SPINA BIFIDA AND INTERMITTENT BLADDER CATHETERIZATION IN THE CONTEXT OF REHABILITATION:

a comparative study of the technical and bio-psycho-social aspects in Brazil and Germany

Presented by

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ABSTRACT

For the majority of individuals with spina bifida (SB) is the intermittent bladder catheterization (IC) required. Identifying the factors involved in IC, especially self-catheterization is fundamental in the development of effective training programs and public policies consistent with patient reality. This study sought to contribute to this end, describing and comparing the technical, bio-psycho-social and familial factors related to the use of IC. The study included 100 Brazilian individuals and 100 German individuals, of which 108 were female and 92 were male, with an age range of 0 to 55 years and a mean age of 14 years. Data were collected using questionnaires, printed (Brazil) and online (Germany), and analyzed using statistical tests, i.e. multivariate logistical regression and analysis of variance. Predictive factors for self-catheterization were defined, such as having six years of schooling or more, not having hydrocephalus, having a lower level of SB (sacral and lumbar), and differences related to country. The study also demonstrated that the non-application of IC was directly influenced by temporary interruptions of the procedure, the daily frequency of IC and the existence of technical difficulties. Also, it is important to note that continence, even partial, was achieved by 61.5% of the participants and that self-catheterization was responsible for increasing the likelihood of continence up to 3 times. The benefits of IC were statistically proven, such as reducing the number of UTIs (urinary tract infections), which were on average higher in Germans than in Brazilians. Interestingly, there was no difference in the number of UTIs among the Germans who performed disinfection (octenidine, polyhexanide), those who cleaned with soap and water and those who did not perform any cleaning before the introduction of the urethral catheter. The preparation of the transition to adulthood starts in childhood also for individuals with SB. Self-catheterization is part of the process of autonomy in self-care and social participation, and therefore deserves to be studied. Cooperative studies between different countries and cultures contribute to understanding the development and rehabilitation of people with SB.

Keywords: spina bífida, spinal dysraphism, myelomeningocele, intermittent catheterization, self-catheterization, neurogenic bladder, rehabilitation, autonomy, participation.

KURZZUSAMMENFASSUNG

Bei den meisten Menschen, die von Spina bifida (SB) betroffen sind, ist der intermittierende Katheterismus (IK) erforderlich. Die Identifizierung relevanter Einflussfaktoren für den IK ist grundlegend, um wirksame Trainings und soziale Maßnahmen entwickeln zu können, die mit der Lebenswirklichkeit der Patienten gut vereinbar sind. Die vorliegende Studie hat zum Ziel, technische, bio-psycho-soziale und familiäre Faktoren bei der Umsetzung des IK bei 100 Personen in Brasilien und 100 Personen in Deutschland zu beschreiben und zu vergleichen. Von den Studienteilnehmern im Alter zwischen 0 und 55 Jahren, und einem Durchschnitt von 14 Jahren, waren 108 weiblich und 92 männlich. Die Daten wurden mithilfe eines Fragenbogens in Papierform (Brasilien) und online (Deutschland) erhoben und mittels statistischer Analysemethoden wie multivariater logistischer Regression und Varianzanalysen ausgewertet. Es wurden prädiktive Faktoren für den Selbstkatheterismus eruiert wie z.B. der Bildungsstand (nach mindestens sechsjährigem Schulbesuch), Ausschluss eines Hydrocephaluses, einer im unteren Bereich angesiedelten SB (im Sakral- und Lumbalbereich) sowie länderspezifische Besonderheiten. Die Studie zeigt darüber hinaus, dass die Nichtanwendung des IK von technischen Schwierigkeiten, von temporären Unterbrechungen der Nutzung sowie der täglichen Anwendungshäufigkeit des IK beeirnflusst wird. Darüber hinaus zeigte sich, dass eine partielle Kontinenz von 61,5% der Studienteilnehmer erreicht wurde und dass die Selbstkatherisierung mit einer dreifach erhöhten Chance auf Kontinenz einhergeht. Die Vorteile des IK konnten statistisch belegt werden, wozu u.a. eine geringere Anzahl von Harnwegsinfekten gehört, die bei den deutschen Teilnehmern jedoch ein höheres Vorkommen im Vergleich zur brasilianischen Stichprobe aufwies. Überraschenderweise wurde keine Unterschiede in der Anzahl von Harnwegsinfektionen bei den deutschen Teilnehmern in Abhängigkeit davon festgestellt, ob sie eine Desinfizierung (Octenidine, Polihexanide) durchführten, ob die Reinigung mit Wasser und Seife stattfand oder ob sie keine Reinigung vor dem Einführen des transurethralen Katheters vornehmen. Die Vorbereitung für den Übergang ins Erwachsenenleben wird auch bei Personen mit SB wird bereits in der Kindheit grundgelegt. Die Selbstkatheterisierung, die wesentlich zum Autonomieprozess im Sinne der Selbstversorgung und sozialen Partizipation, beiträgt, verdient aus diesem Grund vermehrt beforscht zu werden. Vergleichsuntersuchungen in

verschiedenen Ländern und Kulturen leisten einen Beitrag, um die Entwicklung und Rehabilitation von SB-Patienten besser verstehen und fördern zu können.

Schlüsselwörter: Spina bífida, spinale Dysraphie, Myelomeningozele, intermittenderer Katheterismus, Selbskatheterismus, neurogene Blase, Rehabilitation, Autonomie, Partizipation.

RESUMO

Para a maioria dos indivíduos com espinha bífida (EB) o cateterismo vesical intermitente (CI) será necessário. Identificar os fatores que envolvem o CI, em especial o autocateterismo, é fundamental para desenvolver treinamentos eficazes e políticas públicas compatíveis com a realidade dos pacientes. Este estudo procurou contribuir nesse sentido, descrevendo e comparando os fatores técnicos, biopsicossociais e familiares relacionados à realização do CI em 100 indivíduos brasileiros e 100 indivíduos alemães, sendo 108 do sexo feminino e 92 do sexo masculino, com uma faixa etária de 0 a 55 anos e idade média de 14 anos. Os dados foram coletados, mediante questionário, impresso (Brasil) e online (Alemanha), e analisados através de testes estatísticos, como, por exemplo, a regressão logística multivariada e análise de variância. Fatores preditivos para o autocateterismo foram identificados, tais como possuir escolarização de 6 anos ou mais, não apresentar hidrocefalia, ter um nível da EB mais baixo (sacral e lombar), além de diferenças relacionadas à nacionalidade. O estudo mostrou também que a não realização do CI foi influenciada diretamente pelas interrupções temporárias do procedimento, pela frequência diária do CI e pela existência de dificuldades técnicas. Além disso, observou-se que a continência, mesmo que parcial, foi alcançada por 61,5% dos participantes e que o autocateterismo foi responsável por aumentar, em 3 vezes, as chances da continência. Os benefícios do CI foram comprovados estatisticamente, como a redução do número de ITU (infecção do trato urinário), que teve uma média maior nos alemães do que nos brasileiros. Curiosamente, não foi observada uma diferença, no número de ITU, entre os alemães que realizavam a desinfecção (Octenidina, Polihexanide), a higienização com água e sabão e os que não realizavam limpeza alguma antes da introdução do cateter uretral. A preparação da transição para a vida adulta já começa na infância também para o indivíduo com EB. O autocateterismo se insere no processo da autonomia no autocuidado e da participação social, e por isso merece ser estudado. Pesquisas cooperativas entre diferentes países e culturas distintas contribuem para a compreensão do desenvolvimento e da reabilitação das pessoas com EB.

Palavras chave: espinha bífida, disrafismo espinhal, mielomeningocele, cateterismo intermitente, autocateterismo, bexiga neurogênica, reabilitação, autonomia, participação.

SUMMARY

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LIST OF ABBREVIATIONS AND ACRONYMS

AMWF	Association of the Scientific Medical Societies of Germany
ANVISA	National Health Surveillance Agency
ASBH	Association of Spina Bifida and Hydrocephalus of Germany
BH	Belo Horizonte
CIC	Clean Intermittent Catheterization
CI	Confidence Intervals
DATASUS	Database of the Unified Health System
DESTATIS	Federal Statistical Office of Germany
Df	degrees of freedom
DFTN	Defeitos do fechamento do tubo neural
DGU	German Society of Urology
dp	standard deviation
EAU	European Association of Urology
EAU	European Association of Urology
ECLAMC	Latin American Collaborative Study
HC	Hydrocephalus
IBGE	Brazilian Institute of Geography and Statistics
IC	Intermittent Catheterization
IQ	Intelligence quotient
ISC	Intermittent self-catheterization
KAAD	Catholic Academic Service International
LL	Log Likelihood
m	Mean
M.S.	Máster

md	Median
MMC	Myelomeningocele
NTD	Neural Tube Closure Defect
OR	Odds Ratio
OSB	Open Spina Bifida
PU	Polyurethane
PVC	Polyvinyl chloride
SB	Spina Bifida
SE	Standard Error
SINASC	Information System Of Live Births
SPSS	Statistical Package for the Social Sciences
SUS	Brazilian Unified Health System
UTI	Urinary tract infection
VP	Ventriculoperitoneal

1. INTRODUCTION

Spina bifida (SB) or spinal dysraphism (SD) is the most common congenital malformation involving the spinal medulla compatible with life (Catala 2008; Santos & Pereira 2007). Myelomeningocele (MMC) is the most serious form of SB, representing 98.8% of all cases of open SB and 85% of neural tube closure defects (Fernandes 2009; Könü-Leblebicioglu & Yonekawa 2008; Rossi et al. 2007; Rocco et al. 2007).

In the beginning of the 1950s, the rate of survival of individuals with open spina bifida (OSB) was close to 10% (Bowman et al. 2009). Today, with surgery to repair myelomeningocele in the first two hours of life, the control of hydrocephalus (HC) with the use of a shunt, and the treatment of the neurogenic bladder with intermittent bladder catheterization (IC), the survival rate has changed drastically and a large number of children with OSB are surviving and becoming adults (Davis et al. 2006; Araújo & Borigato 2000b; McDonnell & McCann 2000). Bowman et al. (2001), after a 25-year study, confirm that at least 75% of children with MMC will reach adult age (Bowman et al. 2001). Therefore, there will be increasingly more adolescents and young adults with SB seeking rehabilitation services. One of the major challenges for these individuals is the transition from pediatric medical attention to adult health support, demonstrating the need for the development of rehabilitation services directed to this growing population (Bowman et al. 2009). Thus, studies are beginning to look beyond correcting physical inabilities toward understanding and encouraging autonomy and social participation (Fletcher et al. 2010b; Sawin et al. 2007; Davis et al. 2006).

