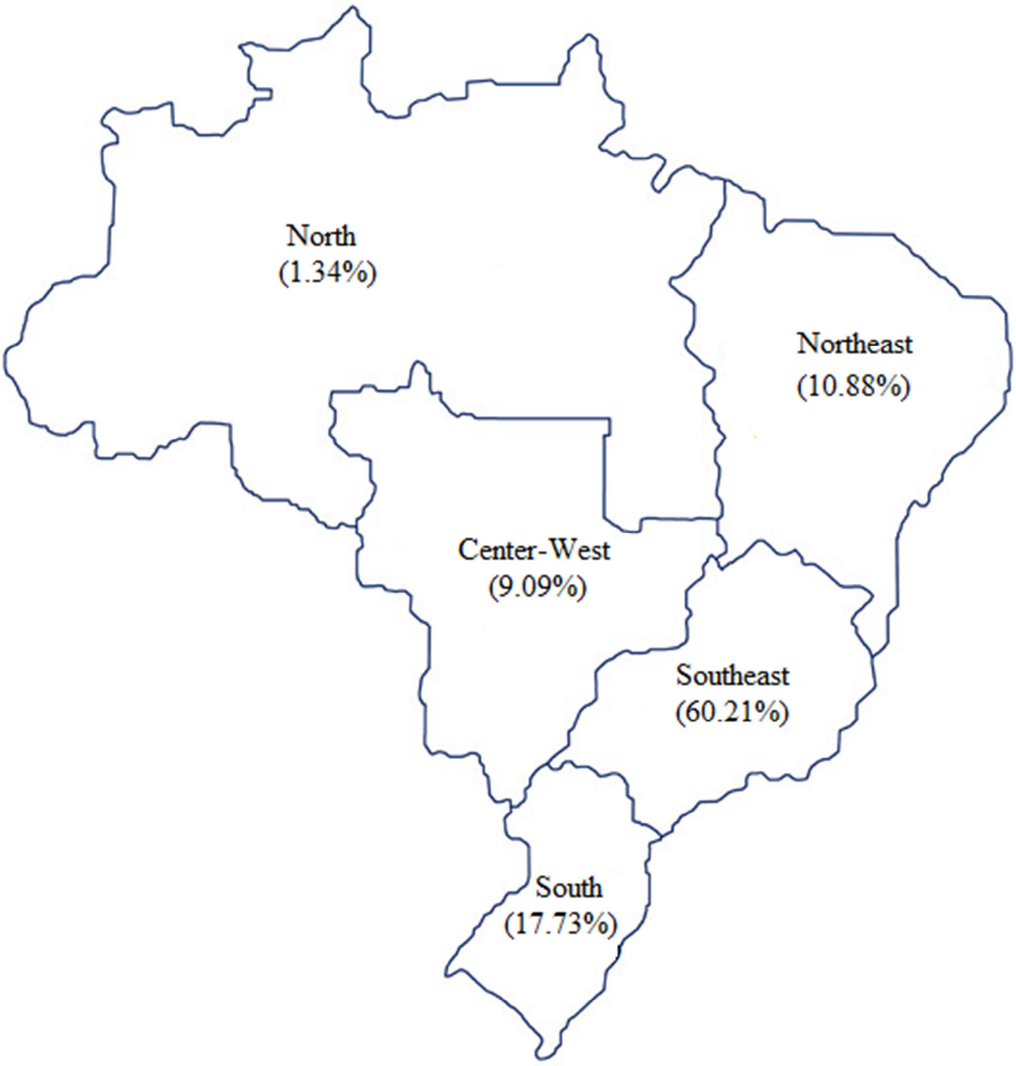
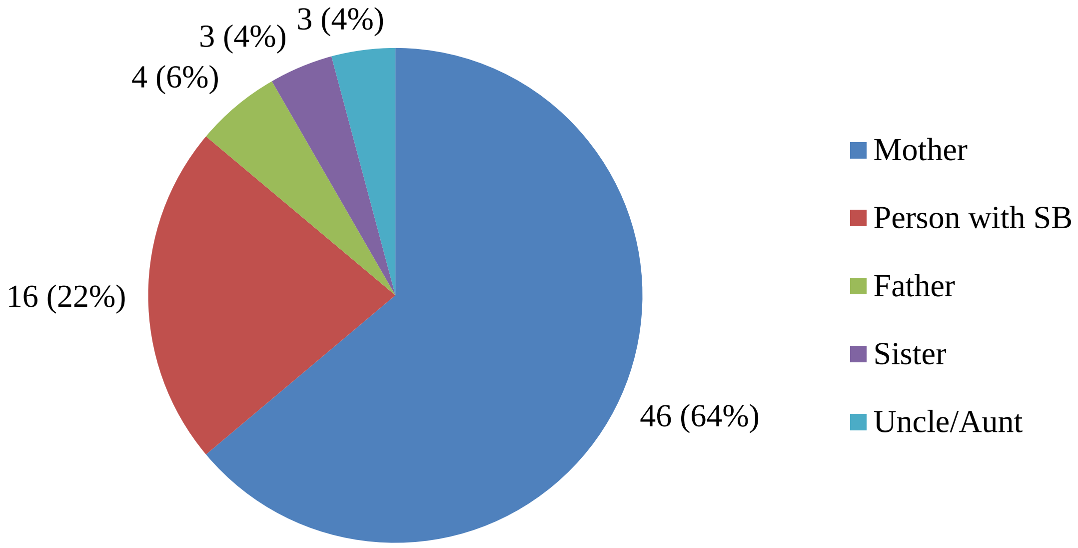


Figure 19. Origin of visits to the MieloForum according to the five Brazilian regions

A total of 671 visits by people living in Brazil was verified, with 404 (60.21%) visits in the Southeast, 119 (17.73%) in the South, 73 (10.88%) in the Northeast, 61 (9.09%) in the Center-West, and 9 (1.34%) in the North. The origin of 5 visits (0.75%) could not be identified.

Graph 1 shows the distribution of MieloForum according to their relationship with the person with spina bifida.

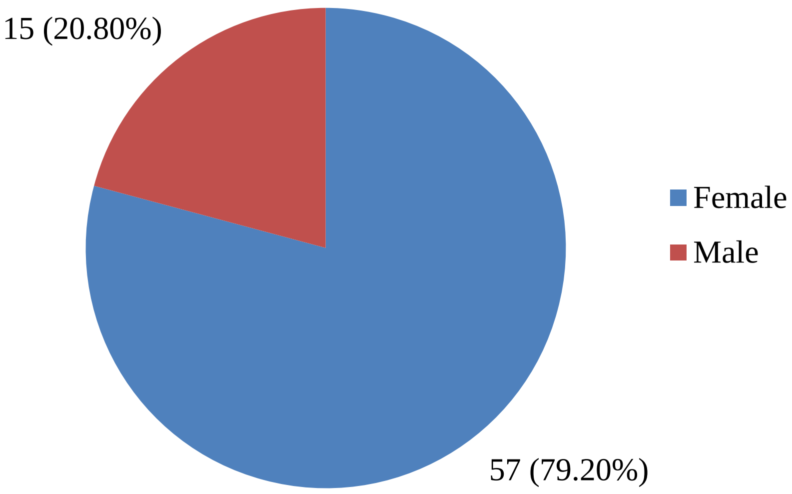


Graph 1. Distribution of all MieloForum users according to the relationship to the person with spina bifida (n=72)

The mothers of people with spina bifida represented 86% of all users, followed by people with spina bifida, fathers, uncles or aunts, and sisters of people with spina bifida. Among the mothers, one woman was pregnant with a child with spina bifida.

The age of the total sample of MieloForum users (n=72) varied from 18 to 58 years, with a median of 32 (13-40) years and a mean of 32.25 (8.015) years.

Graph 2 shows the distribution of the sample according to the gender of the MieloForum users.



*G*raph 2. Distribution of all MieloForum users according to gender (n=72)

Among all MieloForum users, females prevailed, with 57 women (79.20%) and 15 (20.80%) men (Graph 2).

Table 14 presents the evaluation of the level of education of the MieloForum users.

Table 14

Distribution of MieloForum users according to level of education (n=72)

Level of education	Frequency	Percentage	Cumulative percentage
Elementary school	2	2.8%	2.8%
High school	34	47.2%	50.0%
Higher education	36	50.0%	100.0%
Total	72	100.0%	

High school and higher education represented 97.2% of the sample of all MieloForum users.

2) Descriptive statistical analysis of the sociodemographic variables of the 30 MieloForum users (people with spina bifida and family members) who participated in the assessment of the forum

This section will present the descriptive statistical analysis of the sociodemographic variables of the MieloForum users who participated in the assessment of the forum by means of an online questionnaire. The sample was made up of 30 individuals.

All MieloForum users were invited to participate in this study by means of an invitation with a direct link to the online questionnaire, available on the Survey Monkey website. The invitations were sent through Facebook, WhatsApp, personal e-mails, and private messages sent in the MieloForum. Table 15 shows the total number and percentage of the online questionnaires answered, according to the means of promotion.

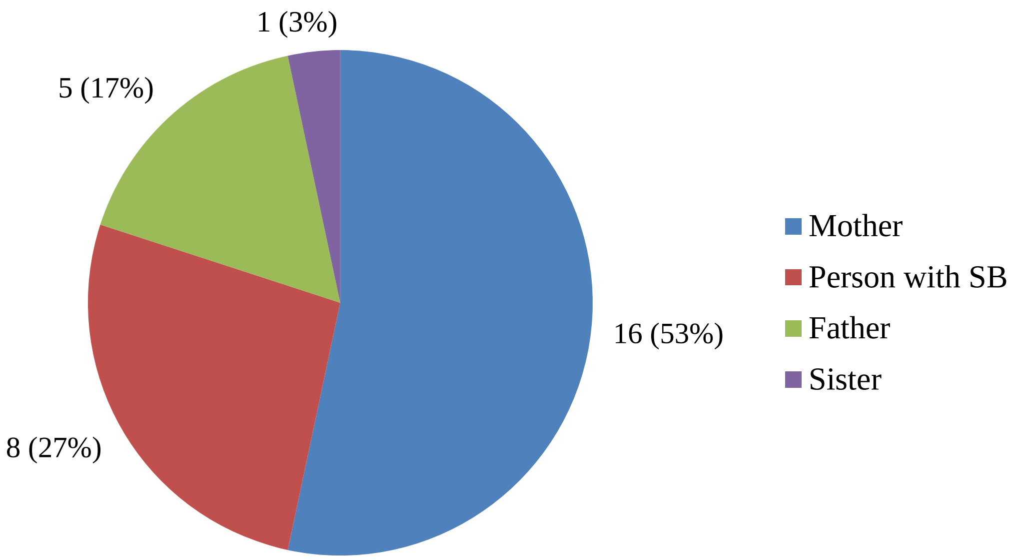
Table 15

Distribution of users who participated in the assessment of the MieloForum according to the means of promotion of the research (n=30)

Means of promotion	Number of questionnaires answered	Number of questionnaires answered in %
Facebook	17	57
Email	9	30
WhatsApp	4	13
Private message (MieloForum)	0	0
Total	30	100

Facebook was the means through which most participants (57%) accessed the online questionnaire, followed by e-mail (30%) and WhatsApp (13%). It is noteworthy that there was no access to the online questionnaire by means of private messages in the MieloForum.

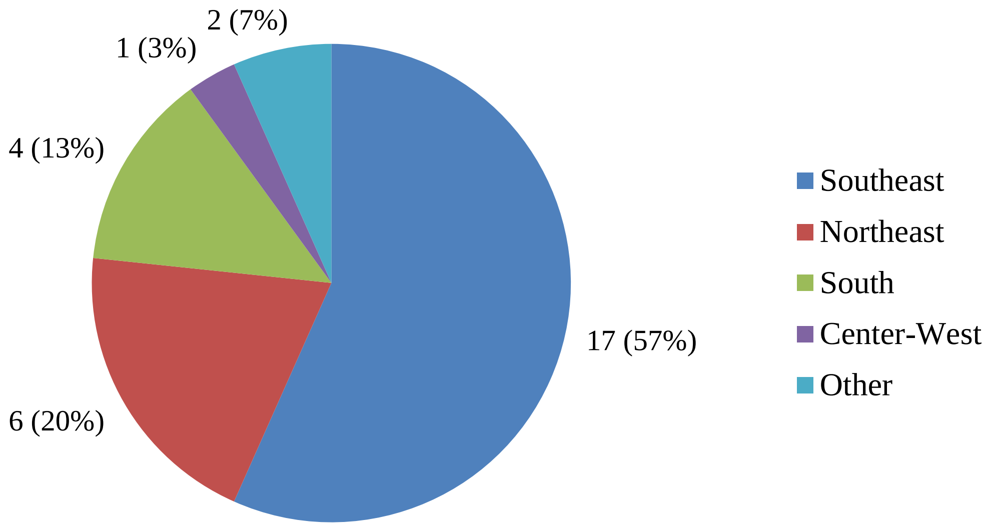
Graph 3 shows the distribution of MieloForum according to their relationship with the person with spina bifida.



Graph 3. Distribution of the sample of users who assessed the MieloForum, according to their relationships to the person with spina bifida (n=30)

The mothers of people with spina bifida represent more than half (53%) of the users who assessed the MieloForum, followed by people with spina bifida (27%), fathers (17%), and sisters (3%) of people with spina bifida. The sum of mothers and people with spina bifida represents 80% of the users who assessed the MieloForum.

Then origin of the users who participated in the assessment of the MieloForum is represented in Graph 4.



Graph 4. Distribution of the origin of the users who assessed the MieloForum (n=30)

Of the five Brazilian regions, North, Northeast, Center-West, Southeast, and South, only the North region had no participants, whereas the Southeast region had the most participation, with 57% of the total sample. It is noteworthy that one participant was from Portugal, and another did not provide his origin, so both were not included.

The age of the sample of users who participated in the assessment of the MieloForum (n=30) varied between 22 and 58 years with a mean of 34.87 (8.34) years and a median of 34.00 (12-36) years.

Regarding gender, the sample of users who assessed the MieloForum was made up of 20 (67%) women and 10 (33%) men.

Table 16 shows the level of education of the users who assessed the MieloForum.

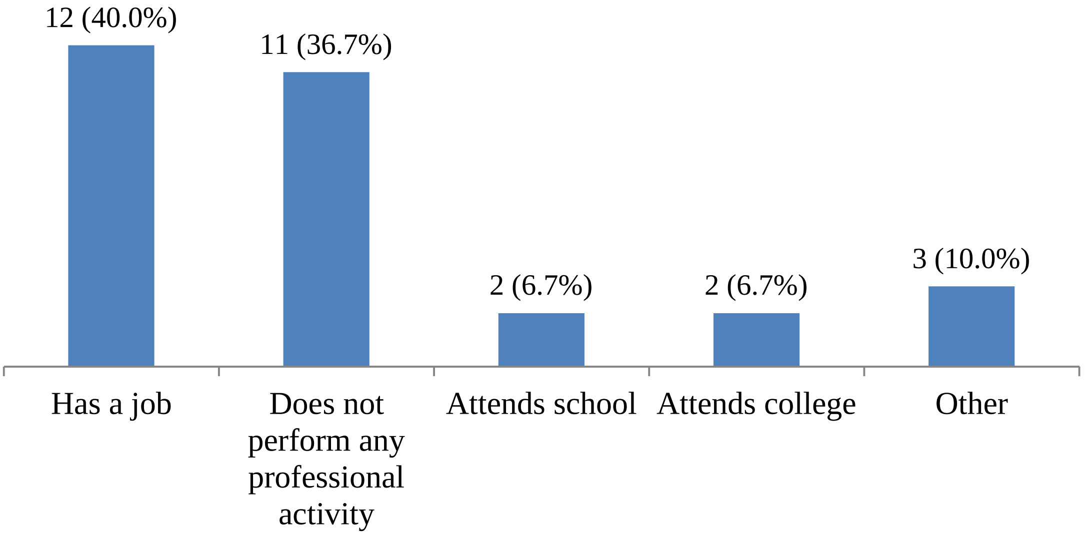
Table 16

Distribution of users who assessed the MieloForum, according to level of education (n=30)

Level of education	Frequency	Percentage	Cumulative percentage
Elementary school	4	13.3%	13.3%
High school	8	26.7%	40.0%
Higher education	18	60.0%	100.0%
Total	30	100.0%	

The level of education that prevailed among users who assessed the MieloForum was higher education (60%).

The users who assessed the MieloForum also answered questions about their current occupation. The results are presented in Graph 5.



Graph 5. Distribution of the occupation of the users who assessed the MieloForum (n=30)

As current occupation, 12 (40%) users who assessed the MieloForum had a job and 11 (36.7%) did not perform any professional activity. The remaining sample attended school, 2 (6.7%) or college, 2 (6.7%), or performed another activity, 3 (10%), such as a volunteer activity or a language course. One person was retired and another was away from work on a leave (Graph 5).

Table 17 presents the data regarding the family income of the users who assessed the MieloForum.

Table 17

Distribution of the monthly family income of the users who assessed the MieloForum, according to the Brazilian minimum wage (n=30)

Monthly family income	Frequency	Percentage	Cumulative percentage
Up to 2 minimum wages (up to R$1,576 or €450)	11	36.7%	36.7%
Between 3 and 5 minimum wages (R$1,576 – R$3,940 or €450 – €1,125)	15	50.0%	86.7%
Six or more minimum wages (+ R$4,728 or €1,350)	2	6.7%	93.35%
I don’t know/I’d rather not answer	2	6.7%	100.0%
Total	30	100.0%	

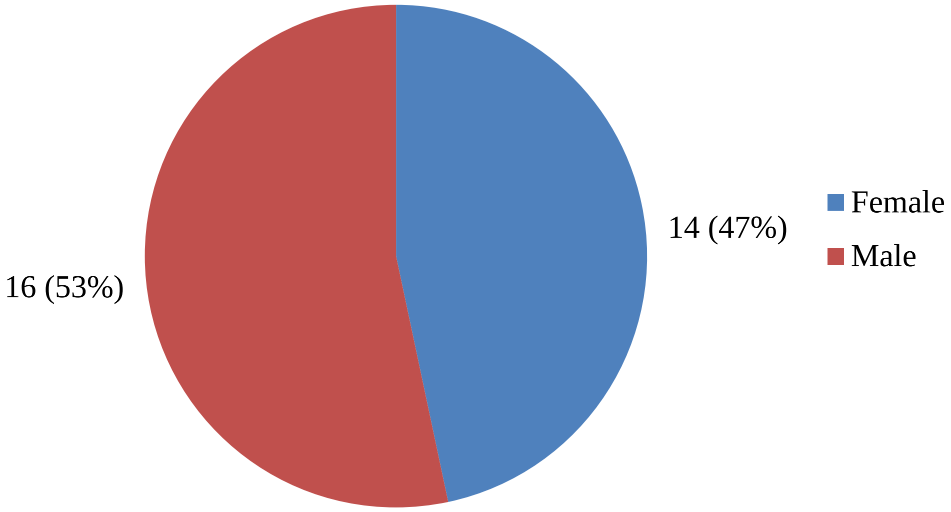
Fifty percent of the sample had a monthly family income between 3 and 5 Brazilian minimum wages, 36% earned up to 2 Brazilian minimum wages, and 6.7% earned 6 Brazilian minimum wages or more.