Despite advances in treatment and management of complications associated with SB, renal deterioration is currently the primary cause of death and morbidity rates among youth with MMC (Hunt & Oakeshott 2003; Araújo & Borigato 2000b). Even though the neurogenic bladder, and resulting threat to the urinary tract, is an important complication related to SB, parents and even health professionals do not view it as a priority for treatment (Araújo & Borigato 2000b). Initially, families notice and are more concerned about motor deficiencies.

After more than three decades of study, intermittent bladder catheterization is considered the treatment of choice worldwide for the prevention of renal deterioration resulting from a neurogenic bladder. The technique for bladder emptying through intermittent surveying, in addition to being the most similar to normal bladder function, is the easiest to execute and does not carry risks for renal function nor for the life expectancy of the patients (AWMF (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellchaften) 2009; Stöhrer et al. 2009; Brazilian Society of Urology 2006; Aslan & Kogan 2002). However, performing bladder self-catheterization, as well as intestinal management, are considered by various researchers as the daily activities of greatest difficulty for training and independent execution by patients with SB (Andrén & Grimby 2000).

Individuals with SB, and consequently bladder dysfunction, need life-long care and represent a clientele requiring periodic health services. New challenges arise during the period of transition between childhood and adolescence/adulthood, such as independence in day-to-day activities, self-care, insertion into the workplace, social and partner relationships, and desire to have children (Barf et al. 2009; Lindehall et al. 2008). Excellence in the rehabilitation of individuals with SB requires personalized multi-disciplinary work that can prevent, monitor and treat complications that can affect functionality. The objective is to improve life expectancy and quality of life for patients, as well as maximize their participation (Bowman et al. 2009; Stöhrer et al. 2009; Cardol et al. 2002). In this sense, rehabilitation professionals play an important role both with the family and with the systems in which the individual is a participant, guaranteeing a better fit between the people with spinal dysraphism and the services available to them (Darrah et al. 2010).

As a nurse at a Brazilian rehabilitation center, I work in neurostimulation and self-care training, daily life activities and vesicointestinal re-education, with an emphasis on teaching IC to patients with SB and their families. Through my observations of patients' difficulties in training and performance of self-catheterization, I found the desire to study IC more in depth in my search for knowledge about how to simplify, transpose difficulties and transform realities through an international exchange experience.

In the present worldwide reality regarding treatment of SB, there is a need to collaborate and share information in order to improve patient care and create opportunities for transcultural research (Ann Alriksson-Schmidt 2009; Käppler 2002). Scientific collaboration between countries is fundamental in order to better understand the needs of individuals with SB and their families, and in order to plan and implement means for them to achieve health, quality of life and social participation. However, in the studied literature, there were no intercultural studies with data from two countries on different continents about IC in individuals with SB. Thus, this study proposes to describe and compare the factors that affect the use of IC in people with SB in Brazil and Germany, and later, to provide suggestions based on the experiences of these two countries.

2. REVIEW OF SCIENTIFIC LITERATURE

In this introductory section, the topics of rehabilitation, spina bifida, neurogenic bladder, intermittent bladder catheterization, and social participation will be conceptualized and clarified using a review of current scientific literature, seeking to contextualize the universe in which the proposed study will take place.

2.1 Rehabilitation

According to Greve, 2007, "Rehabilitation is the process that, using scientific fundamentals, seeks to achieve the development and/or recuperation of an individual's functionality, with the final goal being social insertion" (Greve 2007).

The word 'rehabilitation' primarily comes from Latin *habilitare*, a verb which means 'to become able or apt; to prepare; to prove necessary; to acquire abilities'. Using the prefix, *re-habilitar* means 're-acquire a lost or diminished ability' (Greve 2007).

In pediatrics, rehabilitation versus habilitation is treated as a semantic issue, since the child/youth, being in development, did not acquire certain abilities before becoming disabled. In the case of spina bifida, the lesion is congenital. Therefore, these patients can be referred to as those who need habilitation (Greve 2007; Peres 2007).

Cardol, 2002, states that "the ultimate goal of rehabilitation is to acquire and retain the highest possible level of autonomy, with the aim of maximizing participation" (Cardol et al. 2002). The final section of this literary review will clarify concepts that involve the rehabilitation of individuals with SB, such as autonomy, self-care and participation.

2.2. Neural tube closure defects

The embryological formation of the human nervous system begins with the thickening of the ectoderm, located above the notochord, and constitutes the neural folds which gather to form the neural tube. This process is initiated by both the notochord and the mesoderm. The closing of the neural tube begins in the cervical region and extends cranially (with completion around the 24th day), and caudally to L1-L2 (with completion around the 26th day). However, the closure of the neural tube can occur concurrently at multiple sites. Flaws in this process result in cranial and spinal dysraphism with exposure of nerve tissue, and are referred to as neural tube closure defects (NTDs) (Requeijo 2008; Busam et al. 1993).

Therefore, NTDs are malformations that occur in the initial phase of fetal development, between the third and fifth weeks of embryogenesis, and involve the primitive structures that become the brain and spinal cord. Spinal dysraphism or spina bifida is the most common congenital malformation involving the spinal cord and, along with anencephaly, make up the two most common neural tube defects. Together they account for about 90% of all cases with 10% of the other cases consisting primarily of encephalocele (Catala 2008; Santos & Pereira 2007). Two factors determine the type and severity of dysraphism: the location on the neural tube where the closure malformation occurred and the intensity of this abnormality (Henriques & Pianetti 2011).

The prevalence of NTDs in international literature is 1 case per 1,000 live births; however, there are variations between different regions of the world (Gelineau-van WJ 2001). In Brazil, there are few studies on the prevalence of NTDs. In the available surveys, rates range from 0.83 to 1.87/1,000 births (Pacheco et al. 2006). Between 1967 and 1995, a study by the Latin American Collaborative Study (ECLAMC) of about four million births in Latin America showed a prevalence of 1.5/1,000 live births (Castilla & Orioli 2004; Gelineau-van WJ 2001). In Germany, the average incidence of NTDs between 1997 and 2003 was approximately 0.68/1,000 births (Klusmann et al. 2005).

2.3 Spina bifida

2.3.1. Definition

The term spina bifida was suggested by Tulp in 1651 and intended exclusively to describe a spinal abnormality involving the duplication of the vertebra spinous process, a flawed bone closure in the spinal column. However, the term spina bifida is still widely used as a synonym for spinal dysraphism (Catala 2008; Rossi et al. 2007). Etymologically speaking, the term "dysraphism" means *flaw in the closure of the neural tube* and should therefore be used to refer only to abnormalities of primary neurulation, yet the term has become synonymous with congenital spinal malformation (Rossi et al. 2007).

Spinal dysraphism (SD) or spina bifida (SB) can be classified as either open or closed, as shown in Table 1 (Rossi et al. 2007). Open SB can be divided basically into myelomeningocele (MMC), meningocele and lipomyelomeningocele. Among the neural tube closure defects, MMC is the most common, with 85% of cases worldwide (Fernandes 2009; Rocco et al. 2007).

MMC, the most severe form of open SB and the main focus of this study, represents approximately 98.8% of all cases of open spinal dysraphism (Könü-Leblebicioglu & Yonekawa 2008; Rossi et al. 2007). This is due to a malformation, that is, a closure defect in the caudal portion of the neural tube that occurs around the fourth week of pregnancy (McLone & Dias 1991). MMC is characterized by the presence of a cyst or sac in the dorsal region, composed of dermis, epidermis, meninges (dura mater and arachnoid), degenerated nerve tissue, nerve roots, spinal cord, and is filled with cerebrospinal fluid. The nerve roots that come from the spinal cord, in the region of the lesion, if they appear to be malformed, often result in paralysis, the larger and the higher the lesion site; lying most commonly located between vertebrae L5 and S1 (Plese & Ciquini Junior 1996). The medullar position of the motor nerve roots is referred to as motor level (Table 1). Its definition is important for functional classification and for

patient monitoring since changes in motor level can be a sign of neurological progression. Simply put, in accordance with the region of the spinal lesion, SB may be cervical, thoracic, lumbar or sacral. It should be noted that there are numerous classifications of SB that are even more complex, and that correspond to the following levels: motor, neurological, functional, among others (Verhoef et al. 2006; Rintoul et al. 2002).

Table 1 – Evaluation of motor level

Level	**Muscle**	**Movement**	**Test**
L1-L2	Psoas	Hip flexion	Lift the knee while sitting
L3-L4	Quadriceps	Leg extension	Kick a ball while sitting
L5-S1	Knee flexor	Knee flection	Bend the leg in the prone position
L4-L5	Anterior Tibial	Dorsiflexion of the foot	Walk on heels
S1-S2	Calf	Plantar flexion of the foot	Walk on toes

(SARAH Network of Rehabilitation Hospitals 2009)

Those with closed SB are a more heterogeneous group that is composed of diastematomyelia, tethered cord syndrome, thickening of the *filum terminale* and dermal sinus. Some are not clinically evident at birth, and patients are brought for medical evaluation later in childhood only when complications begin to appear. The clinical exam in this evaluation is significantly useful for the differential diagnosis since skin changes of the sacrococcygeal region are present in 80% of cases. An important finding of this assessment is the presence of a subcutaneous mass, skin folds and tufts of hair and angiomas (SARAH Network of Rehabilitation Hospitals 2009; Rossi et al. 2007).

In spina bifida occulta, there is no neural involvement. There is only an incomplete closure of the vertebral arches that are not associated with other abnormalities and often found at random (Rossi et al. 2007).

Table 2. Type of spina bifida / spinal dysraphism and caracteristics

Type	Disorder	Characteristics
Open	Myelomeningocele	Midline lesion containing cerebrospinal fluid, meninges and marrow elements. Exposed nerve tissue not covered by skin.
	Meningocele	Cystic lesion composed of cerebrospinal fluid, meninges and skin.
	Lipomielomeningocele	Fat mass, usually covered by skin, extending to the spinal cord.
Closed (with neural involvement)	Diastematomyelia	The caudal portion of the spinal cord is broken; the segments are often separated by a bony or cartilaginous spur.
	Tethered cord	Medullar cone and terminal filum attached to the bone structure.
	Dermal sinus	Dermal epithelium that extends from the skin to deeper tissues. Ability to communicate with the subdural space and development of meningitis.
Closed (without neural involvement)	Spina bifida occulta	Incomplete closure of vertebral arches not accompanied by other alterations.

(SARAH Network of Rehabilitation Hospitals, 2009)

2.3.2. History

Spina bifida, also referred to as spinal dysraphism has been present as long as man has inhabited the earth according to anthropological digs in the Americas where terracotta sculptures of people of ancient civilizations with SB lived. Due to lack of treatment

available at the time, it can be concluded that few individuals survived. Descriptions of a disease which seem to be that of SB are also found in the early writings of Hippocrates. The first definitive description of SB is from the sixteenth century and belongs to Dutch physician Peter van Forest. In the sixteenth and seventeenth centuries, many doctors describe SB as an untreatable disease. Only in the eighteenth century do we have a solid clinical description of the association between SB and hydrocephalus, which was presented by Italian professor Morgagni (Goodrich 2008).

Cruveilhier clearly details what is currently called Arnold Chiari II Malformation almost 55 years before Arnold Chiari described, with an anatomical definitive description, that which remains to this day a classic of congenital anomalies of the brainstem associated with hydrocephalus. In 1882, Lebedeff proposed the concept that SB resulted from a failure in the closure of the neural tube early in fetal development. In an effort to broaden the concept of SB, Fuchs introduced the term "Myelodysplasia," in 1910 to denote SB and enuresis associated with foot deformities. Later, Lichtenstein used "spinal dysraphism" to describe a group of disorders of cutaneous, dermal and neural origin (Goodrich 2008).

During the nineteenth century, various attempts were made to correct SB, through puncturing the dysraphic sac, iodine injections and sclerosis; however, all without success. Surgical intervention for SB only became possible in the 1870s with the introduction of aseptic techniques because, prior to that, death from septcemia was often the end result. Surgical treatment utilizing rotation of flaps of skin and muscle was first performed in 1892 by the German surgeon, Bayer. This new technique put the neural elements inside the spinal canal and then covered them with layers of fabric; it was an important concept and a remarkable advance in the treatment of SB (Könü-Leblebicioglu & Yonekawa 2008; Goodrich 2008).

In the first half of this century, surgeons were refining the surgical techniques for repairing myelomeningocele with a closure that utilizes multiple layers such as the dura mater, fascia, muscles and skin. In 1943, Ingraham and Hamlin argued that the surgical repair of myelomeningocele should be postponed until 18 months of age and was

recommended only for children who did not exhibit a severe neurological impairment (Könü-Leblebicioglu & Yonekawa 2008; Goodrich 2008). Following this line of thinking, the surgical treatment of MMC in newborns has been the center of heated scientific discussions for a long time, with researchers debating the social and economic burden that these patients would bring to their parents and society (Requeijo 2008). Correction in the perinatal period, during the first week of life in order to avoid complications, especially infections, has been defended by surgeons since 1960. Currently, surgical correction in the first 24 hours , and no later than 72 hours, after birth has become routine in most countries, including Brazil and Germany (ASBH 2009; Könü-Leblebicioglu & Yonekawa 2008; Goodrich 2008; Perry et al. 2002; Araújo & Borigato 2000b).

Until the beginning of 1950, the survival rate of patients with MMC was only 10% (Laurence 1974). By the 60s, it was estimated that only one in seven people with open SB had a chance to attend school and only one in 70 could achieve normal school performance. Other studies revealed that 90% of patients had died between 6 and 12 years of age. The survival rate beyond the first seven years of life did not exceed 28% of cases, with deaths associated to infection, hydrocephalus with acute decompensation and complications that evolved more slowly, but that also led to death; including, for example, complications with the kidneys and again, hydrocephalus (Requeijo 2008; Zambelli 2006).

A milestone in the natural history of spina bifida occurred in 1950 with the introduction of the ventriculoperitoneal (VP) shunt for treatment of HC. Named *Spitz-Holter,* in honor of its creators, the shunt was designed with silicone at the Children's Hospital of Philadelphia in the United States (Boockvar et al. 2001). In the following decades, the development of even more modern and effective valves associated with clean intermittent bladder catheterization allowed for an increase in survival, as well as quality of life, for patients with this malformation (Zambelli 2006; Requeijo 2008). The health team, however, still faces challenges such as complications with the VP shunt due to its obstruction and displacement, as well as the viability and the simplification of the training techniques for intermittent bladder catheterization (Quinn & Adzick 1997).

An American study of a cohort born between 1975 and 1979 showed that 74% of patients survived to young adulthood (Bowman et al. 2009). With the decrease in myelomeningocele (MMC) mortality and increased patient survival, an increasing number of adolescents and young adults with MMC are seeking rehabilitation services (Davis et al. 2006). Currently, one of the biggest challenges is the transfer of these young adults from pediatric medical care to adult health care, demonstrating the need to develop rehabilitation services aimed at the growing number of adults suffering from SB (Bowman et al. 2009, Bowman 2001).

2.3.3. Epidemiology

Establishing the true incidence of SB is a difficult task, since it would need to include all instances in the population of live births, stillbirths, miscarriages and elective terminations (Vivek 2008; Josan et al. 2008). The incidence of MMC is varied and influenced by geographical, ethnic, and nutritional factors (Bowman 2009). Worldwide, the incidence of NTDs varies from 0.17 to 6.39 per 1,000 live births (Bowman et al. 2009). In the United States, the incidence is 1 per 1000 live births (Fernandes 2009) and affects about 3,000 pregnancies annually (Bowman et al. 2009). In Central Europe, the frequency is 1 to 2 per 1,000 live births (Bartsch et al. 2009). German studies show that the incidence of MMC varies from 0.42 to 0.61:1,000 live births (Luder et al. 1989).

In Brazil, there are few studies regarding the incidence of SB. Of the two studies conducted, the one in Campinas shows a MMC incidence rate of 2.28:1,000 live births (Sbragia et al. 2004), and the other study in Curitiba shows a rate of 1.8:1,000 live births (Ulsenheimer et al. 2004). These data are consistent with the incidence found in Latin America which is 1.5:1,000 births (Nazer et al. 2001). In Belo Horizonte, Brazil there are no prevalent studies specific to SB; however, researchers found a prevalence of neural tube defects of 4.16:1,000 live births (Aguiar et al. 2003). According to SINASC (information system of live births), of the 2,881,581 live births in Brazil in 2009, 461 were reported as newborns with spina bifida (DATASUS 2009).

Since 1980, the prevalence of SB in developed countries has been decreasing due to the administration of folic acid for women during pre and post-conception, food fortification with this vitamin, the availability of prenatal diagnosis and elective termination of pregnancies (Könü- Leblebicioglu & Yonekawa 2008; Souza 2007). The incidence of MMC in these countries is around 0.6 per thousand live births (Könü-Leblebicioglu & Yonekawa 2008).

In England and Wales, the incidence decreased from 2.25/1,000 live births in 1972 to 0.48/1,000 live births in 1990 (Kadir 1999). In Germany, of the approximately 1,000 pregnancies per year that are affected by SB, about 500 of these pregnancies are interrupted at the request of the parents and 500 children are born and live with the malformation. According to ASBH (Association of Spina Bifida and Hydrocephalus of Germany), with an effective prophylaxis with folic acid throughout the country, probably up to 500 of these 1,000 children could be born healthy (ASBH 2009).

SB has a higher frequency in Caucasians, and less frequency in blacks, slightly higher in females and in less disadvantaged social classes (Henriques & Pianetti 2011; Fernandes 2009). In some racial groups, such as Hispanics and Celtics (Irish), the incidence of SB is higher (Bowman 2009).

The risk of recurrence of MMC related to previous family history is described in the following table.

Table 3 - Risk of recurrence of MMC in relation to the degree of family history

Family history with MMC	Risk of recurrence of MMC
Mother and father with MMC	15%
Three previous children with MMC	10%
Mother and previous child with MMC	6.5%
Two previous children with MMC	5.0%
Mother with MMC	5.0%
A previous child with MMC	2.0-2.5%
Siblings with MMC	2.0%
A child with multiple vertebrae or spinal dysraphism	2.0%
Maternal aunt with MMC	1.0%
Maternal age over 35 years	0.33%
Relatives of the first or second degree with MMC	0.3%

(Requeijo 2008; Bowman et al. 2009)

2.3.4. Etiology

The etiology of SB is heterogeneous and multi-factorial, and most cases are the result of a complex interaction between multiple genes and environmental factors that is still poorly understood (Josan et al. 2008; Vivek et al. 2008; Aguiar et al. 2003). Among the risk factors involved are family history, diabetes and maternal obesity, the use of valproic acid and other anticonvulsants during pregnancy, hyperthermia, deficiency of

zinc and folic acid (Josan et al. 2008; Vivek et al. 2008; Könü-Leblebicioglu & Yonekawa 2008; Watkins et al. 2003; Aguiar et al. 2003).

2.3.5. Physiopathology

Spinal dysraphisms are caused by disorders that occur during a limited period of early embryonic development, between the second and sixth weeks of gestation. During this period of embryological development of the spinal cord, there are three consecutive stages: gastrulation (2^{nd} and 3^{rd} weeks), primary neurulation (3^{rd} and 4^{th} week), and secondary neurulation (5^{th} and 6^{th} weeks) (Könü-Leblebicioglu & Yonekawa 2008; Rossi et al. 2007). Surveys confirm that the damages encountered with neural elements in SB happen for two reasons - first, because of a failure in the closure of the neural tube itself and the second occurs during the course of pregnancy with traumas of fetal movement and chemical damage of neural tissue that has come in contact with the amniotic fluid (Chescheir 2009).

2.3.6. Related complications

The clinical manifestations of MMC will depend on which nerve roots and spinal segments were affected (Liptak 2002). These include:

Muscle weakness: some degree of change in muscle strength in lower limbs is exhibited by all patients with MMC. The greater the extent of the spinal cord injury, the greater the motor and sensory difficulty (Palhares 2000).