3) Descriptive statistical analysis of the sociodemographic and health variables of the people with spina bifida who participated in the study

This section will present the descriptive statistical analysis of the sociodemographic and health variables of the people with spina bifida who were MieloForum users or relatives of the users who assessed the forum by means of an online questionnaire. This sample was made up of 30 people with spina bifida.

The age of the sample of people with spina bifida (n=30) varied between 0 and 38 years, with a mean of 12.03 (11.990) years and a median of 8 (22-38) years.

Graph 6 presents the distribution of people with spina bifida according to the gender of the MieloForum user.



Graph 6. Distribution of people with spina bifida according to their gender (n=30)

The sample of people with spina bifida was made up of 14 (47%) women and 16 (53%) men.

Table 18 shows the level of education of the people with spina bifida.

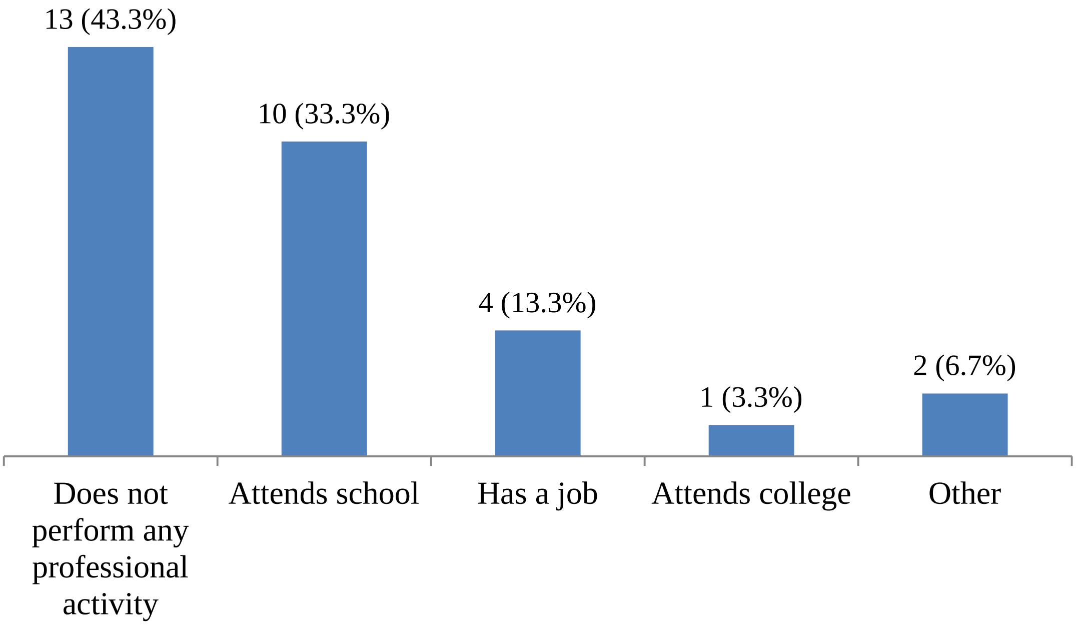
Table 18

Distribution of people with spina bifida, according to their level of education (n=30)

Level of education	Frequency	Percentage	Cumulative percentage
Elementary school	9	30.0%	30.0%
High school	3	10.0%	40.0%
Higher education	7	23.3%	63.3%
Not in school age	11	36.7%	100.0%
Total	30	100.0%	

Elementary education was the level that prevailed among people with spina bifida, representing 30% of the sample. It is noteworthy that 36.7% of the sample were not of school age, that is, they were under seven years of age.

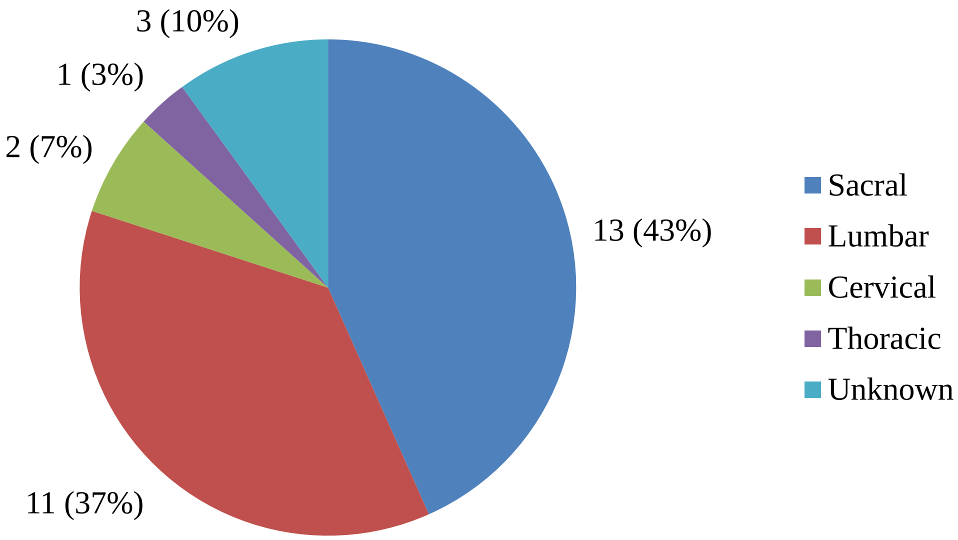
The current occupation of the people with spina bifida is presented in Graph 7.



Graph 7. Distribution of the occupation of the people with spina bifida (n=30)

Thirteen (43.3%) of the people with spina bifida did not perform any professional activity and 10 (33.3%) attended school. The remaining sample attended college, had a job, or performed another activity, such as preparatory courses for public service exams, swimming, or language courses.

People with spina bifida were classified according to the location of the malformation (Graph 8).



Graph 8. Distribution of the people with spina bifida according to the location of the malformation (n=30)

Spina bifida was most frequently found in the sacral region (43%), followed by the lumbar region (37%). Thus, the lumbosacral region represented 80% of the sample. A total of 10% of the individuals could not provide the spina bifida location.

Among the 30 people with spina bifida, 23 (76.7%) presented hydrocephalus. Of these, 21 (91.3%) used a ventriculoperitoneal shunt valve (VPSV).

Table 19 shows the help needed for locomotion by the people with spina bifida.

Table 19

Distribution of the people with spina bifida according to the aid needed for locomotion (n=30)

Locomotion aid	Frequency	Percentage
Walks without help	5	16.6%
Walks with an orthotic device	6	20.0%
Walks with a crutch/cane	2	6.7%
Walks with a walker	2	6.7%
Does not walk, uses a wheelchair	9	30.0%
Baby	6	20.0%
Total	30	100.0%

In addition to the devices used for locomotion, the category “baby” was included in this analysis to consider the potion of the sample that had not reached the age at which gait is acquired. Fifteen (50%) of the people with spina bifida presented gait, five (16.6%) presented gait without assistance, six (20%) used an orthotic device, two (6.7%) used a crutch or a cane, and two (6.7%) used a walker. Among the remaining fifteen (50%), nine (30%) used a wheelchair, and six (20%) were babies.

Table 20 illustrates the distribution of the people with spina bifida according to the performance and type of urinary intermittent catheterization.

Table 20

Distribution of the people with spina bifida according to the performance and type of intermittent urinary catheterization (n=30)

Type of catheterization	Frequency	Percentage	Valid percentage
Self-catheterization	10	33.3%	47.6%
Assisted catheterization	11	36.7%	52.4%
Does not perform catheterization	09	30.0%	----------
Total	30	100.0%	100.0%

The performance of intermittent urinary catheterization was reported by 21 (70%) of the people with spina bifida, whereas 9 (30%) did not perform the procedure. According to the type of urinary catheterization performed, 10 (47.6%) performed self-catheterization and 11 (52.4%) performed assisted catheterization. Among the eight users with spina bifida who assessed the MieloForum, seven (87.5%) performed intermittent urinary self-catheterization.

Table 21 shows the distribution of the people with spina bifida who performed intermittent catheterization according to the frequency with which the procedure was performed.

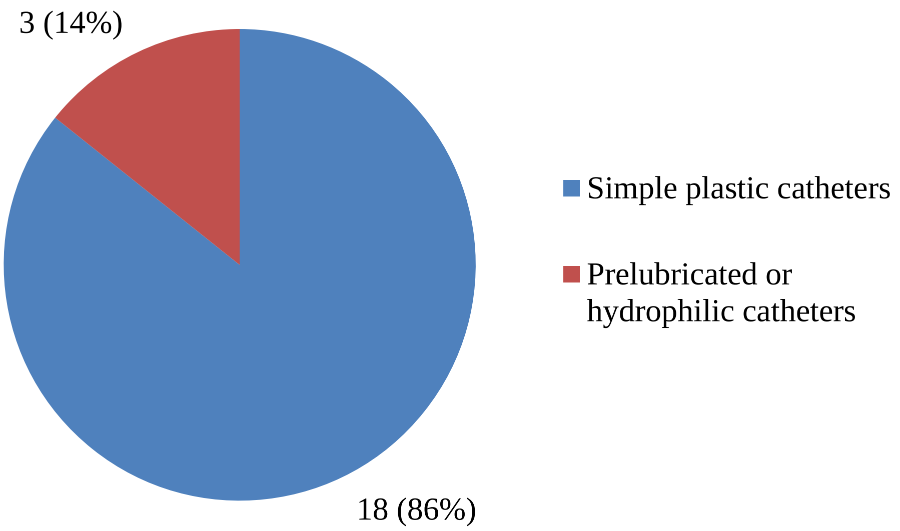
Table 21

Distribution of the people with spina bifida, who perform intermittent urinary catheterization, according to the frequency in which the procedure is performed (n=21)

Frequency of catheterization	Frequency	Percentage	Cumulative frequency
5 times a day	13	61.9%	61.9%
4 times a day	07	33.5%	95.4%
Once a day	01	4.8%	100.0%
Total	21	100.0%	

It is noteworthy that 95.4% of the people with spina bifida who performed intermittent urinary catheterization performed the procedure 4 or 5 times a day.

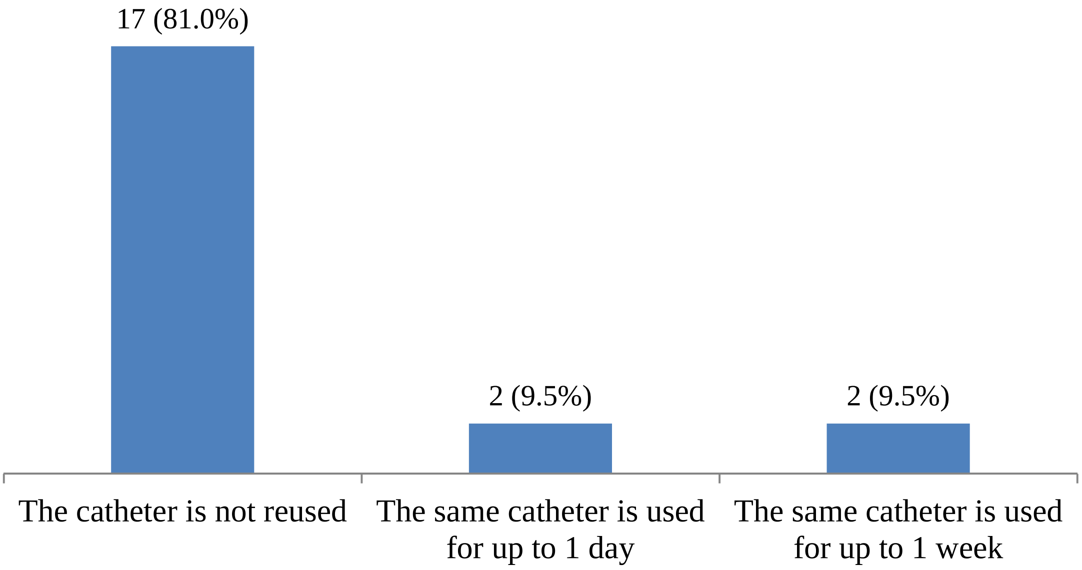
Regarding the type of catheter used for the intermittent catheterization, the Graph 9 shows the distribution of people with spina bifida in two categories, namely simple plastic catheters and prelubricated or hydrophilic catheters.



Graph 9. Distribution of the people with spina bifida who perform intermittent catheterization, according to type of urinary catheter used (n=21)

Eighteen (86%) people with spina bifida who performed intermitted catheterization used simple plastic catheters, and 3 (14%) used prelubricated or hydrophilic catheters.

Graph 10 shows the reuse of catheters for performing intermittent catheterization by the people with spina bifida.



Graph 10. Distribution of the people with spina bifida, who perform intermittent catheterization, according to the reuse of urinary catheters (n=21)

Seventeen (81%) people with spina bifida did not reuse catheters, disposing of them after each procedure. The use of the same catheter for the period of a day was reported by 2 (9.5%) people, and 2 (9.5%) people used the same catheter for up to a week.

Table 22 shows the distribution of the main person responsible for performing intermittent catheterization.

Table 22

Distribution of the main person responsible for performing the clean intermittent urinary catheterization (n=21)

Main person responsible for performing the catheterization	Frequency	Percentage
Mother	9	42.9%
Person with spina bifida	9	42.9%
More than one person responsible	2	9.5%
Health professional or caregiver	1	4.8%
Total	21	100.0%

Mothers and the individuals with spina bifida were the main people responsible for performing catheterization. The group of mothers was more representative than the others, since they were also mentioned in cases when more than one person was responsible for the procedure, such as the mother, father, sister, or a health professional, who assumed the same degree of responsibility. This arrangement could vary according to the context in which the person with spina bifida lived.

Table 23 shows the distribution of the main places where intermittent urinary catheterization was performed.

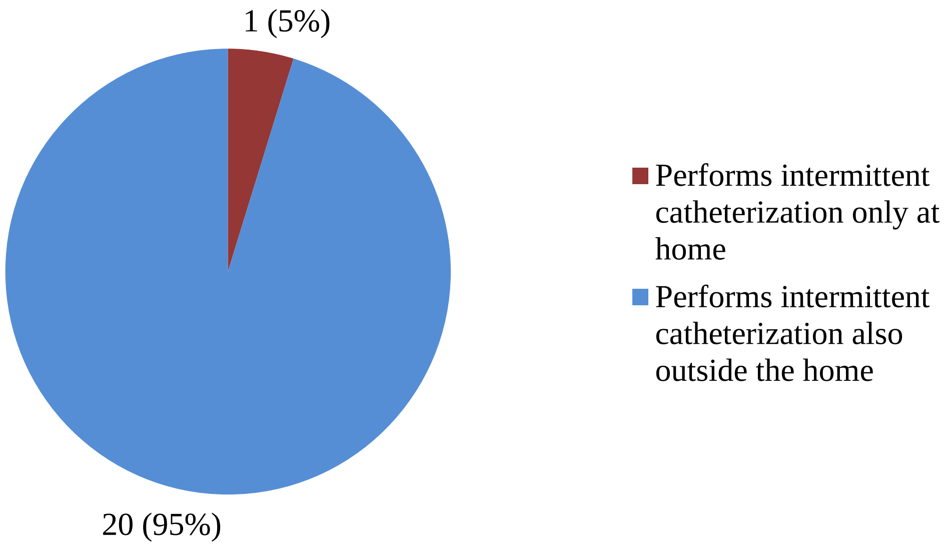
Table 23

Distribution of the main places where intermittent catheterization is performed (n=21)

Place where catheterization is performed	Frequency	Percentage
Bed	13	61.9%
Toilet	5	23.8%
Wheelchair	1	4.8%
Other	2	9.5%
Total	21	100.0%

The most frequent place for performing intermittent catheterization was the bed (61.9%), followed by the toilet (23.8%) and the wheelchair (4.8%). It is important to highlight that the option “other” included associations of more than one place, such as the case of a participant who reported performing the catheterization in bed or in the wheelchair, and another person who performed the procedure standing on his feet.

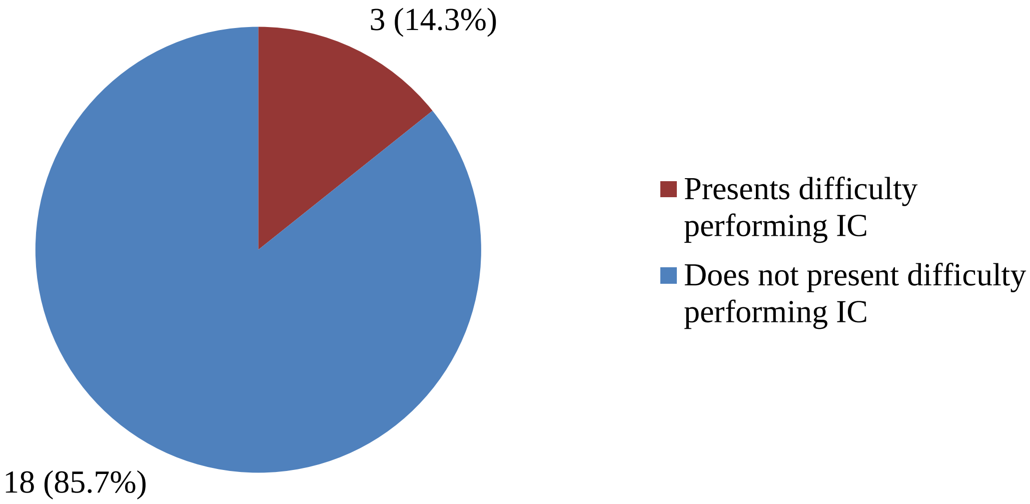
Graph 11 presents the data collected regarding the performance of intermittent catheterization that is also performed outside the home.



Graph 11. Distribution of the people with spina bifida, who also perform intermittent catheterization outside the home (n=21)

Intermittent catheterization was also performed outside the home by 95% of the people with spina bifida who performed the procedure, and 5% stated they only performed the procedure at home.

Graph 12 shows the presence of difficulties during the procedure.



Graph 12. Distribution of the people with spina bifida, who perform intermittent catheterization, according to the presence of difficulties during the procedure (n=21)

Eighteen (85.7%) people reported not having difficulties, 2 (9.5%) reported sphincter resistance, and 1 (4.8%) reported pain or sensitivity. For better visualization of the results, the two last groups were combined, dividing the answers into two large groups, namely one that represented those who presented some difficulty and the other those who presented no difficulty during the intermittent catheterization procedure.

The participants in this study who performed intermittent catheterization answered questions regarding the acquisition of urinary continence, as presented in Table 24. Three categories were established for this variable: total continence (the person does not present urine loss), partial continence (the person presents minor urine loss and only uses a pad) and incontinence (the person presents urine loss and needs to constantly use diapers or urine collectors).

Table 24

Distribution of the people with spina bifida according to their urinary continence after the performance of intermittent catheterization (n=21)

Acquisition of continence after catheterization	Frequency	Percentage	Cumulative percentage
Yes (total continence)	7	33.3%	33.3%
Partial (partial continence)	6	28.6%	61.9%
No (incontinence)	8	38.1%	100.0%
Total	21	100.0%	

Total or partial continence were reported by 61.9% of the people who performed intermittent catheterization, whereas incontinence after the procedure was reported by 38.1%.

Table 25 shows the distribution of people with spina bifida who performed intermittent catheterization according to the professional indicated as being responsible for providing instructions for the technique of intermittent urinary catheterization.

Table 25

Distribution of people with spina bifida who perform intermittent catheterization according to the professional responsible for providing instructions for performing the procedure (n=21)

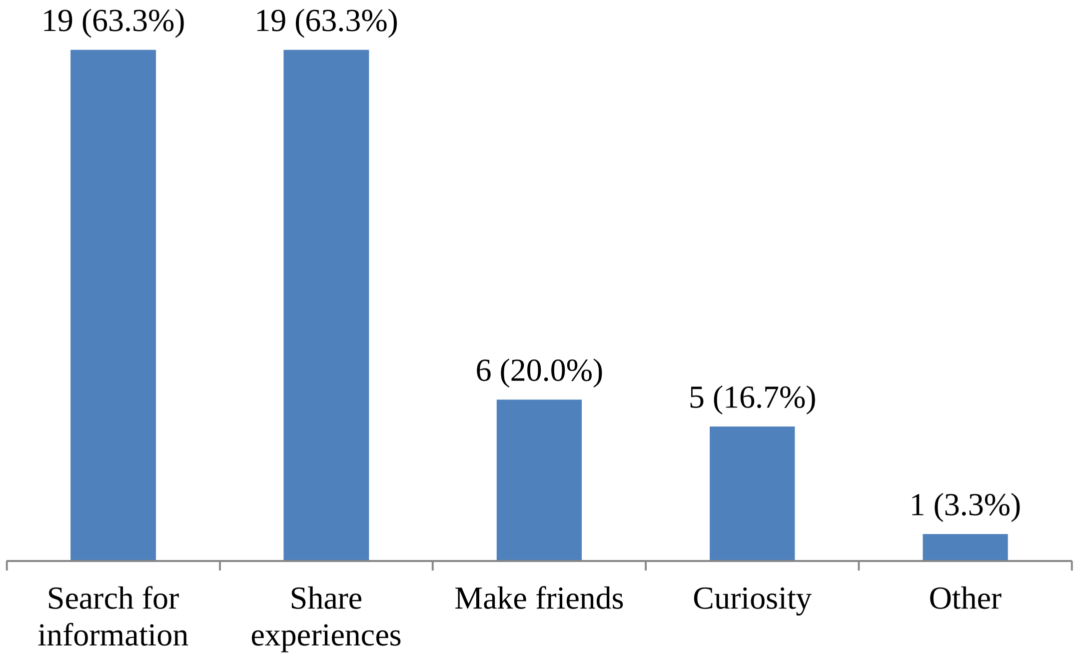
Instruction on the IC technique	Frequency	Percentage
Nurse	10	47.6%
Doctor	10	47.6%
Nurse + Doctor	1	4.8%
Total	21	100.0%

Nurses (47%) and doctors (47%) were mentioned by the participants as performing intermittent catheterization in equal proportions. Only one participant reported having received instructions from both professionals.

4) Descriptive statistical analysis of the variables used for the MieloForum assessment from the perspective of users

This section will present the descriptive statistical analysis of the variables regarding the MieloForum assessment from the perspective of users, obtained by means of the online questionnaire. The same sample of 30 MieloForum users was considered.

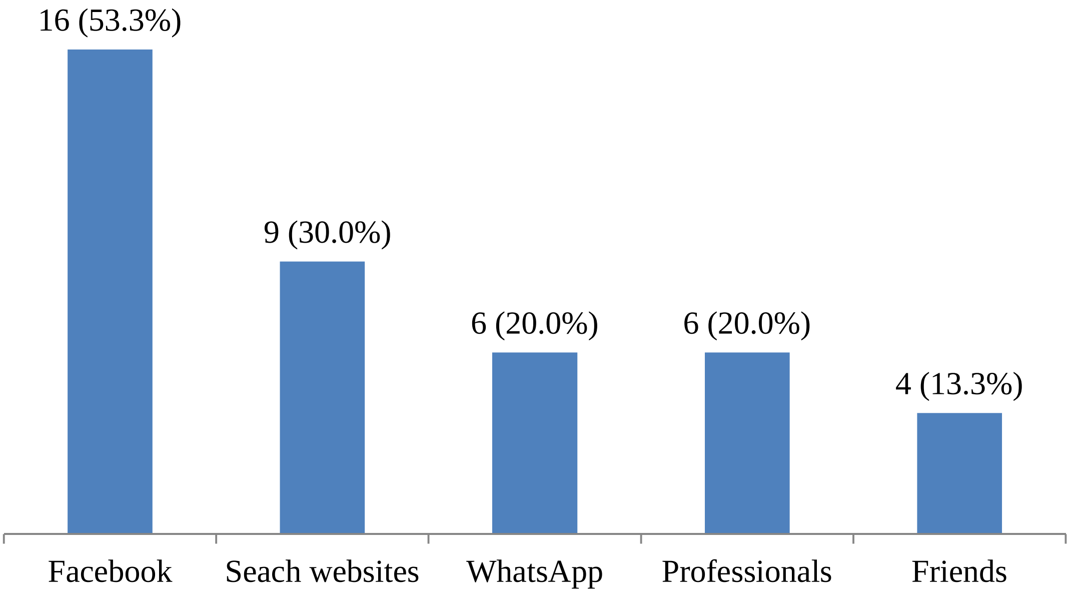
The reasons that users visited the MieloForum are presented in Graph 13.



Graph 13. Distribution of the reasons that users visited the MieloForum

The main reasons that users visited the MieloForum were to search for information (63.3%) and to share experiences (63.3%), followed by making new friends (20%), and curiosity (16.7%). One participant reported having registered in the online forum after being invited by a friend.

The means through which users found out about the MieloForum are presented in Graph 14.



Graph 14. Distribution of the means through which users found out about the MieloForum

Facebook was the most representative means (53.3%), followed by search websites (30%), WhatsApp (20%), professionals (20%), and friends (13.3%).

According to the time of use of the MieloForum by the users who assessed it, 19 (63.3%) had used it for a maximum of one month, 4 (13.3%) for 1 to 3 months, 4 (13.3%) between 3 and 5 months, and 3 (10%) could not answer.

Table 26 shows the assessment of the language and appearance of the MieloForum by users.

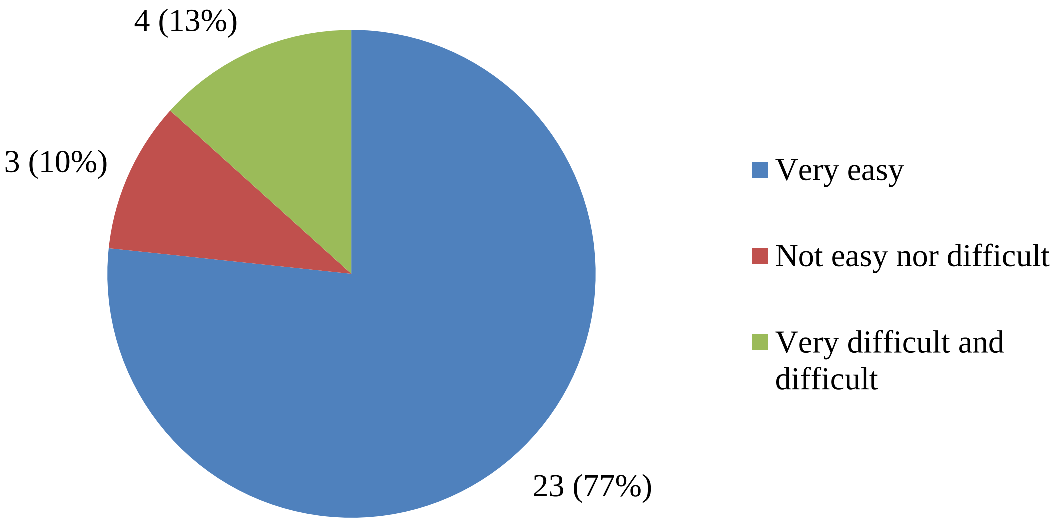
Table 26

Distribution of the assessment of the language and appearance of the MieloForum by users (n=30)

	Understandable language		Adequate appearance	
	Frequency	Percentage	Frequency	Percentage
I agree and I totally agree	27	90%	26	86.7%
I neither agree nor disagree	3	10%	1	3.3%
I disagree and I totally disagree	0	0%	3	10.0%
Total	30	100%	30	100.0%

The language used in the MieloForum was considered understandable by 27 (90%) of the users and its appearance (font, color, format) was considered adequate by 26 (86.7%) of the users who participated in this study.

The users also assessed the MieloForum according to the degree of difficulty of using the forum (Graph 15).



Graph 15. Distribution of the degree of difficulty of using the MieloForum according to the opinion of users (n=30)

It is noteworthy that 23 (77%) users considered it easy or very easy to use the MieloForum, whereas 3 (10%) considered it difficult or very difficult.

Regarding interest in informational texts on the MieloForum, 27 (90%) users reported interest, whereas 3 (10%) did not answer because they had not read the texts. Specifically about intermittent catheterization, 24 (80%) participants mentioned that the texts and discussions on this subject helped or partially helped them clarify questions about it, whereas 3 (10%) said the texts about intermittent catheterization did not help clarify their questions. Three (10%) of the users opted not to answer this question because they did not perform intermittent catheterization.

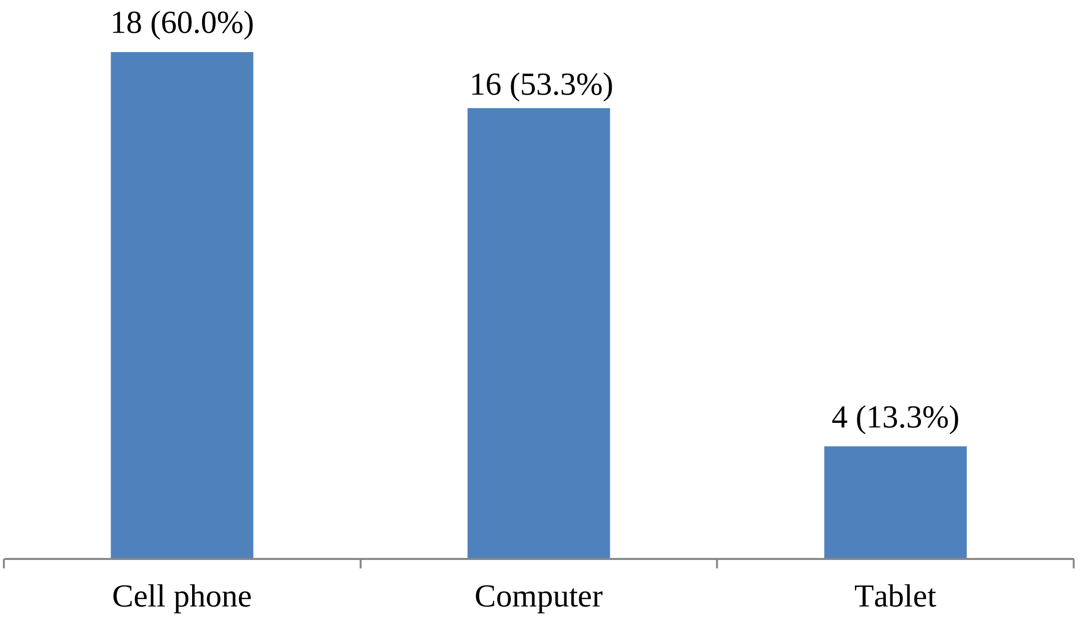
The informational texts on the MieloForum are written by professionals with experience in the rehabilitation of people with spina bifida and based on scientific literature, with the aim of collaborating in the distribution of reliable and accessible information to the potential public.

Initially, the MieloForum was structured to approach the subject of intermittent catheterization as the main topic of discussion. However, as a result of the users' demands in e-mails sent to the MieloForum team and new topics suggested in the discussion threads, other subjects in the universe of myelomeningocele were addressed. These are the subjects that were approached and which generated discussions in the MieloForum:

- Folic acid and prevention of myelomeningocele
- Intrauterine repair (surgery before childbirth)
- Care of the child with spina bifida by the family at home
- The Mitrofanoff principle
- Pressure ulcers
- Sexuality

- Myelomeningocele and allergies
- Home accessibility
- School inclusion
- Sports and physical deficiencies
- Maintenance guide for wheelchairs
- Rights and benefits of people with deficiencies
- Movies about deficiencies

The means through which users accessed the MieloForum are represented in Graph 16.



Graph 16. Distribution of the means through which users accessed the MieloForum

Cell phones were most commonly used by the participants (60.0%), followed by computers (53.3%) and tablets (13.3%) (Graph 16).

Concerning the usefulness of the MieloForum to its users, 29 (96.7%) users considered it useful or partially useful, and 1 (3.3%) user did not consider it useful.

Regarding new friendships made through the MieloForum, 14 (46.7%) users made new friends, and 16 (53.3%) users did not “meet” new people.

The MieloForum users also answered questions regarding recommendation of the forum to other people. These data are presented in Table 27.

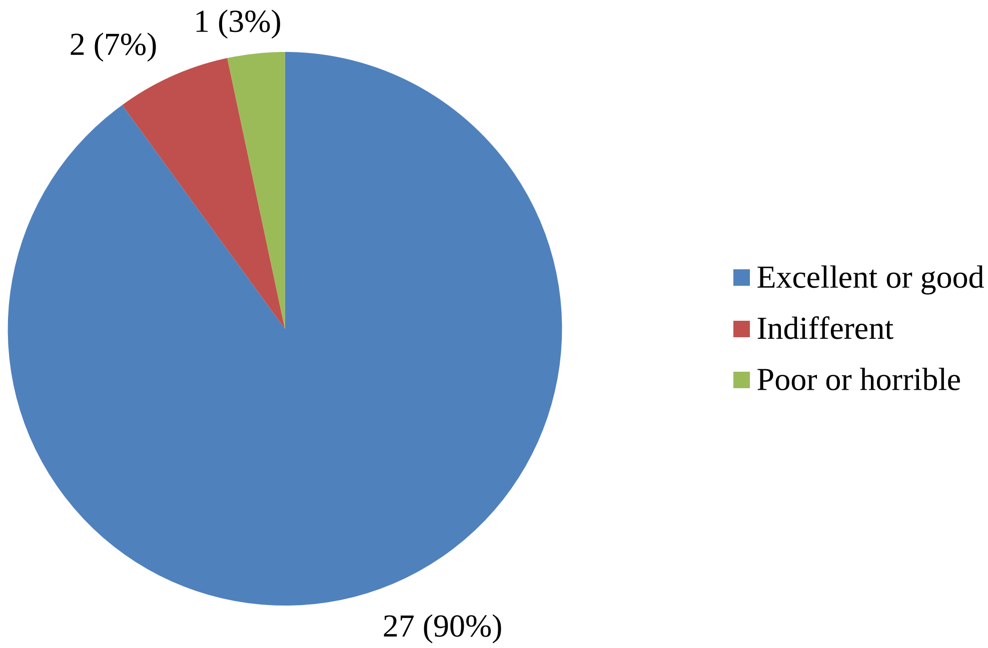
Table 27

Distribution of the results about users’ recommendation of the MieloForum to other people (n=30)

Would you recommend the MieloForum to someone else?	Frequency	Percentage	Cumulative percentage
Yes	25	83.3%	83.3%
Maybe	5	16.7%	100.0%
No	0	0.0%	
Total	30	100.0%	

It is noteworthy that 30 (100%) of the users would recommend (83.3%) or maybe recommend (16.7%) the MieloForum to someone else.

The MieloForum was assessed in a general manner by users, as presented in Graph 17.



Graph 17. Distribution of the general assessment of the MieloForum according to the opinion of users

Twenty-seven (90%) users assessed the MieloForum positively, as “excellent” or “good,” and 1 (3%) user assessed it negatively, as “poor” or “horrible”.

5) Advanced statistical analysis

Following are the results obtained by advanced statistical analysis, aiming at improving the sociodemographic and health characterization of the MieloForum users.

Table 28 represents the statistical analysis of the relationship between the variables “level of education” and “person who assessed the MieloForum (person with spina bifida or family member).”

Table 28

Relationship of the variable “level of education” to the variable “person who assessed the MieloForum” (n=30)

Level of education	Person who assessed the MieloForum		
	Person with spina bifida	Family member	Total
Elementary education	1 (25.0%)	3 (75.0%)	4 (100.0%)
High school	1 (12.5%)	7 (87.5%)	8 (100.0%)
Higher education	6 (33.3%)	12 (66.7%)	18 (100.0%)
Total	8 (26.7%)	22 (73.3%)	30 (100.0%)

* Pearson’s chi square test, p=0.539

No statistically significant relationship was found between the variables “user’s level of education” and “person who assessed the MieloForum (person with spina bifida or family member)” (Pearson’s chi square test, p=0.539).

Table 29 presents the statistical analysis of the relationship between the variables "current occupation" and "person who assessed the MieloForum (person with spina bifida or family member)."

Table 29

Relationship of the variable "current occupation" to the variable "person who assessed the MieloForum" (n=30)

Current occupation	Person who assessed the MieloForum		
	Person with spina bifida	Family member	Total
Attends school	0 (0.0%)	2 (100.0%)	2 (100.0%)
Attends college	1 (50.0%)	1 (50.0%)	2 (100.0%)
Has a job	4 (33.3%)	8 (66.7%)	12 (100.0%)
Does not perform any professional activity	3 (27.3%)	8 (72.7%)	11 (100.0%)
Other	0 (0.0%)	3 (100.0%)	3 (100.0%)
Total	8 (26.7%)	22 (73.3%)	30 (100.0%)

* Pearson's chi square test, p=0.618

No statistically significant relationship was found between the variables "current occupation" and "person who assessed the MieloForum (person with spina bifida or family member)" (Pearson's chi square test, p=0.618).

Table 30 presents the statistical analysis of the relationship between the variables “type of urinary catheterization” and “person who assessed the MieloForum (family member or person with spina bifida).”

Table 30

Relationship of the variables “type of urinary catheterization” and “person who assessed the MieloForum” (n=30)

Type of urinary catheterization	Person who assessed the MieloForum		
	Person with spina bifida	Family member	Total
Self-catheterization	7 (70.0%)	3 (30.0%)	10 (100.0%)
Assisted catheterization	1 (9.1%)	10 (90.9%)	11 (100.0%)
Does not perform catheterization	0 (0.0%)	9 (100.0%)	9 (100.0%)
Total	8 (26.7%)	22 (73.3%)	30 (100.0%)

* Fischer’s exact test, p=0.001

A statistically significant relationship was found between the variables “type of urinary catheterization (self-catheterization or assisted catheterization)” and “person who assessed the MieloForum (family member or person with spina bifida)” (Fischer’s exact test, p=0.001).

Table 31 presents the statistical analysis of the relationship between the variables "performs intermittent catheterization" and "helped clarify questions about intermittent catheterization."

Table 31

Relationship of the variables "performs intermittent catheterization" and "helped clarify questions about intermittent catheterization" (n=27)

Performs intermittent catheterization	Helped clarify questions about intermittent catheterization		
	Yes	No	Total
Yes	18 (85.7%)	3 (14.3%)	21 (100.0%)
No	6 (100.0%)	0 (0.0%)	6 (100.0%)
Total	24 (88.9%)	3 (11.1%)	27 (100.0%)

* Fischer's exact test, p=1.000

No statistically significant relationship was found between the variables "performs intermittent catheterization" and "helped clarify questions about intermittent catheterization" (Fischer's exact test, p=1.000).

Table 32 presents the statistical analysis of the relationship between the variables “general assessment of the MieloForum” and “person who assessed the MieloForum (family member or person with spina bifida).”