Change in skin sensitivity: characterized by a deficit in perception of pain, touch, temperature and/or position of body segments. The serious consequence of this change is the appearance of skin lesions, which may be in the form of burns, bruises and especially pressure ulcers caused by prolonged use of a wheelchair or braces on the lower limbs (Ekmark 2009). An American study of 84 adults with MMC revealed that

54% of these patients had experienced at least one pressure ulcer during their lives (Roach et al. 2011)

Deformities: mainly observed in the spine, hip (dislocation) and lower limbs, the deformities may be present at birth or appear during growth (Sharrard 1993). Scoliosis, congenital kyphosis and hyperlordosis are the principle deformities of the spine. The congenital deformities occur due to muscular imbalance and the presence of abnormal intrauterine movements in addition to vertebral malformations. However, during growth, the deformities may appear because of the habitual positioning of the lower limbs, muscular imbalance and neurological worsening, such as tethered cord syndrome. The deformities may have a negative impact on self-care activities, transfer and gait (Palhares 2000; Campbell 1995).

Limited mobility: in accordance with the degree of impact of the lesion on the nervous system, the patient will have greater or lesser capacity for movement and potential for independence in activities of daily life (Hoffer et al. 1973). Other factors besides the neurological lesion itself can influence the motor development of the child, such as his/her emotional condition, degree of motivation, parental and caregiver investment, cognitive ability, muscle strength and posture while performing tasks (Palhares 2000). Lesion levels and the acquisition of ambulation influence in different ways the performance of children with MMC in their self-care, mobility and social functioning (Collanges et al. 2008).

Obesity / overweight: obesity is a common complication in MMC. Decreased mobility, the use of a wheelchair and the lack of physical activity make these individuals more vulnerable to this complication (Stein et al. 2007). Studies show that obesity may reach as many as 40% of MMC cases (Fiore et al. 1998). An English study of 54 SB patients with a mean age of 35 showed that 55% were overweight (Hunt & Oakeshott 2003). Increased waist circumference can also hinder the positioning and/or visualization of the urethral meatus during the performance of bladder catheterization (Newman & Willson 2011; Stein et al. 2007).

Latex allergy: Patients with SB have a higher risk of latex allergy (Hochleitner et al. 2001). A study of 80 children with SB was conducted to assess the prevalence of allergy to latex. The study revealed that about 40% of children showed some latex sensitivity with specific immunoglobulin, and 15% (12) suffered from clinical reactions such as urticaria, conjunctivitis, angioedema, rhinitis and bronchial hyperreactivity (Ausili et al 2007.).

Intestinal disorders: more than 80% of MMC patients have changes in bowel function (Stein et al. 2007). This occurs as a result of uncoordinated propulsive intestinal action, and changes in the rectal contraction and sensation, and can lead to incontinence and constipation (Liptak 2002; Eire et al. 1998). Intestinal constipation is a key cause of death in patients with SB (Clayton et al. 2010). The neurogenic bowel can be treated with bowel retraining, dietary measures and toilet training with intestinal emptying maneuvers, such as bowel (colon) massages, perianal massage, and digital rectal stimulation associated with the Valsalva maneuver during daily toilet training (Costa & Carvalho 2006). Bowel management, along with bladder control and toilet use, are among the daily life activities that are more difficult for patients with SB in adulthood (Andrén & Grimby 2000).

Urological disorders: may be present in the neurogenic bladder, and include: incontinence, recurrent urinary infections, stones, vesicoureteral reflux, hydronephrosis and deterioration of renal function (Osterlund et al. 2005; Stein et al. 2007). Currently, renal deterioration is the main cause of death among young people with MMC (Hunt & Oakeshott 2003). When the family and the patient, while still a baby, seek rehabilitation services for treatment for motor impairments, the health care team should educate them about bladder dysfunction and the need for urological monitoring to prevent renal deterioration and to preserve the vital renal function (Kari et al. 2009; Araújo & Borigato 2000b).

Malformations in the central nervous system:

- *Hydrocephalus (HC)*: is the accumulation of intracranial cerebrospinal fluid within

the cerebral ventricles which results in dilation. This leads to an imbalance between the production and absorption of the fluid, and may or may not be accompanied by increased intracranial pressure. It is present in about 85 to 90% of patients with myelomeningocele (Fletcher et al. 1992). When an intrauterine diagnosis of hydrocephalus is made, several neurosurgeons recommend that the placement of the ventriculoperitoneal shunt occur at the same time as the surgical repair of MMC (Perry et al. 2002). HC, as well as complications with VP, represents a predictive factor for cognitive difficulties of patients with SB (Amoedo 2005; Barnes et al. 2002; Hunt 1999).

- *Type II Arnold Chiari malformation*: is a congenital brain disorder characterized by cerebellar herniation through the foramen magnum and displacement of the fourth ventricle and the brain stem down into the spinal canal (Henriques & Pianetti 2011; Stevenson & Stevenson 2004). This cerebral malformation has an extremely high frequency in open SB cases, affecting more than 90% of these individuals, and representing the main cause of hydrocephalus in this population (Könü-Leblebicioglu & Yonekawa 2008; Stevenson & Stevenson 2004). The present cerebellar atrophy is associated with cognitive and motor deficits (Salman 2011). About 30% of patients with type II Arnold Chiari malformation may exhibit symptoms such as squinting, wheezing, episodes of apnea, sleep disorders, dysphagia, and changes in upper limb function. These symptoms can also be caused or aggravated by the malfunction of the ventricular shunt (Wolfgang et al. 2002; Lennerstrand et al. 1990).

- *Tethered cord syndrome*: tethered cord syndrome occurs as a consequence of mechanical traction of the medulla with progressive neurological deterioration (Könü-Leblebicioglu & Yonekawa 2008). One third of patients with MMC may develop symptomatic tethered cord such as progressive scoliosis, alterations in gait, spasticity or pain, weakness, lower limb contractures or changes in bladder function. Symptoms may also be found in the upper limbs when spinal stretching occurs in the cervical region (Wolfgang et al. 2002).

Cognitive Alterations: research shows the impact of MMC, and most importantly, of hydrocephalus, on cognitive functions (Amoedo 2005; Plese & Ciquini Junior 1996). About 75% of children with MMC may have below average intelligence and a third may have attention deficit hyperactivity disorder (Liptak 2002). From a cognitive perspective, neurosurgical treatment of HC using a shunt should be performed as early as possible, involving technical (aseptic) care, to avoid as much as possible complications that can lead to inadequate system function or infections that threaten the cognitive development of children with MMC (Fobe et al. 1999). Amoedo, in her characterization of the intellectual performance of 102 Brazilian patients with MMC, noted the difficulty of patients in relation to IQ and perceptual organization performance. She also noted better scores on verbal performance, and like other researchers, highlighted the visuoconstructive and visuoperceptive problems that these patients may have (Amoedo 2005; Dennis et al. 2002). Research shows that even with adequate levels of word recognition, these children live with a significant deficit in reading comprehension, processing speed and working memory, along with a deficit in mathematical skills also frequently associated with HC (Boyer et al. 2006; Barnes et al. 2002; Dennis & Barnes 2002; Barnes & Dennis 1992). Also with respect to mastery of language, many children with SB show adequate development in grammatical and lexical concepts, but they have difficulty in the construction of meaning and in practical communication (Vachha & Adams 2003; Fletcher et al. 2002).

A study of the academic career of patients with SB revealed that intelligence is one of the key contributing factors for an individual to attend a special needs high school, as well as their having hydrocephalus and being confined to a wheelchair. In this study, only half of the participants with HC attended regular high school, while for the participants without HC, high school performance was similar to the general population (92%) (Barf et al. 2004).

Other relataed complications: Other changes associated with SB that deserve the attention of professionals and family members are visual alterations (strabismus), convulsions, short stature, early onset puberty in girls, cryptochidism in boys, sexual

dysfunction (erectile dysfunction, change in libido) and hydrosyringomeylia (Fernandes 2009; Stein et al. 2007; Gamé et al. 2006; Biglan 1995; Lennerstrand et al. 1990).

2.3.7. Diagnosis

The diagnosis of SB can be made beginning in the 11th week of gestation using ultrasound, which has proven to be a good diagnostic tool, with a reliability of up to 75% in case identification. Another possible indication are higher levels of alpha-phytoprotein and amniotic acytelcolinesterase (Henriques & Pianetti 2011; Appasamy et al. 2006; Stevenson & Stevenson 2004; Robbin et al. 1993; Rose & Mennuti 1993). After intra-uterine diagnosis, ultrasound can also allow for fetal monitoring during gestation and obstetric planning. Another exam recommended to complement pre-natal propaedeutics is magnetic resonance. Late diagnosis, realized post-birth, complicates medical intervention and makes it particularly challenging to prepare and orient the parents, who will not be prepared to have a child with a malformation (Henriques & Pianetti 2011). Even in cases where the parents do not want to abort or the law does not permit it, intrauterine diagnosis helps the parents and health team to be better prepared to handle the new situation (Requeijo 2008; Hamilton & Dornan 1992).

In some countries like the United States, the measurement of alpha phytoprotein levels is routinely measured between the 16th and 18th weeks of gestation (Zambelli 2006).

2.3.8. Treatment of spina bifida

OSB is considered a neonatal urgency and intervention involves conditioning the medulla and its roots within the spinal canal, suturing the dural sack and forming a satisfactory cutaneous coating, preferably in the first 24 hours of life (Henriques & Pianetti 2011; Goodrich 2008; Perry et al. 2002).

Fetal surgery guarantees the correction of some fetal problems in the beginning of gestation (Quinn & Adzick 1997). The key advantages to intrauterine surgical treatment, which are promoted by the neurosurgeons that support this technique, include the early protection of the nervous tissue from the amniotic fluid, which can harm the neurons, and reduced inicidence of hydrocephalus and Chiari in patients that are operated on intrauterine. The disadvantages include the risk of early delivery and the risks associated with this surgical procedure for the mother, in addition to increased risk of intrauterine fetal death (Henriques & Pianetti 2011). It can be expected that in the near future, with the refinement of techniques that reduce maternal-fetal risks associated with intrauterine surgery, it will be possible to treat fetal diseases, such as MMC, with fewer risks to the fetus and mother (Quinn & Adzick 1997).

The introduction of the ventriculoperitoneal (VP) shunt for the treatment of hydrocephalus, during the 1950s, was a significant step forward in the increase of life expectancy for patients with spina bifida (Boockvar et al. 2001). A British study indicates that the use of VP for the treatment of HC increased the life expectancy of British babies with SB by up to four times (Hunt & Oakeshott 2003).

The cephalic perimeter of the baby should be measured and monitored daily after birth, as well as conducting transfontanel ultra-sound where HC is suspected (Henriques & Pianetti 2011).