Table 32

Relationship of the variables “general assessment of the MieloForum” and “person who assessed the MieloForum” (n=30)

General assessment of the MieloForum	Person who assessed the MieloForum		
	Person with spina bifida	Family member	Total
Excellent	5 (29.4%)	12 (70.6%)	17 (100.0%)
Good	3 (3.0%)	7 (70.0%)	10 (100.0%)
Indifferent	0 (0.0%)	2 (100.0%)	2 (100.0%)
Poor	0 (0.0%)	1 (100.0%)	1 (100.0%)
Horrible	0 (0.0%)	0 (0.0%)	0 (0.0%)
Total	8 (26.7%)	22 (73.3%)	30 (100.0%)

* Pearson’s chi square test, p=0.750

No statistically significant relationship was found between the variables “general assessment of the MieloForum” and “person who assessed the MieloForum (family member or person with spina bifida)” (Pearson’s chi square test, p=0.750).

The association of the variables “age of the user who assessed the MieloForum” and “means through which the MieloForum is assessed” did not present any statistical significance. The Mann-Whitney U test was used in this analysis, and the respective p values were: “Computer (p=0.771),” “Cell phone (p=0.641),” and “Tablet (p=0.927).”

Table 33 presents the statistical analysis of the relationship between the variables "what was it like to use the MieloForum" and "person who assessed the MieloForum (family member or person with spina bifida)."

Table 33

Relationship of the variables "what was it like to use the MieloForum" and "person who assessed the MieloForum" (n=30)

Person who assessed the MieloForum	What was it like to use the MieloForum?			
	Very easy or easy	Not easy nor difficult	Very difficult or difficult	Total
Family member	17 (77.3%)	2 (9.1%)	3 (13.6%)	22 (100.0%)
Person with spina bifida	6 (75.0%)	1 (12.5%)	1 (12.5%)	8 (100.0%)
Total	23 (76.7%)	3 (10.0%)	4 (13.3%)	30 (100.0%)

* Pearson's chi square test, p=0.962

No statistically significant relationship was found between the variables "What was it like to use the MieloForum?" and "person who assessed the MieloForum (family member or person with spina bifida)" (Pearson's chi square test n, p=0.962).

Table 34 presents the statistical analysis of the relationship between the variables "What was it like to use the MieloForum?" and "level of education of the user who assessed the MieloForum."

Table 34

Relationship of the variables "what was it like to use the MieloForum" and "level of education of the person who assessed the MieloForum" (n=30)

	What was it like to use the MieloForum?			
Level of education	Very easy or easy	Not easy nor difficult	Very difficult or difficult	Total
Elementary education	4 (100.0%)	0 (0.0%)	0 (0.0%)	4 (100.0%)
High school	6 (75.0%)	1 (12.5%)	1 (12.5%)	8 (100.0%)
Higher education	13 (72.2%)	2 (11.1%)	3 (16.7%)	18 (100.0%)
Total	23 (76.7%)	3 (10.0%)	4 (13.5%)	30 (100.0%)

* Pearson's chi square test, p=0.828

Analyzing the relationship of the variables "how the user classified his experience in the MieloForum" and "level of education of the user who assessed the MieloForum" did not result in any statistical significance (Pearson's chi square test, p=0.828).

Table 35 presents the statistical analysis of the relationship between the variables "What was it like to use the MieloForum?" and "age of the user who assessed the MieloForum."

Table 35

Relationship of the variables "What was it like to use the MieloForum?" and "age of the user who assessed the MieloForum" (n=30)

What was it like to use the MieloForum?	n	Mean age in years (standard deviation)
Very easy or easy	23	34.00 (7.937)
Not easy nor difficult	3	35.39 (8.943)
Very difficult or difficult	4	32.50 (5.802)
Total	30	

* Kruskal-Wallis test, p=0.810

No statistically significant relationship was found between the variables “What was it like to use the MieloForum?” and “age of the user who assessed the MieloForum” (Kruskal-Wallis test, p=0.810).

Similarly, no statistically significant relationship was found between the variables “level of education of the user who assessed the MieloForum” and “reason for visiting the MieloForum.” Pearson’s chi square test was used in this analysis, and the respective p values were: “search for information (p=0.214),” “make friends (p=0.855),” “share experiences (p=0.821),” and “curiosity (p=0.861).”

The association of the variables “monthly family income of the user who assessed the MieloForum” and “reason for visiting the MieloForum” did not result in any statistical significance. Pearson’s chi square test was used in this analysis, and the respective p values were: “search for information (p=0.540),” “make friends (p=0.675),” “share experiences (p=0.897),” and “curiosity (p=0.406).”

No statistically significant relationship was found between the variables “family income of the user who assessed the MieloForum” and “means through which the MieloForum is accessed.” Pearson’s chi square test was used in this analysis, and the respective p values were: “computers (p=0.492),” “cell phones (p=0.296),” and “tablets (p=0.786).”

Similarly, no statistically significant relationship was found between the variables “origin of the user who assessed the MieloForum” and “means through which the MieloForum is accessed,” with the exception of tablets. Pearson’s chi square test was used in this analysis, and the respective p values were: “computers (p=0.381),” “cell phones (p=0.215),” and “tablets (p=0.049).”

6. DISCUSSION

For didactic purposes, the discussion was also organized in two phases, following the same pattern used in the methodology and in the results. The first phase consisted mainly of the construction and validation of the virtual forum and the instrument used for assessment of the forum. In the second phase, the virtual forum was assessed from the perspective of users.

PHASE 1: Construction and validation of the virtual forum and the instrument for assessing the forum from the perspective of users

6.1. DEVELOPMENT OF THE VIRTUAL FORUM

During the development of the MieloForum, it was noted that the number of studies on the use of the Internet by communities, professionals, and students has been increasing in the last few years (Alves & Cogo, 2014; Cristancho-Lacroix et al., 2013; Santiago et al., 2013), which demonstrates the interest of researchers in working on this subject and its potential as an area for investigation.

It is worth emphasizing that the MieloForum is not identical to the German forum (the Sternchen-Forum); rather, it is a version that was created based on the German version, aiming at the Brazilian population. Based on this experience, it was possible to identify social and cultural differences that directly influenced the construction phase of the MieloForum, and the existence of an instrument similar to the one this study proposed to build contributed to its conception and development.

The partnerships between Brazilian and German institutions played a fundamental role in the realization of this project. The Sternchen-Forum and the

German Association for Spina Bifida and Hydrocephalus provided the MieloForum with experiences and suggestions that improved the work and reflected directly on its quality.

Using the four-stage (scope definition, planning, production, and implementation) model for software creation allowed the authors to systematically plan the development of this project and create a rigorous methodological path to guide its development. In addition, the experience of some members of the team in this methodology reinforced the functionality of this model (Goes, 2010).

The use of the Internet is an alternative that has become increasingly accessible for exchanging experiences and knowledge. The development of research in the health and informatics areas has been growing in the last few years, and so has the concern with distributing accessible and reliable virtual information. By building a virtual forum for people with spina bifida and their families, the authors of this study aimed to contribute to this line of research.

6.2. VALIDATION OF THE VIRTUAL FORUM BY EXPERTS

As described in the methodology, the MieloForum was assessed by health and informatics experts in order to be validated. According to Rubio et al., three to ten experts in each group is enough, which generates a sample of six to 20 experts (Rubio et al., 2003). However, as stated by Alexandre and Coluci (2011), there is controversy in the literature on this point. The number of participants was higher than expected, as the sample was made up of 28 experts and was therefore larger than suggested by the authors mentioned above. This can be explained by the absence of an exclusion criterion and the nationwide reach intended for the study, which led to the selection of representatives from each Brazilian region (North, Northeast, Center-West, Southeast and South).

A total of 22 informatics and 37 health experts were invited to participate in the study, but only 11 professionals from the first group and 17 from the second group agreed. It is important to emphasize that the selection of experts followed the recommendations of Alexandre and Coluci (2011): "As regards selection, the experience and qualifications of the members of this committee must be taken into consideration." The authors searched for professionals with expertise in the development of software/systems/websites in the informatics area, and with experience in rehabilitation in the health area; 75% of the sample met both criteria, whereas only 15% indicated they did not have experience in those areas. This is not believed to have compromised the quality of the assessments, since all experts had the preestablished qualifications and professional experience in their area of expertise.

The help of experts in the area and the use of scientific material and specific literature are needed for software to present appropriate content, as pointed out by Rouse (1999) and Góes (2010). In addition, ergonomics assessment by the informatics experts allowed adjustment of aspects that had not been previously considered (Barbosa & Marin, 2009). The validation of the MieloForum by both informatics and health experts had substantial importance in making improvements possible. Other authors have also highlighted that the participation of experts made essential contributions to their projects (Goes, 2010; Martins et al., 2012; P. Oliveira & Pagliuca, 2013).

Assessment of the general impression of the virtual forum by health and informatics experts

All of the health and the informatics experts participated in the assessment of the general impression of the MieloForum, since the aim of this step was to submit the virtual forum to a general and nonspecific analysis.

According to the observations of the experts, two criteria did not reach the minimum CVI (0.80), and changes were made in response to their suggestions; those adjustments included granting reading access to the theoretical content to all visitors, adding dates to the publications, highlighting buttons (reply, mention, and create a new thread), redesigning the logo, and providing access to more images. In addition to helping users understand the themes discussed and the operation of the MieloForum, these changes are expected to encourage the inclusion of new users. Although it was a coherent suggestion from an expert, it was not possible to increase the usable area of the forum, since the virtual tool does not allow the addition of content beyond its borders.

All suggestions generated by the questions “Would you like to change anything in the forum?” and “Would you like to add anything to the forum?” were followed and the resulting changes are presented in Table 7. The following suggestions could not be followed, due to limitations of the virtual tool or because the team decided so after discussing them.

- Replacing the name “*MieloForum*” with “*Spina Bifida Virtual Forum.”* The authors believe that the first name is more pertinent, especially because it is only one word, which may facilitate advertising.
- Including the possibility of sharing MieloForum content. This suggestion was not followed in order to prevent users from transferring participation to other virtual social networks.

- Transferring the subdivisions of "*Learn more about Myelomeningocele*" to the main page. The authors believe that this change in not pertinent, because other topics also have subdivisions and changing one would lead to a divergence with the organizational logic of the theoretical content.
- Creating a space dedicated to reporting experiences. If such a space existed, maybe the users would stop participating in discussions to use it. In addition, thread discussions are already expected to include individual experiences.
- Remodeling the graphic project and making the interface more dynamic. It was not possible to remodel the graphic project and make the interface more dynamic because of limitations of the virtual tool.
- Changing the characters required to confirm registration in the virtual forum. This suggestion was discussed with the informatics experts, who emphasized the importance of retaining this method, as it contributes to the safety of the MieloForum.

After team discussion, it was concluded that some of the observations made by the experts regarding the assessment of the general impression of the virtual forum were relevant and interesting, but they would not be followed at this point because they are not the objective of this study. However, the authors plan on considering them in the future. These suggestions are listed below.

- Adding illustrative material to the topic *"Intermittent catheterization."* It is noteworthy that a video about this procedure is being produced and will be added to the MieloForum once it is finished.
- Including qualified areas in the virtual forum for institutions, professionals, researchers, and related organizations.

Validation of the virtual forum content by health experts

The MieloForum content was assessed exclusively by health experts, since the aim of this step was to submit the forum to a specific analysis of its theoretical content. That is because the MieloForum is targeted to people with spina bifida and their families, so professionals like nurses, doctors, psychologists, and physical therapists contributed to analyzing this context.

The fact that all criteria from the questionnaire for content analysis reached the minimum CVI of 0.80 may be explained by the expertise of the team that prepared this material, as it was made up of health professionals with experience in rehabilitation and knowledge of these subjects.

Based on the assessments of the health experts and to improve the theoretical texts, aimed at helping users understand them more easily, the presentation of the content on medications in the topic "*Neurogenic bladder treatment*" was reformulated. The authors added to this topic a paragraph about the caliber of the catheter for intermittent catheterization, which must be adequate for each patient and may vary between 4 and 14 Fr (SBU, 2008). Another change in this context refers to the exclusion of the use of boric acid and the inclusion of water and neutral soap in this procedure, which are indicated for hygiene of the hands and urethral meatus (Webster et al., 2001).

A systematic review of the theoretical content was performed to improve the quality of the material, aiming at following the worthwhile suggestions of the health experts in terms of contextual and grammar corrections. After the modifications, the refinement of the texts available in the MieloForum was evident.

The tool did not present any limitation to following the health experts' suggestions. Some observations regarding the virtual tool were similar to observations of the informatics experts, and will be discussed later.

After discussion, the team decided that the following suggestions could not be followed.

- "*The figures could be colored, instead of black and white.*" This suggestion could not be followed. The figures available in the MieloForum were not produced by the authors, so they are not allowed to change them without permission from the authors.
- Expert 12H stated "(...) *I believe the presentation of the forum, where the objectives are stated, should appear on the first page*". The objectives of the forum are already presented in "*Terms of Use*" and "*Welcome,*" which are located on the first page. The authors believe that bringing this content to the first page would lead to repetitive information on the same page.
- The titles and subtitles of the MieloForum were reviewed, because Expert 11H stated *"...the titles and subtitles could be in larger font… and fewer words...,*" but the authors decided not to change them because they believe the theme approached would not be clear.

Interface ergonomics assessment of the virtual forum by informatics experts

The informatics experts assessed the interface ergonomics of the virtual forum. The health experts did not participate in this step because the questionnaire had topics specifically related to the informatics area.

Based on the assessments of the informatics experts and to improve the icons in the MieloForum to make them more self-explanatory, the icon images for "*Members,*" "*Sign in*" and "*Sign out*" were replaced. Regarding the same subject, an expert stated that in his opinion "*(...) the use of icons on the main page of the forum doesn't conform to the standard image of forums.*" The icons on the main page were kept, because in addition to representing what the virtual tool offers, the researchers believe they will help users understand how the forum works, considering possible cognitive limitations related to myelomeningocele and hydrocephalus. A study developed with young adults with cerebral palsy and myelomeningocele observed that typing speed, cognitive skills, and perception of the need for additional support were factors that influenced the use of a virtual tool (Barnfather et al., 2011). Following this line of thinking, it is recommended that virtual environments be developed and adapted to the potential public so that information is accessible to all users (Brasil, 2014).

Another subject discussed was that the forum layout had the format of an old information system. For this observation, once again, the limitations imposed by the tool did not make it possible to develop significant changes in this context. However, a link with explanatory content on its operation was created with the aim of facilitating the use of the tool.

The texts presented in the forum were reviewed to improve their quality, and style resources such as bold, italic, and underline were standardized.

As expected, visual codes were found to be similar in all pages. However, this criterion did not reach the minimum CVI score and no changes were proposed by the experts. Therefore, the format was kept, since the tool presents limitations that do not allow for changing it.

Similar to what was described in the assessment of the general impression of the forum, the following suggestions from the interface ergonomics assessment could not be followed due to limitations of the virtual tool:

- Expert 10I stated that "*Submenus inside the options demand more clicks, delaying the user from reading the content.*" Submenus inside the options demand more clicks, delaying the user from reading the content. Following suggestions from the interface ergonomics assessment, Expert 8I mentioned, "(...) *always scrolling down to the content [below the main menu], because using screens with lower resolution (...) facilitates users' view.*"

- Expert 10I suggested that "*Information should appear on the screen without the use of the mouse scroll.*" This modification could not be applied to the virtual tool.

A limitation of the data collection instrument used for the interface ergonomics assessment was the criterion regarding the presentation of changes in the current status of users. The MieloForum does not have this functionality, nor is there any reason for the lack thereof, thus this aspect was considered not applicable to the present study.

Another limitation refers to the use of phpBB software, and it is noteworthy that this software was chosen because it is also used by the Sternchen-Forum. Although the software allows the creation of virtual forums and has an extensive database, style packages and images to customize the interface, significant difficulties were found in applying suggestions made by the experts.

The researchers intend to continue this project and approach new subjects regarding myelomeningocele, planning a new virtual tool that provides greater usability and better interface to users.

6.3. VIRTUAL FORUM ACCESSIBILITY CHECK WITH WEB ACCESSIBILITY CHECKER (ACHECKER)

Regarding the problems found on the first, seventh and eleventh pages related to the code <***b***> (bold in HTML), Web Accessibility Checker uses HTML5 to assess accessibility, that is, it claims that all codes <***b***> should be replaced in the source code with <***strong***> (bold in HTML5). However, since the MieloForum uses the phpBB tool, the researchers decided not to follow this suggestion, because it would make it more difficult to make changes in the forum and change the tool standard.

Another problem detected on the first page was related to the code <*h1*> (heading in HTML), claiming it was empty. After analysis, it was found that <*h1*> is one of the possible changes that can be made with a tool that facilitates using phpBB, the Administration Control Panel (ACP). The researchers decided to use the logo and the name of the forum in the heading, because removing the code <*h1*> would exclude the use of this tool, which could hamper future updates and adaptations of the MieloForum.

The problems regarding the code ***<i>*** (italic in HTML) found on the fourth page were not changed, because Web Accessibility Checker currently uses HTML5 to assess accessibility, that is, it claims that all codes ***<i>*** should be replaced in the source code with ***<em>*** (bold in HTML5). This would make it more difficult to make changes in the MieloForum and change the tool standard, since the forum uses the phpBB tool.

The problem identified with the name of objects in the Cascading Style Sheets (CSS) was not changed, for standardization purposes and because using the ACP makes it easier for administrators to make changes in the forum.

The Internet makes a vast amount of information available to populations with various characteristics, which generates various skills and demands (Amaral, 2012). Hence, ensuring accessibility to all users is a great challenge, even with all the recommendations provided by the World Wide Web Consortium (W3C, 2013). Different tools proposed to assess accessibility oppose artifacts to guidelines with the aim of obtaining automated results, producing tests and generating data, such as the location of problems in the code and specific flaws (Amaral, 2012).

In the case of the MieloForum, a basic accessibility analysis was performed. To facilitate data processing, in the face of providing a common language, AChecker was used to review the accessibility of the web pages based on a variety of international accessibility guidelines. The forum administration system used by the MieloForum is the phpBB. This system has an old platform and encounters some problems with the new patterns of the W3C, and consequently of AChecker. The style that was developed by the phpBB community did not allow the researchers to correct all that problems identified, which is a limitation of the platform.

It is important to highlight that criteria of usability and accessibility were carefully analyzed during the process of construction of the MieloForum. It was a great challenge to develop a virtual tool that would effectively provide users with an environment of learning and mutual support in a safe manner. However, according to the results found in the AChecker analysis, the platform used did not allow for making all the suggested changes; therefore, converting the forum to a more modern platform is recommended.

6.4. CERTIFICATION OF THE VIRTUAL FORUM WITH THE HEALTH ON THE NET FOUNDATION (HON)

The recognition of the Internet as a source of health information has led to growing concerns about the quality and transparency of the information offered to the population (Car, Lang, Colledge, Ung & Majeed, 2011; Fagnano, Halterman, Conn & Shone, 2012; Ipser, Dewing, & Stein, 2007). Considering this, initiatives have been developed to establish quality criteria for health-related sites. Following this trend, the MieloForum was submitted to the quality assessment of the Health on the Net Foundation (HON). The HON recommends that the quality of sites be certified by a neutral organization based on quality criteria such as the HONcode (Boyer, Gaudinat, Baujard & Geissbühler, 2007; Silveira et al., 2012).

The certification of the MieloForum by the HONcode was extremely productive, because it led to essential modifications in the tool for adequacy, raising it to international standards. The certification of virtual tools through the HONcode has also been used in other studies (Amaral, 2012; Ipser et al., 2007; Silveira et al., 2012). It is worth highlighting that this certification requires annual reevaluation.