The life expectancy of patients with MMC has increased significantly as a result of the advancement of treatments such as the early closure of the sack, the use of a shunt for the treatment of HC, and the urological control of the neurogenic bladder, which was strongly affected by the introduction of intermittent clean catheterization associated with pharmacotherapy (Stein et al. 2007; Liptak 2002).

A study conducted in the United States indicated that the estimated cost for a child with SB throughout his/her lifetime is approximately US$294,000.00 (Botto et al. 1999).

Caring for a child with MMC alters family dynamics, requires the family to readjust its daily routine and financial resources, and learn how to provide care, for example: performing intermittent bladder catheterization, administering ongoing medications, procedures to prevent skin lesions, the use of braces, among others (Fletcher et al. 2010a; Gaiva et al. 2009; Botto et al. 1999). Caregivers and patients have difficulty living with each other, experience physical and emotional burdens, in addition to full-time accompaniment for ambulatory and rehabilitation needs. Therefore, it is common for the mother to assume responsibility for the care of the child throughout his/her lifetime (Gaiva et al. 2009). Gaiva et al. suggest that the models of care should be focussed on the needs of the patient and his/her family and not only on the pathological process of MMC (Gaiva et al. 2009).

2.3.9. Prevention

Studies prove that folic acid supplements taken during the periconceptional period and during the first trimester of pregnancy reduce the risk of occurrence and recurrence of neural tube defects by about 50 to 70% (Wolff et al. 2009; Aguiar et al. 2003). An American study between 1990 and 1999 showed a drop of 19% in cases of NTDs after it became a requirement for foods to be fortified with folic acid (Honein et al. 2001). For the prevention of SB, in addition to the folic acid supplements, genetic counselling and pre-natal diagnosis of neural tube malformations are also important (Aguiar et al. 2003).

Today, it is recommended that folic acid be taken as a precaution beginning three months before conception and until at least three months after menstruation stops. However, this is not easily followed since few women know that they will be pregnant three months in advance. If a pregnant woman begins to take folic acid only after her period is late, the protective effect of folic acid will be reduced (Pietrzik 2009). It would be more effective and economical if all women who wanted to have children were recommended to take folic acid after they stop using contraceptives, or if all women of a fertile age were to take it, since taking it over a prolonged period does not

have any side effects (Pietrzik 2009). However, according to the American Society for Bioethics and Humanities (ASBH), only about 20% of German pregnant women used preventative folic acid prior to conceiving. Pediatricians and medical associations are asking German authorities to require the addition of folic acid to basic foods such as flour and salt, although currently food fortification is the decision of the manufacturers of these foods (ASBH 2009). In Brazil, the National Health Surveillance Agency (ANVISA) ruled in December 2002 that wheat and corn flours throughout the country must be fortified with folic acid, with implementation effective June, 2004 (Orioli et al. 2011; Grillo & da Silva 2003). A study using data from SINASC (information system of live births), revealed that, from 2004 to 2006, there was a significant reduction in the number of babies born with SB in Brazil, approximately 39%, most likely related to the program of food fortification with folic acid (Orioli et al. 2011).

The dose of acid folic usually recommended for pregnant women is 0.4mg per day. For women who have in their family history a child born with SB, the recommended dose is between 4 and 5mg (Wolff et al. 2009; Pietrzik 2009; Werler et al. 1993).

There is a difference of opinion worldwide regarding fetal malformations and terminating pregnancy. In almost all of Europe, abortion is not illegal under controlled circumstances. In Germany, the termination of pregnancy is regulated by articles 218 and 219 of the Penal Code. Abortion is only permitted until the 12th week and when requested by the woman after receiving medical advice, or in situations of violence or other sexual crimes. After 12 weeks, it can only be done for medical reasons or in the case of adverse social conditions. Medical indications can include risk of death or serious health implications for the pregnant woman or the fetus, for which congenital malformations, such as spina bifida, are included (Bartsch et al. 2009). In this case, in Germany, for every 100 cases of spina bifida, close to 75 are diagnosed intrauterine and of these 50 choose to terminate the pregnancy and 25 continue with the pregnancy. The remaining 25% of cases are not diagnosed during the prenatal period. Therefore, of the approximately 800 German fetuses that are diagnosed with NTD every year, 400 are aborted and 400 are taken to term (Pietrzik 2009).

In the 17 European countries that Garne studied in 2005, the cases of diagnosed congenital malformations were distributed as follows: 53% were born alive, 4% were stillborn and 43% had terminated the pregnancy. The detection rate of malformations during the prenatal period was about 64% overall. In these same countries in Europe, between 1996 and 1999, there were 599 cases of spina bifida, of which 68% were diagnosed prenatally and termination of pregnancy occurred in 314 cases, representing 52% of the total and 77.5% of the diagnosed cases (Garne et al. 2005).

In Brazil, abortion is prohibited, with the exception of cases that fall under article 128 of the Penal Code, when there is no other means of saving the life of the mother or when the pregnancy was the result of rape. Today, the termination of pregnancy in cases of encephalocele is under review by the Federal Supreme Court (Brasil 1988). Throughout South America, the rules surrounding the termination of pregnancy is similar to that of Brazil (Grillo & Silva 2003).

2.4. Bladder dysfunction

2.4.1. Urinary System

The urinary system is divided into the upper urinary tract and the lower urinary tract. The upper urinary tract, composed of the kidneys and ureters, is responsible for glomerular filtration, as well as producing and sending urine to the bladder. The lower urinary tract, composed of the bladder, urethra and urethral sphincter, receives sympathetic, parasympathetic and somatic innervation, stores the urine in the bladder and promotes the voluntary emptying of the bladder at regular intervals (Araújo & Borigato 2000b; Gomes et al. 2007). Urination is the final product of this complex neurophysiological process and it is not yet completely understood (Cintra 2010). However, it is a mechanical process, controlled by the neuromuscular system and the result of the coordinated effort between the expulsive action of the bladder and the

urethral resistance (sphincter) to this action (Rodrigues Netto Jr & Wroclawski 2000; Rodrigues Netto Jr et al. 2007).

The central nervous system's role is to control, coordinate and modulate the urination reflex, integrating the sensation and voluntary control of urination. The bridge controls the synergy between the phases of storage and bladder emptying, and coordinates the contraction of the detrusor muscle and the relaxation of the sphincter. When these functions work in harmony, it is referred to as vesical sphincter synergy, and when they do not, vesical sphincter dyssynergia, which is usually caused by a neurological lesion. Vesical sphincter dyssynergia can lead to obstructed urinary flow, elevated urination pressure, incomplete bladder emptying and an increase in bladder pressure. These changes, which are related to the progressive damage of bladder complacency observed in the neurogenic bladder, result in urological complications (Cintra 2010).

The autonomic nervous system influences the lower urinary tract through the sympathetic system during the phase of urine storage, and it is responsible for continence by the parasympathetic system stimulating detrusor contraction during bladder emptying (Cintra 2010).

Specifically, the process of normal urination can be described and divided into two phases:

- *Filling phase:* the stretching of the bladder activates the vesical afferent nerves, accompanied by vesical reflex inhibition (via the hypogastric nerve) and the simultaneous stimulation of the external sphincter (via the pudendal nerve). The pontine micturition center continously monitors the state of bladder emptying, maintaining the inhibitory influence over the sacral medullary center, which innervates the bladder, unleashing the progressive activation of the external sphincter (Gomes et al. 2007).
- *Emptying phase:* once the critical level of bladder filling is reached, urination is desired. At this moment, the pontine micturition center stops the inhibition of the sacral micturition center (parasympathetic), which activates bladder

contraction (via the pelvic nerve). At the same time, the reflex inhibition of the bladder (via the hypogastric nerve) by the sympathetic system is also stopped, while the somatic activation of the sphincter is inhibited, relaxing it and guaranteeing the coordination of urination (Gomes et al. 2007).

In children, the neurological paths that are responsible for controlling urination are immature and not completely developed (Araújo & Borigato 2000b). As the nervous system matures, voluntary control of urination begins. At about two or three years of age, the child begins to perceive bladder function, able to retain urine for longer periods and urinating with less frequency and with self-control (Fowler et al. 2008).

2.4.2. Neurogenic bladder

Bladder dysfunction in MMC, characterized by the congenital neurogenic bladder, is present in close to 95% of patients, occurring as a result of the interruption of the neural pathways between the pontine and medullar micturition centers, more specifically in the sacral region (Cintra 2010; Rodrigues Netto Jr et al. 2007). The neurogenic bladder is characterized by innervation disturbances which change the dynamic of bladder storage and emptying, resulting in two key consequences: renal deterioration and urinary incontinence (Henriques & Pianetti 2011; Araújo & Borigato 2000b).

There are various ways to classify the neurogenic bladder. It can be classified as hyper-reflexive (spastic: with the presence of uninhibited bladder contractions and elevated intravesical pressure) and areflexic (flaccid: with the presence of detrusor sphincter dyssynergia and elevated residual volumes). Both can present risks to the urinary tract (Rodrigues Netto Jr et al. 2007; Moreira 2001; Rodrigues Netto Jr & Wroclawski 2000). Another classification from the urological perspective separates the bladder into: high risk bladder and low risk bladder. The high risk bladder is characterized by vesical sphincter dyssynergia, reduced vesical complacency with elevated detrusor pressure at the end of bladder filling, elevated micturition pressure and incomplete bladder emptying. The low risk bladder presents sphincter deficiency, low micturition pressure

and satisfactory bladder emptying; however, it causes social challenges due to urinary incontinence (Cintra 2010).

German scholars use the classification of the neurogenic bladder, in patients with SB, based on the detrusor and sphincter dysfunctions, which can be divided into four types (Stein et al. 2007; Beetz & Stein 2009):

- Type 1: detrusor hypoactivity and sphincter hypoactivity
- Type 2: detrusor hypoactivity and sphincter hyperactivity
- Type 3: detrusor hyperactivity and sphincter hypoactivity
- Type 4: detrusor hyperactivity and sphincter hyperactivity

In type 4, the neurogenic bladder represents the greatest risk to the renal function, while in type 1, it represents the least risk to the upper urinary tract (Stein et al. 2007).