6.5. CREATION, VALIDATION AND PRETEST OF AN ONLINE QUESTIONNAIRE TO ASSESS THE VIRTUAL FORUM FROM THE PERSPECTIVE OF USERS

A literature search found few instruments that aim to assess virtual support network and learning tools, maybe because this is a relatively new area of research.

The search for a data collection instrument that would fit this study and include reliability and validity criteria was not successful. Other authors have stated that these criteria directly influence the credibility of research results (S. Couto et al., 2009). For this reason, the researchers opted to build and validate a new instrument.

The use of previous studies (Chorbev et al., 2011; Faleiros-Castro, 2012; Vasconcelos et al., 2013) and the professional experience of the team developing this project had a positive and significant influence on the structure and organization of the questions for the construction of the new instrument (online questionnaire).

Experience and qualifications are important points to be considered for the selection of a group of experts (Alexandre & Coluci, 2011). For the development of the validation process for the online questionnaire, selection was based on the experience and qualifications of the group of experts, which was exclusively made up of nurses with experience in the rehabilitation of patients with spina bifida. These professionals were selected to participate in this step because they were directly engaged in the rehabilitation of people with spina bifida, including providing guidance on intermittent catheterization, and because they were qualified for this activity.

The inclusion of assessment criteria allowed the experts to establish similar language, with the options: “inadequate,” “adequate with many alterations,” “adequate with a few alterations,” and “adequate with no alterations.” In addition to selecting one of these options, the experts made suggestions and additional comments that allowed the researchers to make changes in the online questionnaire, contributing to the creation of a consistent and reliable instrument for the proposed objective. Other authors have also stated that the collaboration of experts generated positive results in their studies (Lobão & Menezes, 2012; M. Lopes, Silva & Araujo, 2013; Martins et al., 2012; P. Oliveira & Pagliuca, 2013; Vituri & Matsuda, 2009).

The participation of laypeople in the pretest contributed to making the questions of the instrument understandable and creating a structure feasible for application to this public. The researchers believe that carrying out the pretest prior to the final application of the questionnaire reduced the risk of obtaining incorrect data. Other authors have stated that when a pretest is not applied, which happens with a great number of evaluative instruments created in graduate academic research, the psychometric characteristics of these instruments, such as validity and reliability, remain unknown (Pilatti et al., 2010).

Similar to a study with the objective of creating an instrument to assess the responsibilities of the nursing service of a teaching hospital (Rodrigues, Vituri, Haddad, Vannuch, & Oliveira, 2012), in the present study, the online questionnaire was reformulated based on the answers and suggestions presented by the participants from the pretest and the validation process. The difficulty mentioned by a participant concerning trying to give more than one answer to the question about the current occupation of the participant was resolved by allowing the inclusion of more than one answer to this question. The other changes made to the online questionnaire were the inclusion of the subject of hydrocephalus, and the addtion of the term “also” in the question regarding urinary catheterization out of the home. These changes improved the instrument, directly and positively impacting its quality.

The assessment of the virtual forum from the perspective of users by means of an online questionnaire was found to be a way to hone the virtual health forum. The validation of the data collection instrument by experts and the pretest with a sample of the potential study population brought significant improvements to the instrument. The results obtained corroborated the importance of the validation and pretest of data collection instruments, since that contributes to adjusting the instrument questions to the specific content and target public, granting reliability and validity to the study.

Phase 2: Assessment of the virtual forum from the perspective of users

6.6. ASSESSMENT OF THE VIRTUAL FORUM FROM THE PERSPECTIVE OF USERS

This section will address the results collected with the online questionnaire that was validated in the first phase of this research, in relation to the sociodemographic variables of the MieloForum users, the sociodemographic and health variables of the people with spina bifida, and the assessment of the MieloForum from the perspective of users.

The direct link to the online questionnaire, available on the Survey Monkey platform, was sent to the MieloForum users by means of personal e-mail, Facebook, WhatsApp groups, and private messages in the MieloForum. The fact that 57% of the participants accessed the data collection instrument through Facebook reinforces the potential of this social network as a means to distribute information and evidences its use by MieloForum users. The use of Facebook was important in the advertising process for the MieloForum, the collection of new users, and sharing discussion threads. These activities were developed with spina bifida groups that already existed in this social network that were made up of people with spina bifida and their families. The links provided in the social network led users to the MieloForum page. These findings corroborate the statement that social networks facilitate exchange of information, interaction, and collaboration among users, and that in addition to these functions, Facebook enables the development of heterogeneous and collaborative activities (Al Mamun, Ibrahim & Turin, 2015; Cerdà & Planas, 2011; Veale et al., 2015).

Sociodemographic Data for MieloForum users

The MieloForum was developed for individuals with spina bifida and their families. The prevalence of the participation of mothers, in both the sample of MieloForum users (64%) and in the sample of users who assessed the MieloForum (54%), is in agreement with the literature. Some authors have found that spina bifida is a chronic condition that interferes with family routines, especially those of mothers, who in most cases take over the responsibility for their children's care (Gaiva et al., 2009). Similarly, other Brazilian studies have described mothers as the main family caregivers for children with deficiencies (Cipriano & Queiroz, 2008; R. Costa et al., 2012). It is important to consider the inclusion of the family in the rehabilitation process as part of the team, as this favors better adherence to proposed activities (Faleiros-Castro & de Paula, 2013). In addition, the development of research involving families must be encouraged, since they assume a fundamental role in cases where their children must receive treatment (Käppler, 2005). The objective of this cooperation between professionals and family members is not to transform these family members into therapists, but for professionals to use their technical knowledge to help the family keep playing their natural role of caregivers during their children's development (Braga & Campos da Paz Júnior, 2008).

The creation of a virtual tool in health that is accessible and adequate for both people with spina bifida and their family members favors access to information on this malformation and the exchange of experiences among users, adding knowledge and enabling the establishment of a network of mutual support. In this context, the researchers agree with other authors that the use of online health services should be encouraged not only for the patient population and professionals, but also for family members, including their participation (Moreno, Ralston, & Grossman, 2009). For this reason, the MieloForum was developed with a focus both people with spina bifida and on their families.

The age of the MieloForum users varied between 18 and 58 years old. The participants in an American study that searched virtual environments for forums on the use of electronic cigarettes were between 18 and 71 years old, with most being between 26 and 35 years old (Hua, Alfi & Talbot, 2013). A Brazilian study on the use of a virtual environment in the relationship of trust between health professionals and patients was developed with participants between 30 and 50 years old (Portella et al., 2012). According to the Brazilian Institute of Geography and Statistics (IBGE), from 2005 to 2008 there was an increase in the use of the Internet by all age groups, especially among people between 10 and 14 years old. From 2008 to 2011, the greatest changes occurred in the groups over 30 years old, especially for the group 50 years old or older (IBGE, 2013a). These data provide evidence that the Internet is increasingly accessible and used by people from different age groups, including adolescents, adults, and elderly people.

The prevalence of women was observed in both the sample of MieloForum users (79%) and in the sample of users who assessed the forum (67%). The IBGE states that, from 2005 to 2011, the growth in Internet access by women was greater than that observed among men; however, the percentage of men who access the Internet was still higher (IBGE, 2013a). Two aspects must be considered in an attempt to explain the predominance of females among the participants of this study: the growth of this public in the virtual environment; and the significant involvement of mothers of children with deficiencies in the context of rehabilitation, care, and the search for health information, which is also reflected in the virtual environment. These findings corroborate the traditional relationship of women and mothers to the practice of caring for their children (Muylaerte, Delfini & Reis, 2015).

Regarding the origin of the visits, although the MieloForum received visits from all Brazilian regions, there was prevalence of visits from the Southeast region. The Southeast region had more visits among both the sample of users who assessed the forum (57%) and in the assessment of all visits between November 2014 and April 2015 (60.21%). This is the richest region in Brazil, with the highest gross national product (GNP) (IBGE, 2013b). Considering the same period, the sum of the origin of these visits, including those from the Southeast, Center-West and South regions of Brazil, represented 86% of all visits. Similar results are observed in the IBGE data, which show that in the Southeast, Center-West, and South regions of Brazil, more than 50% of the population has Internet access, whereas only about 35% of the population from the

North and Northeast regions do so (IBGE, 2013a). These results are significant for the present study because they show that the MieloForum is a virtual tool used in all five regions of Brazil, despite the cultural and economic diversity of the Brazilian population and the extensive territory of this country. It is noteworthy that one participant was from Portugal, showing that the MieloForum reached other Portuguese-speaking countries besides Brazil.

The results of this study showed that among all users of the MieloForum, 2.8% had at least incomplete elementary education, 47.2% had at least incomplete high school education, and 50% had incomplete undergraduate education. A Brazilian study that assessed Internet access found that among people with less than four years of education, 11.8% accessed the Internet, and as years of education increased, so did the percentage of access, which reached 90.2% among those with 15 years or more of education (IBGE, 2013a). In the same context, a study in the US developed in Boston verified that 86% of the people with high school education had access to computers and the Internet, whereas that figure was 97% of those with higher, which suggests that the level of education influences the use of online tools (Goodman, Jette, Houlihan & Williams, 2008). Although these results suggest that the higher the level of education, the greater the proportion of people who access the Internet, the present study found no statistically significant difference between the high school and higher education levels for MieloForum users, showing that the forum was accessible to both levels of education.

Data on the monthly family income of users who assessed the MieloForum revealed that 86.7% of the sample earned up to 5 Brazilian minimum wages, being that 50% earned between 3 and 5 minimum wages and 36.7%, up to 2 minimum wages. According to IBGE, the percentage of people who use the Internet increases with family income; however, in the present study, there was an increase in the number of people who use the Internet across all levels of monthly income (IBGE, 2013a). Even though it was used more by people with higher income, the MieloForum was used by people from all social classes, in line with its objective of being accessible to the entire Brazilian population regardless of purchasing power.

Although the MieloForum was permeated by people of all social classes, such digital inclusion is believed to have been favored by the incentive given to the participation of individuals with a family income of up to 2 minimum wages. In this context, it is worth mentioning that public policies should include the use of new technologies to improve the living conditions of low-income populations, with the objective of reducing digital exclusion and its negative impact on the distribution of wealth and opportunities (Sorj & Guedes, 2005).

In general, the central parameter used by statistical studies is the division between those who do and do not have computers in the household. However, in 2005, only half of low-income individuals who had computers at home had Internet access (Sorj & Guedes, 2005). The proportion of people who use the Internet increases with monthly income. In 2013, those who earned over 10 minimum wages presented the greatest percentage (89.9%), while the lowest (23.9%) was presented by those who earned no income up to ¼ of the minimum wage (IBGE, 2013). Furthermore, the promotion of digital inclusion must consider the quality of the Internet and user skills in terms of using information access tools (Bottentuit Jr. & Firmo, 2004).

Strategies to encourage the participation of low-income individuals must take into account computer and Internet access outside of the household, which can be a democratizing factor in this context (Sorj & Guedes, 2005). Computer use outside of the household in public and free spaces such as libraries is a possible strategy against social exclusion. Another possible form of cooperation in favor of digital inclusion lies in the participation of private initiatives, which could provide financial support to communities and organizations that develop work in the area.

In addition to digital inclusion policies, the forum must also work on its advertising in order to attract more low-income users. Publicity in public health services, whether through the use of posters/pamphlets or actions developed together with health professionals could be useful. Another possible effective strategy would be advertising the MieloForum through the Brazilian television system; however, this option is currently economically unviable due to its high cost.

We also emphasize the correlation between income level, education level and computer ownership, being that education level has been considered essential to this triad (Sorj & Guedes, 2005). In light of previous data, we observed that only 2.5% of the users had completed elementary education, while in terms of family income, approximately 37% earned up to 2 minimum wages, showing that education level may have been more important than family income in determining participation in the MieloForum and the search for health information.

Among users who assessed the MieloForum, 36.7% did not perform any type of professional activity. According to the IBGE, 39.9% of the Brazilian population who do not have a job access the Internet (IBGE, 2013a). Still in this context, since MieloForum users are mostly relatives of people with spina bifida, it is necessary to consider that in the Brazilian reality, as described by other authors, most of the family caregivers of children with deficiencies do not carry out any professional activities due to the need to dedicate most of their time to the care of the children (Cipriano & Queiroz, 2008; R. Costa et al., 2012).

Sociodemographic and health variables of people with spina bifida

The age of the individuals with spina bifida varied between 0 and 38 years old, with a mean of 12 years. This corroborates the results of a previous study developed with 200 Brazilian and German individuals with spina bifida, in which the mean age of the Brazilian sample was 14.5 years, whereas the mean age of the German participants was 19 years (Faleiros-Castro, 2012). This study also found that the Brazilian population with spina bifida was younger than the German.

Regarding the gender of the individuals with spina bifida, 47% was female and 53% was male. Similar data were found by other authors. An American study developed with 50 adolescents with spina bifida found that 48% of the sample was female and 52% was male (Betz et al., 2014). A study of 200 Brazilian and German individuals with spina bifida found that 43% of the Brazilian sample was female and 57% was male, whereas 65% of the German sample was female and 35% was male (Faleiros-Castro, 2012).

To discuss the level of education of the individuals with spina bifida in this study, it is necessary to consider that 36.7% were not of school age and that 30% had completed up to elementary education. This last result may be related to the age of these individuals, because the mean of 12 years theoretically refers to the first school years. Similar data were found in another study with Brazilian individuals with spina bifida, which showed that 41% of the sample was neither of school age nor in the childhood education stage, 5% went to “special schools,” 26% had between 1 and 5 years of education, and 28% had between 6 and 12 years of education (Faleiros-Castro, 2012). A study developed exclusively with adult patients with spina bifida in Chicago (US) found that 36% of the participants had completed education through high school and 49% had an undergraduate degree (Bowman, McLone, Grant, Tomita & Ito, 2001).

Regarding the occupation of the individuals with spina bifida, a study developed with people with spina bifida in Germany found that 45% of the sample went to school or college, 24% had a job, 19% were infants or attended kindergarten, 10% did not have an occupation, and 2% were pensioners (Faleiros-Castro, 2012). It is noteworthy that in the present study, although 43.3% of the individuals with spina bifida reported not performing any activity, it is important to consider that 36.7% were children of school age. Analysis of the rest of the sample showed that most individuals performed some activity, be it going to school or college, or working in a job.

The predominance of spina bifida at the sacral level (43.33%) found in this study differs from other studies that found the lumbosacral region to be the most affected. Another study reported that spina bifida was more frequently found in the lumbosacral region (52.4%) among 98 patients (Zambelli, 2006). The lumbosacral region represented 84% of the sample in a Brazilian study developed with 108 patients with spina bifida (Castro, Moraes, Martins & Comácio, 2010). In the present study, the total of the lumbar and sacral regions accounted for 80% of the sample. The predominance of the sacral region is believed to be an error caused by the fact that this information was reported by laypeople, rather than obtained from medical documents, as in the studies referenced. In addition, 10% of the sample could not provide the spina bifida location, showing a possible deficit of information on spina bifida among these individuals.

The presence of hydrocephalus was mentioned by 76.7% of the sample; of those, 91.3% used a ventriculoperitoneal shunt valve (VPSV), which corroborates the data found in the literature. A study developed with 71 patients with spina bifida stated that 86% of the sample presented hydrocephalus, and among those, 95% had used a VPSV at least once (Bowman et al., 2001). Another study developed with 200 individuals with spina bifida observed that 83% of the sample presented hydrocephalus, and among those, 86% had used a VPSV (Faleiros-Castro, 2012). This result can be explained by the improvements made in shunt valves and the standardization of medical guidelines for the treatment of hydrocephalus (Boockvar et al., 2001; Zambelli, 2006).

The use of a wheelchair as a locomotion aid was mentioned by 30% of the individuals with spina bifida in this study. This finding is in agreement with those of other authors (Amari et al., 2010; McDonnell & McCann, 2000; Pauly & Cremer, 2013). Another study with Brazilian and German individuals with spina bifida found that 41% of the sample did not have gait skills and moved around with the aid of a wheelchair (Faleiros-Castro, 2012). Another result found by the same author was that individuals with a thoracic injury were 14 times more likely to use a wheelchair full time when compared to those who had lumbar or sacral injury.

In the present study, 33.3% of the individuals with spina bifida performed intermittent urinary self-catheterization, 36.7% performed assisted urinary catheterization, and 30% did not perform this procedure. A comparative study between Brazil and Germany found that 31% of the Brazilian sample performed urinary self-catheterization, 63% performed urinary assisted catheterization, and 6% did not perform this procedure (Faleiros-Castro, 2012). Considering only the eight users who had spina bifida and assessed the MieloForum, a frequency of 87.5% was observed for intermittent self-catheterization, suggesting that the autonomy and cognitive capacity of these individuals favored their participation in the MieloForum and the performance of urinary self-catheterization.

Intermittent self-catheterization was performed four or five times a day, as reported by 95.4% of the participants in this study who performed the procedure. Similar data were also found in other studies (J. Costa et al., 2009; R. Costa et al., 2012). Usually, urinary catheterization is recommended four to six times a day, according to individual considerations such as bladder capacity, hydric intake, post-urination residue, and urodynamic parameters (SBU, 2008).

About 86% of the participants in this study used plastic catheters to perform intermittent catheterization and 14% used prelubricated or hydrophilic catheters. Another study developed with people with spina bifida verified that the most commonly used catheters among the Brazilian sample were plastic catheters without coverings (78%), and among the German sample it was hydrophilic (60%) (Faleiros-Castro, 2012). There is no consensus in the literature regarding the use of plastic or prelubricated and hydrophilic catheters. The first is a cheaper alternative, whereas the second is more practical and comfortable (Faleiros-Castro, 2012). Other authors state that there are significant differences regarding complications originating from the use of each type of catheter, such as urinary infections (Ercole et al., 2013; Kiddoo et al., 2015). Others reinforce the decreased frequency of complications when using hydrophilic catheters (Cardenas et al., 2011), besides the decreased rate of urethral complications in the long term, such as urethral stricture (Hedlund, Hjelmås, Jonsson, Klarskov & Talja, 2001).

The predominance of the use of plastic catheters reflects the economic difficulties found in Brazil. Hydrophilic catheter scould be a better option, but, it is not provided by the Unified Health System (SUS), which makes its use less frequent. Plastic catheters, on the other hand, are cheaper and are distributed free by the government (Faleiros-Castro, 2012).

Regarding the reuse of urinary catheters, 81% of the individuals with spina bifida who performed intermittent catheterization used catheters only once, and 19% reused catheters. Reusing catheters for intermittent catheterization is a controversial subject in the literature. Some authors state that the use of sterile catheters does not reduce the incidence of urinary infections when compared to the use of clean catheters for several catheterizations (Ercole et al., 2013). Other authors state that, even though many studies report that reusing catheters does not increase the risk of urinary infection, the mothers of children with spina bifida do not feel safe reusing them and prefer not to, unless the quantity available is not enough for single use (J. Costa et al., 2009).

No scientific protocols were found regarding the cleaning and storage of catheters, though manufacturers recommend that they be used only once. Similar to the results found in the present study, and in addition to the aforementioned arguments, single use of catheters encourages autonomy, the development of urinary self-catheterization, and adherence to the procedure, since it facilitates application of the technique, eliminating catheter cleaning and storage steps. Moreover, it can be an economic alternative in the long term, since adherence to urinary catheterization increases and the risk of complications of not performing the procedure decreases, reducing the need for hospital consultations and surgical procedures (Faleiros-Castro, 2012).

Regarding the main persons responsible for performing intermittent catheterization, mothers and people with spina bifida themselves those responsible for the procedure. The group of mothers was more representative, in agreement with the literature (J. Costa et al., 2009; Kanaheswari, Razak, Chandran & Ong, 2011). Similar results were found in another study developed with 100 Brazilians with spina bifida, in which the mothers were mentioned by 71% of the sample as the person responsible for performing urinary catheterization (Faleiros-Castro, 2012). Other Brazilian authors say that the responsibility for the procedure is generally taken by the mothers, who assume the role of caregivers of children with deficiencies (Gaiva et al., 2009).

As observed in the present study, the place in the home that was more frequently used for performing intermittent catheterization was the bed (61.9%), followed by the toilet (23.8%). These data corroborate the results of another Brazilian study with children with spina bifida, which showed that lying down in bed was reported by 81.8% of the sample, followed by sitting on the toilet (J. Costa et al., 2009). According to the same authors, these results can be explained by the fact that the bedroom is considered one of the most private places in one's residence. However, the sitting position favors urine drainage, and using the toilet decreases the time necessary for performing the procedure, also allowing saving on supplies, since in the shower the technique does not require the use of gauze for genital hygiene.

The performance of intermittent catheterization outside the home represents a factor that favors the social participation and inclusion of people who perform the procedure. In the present study, 95% of the individuals also performed the procedure outside the home. A similar result (81%) was found in another study (Faleiros-Castro, 2012). This finding reinforces the hypothesis that the MieloForum users have autonomy, which favors their participation.

The present study showed that 85.7% of the individuals who perform intermittent catheterization did not report having difficulty performing the procedure. However, urethral resistance, pain, and sensitivity were mentioned. These difficulties were also reported in other studies (Borzyskowski, Cox, Edwards & Owen, 2004; J. Costa et al., 2009; Faleiros-Castro, 2012). Difficulties related to the intermittent catheterization technique, whether technical, emotional, or financial, or related to the home, can lead to interruption of the procedure (Faleiros-Castro, 2012). Nonetheless, emotional difficulties were not reported by any of the participants.

In the present study, total or partial urinary continence was reported by 61.9% and urinary incontinence by 38.1% of the individuals who perform intermittent catheterization. Urinary incontinence can be considered one of the main problems that compromises the quality of life of people with neurogenic bladder, since it interferes negatively in their independence and social participation (Fischer, Church, Lyons & McPherson, 2015; Stulzer, 2009). Performance of intermittent catheterization and increased frequency of this procedure are factors that may increase the chances of achieving urinary continence (Faleiros-Castro, 2012). Moreover, it is necessary to consider that to achieve urinary continence, factors such as detrusor hyperactivity, sphincter deficit, and decreased bladder compliance, or a combination of these factors, must be assessed, and the combination of treatments such as urinary catheterization, use of medications, and surgery may be necessary (Cole et al., 2003).

In the present study, the professionals mentioned as responsible for guiding the intermittent catheterization procedure were nurses and doctors, in equal proportions. A Brazilian study pointed out that most people were trained by nurses (J. Costa et al., 2009). Nurses can facilitate understanding of neurogenic bladder and urinary catheterization by means of educational activities. In addition, the bond created between nurses and patients and their families contributes to adherence to the procedure (J. Costa et al., 2009). A study on the learning of intermittent self-catheterization by children between 7 and 12 years old observed that approaches in groups and by a multiprofessional team favored the learning process (Cobussen-Boekhorst et al., 2010). It is noteworthy that a good or excellent understanding of the procedure can positively influence adherence and decreasing interruption rates (Faleiros-Castro, 2012).

MieloForum assessment from the perspective of users

This section presents a discussion of the results of assessment of the MieloForum from the perspective of users. But first, it is important to highlight that a virtual forum can be understood as a place where people gather to discuss a predetermined subject (J. Araújo & Dieb, 2010). This type of virtual tool is currently an object of interest by researchers, and it is used in several sectors, such as in the areas of education (Buil, Hernández, Sesé & Urquize, 2012; Jardine, 2011; Rozenfeld, 2014), health (Chaparro-Díaz, 2013; McKechnie, Barker & Stott, 2014; Zhang, Cho & Zhai, 2015) and for approaching political-social subjects (Milane & Laniado, 2007; Restrepo, 2013; Sampaio, 2012). The growing number of studies involving the informatics and the health areas in the last few years is notable; however, few studies have addressed virtual forums and chronic diseases, and none was found on virtual forums and spina bifida.

The two main reasons that users accessed the MieloForum were searching for information and sharing experiences. The search for health information on the Internet is significantly related to the presence of chronic diseases or severe health impairments (Gidwani & Zulman, 2015). People with deficiencies or chronic diseases are more inclined to use the Internet to access websites with health information (Kaye, 2000; Oh & Cho, 2015). Besides the search for information, people who are suffering from diseases in general search for virtual communities where they can share their experiences (Garbin et al., 2008).

Level of education and family income had no influence on reasons for visiting the MieloForum, showing that the search for information and sharing experiences, regardless of these factors, were the reasons that users visited the forum.

A study developed with adolescents with spina bifida found that 67% of the sample did not use the Internet to search for health information, and the participants who searched for such information mainly used Google, Wikipedia, and the specific websites of spina bifida associations (Betz et al., 2014). This finding differs from the present study, since the results show that one of the main reasons users visited the MieloForum was to search for health information. However, it is important to consider that the public of the MieloForum is made up of adults with a mean age of 32 years, rather than adolescents, which probably influenced the results. An explanation for these divergent data could be that the use of the Internet varies according to age. Generation X, which comprises individuals between 33 and 44 years old, uses the Internet for bank transactions, purchases, and searching for health information. However, for Generation Y, individuals between 18 and 32 years old, the Internet is considered to be a means of entertainment and communication among friends and relatives (Jones, 2009). The authors of the present study agree with those who state that further investigations are necessary to better understand why, in general, adolescents with spina bifida do not use the Internet to search for health information, despite its great availability in the virtual environment (Betz et al., 2014).

The importance of communication and information technologies in access to health information is notable (P. Sousa, Fonseca, Gaspar & Gaspar, 2015). The Internet offers a huge amount of updated information that can be quickly accessed at any time, through health websites, virtual communities, and support groups, so its role has been increasingly valued (Garbin et al., 2008). Added to this, the environments of social media have increasingly offered places where patients can find health information (Huh, Yetisgen-Yildiz & Pratt, 2013). This access to information on diseases, symptoms, medications, and treatments has created what is called the “expert patient” (Garbin et al., 2008). However, there is still a big problem related to the use of the Internet to obtain health information, which is lack of knowledge, mainly among the young public, about assessing the credibility of websites (Trettin, May & McKeehan, 2008). For this reason, certification of the MieloForum by the Health on the Net Foundation (HONcode) was essential to ensure the quality of the information available to its users on the forum.

Clarification of questions about intermittent catheterization, by means of informational texts and discussions in the MieloForum, was reported by 80% of the participants (10% did not perform intermittent catheterization). These data confirm that informational texts on this procedure are useful, not only for those who already routinely perform intermittent catheterization, but also for people who are searching for information regarding the technique. This reinforces the potential of this virtual tool as a means of distributing health information.

Regarding the language used in the MieloForum, 90% of the users considered it understandable. It is noteworthy that this result must be directly related to the fact that the theoretical texts were written by health professionals with experience in the rehabilitation of individuals with spina bifida, using language aimed at the lay public. In addition, validation of the MieloForum content by health experts, including nurses, doctors, psychologists, and physical therapists, led to a review of the content, contributing to grammatical and contextual adaptations and improvements.

The appearance of the MieloForum was considered adequate by 86.6% of the users who assessed the forum. Important improvements in this context were made, based on suggestions from the informatics experts, which certainly contributed to the approval of the appearance of the MieloForum by its users. The effort to present quality interfaces in virtual programs reflects the concern about promoting the satisfaction of users (P. Sousa et al., 2015).

Using the MieloForum was considered “very easy” or “easy” by 76.7% of the users who assessed the forum, regardless of age, level of education, and type of user (family member or person with spina bifida).

The most commonly used means of access to the MieloForum was cell phones (60.0%), followed by computers (53.3%). According to the IBGE, in 2005, 36.6% of people over 10 years of age had cell phones in Brazil. In 2011, this number increased to 69.1% (IBGE, 2013a). This shows that the use of cell phones is growing among the Brazilian population, which explains the results found in this study. Over the last few years, advances in information technologies and mobile devices have played a significant role in modern solutions in the health area (B. Silva, Rodrigues, Díez, Coronado & Saleem, 2015). Mobile devices, cell phones, and tablets were used by 73.3% of the users to access the MieloForum. This result suggests that making virtual health forums compatible with cell phones and tablets is necessary in order for such forums to stay up-to-date and follow the trends of use of mobile devices by the population. Other studies in the health area have been developed with mobile devices, such as one that addressed the development of an application for mobile devices by diabetic patients (Arnhold, Quade & Kirch, 2014) and another on the assessment of an application for people who smoke (Ubhi, Michie, Kotz Wong, & West, 2015).

The association of the variable “means of access” with “monthly family income” and “age” of the MieloForum users did not show any statistical significance, which allows us to state that age and monthly family income did not influence the means of access. In this context, a statistically significant relationship was observed for the association of “means of access” with “origin of the user.” The use of tablets, although representing only 13% of the sample, was exclusively related to the Southeast region of Brazil, which is the region with the highest GNP (IBGE, 2013b).

There have been other studies that investigated the means of access to the Internet among people with deficiencies. A study developed in the United States with people with spinal cord injury found that 69.2% used computers and 94.2% of the computers used had access to the Internet (Goodman et al., 2008). In California, a study found significant differences among individuals with and without deficiencies, regarding the probability of having computers at home and using the Internet. People with deficiencies were less likely to have computers at home than individuals without deficiencies (23.9% vs. 51.7%) and had fewer chances of using the Internet (11.4% vs. 31.1%) (Kaye, 2000). These data reinforce the need for developing virtual tools that are accessible to and appropriate for people with deficiencies.

Using the MieloForum was considered useful by 96.7% of the users. Other studies in the health area developed in Latin America, Europe and North America have also reported positive results regarding the use of virtual forums (Chaparro-Díaz, 2013; McKechnie et al., 2014). The Internet in the health context, specifically for the distribution of health information, must be considered a tool through which the population can find information complementary to that received through traditional means (Betz et al., 2014). Another purpose for the virtual forum, which was among the main reasons that influenced the participation of users, was the need to find a support network and to participate in groups with questions in common. Hence, it is evident that the use of a virtual forum has the potential to benefit users in several ways, such as access to information, establishment of a network for mutual support, and, consequently, empowerment.

Formal and regular assessment of a virtual health tool by users is essential to improve the resources and information it provides (Rosenfeld, Shepherd, Agunwamba & McCray, 2013). The MieloForum was assessed as excellent or good by 90% of the sample, and 100% of the users with spina bifida assessed it positively. Another important result in this context is that 83.3% of the sample recommended the MieloForum to someone else. These results show that, despite the limitations of this virtual tool pointed out by the informatics experts, it met the users' expectations. However, despite the approval of users, it is believed that migration to a more dynamic platform with more options for exploration would increase the possibilities for approaching the theoretical themes and discussion topics, encouraging the participation of users.

It is noteworthy that the limitations of the virtual tool (phpBB), which did not allow application of some of the improvements suggested by the informatics experts, compromised the dynamism of the forum and the development of a layout more attractive to the public. Another limitation was the size of the sample of users who assessed the MieloForum, which was not probabilistic and therefore did not allow the results to be considered applicable to the population in question. Another aspect to be pointed out is the pretest of the online questionnaire, which did not include the participation of people who represented users with spina bifida and family members of all educational levels, which would be ideal.

The relevant points of this study include the involvement of a group of informatics, health and interdisciplinary researchers, which enabled the construction and update of the MieloForum based on specific knowledge in each area. Cooperation and collaboration with people in Germany who are involved in work with a virtual forum for people with spina bifida, and with associations for this population, allowed the exchange of experiences between these two countries in both the economic and cultural aspects. It is also important to highlight the concern of the researchers to develop a virtual tool that was validated by experts, to ensure the efficiency and quality of the MieloForum for its users. Another point was the creation and validation of a questionnaire for assessment of the MieloForum from the perspective of users, which demonstrates the concern with obtaining reliable results that could improve this tool, according to the opinion of users.

7. FINAL CONSIDERATIONS

The advance of technology and the expansion of the Internet have radically changed the distribution of and the access to information. As a result, the search for information in the virtual environment, involving areas such as security, health, education, and entertainment, are increasingly present in people’s lives.

The creation of the MieloForum was motivated by the desire to favor the empowerment of people with spina bifida. Empowerment is directly related to the autonomy, which helps individuals decide on matters in areas like politics, education, health, and culture.

Despite the evident increase in research on the use of the Internet, few studies in this area have involved people with spina bifida. No studies were found specifically about this population and the use of virtual forums. Thus, two factors were essential to guiding the development of this study. The first was partnership with a German forum, the Sternchen-Forum; their previous experience with a virtual forum and people with spina bifida and their families helped in the design and development of this project, despite cultural differences. The second was the experience of the members of the team, who idealized this project with the methodology used for the creation of the MieloForum and with the rehabilitation of this population.

A great challenge in this study was to build a virtual forum that was accessible for both people with spina bifida and their families. It is noteworthy that the tool was supposed to meet the demands of a heterogeneous group and consider possible complications of the congenital malformation in question and the resulting cognitive limitations. Hence, it was developed with the collaboration of professionals with experience in the rehabilitation of this population, who created the texts, figures, and interface of the MieloForum.

One of the main objectives of the present study was the creation of a virtual forum for the Brazilian population with spina bifida and their families, based on a German model, where people could find accurate information and establish a network of mutual support. Therefore, it was fundamental that the tool be validated by health and informatics experts, aiming at accessibility, usability, and good quality of the health information available in the MieloForum.

In the assessment of the theoretical content, the health experts confirmed the reliability of the information provided to the public. In this context, none of the items assessed reached the preestablished content validity index (0.80). This can be explained by the exclusive participation in the creation of this material of health professionals who had experience in the rehabilitation of people with spina bifida.

The initial idea that the MieloForum would be a forum for people with spina bifida and their families with a focus on intermittent catheterization was found to be insufficient, in view of the demand for other subjects generated by the users. The addition of other subjects in the context of spina bifida into the virtual forum was inevitable and fundamental to maintaining and encouraging the participation of users, besides favoring the distribution of information on spina bifida in other contexts, contributing to the rehabilitation, autonomy, and empowerment of users.

It is important to emphasize that there are two main issues in making contents available in a virtual forum: allowing for updating or acquiring new knowledge; and the possibility of transmission of knowledge that is not always trustworthy, which can generate harm to the population, especially in the health area. For this reason, the submission of the MieloForum to analysis by the Health on the Net Foundation certified the virtual forum's aim of providing quality, objective, and transparent information. This certification, which is renowned and respected internationally in the health area, validated the values of this project.

The participation of informatics experts not only generated a variety of alterations in the interface that favored usability and accessibility, but also encouraged reflection on the part of the researchers about the possibility of replacement of the virtual platform with one that will meet the demand for a more dynamic interface in the near future. Limiting factors were observed during validation of the forum by the informatics experts, who made some suggestions that were not followed because of the limitations of the virtual tool (phpBB). The use of Web Accessibility Checker allowed identification of problems in the source code of single pages, due to the use of HTML rather than HTML5, which is the standard language currently recommended by the W3C.

Facebook was a useful tool to promote the MieloForum and to bring in new users, through the groups of people with spina bifida and the page of the MieloForum. Moreover, it helped find participants for the research, since the social network was used to promote the forum and to invite users to answer the online questionnaire for the assessment of the MieloForum.

The assessment of the MieloForum from the perspective of users is believed to have unique importance, since it considered the opinion of users, which allowed improvements in the tool. The researchers were not successful in their attempts to find a data collection instrument that had already been validated and used in other studies for the assessment of a virtual forum from the perspective of users. Therefore, it was necessary to build and validate a new questionnaire for this purpose. The participation of experts and the application of a pretest with users were considered essential for the validation of the new questionnaire, since it allowed the instrument to be valid, reliable, and trustworthy by means of the improvements and adaptations made and, consequently, improved the quality of the data collected.

According to the characteristics of the users of the MieloForum, most of the users who have spina bifida perform urinary self-catheterization, and study or work. These characteristics allowed the supposition that users of the MieloForum with spina bifida have autonomy and cognitive capacity that favor their participation in the forum.

This study was successful in achieving the objectives proposed, based on the results of the assessment of the MieloForum from the perspective of users. The fact that the MieloForum received a positive assessment, both in general and in terms of language, appearance, and usefulness to users, regardless of being people with spina bifida or family members, age, and level of education, reinforces the idea that the forum was considered adequate by its public, despite its heterogeneity. The number of users registered and the participation in the forum are growing and show that the MieloForum reaches the target public and favors the formation of a network of exchange of information and mutual support among its users.

Considering access to the Internet and the use of computers and mobile devices, there is demand for use of the Internet as a means of distribution of health information and tools that collaborate with virtual education in health. The development of studies using virtual learning tools that address chronic diseases such as spina bifida and subjects including rehabilitation, social inclusion, and empowerment is a current need of public interest that must be met, aiming at the accessibility and democratization of health information.

In face of the facts revealed and considering perspectives for the future, the researchers suggest the development of further studies on the use of the Internet in the health area, considering the topic of rehabilitation. They believe in the strong potential of this context and in the benefits for the population as regards health education, rehabilitation, and social participation.

Suggestions and final observations by the author of this study

According to the experience of the author in the development of a virtual forum (MieloForum) for Brazilian people with spina bifida and their family members, based on a German model, and considering her experience in the context of rehabilitation of this population in both countries, a few suggestions and observations are offered with the aim of contributing to future studies.

A literature review indicates that the use of the Internet in the health area is increasingly studied in the academic environment. However, studies related to spina bifida are still recent and scarce. Thus, the involvement of an interdisciplinary team, involving professionals in the health and informatics areas, and the collaboration of people with experience in a virtual forum for people with spina bifida, were essential for the development of this project.

When attempting to work with a virtual health forum, perceptive work is needed in the development of the material to be provided in the forum, and discussions must be monitored, always aiming for trustworthiness and adequacy of information. Therefore, the qualification of people to elaborate the material and moderate the discussions is needed. The material provided in the MieloForum was elaborated based on the academic literature, books in the health area and scientific articles, and the bibliographic sources were disclosed to students. To monitor the dialogues among the users, an on-duty system was set up, in which a person from the MieloForum team reviews the content posted by users as per its pertinence to the topic in discussion every 12 hours.

Although the options “chats” and “private messages” were offered, these functions were not commonly used by MieloForum users. The author supposes that these options may be more dynamic and known by the public in Facebook or WhatsApp, and that the distribution of health information may be the main use of the MieloForum. In this context, and since the MieloForum assumed the distribution of information as one of its main functions, the MieloForum team worked to create threads and provide informational materials on the subjects of interest and on those requested by the users.

Based on the experience and perception of the author, Germany is actively involved in the social inclusion of people with physical deficiencies in several social contexts, such as education, work, leisure, and culture, by means of activities and initiatives. In this context, associations for people with deficiencies, specifically with spina bifida and hydrocephalus, play an important role and feature communication with other initiatives, such as virtual forums. This articulation of associations favors the quality and promotion of activities offered, generating more visibility in society and contributing to empowerment and achieving rights for people with deficiencies.