The scientific community is familiar with the diverse symptoms and changes to the urinary tract as a result of the neurogenic bladder, including urinary incontinence, repeat urinary tract infection, vesicoureteral reflux, dilatation of the upper urinary tract (hydronephrosis), pyelonephritis, urolithiasis and, finally, renal insufficiency (Rodrigues Netto Jr et al. 2007; Stein et al. 2007; Segal et al. 1995). Basically, these changes to the urinary tract primarily occur because, during the filling phase, involuntary bladder contractions can happen, resulting in increased intravesical pressure and thus complicating the release of urine to the upper urinary tract, vesicoureteral reflux and hydronephrosis.

Micturition dysfunction is relevant in three aspects of patients' lives (Cintra 2010):
- potential urological complications that can lead to deterioration of the urinary tract, resulting in renal insufficiency and/or the need for extensive surgeries;
- social isolation, such as difficulties with social integration and work performance due to involuntary, undesired urinary leakages;
- difficulty with sexual (re)habilitation.

Urinary incontinence usually occurs due to the absence of the sensation of bladder fullness and of voluntary control of the sphincter, caused by neural interruption of the spinal dysraphism. A study of 121 participants with SB between 15 and 35 years of age showed that patients who had urinary incontinence were less likely to be sexually active (Cardenas et al. 2008). In addition to causing discomfort and social restrictions for the patient, bladder incontinence can lead to skin lesions, such as ammoniacal dermatitis and fungal infections (Costa & Carvalho 2006).

In a study conducted in Brazil, in the city of Brasilia, with 127 infants with MMC and an average age of 8 months, it was observed that 52% of these children already showed risk of renal deterioration in the first urological evaluation, with dilatation of the upper urinary tract, vesicoureteral reflux or elevated urination pressure (Araújo & Borigato 2000b). In another study by Stein of newborns with MMC, he reported that 30% had vesicoureteral reflux (Stein et al. 2007).

The height and location of the spinal dysraphism are not always directly related to the neurogenic behavior of the detrusor muscle and the sphincters. Nevertheless, changes in the standard bladder function throughout the lifetime of the patient are possible, such as cases of symptomatic tethered cord syndrome (Stein et al. 2007).

2.4.3 Treatment of neurogenic bladder

Renal deterioration is currently the leading cause of death among young people with MMC (Hunt & Oakeshott 2003). Therefore, the urological evaluation of the patient with OSB should begin as early as possible, preferably during the neonatal period, soon after the newborn is stabilized following the surgery to close the medullary canal and the insertion of the ventriculoperitoneal shunt, approximately 4 to 6 weeks after birth. Later, urological monitoring of these patients should be done regularly to assess renal function and prevent lesions and urinary tract infections (Clayton et al. 2010; Stöhrer et al. 2009; D'Ancona & Silva Jr. 2007; Brazilian Society of Urology 2006).

Urological treatment aims to protect the upper urinary tract, control urinary infection and promote bladder continence in two key aspects: maintain urine storage under low pressure and promote complete bladder emptying (Cintra 2010; Clayton et al. 2010; Stöhrer et al. 2009; Beetz & Stein 2009). This requires intermittent bladder catheterization (IC), along with pharmacotherapy, as the first treatment option, which revolutionized the treatment of the neurogenic bladder. The second option involves a more invasive treatment – urological surgeries – such as vesicostomy, Mitrofanoff, bladder enlargement and sphincter surgeries (Deshpande et al. 2010; Gomes et al. 2007; Morrisroe et al. 2005; Rodrigues Netto Jr & Wroclawski 2000; Segal et al. 1995). Studies of the use of electrical stimulation for treatment of the neurogenic bladder in patients with MMC still present controversial results. There are very few studies of the stimulation of the sacral nerve in children with OSB, which is more invasive and complex, as is neuromodulation and Biofeedback therapy (Bjerklund Johansen et al. 2007; Brazilian Society of Urology 2006; Aslan & Kogan 2002).

According to the European urological guidelines, and the rehabilitation hospital where this study took place in Brazil, the urological procedures recommended for patients with a neurogenic bladder include urological anamnesis, as well as urological and laboratory tests as described in Table 4 (Stöhrer et al. 2009; D'Ancona & Silva Jr. 2007; Stein et al. 2007; European Association of Urology 2006; Segal et al. 1995).

Table 4 – Urological procedures recommended by age

Exam	**6–12 weeks**	**6 months**	**9 months**	**12 months**	**6/6 months until growth stops**	**Annually after growth**
Urological anamnesis	X	X	X	X	X	X
Urine test	X	X	X	X	X	X
Ultrasound	X	X	(X)	X	X	X
Laboratory (renal function)	X			X		X
Vídeo urodynamic	(X)			X		X*
Scintigraphy**						

* done annually only until growth stops; after, only in cases of clinical or radiological change

** only done in cases of hydronephrosis or repetitive UTI

Asymptomatic bacteriuria is common in about 75% of patients with a neurogenic bladder who do IC. Studies of children with MMC have proven that *Escherichia coli* is the most frequently detected pathogen in urine tests (Schlager et al. 2001). However, the bacteriuria does not represent additional risk, and it is generally caused by microorganisms with low virulence, not requiring treatment with antibiotics, except in cases where there are other related anomalies, such as serious vesicoureteral reflux. The evaluation and diagnosis of urinary infection are done based on these three criteria: 1) presence of clinical symptoms, such as fever, discomfort, suprapubic pain, loss of appetite; 2) evidence of changes in macroscopic urine (leukocyturia, hematuria); 3) detection of more than 100,000 bacterial colonies in the urine culture (Stein et al. 2007).

Some procedures can support UTI prophylaxis, such as the use of urinary acidifiers, adequate fluid consumption, increasing the dose of anticholinergics, reviewing the catheterization technique, increasing the frequency of catheterization, and regularity of intestinal functioning (Newman & Willson 2011; Stein et al. 2007). More recent studies also encourage the use of a new catheter for every procedure, as a means of supporting UTI prophylaxis (Newman & Willson 2011; Woodbury et al. 2008).

2.4.3.1. Pharmacotherapy

Pharmacotherapy is a strong ally of IC in the treatment of the neurogenic bladder. Some of the lead drugs used today include:

- Anticholinergics: this group of medications contains substances that antagonize the muscarinic acetylcholine receptors. Some of the most commonly used drugs in this group include: oxybutynin, tolterodine, trospium chloride, propiverine, and darifenacin, among others. These are the top medications in the treatment of the neurogenic bladder, and the class of drugs that has been tested the most and that has the most proven effectiveness today. The top drug in both Germany and Brazil is oxybutynin (Cintra 2010; AWMF 2009; Stein et al. 2007). Antimuscarinics, of which oxybutynin is the most common, are widely used in the treatment of detrusor hyperactivity, resulting in improved complacency and bladder capacity (Beetz, Stein 2009). Goessl reported oxybutynin having a positive effect on detrusor hyperactivity in up to 93% of the patients with MMC that he studied (Goessl et al. 1998). The disadvantages of oxybutynin are its side effects, primarily xerostomia (dry mouth), intestinal changes (constipation), intolerance to heat, among others, all of which are the main motive to stop medication (Cintra 2010; Aslan & Kogan 2002; Ferrara et al. 2001).

- Alpha-blockers: group of medications that block the alpha-adrenergic receptors and are used to reduce resistance to bladder emptying by reducing muscular tonus. The most common alpha-blocker is doxazosin (Stein et al. 2007).

– Antibiotics: Today, the antibiotic prophylaxis of UTI associated with IC is considered risky and not necessary for the majority of patients (AWMF 2009; Brazilian Society of Urology 2006). Specifically, they can be used in the prophylaxis of UTI in babies, during the first months after initiating IC, or for patients with serious vesicoureteral reflux (III-V degree), to avoid ascending urinary tract infection. The prophylactic antibiotics that are the top choice for infant treatment are nitrofurantoin and sulfametoxazol-trimetoprima (Stein et al. 2007; Brazilian Society of Urology 2006).

- Urinary acidifiers: as a means of support in the prophylaxis of UTIs, acidifiers, such as products with a base of cranberry and L-methionine and even fruit juices rich in Vitamin C (ascorbic acid), are considered effective (AWMF 2009; Beetz, Stein 2009). It has been proven that, creating an acidic environment using these acidifiers is bactericidal and bacteriostatic, primarily against gram-negative bacteria, thus being effective in preventing UTI (Stein et al. 2007).

– Intravesical medications: intravesical instillation is an alternative when oral medication will have undesirable side effects. The most commonly used instilled medication is oxybutynin, which is better tolerated in this format, causing fewer side effects (Stöhrer et al. 2009; Aslan, Kogan 2002; Ferrara et al. 2001).

– Botulinum toxin: after attempting oral medication to treat detrusor hyperactivity, the use of botulinum toxin injections has proven an effective option for some patients (Deshpande et al. 2010; Stöhrer et al. 2009; Stein et al. 2007).

2.5. Intermittent bladder catheterization (IC)

After 30 years of study, intermittent bladder catheterization is considered the worldwide standard treatment for the neurogenic bladder. The technique for bladder emptying through intermittent surveying, in addition to being the most similar to normal bladder function, is the easiest to execute and does not carry risks for renal function nor for the life expectancy of the patients. Thus, IC is the best method for bladder emptying today (Stöhrer et al. 2009; AWMF 2009; Aslan & Kogan 2002). According to the German Society of Urology, close to 70% of German patients with a neurogenic bladder can be successfully treated with this conservative treatment (AWMF 2009).

IC is preferably done by the individual, in which case it is referred to as self-catheterization. Although, in some cases, primarily for children and adolescents, it is necessary for outside supervision to ensure a regular schedule and adequate hygiene. When IC is done by a another person, it is called assisted catheterization, which in some cases can be done with the participation of the patient, who helps in the removal of the catheter, cleaning of the urethral meatus, etc (Association for Continence Advide 2003).

2.5.1. History

Bronze and pewter catheters have been known to exist since 3000 AD in Egypt. In Mesopotamia, gold catheters were used and in China there are reports of the use of catheters 100 years BC. Roman and Greek writers mentioned the use of olive oil and butter as lubricants (Roach et al. 2011; Grigoleit et al. 2006; Moll 2001).