There are some associations for people with spina bifida and their families in Brazil, but they work in isolation, without coordination or formal communication It is believed that the creation of an association of national reference and integrated work with all other spina bifida associations in the country would bring the establishment of a support network with greater political power to demand the rights of people with deficiencies. There is also a significant number of virtual pages and WhatsApp groups created for this public that do not communicate either. It would be interesting to contact the administrators of these initiatives with the aim of creating a network with the potential of representing this population and promoting their inclusion and participation in society. Moreover, the exchange of information and the development of group actions among these associations and other initiatives would help promote exchange of knowledge, development of activities, and acquisition of greater social representation.

Experience with the MieloForum shows that constant updates are a challenge that demands time and financial resources. An example of the need for updates is the phpBB (managing system for virtual forums) used in both the German (Sternchen-Forum) and the Brazilian (MieloForum) forums. The limitations of this tool made it impossible to make alterations to create a more attractive layout and a more dynamic forum for users, so the author suggests the use of another tool, or even the creation of a new one, with more possibilities for resources for virtual forums. In this context, the development team for the MieloForum was recently provided with funding from the Coordination for the Improvement of Higher Education Personnel (CAPES) of the Brazilian government, which will allow updating the platform and developing a website that will host three virtual health forums: the MieloForum; a forum for people with cerebral palsy; and another for people with spinal cord injury.

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APPENDICES

APPENDIX 1

Free and Informed Consent Form for the health experts

Gostaríamos de convidá-lo (a) para participar, na qualidade de juiz, da pesquisa intitulada “Espinha Bífida e o Cateterismo Vesical Intermitente: desenvolvimento e avaliação de um fórum virtual para pacientes e familiares”, realizada pela aluna de doutorado Naira Beatriz Favoretto da Universidade Técnica de Dortmund/Alemanha, sob orientação do Prof. Dr. Christoph Käppler da Universidade Técnica de Dortmund/Alemanha e da Prof^{a}. Dr^{a} Fabiana Faleiros da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP-USP). O objetivo deste estudo é Desenvolver e avaliar um fórum virtual brasileiro para indivíduos com espinha bífida e seus familiares sobre o cateterismo vesical intermitente. Para participar desta pesquisa você avaliará o Fórum Virtual (MieloForum) e responderá a um questionário composto por três etapas: Caracterização dos Participantes, Avaliação Geral e Avaliação do Conteúdo do Fórum Virtual. O questionário contém 31 perguntas e será enviado por e-mail. Você utilizará cerca de 20 minutos para preenchê-lo e depois você deverá reenviá-lo por e-mail aos pesquisadores. Sua participação ajudará a aprimorar o Fórum e assim apoiar indivíduos com espinha bífida na troca de experiências e na superação de desafios, como a realização do cateterismo vesical intermitente. Sua participação é voluntária e livre de custos de qualquer natureza. Você não receberá nenhuma gratificação por fazer parte desta pesquisa. Se em algum momento você apresentar algum tipo desconforto, de qualquer natureza, decorrente da participação nesta pesquisa ou do manuseio da ferramenta eletrônica, nos colocamos à disposição para esclarecer dúvidas e minimizar quaisquer dificuldades que possam ocorrer. Você tem direito à indenização, conforme as leis vigentes no Brasil, caso ocorra dano decorrente da sua participação nesta pesquisa. Os dados obtidos serão utilizados unicamente para fins de pesquisa e publicados em revistas especializadas nas áreas do estudo, preservando seu anonimato. Você poderá tirar suas dúvidas sobre o projeto e sua participação, via e-mail ou telefone, que estão no final deste documento. Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa (CEP) da Escola de Enfermagem de Ribeirão Preto/USP, pois respeita as questões éticas necessárias para a sua realização. O CEP também tem a finalidade de proteger as pessoas que participam da pesquisa e preservar seus direitos. Assim, se for necessário, entre em contato com esse CEP pelo telefone (16)3602-3386 (segunda a sexta, das 8 às 17 horas). Você poderá imprimir uma cópia desse documento se desejar.

Eu, ____________________________________, CPF ______________________________
e-mail: ____(opcional) estou satisfatoriamente informado(a) e esclarecido(a) e aceito participar deste estudo.

Pesquisadores responsáveis: Profa. Dra. Fabiana Faleiros, Prof. Dr. Christoph Käppler e Ms. Naira Beatriz Favoretto
E-mail: fabifaleiros@eerp.usp.br ou nairafavoretto@gmail.com
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APPENDIX 2

Free and Informed Consent Form for the informatics experts

Gostaríamos de convidá-lo (a) para participar, na qualidade de juiz, da pesquisa intitulada "Espinha Bífida e o Cateterismo Vesical Intermitente: desenvolvimento e avaliação de um fórum virtual para pacientes e familiares", realizada pela aluna de doutorado Naira Beatriz Favoretto da Universidade Técnica de Dortmund/Alemanha, sob orientação do Prof. Dr. Christoph Käppler da Universidade Técnica de Dortmund/Alemanha e da Prof^{a}. Dr^{a} Fabiana Faleiros da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP-USP). O objetivo deste estudo é Desenvolver e avaliar um fórum virtual brasileiro para indivíduos com espinha bífida e seus familiares sobre o cateterismo vesical intermitente. Para participar desta pesquisa você avaliará o Fórum Virtual (MieloForum) e responderá a um questionário composto por três etapas: Caracterização dos Participantes, Avaliação Geral e Avaliação Ergonômica de Interface do Fórum Virtual. O questionário contém 44 perguntas e será enviado por e-mail. Você utilizará cerca de 25 minutos para preenchê-lo e depois você deverá reenviá-lo por e-mail aos pesquisadores. Sua participação ajudará a aprimorar o Fórum e assim apoiar indivíduos com espinha bífida na troca de experiências e na superação de desafios, como a realização do cateterismo vesical intermitente. Sua participação é voluntária e livre de custos de qualquer natureza. Você não receberá nenhuma gratificação por fazer parte desta pesquisa. Caso queira desistir de participar do estudo, poderá fazê-lo a qualquer momento, sem prejuízos, ficando garantida a sua liberdade de retirada do consentimento. Se em algum momento, você apresentar algum tipo desconforto, de qualquer natureza, decorrente da participação nesta pesquisa ou do manuseio da ferramenta eletrônica, nos colocamos à disposição para esclarecer dúvidas e minimizar quaisquer dificuldades que possam ocorrer. Você tem direito à indenização, conforme as leis vigentes no Brasil, caso ocorra dano decorrente da sua participação nesta pesquisa. Os dados obtidos serão utilizados unicamente para fins de pesquisa e publicados em revistas especializadas nas áreas do estudo, preservando seu anonimato. Você poderá tirar suas dúvidas sobre o projeto e sua participação, via e-mail ou telefone, que estão no final deste documento. Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa (CEP) da Escola de Enfermagem de Ribeirão Preto/USP, pois respeita as questões éticas necessárias para a sua realização. O CEP também tem a finalidade de proteger as pessoas que participam da pesquisa e preservar seus direitos. Assim, se for necessário, entre em contato com esse CEP pelo telefone (16)3602-3386 (segunda a sexta, das 8 às 17 horas). Você poderá imprimir uma cópia desse documento se desejar.

Eu, ____, CPF ______________________
e-mail: ____(opcional) estou satisfatoriamente informado(a) e esclarecido(a) e aceito participar deste estudo.

Pesquisadores responsáveis: Profa. Dra. Fabiana Faleiros, Prof. Dr. Christoph Käppler e Ms. Naira Beatriz Favoretto
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APPENDIX 3

Free and Informed Consent Form for the experts who participated in the validation of the online questionnaire

Gostaríamos de convidá-lo(a) para participar da pesquisa intitulada “Espinha Bífida e o Cateterismo Vesical Intermitente: desenvolvimento e avaliação de um fórum virtual para pacientes e familiares”, realizada pela aluna de doutorado Naira Beatriz Favoretto da Universidade Técnica de Dortmund/Alemanha, sob orientação da Profa. Dra. Fabiana Faleiros, da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP-USP) e do Prof. Dr. Christoph Käppler, da Universidade de Dortmund/Alemanha. O objetivo deste estudo é “Desenvolver e avaliar um fórum virtual brasileiro para indivíduos com espinha bífida e seus familiares sobre o cateterismo vesical intermitente”. Para participar desta pesquisa você avaliará um questionário virtual que será posteriormente respondido pelos usuários do Fórum para a caracterização dos usuários e avaliação do Mielofórum. Para isso responderá a um questionário que será enviado por e-mail, composto por 32 questões de múltipla escolha. Você utilizará cerca de 25 minutos para preenchê-lo. Sua participação poderá ajudar a melhorar o Fórum e assim auxiliar indivíduos com espinha bífida na superação das dificuldades para a realização do cateterismo vesical intermitente e na troca de experiências. Sua participação é voluntária e livre de custos de qualquer natureza. Você não receberá nenhuma gratificação por fazer parte desta pesquisa. Caso queira desistir de participar do estudo, poderá fazê-lo a qualquer momento, sem prejuízos, ficando garantida a sua liberdade de retirada do consentimento. Se em algum momento, você apresentar algum tipo desconforto, de qualquer natureza, decorrente da participação nesta pesquisa ou do manuseio da ferramenta eletrônica, nos colocamos à disposição para esclarecer dúvidas e minimizar quaisquer dificuldades que possam ocorrer. Você tem direito à indenização, conforme as leis vigentes no Brasil, caso ocorra dano decorrente da sua participação nesta pesquisa. Os dados obtidos serão utilizados unicamente para fins de pesquisa e publicados em revistas especializadas nas áreas do estudo, preservando seu anonimato. Você poderá tirar suas dúvidas sobre o projeto e sua participação, via e-mail ou telefone, que estão no final deste documento. Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa (CEP) da Escola de Enfermagem de Ribeirão Preto/USP, pois respeita as questões éticas necessárias para a sua realização. O CEP também tem a finalidade de proteger as pessoas que participam da pesquisa e preservar seus direitos. Assim, se for necessário, entre em contato com este CEP pelo telefone (16)3602-3386 (segunda a sexta, das 8 às 17 horas). Por favor, antes de aceitar participar da pesquisa, veja o questionário que deverá responder. Você poderá adquirir uma cópia desse documento solicitando às pesquisadoras.

Eu,____,
CPF___________________, e-mail:_________________________________
(opcional)
estou satisfatoriamente informado(a) e esclarecido(a) e aceito participar deste estudo.

Pesquisadores responsáveis: Profa. Dra. Fabiana Faleiros, Prof. Dr. Christoph Käppler e Ms. Naira Beatriz Favoretto

E-mail: fabifaleiros@eerp.usp.br ou nairafavoretto@gmail.com

Telefone: (16) 3602-0183

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APPENDIX 4

Free and Informed Consent Form for the forum users who participated in the pretest of the online questionnaire

Gostaríamos de convidá-lo (a) para participar da pesquisa intitulada "Espinha Bífida e o Cateterismo Vesical Intermitente: desenvolvimento e avaliação de um fórum virtual para pacientes e familiares", realizada pela aluna de doutorado Naira Beatriz Favoretto da Universidade Técnica de Dortmund/Alemanha, sob orientação do Prof. Dr. Christoph Käppler da Universidade Técnica de Dortmund/Alemanha e da Prof^{a}. Dr^{a} Fabiana Faleiros da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP-USP). O objetivo deste estudo é Desenvolver e avaliar um fórum virtual brasileiro para indivíduos com espinha bífida e seus familiares. Para participar desta pesquisa você avaliará o questionário online para avaliação do Fórum Virtual (MieloFórum) que será aplicado aos usuários dessa ferramenta. O questionário contém no máximo 40 perguntas e será enviado por e-mail. Você utilizará cerca de 20 minutos para preenchê-lo e depois você deverá reenviá-lo por e-mail aos pesquisadores. Sua participação ajudará a aprimorar o Fórum e assim apoiar indivíduos com espinha bífida na troca de experiências e na superação de desafios. Sua participação é voluntária e livre de custos de qualquer natureza. Você não receberá nenhuma gratificação por fazer parte desta pesquisa. Caso queira desistir de participar do estudo, poderá fazê-lo a qualquer momento, sem prejuízos, ficando garantida a sua liberdade de retirada do consentimento. Se em algum momento você apresentar algum tipo desconforto, de qualquer natureza, decorrente da participação nesta pesquisa ou do manuseio da ferramenta eletrônica, nos colocamos à disposição para esclarecer dúvidas e minimizar quaisquer dificuldades que possam ocorrer. Você tem direito à indenização, conforme as leis vigentes no Brasil, caso ocorra dano decorrente da sua participação nesta pesquisa. Os dados obtidos serão utilizados unicamente para fins de pesquisa e publicados em revistas especializadas nas áreas do estudo, preservando seu anonimato. Você poderá tirar suas dúvidas sobre o projeto e sua participação, via e-mail ou telefone, que estão no final deste documento. Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa (CEP) da Escola de Enfermagem de Ribeirão Preto/USP, pois respeita as questões éticas necessárias para a sua realização. O CEP também tem a finalidade de proteger as pessoas que participam da pesquisa e preservar seus direitos. Assim, se for necessário, entre em contato com esse CEP pelo telefone (16)3602-3386 (segunda a sexta, das 8 às 17 horas). Você poderá imprimir uma cópia desse documento se desejar.

Eu, ____, CPF __________________, e-mail: ____(opcional) estou satisfatoriamente informado(a) e esclarecido(a) e aceito participar deste estudo.

Pesquisadores responsáveis: Profa. Dra. Fabiana Faleiros, Prof. Dr. Christoph Käppler e Ms. Naira Beatriz Favoretto

E-mail: fabifaleiros@eerp.usp.br ou nairafavoretto@gmail.com

Telefone: (16) 3602-0183

CEP/EERP -USP: Av. Bandeirantes, 3900, CEP: 14040-902, Ribeirão Preto, tel: (16) 3602-3386

APPENDIX 5

Free and Informed Consent Form for the users who participated in the assessment of the virtual forum

Gostaríamos de convidá-lo (a) para participar da pesquisa intitulada “Espinha Bífida e o Cateterismo Vesical Intermitente: desenvolvimento e avaliação de um fórum virtual para pacientes e familiares” realizada pela aluna de doutorado Naira Beatriz Favoretto da Universidade de Dortmund/Alemanha, sob orientação do Prof. Dr. Christoph Käppler da Universidade de Dortmund/Alemanha e da Profª. Drª Fabiana Faleiros da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP-USP). O objetivo deste estudo é desenvolver e avaliar um fórum virtual brasileiro para indivíduos com espinha bífida e seus familiares. Para participar desta pesquisa você responderá a um questionário online para avaliação do Fórum Virtual (MieloFórum). O questionário contém no máximo 40 perguntas e você utilizará cerca de 20 minutos para preenchê-lo. Sua participação ajudará a aprimorar o Fórum e assim apoiar indivíduos com espinha bífida e seus familiares na troca de experiências e na superação de desafios. Sua participação é voluntária e livre de custos de qualquer natureza. Você não receberá nenhuma gratificação por fazer parte desta pesquisa. Caso queira desistir de participar do estudo, poderá fazê-lo a qualquer momento, sem prejuízos, ficando garantida a sua liberdade de retirada do consentimento. Se em algum momento você apresentar algum tipo desconforto, de qualquer natureza, decorrente da participação nesta pesquisa ou do manuseio da ferramenta eletrônica, nos colocamos à disposição para esclarecer dúvidas e minimizar quaisquer dificuldades que possam ocorrer. Você tem direito à indenização, conforme as leis vigentes no Brasil, caso ocorra dano decorrente da sua participação nesta pesquisa. Os dados obtidos serão utilizados unicamente para fins de pesquisa e publicados em revistas especializadas nas áreas do estudo, preservando seu anonimato. Você poderá tirar suas dúvidas sobre o projeto e sua participação, via e-mail ou telefone, que estão no final deste documento. Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa (CEP) da Escola de Enfermagem de Ribeirão Preto/USP, pois respeita as questões éticas necessárias para a sua realização. O CEP também tem a finalidade de proteger as pessoas que participam da pesquisa e preservar seus direitos. Assim, se for necessário, entre em contato com esse CEP pelo telefone (16)3602-3386 (segunda-feira a sexta-feira, das 8 às 17 horas). Você poderá receber uma cópia desse documento se desejar, para isso envie um e-mail aos pesquisadores solicitando-a.

E-mail: fabifaleiros@eerp.usp.br ou nairafavoretto@gmail.com
Telefone: (16) 3315-0183

☐ Estou esclarecido e aceito participar
☐ Não estou esclarecido e não aceito participar

APPENDIX 6

Instrument for the characterization of the health experts who participated in the validation of the virtual forum

Sexo: ( ) Feminino ( ) Masculino

Idade: _______ anos

Titulação acadêmica:
( ) Graduação. Área: __________________________
( ) Especialização. Área: _______________________
( ) Mestrado. Área: ___________________________
( ) Doutorado. Área: __________________________
( ) Pós Doutorado. Área: _______________________

Área de atuação profissional atual:_________________________________
Tempo de atuação profissional (referente à questão acima): ________ anos

Você tem experiência profissional em Reabilitação? Se sim, quanto tempo atuou na área?
____

Participou de algum evento científico nos últimos 2 anos relacionado a sua área de atuação profissional?
( ) Sim ( ) Não

APPENDIX 7

Instrument for the characterization of the informatics experts who participated in the validation of the virtual forum

Sexo: ( ) Feminino ( ) Masculino

Idade: _______ anos

Titulação acadêmica:
( ) Graduação. Área: ___________________________
( ) Especialização. Área: ________________________
( ) Mestrado. Área: ____________________________
( ) Doutorado. Área: ___________________________
( ) Pós Doutorado. Área: ________________________

Área de atuação profissional atual:____
Tempo de atuação profissional (referente à questão acima): ________ anos

Você já trabalhou com desenvolvimento de software/sistema e/ou ensino a distância? Se sim, quanto tempo?
____

Participou de algum evento científico nos últimos 2 anos relacionado a sua área de atuação profissional?
( ) Sim ( ) Não

APPENDIX 8

Instrument for the assessment of the general impression of the virtual forum

CRITÉRIOS	**Discordo Forte-mente**	**Discor do**	**Concor do Forte-mente**	**Concor do**	**Não Sei**	**Obser-vações**
1. A interface favorece a participação do usuário no Fórum.						
2. A apresentação do conteúdo favorece a participação do indivíduo no Fórum.						
3. As figuras e fotos ajudam na compreensão da temática do Fórum.						
4. O Fórum tem indicação de uso como ferramenta educacional.						
5. As limitações do Fórum não excedem sua utilidade como ferramenta informativa e de apoio mútuo aos usuários.						
6. O nome do Fórum (MieloFórum) é adequado.						
7. Recomendo o Fórum para os indivíduos com espinha bífida e seus familiares.						
8. Você gostaria de mudar alguma coisa no Fórum? ( ) Sim ( ) Não						
9. Você gostaria de incluir alguma coisa no Fórum? ( ) Sim ( ) Não						

Adapted (GÓES, F. 2010).

APPENDIX 9

Instrument for the assessment of the content of the virtual forum

CRITÉRIOS	**Discordo Fortemente**	**Discordo**	**Concordo Fortemente**	**Concordo**	**Não Sei**	**Observações**
1. Os objetivos do Fórum estão claramente definidos.						
2. O Fórum tem coerência com os objetivos a que se propõe.						
3. O conteúdo é atualizado.						
4. O conteúdo apresenta organização lógica.						
5. O conteúdo é coerente com o público alvo.						
6. As informações são claras e concisas.						
7. Os textos são de fácil leitura.						
8. A apresentação de figuras e fotos é relevante para as informações incluídas nos textos.						
9. A gramática é utilizada corretamente.						
10. Os termos são utilizados corretamente.						
11. A apresentação do conteúdo cativa à atenção dos usuários.						
12. O fórum estimula a participação do usuário.						
13. A interação entre os usuários ocorre de maneira efetiva.						
14. O fórum permite o aprendizado por meio de troca de experiências entre os usuários.						
15. O Fórum estimula o apoio mútuo.						

Adapted (GÓES, F. 2010).

APPENDIX 10

Instrument for the interface ergonomics assessment of the virtual forum

CRITÉRIOS	**Discordo Fortemente**	**Discordo**	**Concordo Fortemente**	**Concordo**	**Não Sei**	**Observações**
1. As páginas de menus possuem títulos e cabeçalhos.						
2. Os painéis de menus são formados a partir de um critério lógico de agrupamento de opções.						
3. Os nomes das opções de menu são concisos.						
4. A estrutura dos menus concebida de modo a diminuir os passos necessários para a seleção.						
5. O uso de abreviaturas é minimizado nos menus.						
6. Os ícones são legíveis.						
7. Os ícones são distintos uns dos outros e possuem sempre o mesmo significado de uma tela para outra.						
8. Os ícones são econômicos sob o ponto de vista do espaço nas telas.						
9. O usuário sempre comanda a navegação no sistema.						
10. O usuário pode interromper e retomar um diálogo a qualquer instante.						
11. O usuário pode se deslocar de uma parte a outa do sistema rapidamente.						
12. As frases das mensagens de erro são concisas e objetivas.						
13. Os dados a serem lidos são apresentados de forma contínua.						
14. O Fórum adota códigos significativos ou familiares aos usuários.						
15. Os significados usuais das cores são respeitados nos códigos de cores definidos.						

16. A apresentação de textos e recursos de estilo (itálico, negrito, sublinhado ou diferentes fontes) é empregada adequadamente.						
17. Os códigos visuais são empregados para associar diferentes categorias de dados distribuídos de forma dispersa nas telas.						
18. Os itens selecionados para alteração, atualização ou acionamento estão destacados dos outros.						
19. Qualquer mudança na situação atual de objetos de controle é apresentada visualmente de modo claro ao usuário.						
20. Os controles e comandos encontram-se visualmente diferenciados das informações apresentadas nas telas.						
21. As telas apresentam somente os dados e informações necessários e indispensáveis para o usuário em sua tarefa.						
22. A densidade informacional das janelas/telas é reduzida.						
23. O design não sobrecarrega a memória.						
24. O espaço de apresentação está diagramado em pequenas zonas funcionais.						
25. A disposição dos objetos de interação de uma caixa de diálogo segue ordem lógica.						
26. Os links funcionam corretamente.						
27. A otimização do sistema é adequada para diferentes larguras de banda.						
28. O sistema funciona corretamente em diferentes navegadores.						

Adapted (GÓES, F. 2010).

APPENDIX 11

Instrument for the characterization of the health experts who participated in the validation of the online questionnaire

Sexo: ( ) Feminino ( ) Masculino

Idade: _______ anos

Titulação acadêmica:
( ) Graduação. Área: __________________________
( ) Especialização. Área: _______________________
( ) Mestrado. Área: ___________________________
( ) Doutorado. Área: __________________________
( ) Pós Doutorado. Área: _______________________

Área de atuação profissional atual:____
Tempo de atuação profissional (referente à questão acima): ________ anos

Você tem experiência profissional em Reabilitação? Se sim, quanto tempo atuou na área?
____

Participou de algum evento científico nos últimos 2 anos relacionado a sua área de atuação profissional?
( ) Sim ( ) Não

APPENDIX 12

Instrument used by the experts in the validation of the online questionnaire

Legenda:
0: não adequado
1: adequado com várias alterações
2: adequado com poucas alterações
3: adequado sem alterações

Questão 1- Convite ao usuário do Mielofórum para participação da pesquisa
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 2- Quem responderá este questionário?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 3- Data de nascimento da pessoa com Mielomeningocele/ Espinha Bífida:
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 4- Gênero/sexo da pessoa com Mielomeningocele/ Espinha Bífida
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 5- Qual o grau de escolaridade da pessoa com Mielomeningocele/ Espinha Bífida?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 6- Qual a ocupação atual da pessoa com Mielomeningocele/ Espinha Bífida?

Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 7- Qual a localização da Mielomeningocele/ Espinha Bífida/?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 8- Quais auxílios para a locomoção são utilizados?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 9- Atualmente o paciente realiza: (autocateterismo, cateterismo com auxílio...)
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 10- Qual a frequência que o cateterismo vesical é realizado?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 11- Você reaproveita a sonda?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 12- Qual a principal pessoa responsável pelo cateterismo?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 13- Onde o cateterismo é realizado?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 14- Faz o cateterismo fora do domicílio?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 15- Enfrenta dificuldade na realização do cateterismo?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 16- Alcançou continência urinária após o cateterismo?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 17- Quem lhe treinou para fazer o cateterismo?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 18- Qual o principal motivo que te trouxe ao Mielofórum?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 19- Como você descobriu o Mielofórum?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 20- A linguagem utilizada no Mielofórum é compreensível.
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 21- O visual do Mielofórum (letra, cor e formato) é adequado.
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 22-Você se interessou pelos textos informativos que estão no Mielofórum?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 23- Na sua opinião como foi navegar no Mielofórum?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 24- O Mielofórum lhe ajudou a discutir ou esclarecer dúvidas sobre o cateterismo vesical (cat)?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 25- O Mielofórum é útil para você?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 26- Você fez amigos no fórum?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 27- Você indicaria o fórum para outra pessoa?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 28- De modo geral, como você avalia o fórum?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 29- De onde você acessa o Mielofórum?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 30- Qual a faixa de renda mensal da sua família?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 31- Quantas pessoas são sustentadas com essa renda familiar?
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

Questão 32- Por favor, nos ajude a melhorar o Mielofórum, adicione aqui seus comentários e sugestões:
Quanto à clareza: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à compreensão: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à linguagem utilizada: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Quanto à relevância: ( ) 0 ( ) 1 ( ) 2 ( ) 3
Sugestões:

APPENDIX 13

Instrument for the characterization of the forum users who participated in the pretest of the online questionnaire

Sexo: ( ) Feminino ( ) Masculino

Idade: _______ anos

Relação com a pessoa com espinha bífida:
( ) o próprio participante tem espinha bífida
( ) o participante é parente de uma pessoa com espinha bífida
Especifique: ____

Nível de escolaridade:
( ) Ensino Fundamental Incompleto
( ) Ensino Fundamental Completo
( ) Ensino Médio Incompleto
( ) Ensino Médio Completo
( ) Ensino Superior Incompleto
( ) Ensino Superior Completo
( ) Nunca frequentou a escola
( ) Outro. Especifique: ____________

APPENDIX 14

Instrument used by the forum users in the pretest of the online questionnaire

1. Para você como foi responder ao questionário *online*?
(   ) Muito difícil
(   ) Difícil
(   ) Nem fácil e nem difícil
(   ) Fácil
( ) Muito fácil

2. Você encontrou alguma dificuldade para responder ao questionário *online*?
(   ) Não (   ) Sim. Especifique: ____

3. De maneira geral, quanto à clareza, compreensão, linguagem utilizada e relevância, como você avalia as questões do questionário *online*?
(   ) Muito inadequadas
(   ) Inadequadas
(   ) Indiferente
(   ) Adequadas
(   ) Muito adequadas

4. O questionário online é adequado para avaliar o MieloFórum.
(   ) Discordo completamente
(   ) Discordo
(   ) Nem concordo e nem discordo
(   ) Concordo
(   ) Concordo completamente

5. Você gostaria de acrescentar ou modificar alguma coisa no questionário online?
(   ) Não (   ) Sim
Especifique:____

APPENDIX 15

Final version of the online questionnaire for the assessment of the virtual forum by users

01. TCLE (Apêndice 5) (   ) Estou esclarecido e aceito participar (   ) Não estou esclarecido e não aceito participar
02. Quem responderá o questionário? ( ) Pessoa com Mielomeningocele/Espinha Bífida ( ) Mãe ( ) Pai ( ) Outro (especifique) ______________________
03. Qual a sua data de nascimento (preencha com os dados do familiar da pessoa com Mielomeningocele/Espinha Bífida)? Ex: 18/11/1980 (DD/MM/AAAA) ____/_____/_________
04. Qual o seu grau de escolaridade (preencha com os dados do familiar da pessoa com Mielomeningocele/Espinha Bífida)? ( ) Ensino fundamental incompleto ( ) Ensino fundamental completo ( ) Ensino médio incompleto ( ) Ensino médio completo ( ) Ensino superior incompleto ( ) Ensino superior completo ( ) Nunca frequentou a escola ( ) Outro (especifique)________________________
05. Qual é a sua ocupação atualmente (preencha com os dados do familiar da pessoa com Mielomeningocele/Espinha Bífida)? ( ) Frequenta a escola ( ) Frequenta um curso técnico profissionalizante ( ) Frequenta a faculdade ( ) Tem um emprego ( ) Não realiza nenhuma atividade ( ) Outro (especifique)_________________________
06. Qual a data de nascimento da pessoa com Mielomeningocele/Espinha Bífida? Ex: 18/08/1985 (DD/MM/AAAA) ____/_____/___________
07. Qual o sexo da pessoa com Mielomeningocele/Espinha Bífida? (   ) Feminino (   ) Masculino

08. Qual o grau de escolaridade da pessoa com Mielomeningocele/Espinha Bífida?
( ) Ensino fundamental incompleto
( ) Ensino fundamental completo
( ) Ensino médio incompleto
( ) Ensino médio completo
( ) Ensino superior incompleto
( ) Ensino superior completo
( ) Nunca frequentou a escola
( ) Outro (especifique)________________________

09. Qual a ocupação atual da pessoa com Mielomeningocele/Espinha Bífida?
( ) Frequenta a escola
( ) Frequenta um curso técnico profissionalizante
( ) Frequenta a faculdade
( ) Tem um emprego
( ) Não realiza nenhuma atividade
( ) Outro (especifique)_________________________

10. Qual a faixa de renda mensal da sua família?
( ) 1 salário mínimo (R$ 788,00)
( ) Até 2 salários mínimos (R$ 1.576,00)
( ) Até 3 salários mínimos (até R$ 2.364,00)
( ) Mais de 3 até 5 salários mínimos (R$ 2.364,00 até R$ 3.940,00)
( ) Mais de 6 e até 8 salários mínimos (R$ 4.728,00 até R$ 6.304,00)
( ) Mais de 9 salários mínimos (a partir de R$ 7.092,00)
( ) Não sei/ Não quero responder

11. Quantas pessoas são sustentadas com essa renda familiar?
( ) Uma
( ) Duas
( ) Três
( ) Quatro
( ) Cinco
( ) Mais de cinco
( ) Não sei/Não quero responder

12. Qual a localização da Mielomeningocele/Espinha Bífida?
( ) Cervical
( ) Torácica
( ) Lombar
( ) Sacral
( ) Não sei

13. A pessoa com Mielomeningocele/Espinha Bífida tem Hidrocefalia?
( ) Sim
( ) Não

14. A pessoa com Mielomeningocele/Espinha Bífida tem válvula para tratamento da Hidrocefalia?
( ) Sim
( ) Não

15. Quais auxílios para locomoção são utilizados?
( ) Anda sem auxílio
( ) Anda com órtese
( ) Anda com muletas/begalas
( ) Anda com andador
( ) Não anda, usa cadeira de rodas
( ) Outro (especifique)______________________

16. Atualmente a pessoa com Mielomeningocele/Espinha Bífida realiza:
( ) Autocateterismo urinário (a pessoa com mielo realiza o cateterismo sozinha)
( ) Cateterismo urinário assistido (o cateterismo é realizado por outra pessoa)
( ) Não realiza o cateterismo urinário

17. Quantas vezes o cateterismo urinário é realizado por dia?
( ) 1 vez ao dia
( ) 2 vezes ao dia
( ) 3 vezes ao dia
( ) 4 vezes ao dia
( ) 5 vezes ao dia
( ) Outro (especifique) _____________________

18. Que tipo de sonda/cateter é usada no cateterismo urinário?
( ) Cateter de plástico
( ) Cateter hidrofílico ou pré-lubrificado
( ) Cateter de metal
( ) Cateter de vidro
( ) Outro (especifique) ______________________

19. A sonda/cateter para o cateterismo urinário é reaproveitada?
( ) Não, a sonda é usada uma única vez e depois jogada fora
( ) Sim, a mesma sonda é usada durante o dia todo
( ) Sim, a mesma sonda é usada a semana toda
( ) Sim, a mesma sonda é usada por mais de uma semana
( ) Outro (especifique) ____________________________

20. Qual a principal pessoa responsável por realizar o cateterismo urinário?
( ) Pessoa com mielo
( ) Mãe
( ) Pai
( ) Irmãos
( ) Avós
( ) Tio/Tia
( ) Profissional de saúde ou cuidador
( ) Outro (especifique) ________________________

21. Onde o cateterismo urinário é realizado?
( ) Cadeira de rodas
( ) Vaso sanitário
( ) Cama
( ) Outro (especifique) ___________________________

22. O cateterismo urinário é feito também fora do domicílio?
( ) Sim
( ) Não

23. Enfrenta dificuldade na realização do cateterismo urinário?
( ) Não
( ) Sim, resistência esfincteriana (dificuldade para passar a sonda no canal da urina)
( ) Sim, dificuldade de posicionamento (dificuldade de achar uma posição para fazer o cateterismo)
( ) Sim, dificuldade de visualização do meato uretral (dificuldade para achar o canal da urina)
( ) Sim, dor/sensibilidade (dor na hora de passar a sonda)
( ) Sim, dificuldade emocional (medo, vergonha, insegurança, desmotivação, não aceitação, entre outros)
( ) Sim, dificuldade porque o banheiro é inadequado
( ) Outro (especifique) ____________________________

24. Conseguiu continência urinária após o cateterismo urinário?
( ) Sim (sem perda urinária, não utiliza fraldas/coletor e nem absorventes)
( ) Parcial (tem pouca perda de urina, precisa usar apenas absorventes)
( ) Não (tem perda de urina, precisa usar fraldas ou coletor urinário constantemente)

25. Quem te orientou como fazer o cateterismo urinário?
( ) Enfermeiro
( ) Médico
( ) Conhecidos (amigos/parentes)
( ) Não recebi nenhuma orientação
( ) Outro (especifique) ___________________________

26.Qual o principal motivo que te trouxe ao MieloFórum?
( ) Buscar informações
( ) Fazer amigos
( ) Compartilhar experiências
( ) Curiosidade
( ) Outro (especifique) __________________________

27. Como você descobriu o MieloFórum?
( ) Internet
( ) Whatsapp
( ) Facebook
( ) Amigos
( ) Profissionais

28. Há quanto tempo você utiliza o MieloFórum?
(   ) Menos de 1 mês
(   ) 1 mês
(   ) 2 meses
(   ) 3 meses
(   ) 4 meses
(   ) 5 meses
(   ) Não sei

29. A linguagem utilizada no MieloFórum é compreensível?
(   ) Concordo totalmente
(   ) Concordo
(   ) Nem concordo e nem discordo
(   ) Discordo
(   ) Discordo totalmente

30. O visual do MieloFórum (letra, cor e formato) é adequado?
(   ) Concordo totalmente
(   ) Concordo
(   ) Nem concordo e nem discordo
(   ) Discordo
(   ) Discordo totalmente

31. Você se interessou pelos textos informativos que estão MieloFórum?
(   ) Sim
(   ) Não
(   ) Não li

32. Como foi navegar no MieloFórum?
(   ) Muito fácil
(   ) Fácil
(   ) Nem fácil, nem difícil
(   ) Difícil
(   ) Muito difícil

33. O MieloFórum te ajudou a discutir ou esclarecer dúvidas sobre o cateterismo urinário (Cat)?
(   ) Sim
(   ) Parcialmente (mais ou menos)
(   ) Não
(   ) Não realizo o cateterismo urinário

34. O MieloFórum é útil para você?
(   ) Sim
(   ) Parcialmente (mais ou menos)
(   ) Não

35. Você fez amigos no MieloFórum?
(   ) Sim
(   ) Não

36. Você indicaria o MieloFórum para outra pessoa?
(   ) Sim
(   ) Talvez
(   ) Não

37. De modo geral, como você avalia o MieloFórum?
(   ) Excelente
(   ) Bom
(   ) Indiferente
(   ) Ruim
(   ) Péssimo

38. De onde você acessa o MieloFórum?
(   ) Computador de casa
(   ) Computador da Lan house
(   ) Computador de amigos/parentes
(   ) Celular
(   ) Tablet/Ipad
(   ) Outro (especifique)

39. Por favor, nos ajude a melhorar o MieloFórum, adicione aqui seus comentários e sugestões:
____

40. A equipe do MieloFórum agradece a sua participação!
Os resultados dessa pesquisa ajudará a aprimorar o MieloFórum e assim apoiar as pessoas com Mielomeningocele/Espinha Bífida e seus familiares.
Caso você queira receber o resultado desta pesquisa, deixe o seu e-mail que o enviaremos a você.
Nome: ______________________________
E-mail:______________________________

Adapted (CHORBEV, et al., 2011; FALEIROS-CASTRO, F., 2012; VASCONCELOS, et al., 2013).

ANNEX

ANNEX 1

Document of approval of the research project by the Research Ethics Committee of the Ribeirão Preto College of Nursing

ESCOLA DE ENFERMAGEM DE RIBEIRÃO PRETO DA UNIVERSIDADE DE SÃO PAULO
Centro Colaborador da Organização Mundial da Saúde para o Desenvolvimento da Pesquisa em Enfermagem
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www.eerp.usp.br - eerp@edu.usp.br

COMITÊ DE ÉTICA EM PESQUISA DA EERP/USP

Of.CEP-EERP/USP – 261/2013

Ribeirão Preto, 6 de novembro de 2013

Prezada Senhora,

Comunicamos que o projeto de pesquisa, abaixo especificado, foi analisado e considerado **APROVADO AD REFERENDUM** pelo Comitê de Ética em Pesquisa da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo, em 6 de novembro de 2013.

Protocolo: **18774213.9.0000.5393**

Projeto: Espinha Bífida e o Cateterismo Vesical Intermitente: desenvolvimento e avaliação de um fórum virtual para pacientes e familiares.

Pesquisadores: Fabiana Faleiros Santana Castro

Em atendimento à Resolução 466/12, deverá ser encaminhado ao CEP o relatório final da pesquisa e a publicação de seus resultados, para acompanhamento, bem como comunicada qualquer intercorrência ou a sua interrupção.

Atenciosamente,

Claudia B. Santos

Profª. Drª. Claudia Benedita dos Santos
Coordenadora do CEP-EERP/USP

Ilma. Sra.
Profª. Drª. Fabiana Faleiros Santana Castro
Departamento de Enfermagem Geral e Especializada
Escola de Enfermagem de Ribeirão Preto - USP