However, the concept of intermittent catheterization was introduced by Ludwig Guttmann only during the Second World War in Great Britain, when he was able to prevent complications in the urinary tract using this sterile procedure (AWMF 2009). In 1972, Lapides et al. introduced the concept of clean intermittent catheterization (CIC) for the treatment of bladder dysfunction, adapted the technique of sterile bladder catheterization to the clean version, and began to offer this procedure in patients'

homes, significantly improving their quality of life (Lapides et al. 1972). In this same study, Lapides and his colleagues concluded that, despite the introduction of bacteria into the bladder region through the catheter during CIC, the organism's natural resistance impedes the development of urinary infections, added to the fact that the procedure promotes the periodic emptying of the bladder, stopping bacteria multiplication. Thus, these researchers concluded that the reduced resistance of the bladder tissue toward the invasion of microorganisms is due to some kind of structural abnormality in the bladder. They suggested then that the most common cause of susceptibility to bacterial invasion in these individuals is reduced blood flow in the bladder, which is the result of increased intravesical pressure and the over-stretching of this organ, since efficient blood flow acts as a barrier to infection (Lapides et al. 2002). Following this reasoning, it can be deducted that one of the justifications for using IC with lower UTI rates would be that regular emptying of the bladder reduces intravesical pressure, improving blood circulation in the bladder wall, and making the bladder mucous membrane more resistant to infectious bacteria (Newman & Willson 2011).

2.5.2. IC indications and contraindications

IC is indicated to protect the upper urinary tract, controlling UTI and promoting possible urinary continence. It is focussed on two basic actions: maintain urine storage at low pressure (avoiding high bladder pressure) and complete bladder emptying (avoiding high residual bladder volumes) (Cintra 2010; AWMF 2009; Beetz & Stein 2009). Thus, IC is considered effective at preserving renal function since it maintains an empty bladder, reduces urinary infections and creates the possibility of bladder continence. As such, patients are relieved of embarrassment due to urine loss, facilitating social participation and sexual activity (Katrancha 2008; Furlan 2003; Oakeshott & Hunt 1992; van Gool et al. 1991).

For children with SB, IC is defended by various researchers as a safe and effective method for treating the neurogenic bladder, and should be initiated early, as soon as detrusor hyperactivity is diagnosed (Jong et al. 2008; Stein et al. 2007; Dik et al. 2006;

Goessl et al. 1998). Research indicates that the earlier the neurogenic bladder in patients with SB is treated with IC and pharmacotherapy, the lower the possibility of requiring bladder enlargement in the future (Kaefer et al. 1999). In addition to being a highly tolerated procedure by children, the other advantage of IC being established early is that parents and patients can develop the habit, making it a natural part of their daily routine. This is important because more than 90% of patients with MMC will need to use IC for the rest of their lives (Stein et al. 2007; Lindehall et al. 2004; Edwards et al. 2004; Segal et al. 1995). Consequently, children who use IC experience less fear during urodynamic tests, which are a necessary part of urological control (Stein et al. 2007).

In order to help acquire continence it is recommended that IC be done at least four times per day, along with adjustments to liquid consumption and the use of medications (Costa & Carvalho 2006; Oakeshott & Hunt 1992). Research shows that close to 60% of patients achieve continence with IC and that urine loss between catheterizations tends to diminish over time (Robinson et al. 1985; Hunt et al. 1984).

With respect to the probing path, transurethral catheterization is indicated and cited by researchers more than suprapubic catheterization, and has lower UTI rates (Pannek & Stöhrer 2008). When compared with vesical delay probe, IC is also considered the better alternative because of its lower incidence of complications such as UTI, urethral trauma, vesical lithiasis and deterioration of the urinary tract. It also facilitates improved self-care and independence, reduces the need for equipment (such as urine collection bags), has fewer barriers to intimacy and sexual activity, and higher sperm quality (Newman & Willson 2011; Cintra 2010). The use of the Crede and Valsava maneuvers for bladder emptying is obsolete. Yet use of the nighttime catheter is an option for patients with high intravesical pressure (Stein et al. 2007).

The key contraindications of IC are: urethral stenosis, false urethral passages, stones, serious urinary tract infection, difficult financial conditions, lack of family support, lack of interest and motivation on the part of the patient (Moreira 2001). Potential complications of IC can include UTI and pain or discomfort, which are normally only present when beginning to use catheterization, but can be aggravated by anxiety and

fear. For male patients, there is also the development of long-term narrowing of the urethra or false urethral passage (Newman & Willson 2011; Pannek et al. 2006). However, studies of children with SB show a low incidence of genitourinary complications related to IC (Campbell et al. 2004).

The patients that do IC should receive urological monitoring by a specialized team that monitors the urinary tract through exams such as ultrasound, urodynamic tests, urethrocystography, laboratory tests, among others as described in Table 4 of chapter "Treatment of neurogenic bladder" (Oakeshott & Hunt 1992).

2.5.3. Intermittent bladder catheterization technique

A study of bibliographical review conducted by Moore in 2007 specifically states that, based on research data to the present moment, it is not possible to confirm that one type of technique (clean or aseptic), catheter (coated or non-coated, disposable sterile or clean reusable), method (self-catheterization or assisted catheterization) or strategy is better than another (Moore et al. 2007; Moore et al. 2006).

Today in Brazil, the most used technique by patients is the clean technique. In Germany, as well as across the European continent in general, the most popular technique is aseptic, but there is also use of the clean technique with a single-use catheter (AWMF 2009). The three techniques used today worldwide are described below, along with the studies that justify their use, which are often controversial (Newman & Willson 2011):

- *Clean intermittent bladder catheterization*: also called the clean technique with reusable catheter (Newman & Willson 2011). When properly described, the clean technique involves washing of hands, use of clean catheters (to be reused) and lubricants (sterile or not), and the washing of the urethral meatus before inserting the catheter (Costa & Carvalho 2006). Between the washing of the urethral meatus and the insertion of the catheter, it is recommended that the

hands be washed a second time. With respect to reusing the catheter, normally it is replaced every week, but some services advise it be replaced daily (Association of Social Pioneers 2010; Costa & Carvalho 2006; Campbell et al. 2004). However, there is no consensus yet, nor standard protocol, regarding the re-use of catheters (Newman & Willson 2011).

The clean technique does not seem to be associated with a higher rate of symptomatic UTI than the sterile technique, which increases the costs of the procedure (Cintra 2010; Willson et al. 2009; Moore et al. 2006; Aslan & Kogan 2002). The re-use of catheters and the use of non-sterile lubricants also do not seem to affect the frequency of symptomatic UTIs and reduces the costs of IC (Cintra 2010; Moore et al. 2006; Aslan & Kogan 2002). American researchers who compared the use of sterile catheters with clean ones in 10 children with MMC and neurogenic bladders over an 8-month period report that they did not observe a significant difference in the reduction of bacteriuria using either catheters (Schlager et al. 2001).

- *Clean intermittent bladder catheterization with single-use catheter:* This technique is exactly the same as the clean technique; however, the sterile catheters are discarded after use, and they are not reused (Newman & Willson 2011).

The clean technique with the single-use catheter is faster, more practical and more comfortable for both the patient performing self-catheterization and for family members performing assisted catheterization, since the stages of lubrification and washing the catheter for re-use are not necessary. The cost of the materials required for this technique are lower than for sterile catheterization, however higher than for clean catheterization (Newman & Willson 2011; Pannek & Stöhrer 2008).

- *Aseptic intermittent bladder catheterization:* The steps for the aseptic technique are exactly the same as the clean technique, with the only difference being that this technique uses exclusively sterile utensils, for example, pre-lubricated, disposable sterile catheter, disposable sterile gloves, or packaging

(with introductory “no-touch” tag), that allows the procedure to be performed without touching the catheter, and disinfection of the urethral meatus to be done with antiseptic solutions (Newman & Willson 2011; AWMF 2009; Stöhrer et al. 2009; Pannek & Stöhrer 2008).

Considering that the bladders of healthy people are sterile, in the last 15 years, the German Society of Urology (DGU) established the aseptic technique. In a retrospective analysis of these years, the DGU states that aseptic self-catheterization, even without the use of antibiotic prophylaxis, can reduce the annual incidence of urinary infections in patients. As a result, the DGU and the urological policies for the treatment of the neurogenic bladder, established by the European Association of Urology (EAU), considered the aseptic technique better than the clean technique since it has the benefit of reducing potential contamination (Stöhrer et al. 2009; AWMF 2009; Pannek & Stöhrer 2008; Grigoleit et al. 2006; Pannek et al. 2006; Association for Continence Advide 2003).

There is consensus among urological specialists that patients with immunosuppressed medical conditions should be catheterized with a sterile technique or a single-use catheter. Catheterization in hospitals and nursing homes is performed aseptically because of the high risk of nosocomial infections. Newman indicated that in cases of bladder catheterization assisted by relatives and/or caregivers, the use of sterile and disposable materials is recommended to minimize the transfer of skin flora into the bladder, thus decreasing the possibility of cross infection (Newman & Willson 2011).

2.5.4.1. Frequency

The daily frequency indicated for intermittent catheterization ranges from four to six procedures per day. This figure can vary according to bladder capacity, residual volume and involuntary urinary loss between the intervals of IC. This frequency should be enough to prevent bladder over-stretching, considering that a quantity of about 400 to 500 ml is removed per procedure in adults (Newman & Willson 2011; AWMF 2009).

Less frequent catheterizations may present high bladder volume and thus a higher risk of UTI; more frequent catheterizations have a higher risk of cross infections (Stöhrer et al. 2009). According to Lapides, the frequency of catheterization is more important from the point of view of prevention of complications than the sterility of the materials used (Lapides et al. 2002).

2.5.4.2. Positioning

During catheterization, the patient may be sitting, standing or laying down, and the procedure can be performed on the toilet, in a wheelchair or in bed. In men, the position of the penis must make a right angle to the pubic area to mitigate the curvature and thus avoid male urethral trauma (Morooka & Faro 2002). There are resources such as mirrors with bars placed between the legs that facilitate positioning, visualization of urethral meatus, and the freeing up of the hands during the administration of the technique maily for women, and also for man with large waist circumference (Newman & Willson 2011; Morooka & Faro 2002; Oakeshott & Hunt 1992). During the training of women with IC, Lapides and his colleagues observed that over time, women stop using the mirror and begin using only touch to locate the urethral meatus (Lapides et al. 1972).

Children who do not yet self-catheterize should be encouraged to do it in a half-sitting position which, by facilitating their visualization of the technique, can help them learn the steps of the procedure. As a result, children will develop a more proactive stance when others are working with their bodies, thus facilitating their future autonomy in doing IC.

2.5.4.3. Genital washing/disinfection

Today, the washing of the urethral meatus is performed using various types of substances, including: water and soap (preferably with a neutral pH), water, sterile water, and boric acid (3% solution of boric acid). For disinfection, there are also

alternative antiseptic solutions (octenidine dihydrochloride alcohol solution and 0.1% solution polyhexanide) that are used in countries with high economic conditions such as Germany. In Brazil, the most frequent option is water and neutral soap (Costa & Carvalho 2006; Morooka & Faro 2002). The use of boric acid is forbidden in some countries like the United States, while other solutions have no known contraindications in the scientific community (José et al. 2007; Siegel & Wason 1986). However, not enough studies have been conducted to determine the ideal substance for cleaning of the genitalia during IC, and current studies found no difference in rates of UTI and bacteriuria between disinfection with antiseptics and washing with other substances like water (sterile or potable water) (Al-Farsi et al. 2009; Willson et al. 2009; Cheung et al. 2008; Webster et al. 2001).

2.5.4.4. Lubrication

The use of a lubricant is important to facilitate the introduction and insertion of the catheter. It also reduces the risk of urethral injuries, especially in the male population, as well as discomfort in patients with continued urethral sensitivity (Newman & Willson 2011; Costa & Carvalho 2006). Lubrication can be performed directly on the urethral meatus and/or around the catheter. The lubrication of the catheter can occur in two ways: first, the catheter is pre-lubricated with gel or with a hydrophilic coating, which after 30 seconds of contact with an aqueous medium, develops a lubricated surface. The second method involves a water-based gel lubricant, which may or may not contain analgesics and antibiotics (gentamicin), and is placed on the catheter and/or inserted into the urethral opening. Some patients use only water as a lubricant and some women do not use any lubricant at all (Newman & Willson 2011; Lapides et al. 2002).

2.5.4.5. Type of Catheters

Urethral catheters may differ in several ways including the type of material they are made of,which can range from plastic polyvinyl chloride (PVC), polyurethane (PU),

latex and metal. In relation to lubrication, catheters can have either a hydrophilic coating (hydrophilic catheter), pre-lubricated with gel or be non-lubricated. In relation to length, the shortest catheter is about 20 cm for females and the longest is about 40 cm for males. With respect to diameter, the most commonly used catheters vary from no. four to no. 16. Regarding the catheter tip (option found in most modern catheters), it can be curved or straight. The catheter may also be equipped with an attachment for urine collection (Newman & Willson 2011). The type of packaging is also a variable that must be considered because it compensates for any difficulties associated with physical and cognitive disabilities (Newman & Willson 2011; Bjerklund Johansen et al. 2007). The packaging may include a catheter with a 'no-touch sleeve', which allows for the performance of IC without touching the catheter. This device, in an “in vitro” study, allowed for the significant benefit of reducing the potential for external contamination of the catheter (Hudson & Murahata 2005). It is important to highlight that non-flexible catheters, for example those made of metal, are recommended for women only because they may cause urethral trauma in men.

The choice of catheter requires consideration of ease of use, disposal, and ease of uretheral insertion. Special attention should be paid to the drainage openings as well as the catheter tip in order to avoid friction and urethral trauma (AWMF 2009; Bjerklund Johansen et al. 2007). The use of large caliber catheters proved to be advantageous in the prevention of urethral complications, therefore it is recommended that patients use the largest caliber possible (Stein et al. 2007; Lindehall et al. 2004). The catheters for patients with SB should be latex-free, due to the increased risk of allergy in this population (AWMF 2009). Experts at EAU (European Association of Urology) suggest that silicone catheters have more advantages over latex (Stöhrer et al. 2009), but so far the studies on the material and type of catheter for the performance of IC are still insufficient to define an ideal catheter (Parker et al. 2009; Grigoleit et al. 2006; Pannek et al. 2006). At this point, patients choose the catheter based on their financial situation and personal preference (Campbell et al. 2004).

The use of pre-lubricated catheters with either hydrophilics or gel, are expensive options from an economical perspective because they cost about 10 times more than the plastic

catheter (polyurethane). Still, they represent an extremely attractive alternative for smoother urethral insertion with a lower incidence of complications (ex: stenosis), which is more practical and comfortable for the patient (Cintra 2010; AWMF 2009; Association for Continence Advide 2003; Hedlund et al. 2001). Studies on catheter preference among patients who undergo bladder catheterization showed that, between the PVC and the hydrophilic catheters, the majority of patients, about 93%, preferred the hydrophilic catheter (Bjerklund Johansen et al. 2007; Stensballe et al. 2005). Some studies indicate that using hydrophilic catheters for IC may lead to lower rates of bacteriuria and microscopic hematuria, postponing the need for antibiotic therapy for treatment of UTIs and less long term urethral complications, such as urethral stricture (Cardenas et al. 2011; Stensballe et al. 2005; Hedlund et al. 2001; Waller et al. 1995).

In Brazil, there are basically two popular choices of probes: the polyvinyl chloride plastic (polyurethane) catheter, popularly known as the Nelaton catheter and most widely used today, and the metallic catheter which is still used by some female patients because of its extremely low cost and/or preference in handling compared with a plastic probe.

In Germany, there are two main types of single-use catheters that differ in the type of lubrication, using either hydrophilics or gel. These catheters have two formats. The first is composed of a closed system attached to the urine collection bag for use away from home because it allows for greater mobility during the procedure. The second type consists only of the lubricated catheter yet is specially adapted so that contact with the hands is not necessary. This version is used more at home (AWMF 2009).

It is noteworthy that, *a priori*, in accordance with the written instructions on manufacturer packaging, all catheters are single-use and no manufacturer has a protocol to standardize the reuse of catheters (Newman & Willson 2011).

Lastly, after comfortable positioning, proper cleaning, and lubrication of the urethral meatus, the catheter should be introduced via the urethral meatus until urine begins to flow; it should be slowly withdrawn only when the urine flow is ended. The drainage of

urine can occur directly in the toilet, into a bag or in another sanitary receptor; some catheters have a urine collection system attached. When the patient is capable of voluntary urination, he should be first instructed how to urinate and after that, receive instruction about IC (Assis & Faro 2011).

2.5.5. Training

Studies indicate that starting at five and six years of age, children without cognitive alteration, are already able to self-catheterize (Beetz & Stein 2009). The IC technique, generally evaluated as simple for patients with traumatic spinal cord injury and those practicing assisted catheterization, is often considered complex and difficult to learn quickly by all SB patients. One of the reasons noted, in addition to the physical difficulties already described, are cognitive changes, such as visuoconstructive and visuoperceptive difficulties, and working memory (Amoedo 2005; Dennis et al. 2002).

Good training should be individualized and comprehensive, include theory, practice and education of patients and their families in relation to urological complications of SB, as well as the main recommendations and objectives of IC. This way, patients and family members should be able to understand the diagnosis, examination results, recommendations for IC, the method used in bladder catheterization, and the administration of medication. Additionally, patients should understand the symptoms and risks involved, including a notion of asymptomatic bacteriuria, macroscopic urine, and the acquisition of knowledge pertaining to social rights in accordance with the laws of each country. Having a professional reference team available during the gradual learning of IC acts as a support and is essential for successful training (Stein et al. 2007).

During training, some strategies like those that utilize a step by step demonstration of the procedure and simulation of the technique using dolls, toys, and positive reinforcement are recommended by several authors (Segal et al. 1995; Neef et al. 1989; Hannigan 1979). For children, in the meetings leading up to the training, the coach

should encourage the patient to touch the catheterization material, in particular the catheter itself, which will be used during the training on dolls. The use of dolls reduces anxiety and provides the added benefit of allowing for technical errors to be detected and corrected before actual performance (Segal et al. 1995). A strategy for adolescents and adults, and for parents, is to clarify all doubts, using pictures, photos and videos if necessary, beforehand. It is extremely important that the person responsible for the catheterization is relaxed, and in cases of assisted IC, that this sentiment is passed on to the child during the procedure. This model can facilitate the acceptance, learning and reduction of anxiety during the training of IC ((Segal et al. 1995).

In both Brazil and Germany, the instruction of IC is performed under the supervision of professionals with experience in rehabilitation, who are most often nurses with higher education, as recommended by the British Association for Continence Care (Association for Continence Advide 2003; Furlan 2003). A British study on the emotional responses of patients learning IC says that an individualized and empathetic approach by nursing staff is vital in this process, and as a result, has been recognized and valued by the research participants (Ramm & Kane 2011; Costa & Carvalho 2006).

The learning of IC in Brazil takes place in two formats. The first requires admittance to a rehabilitation hospital for a period of two to seven days, and the second happens on an outpatient basis over a period of time that varies from one to three days. For both options, the training takes place on an individual basis and the period can vary depending on the mode of catheterization (either self-catheterization or assisted catheterization) and the difficulty of learning the technique by the person responsible for the procedure (patient or family). In cases of self-catheterization training, there is the option of a home visit to train the patient in his home environment, according to Edwards (Edwards et al. 2004).

IC training in Germany also happens in clinics, hospitals, home care services and trainings sponsored by catheter manufacturers who arrange group trainings over a weekend in a youth hostel (AWMF 2009).

Costa, 2006, who investigated the factors interfering with the performance of CIC in Brazilian children with MMC from the perspective of the caregiver, cites the positive influence of financial aid, government issued CIC material, the presence of piped water and basic sewage system at home, caregiver skills, and acceptance of the procedure by the child and the caregiver. Among the factors that interfered negatively with CIC were urinary leakage in between procedures, the continuous use of diapers and urethral sensitivity (Costa & Carvalho 2006; Robinson et al. 1985). A British study with 40 patients undergoing IC reveals that both assisted catheterization and self-catheterization themselves are not the cause of major emotional and behavioral problems, but problems related to the bladder may be the focus of considerable tension in family relationships (Borzyskowski et al. 2004). In this sense, strategies that foster an understanding of the goals of IC among children and their families should be used by health professionals (Costa & Carvalho 2006; Edwards et al. 2004).

In order to manage IC, patients are encouraged, at least initially and prior to urological review, to keep daily track of their catheterization. The notes should include: the date, time, volume drained, urinary leakage during intervals between catheterization, water intake and urine appearance (Newman & Willson 2011; Schultz-Lampel & Schönberger 2004).

2.5.6. Self-catheterization

Self-catheterization helps in the self-liberating process of the individual, benefitting him/her not only physically, but also psychologically, to balance control of his/her body, privacy, freedom, and increase self-esteem (Edwards et al. 2004). Studies prove that adherence to life-long intermittent catheterization is greater among individuals who use self-catheterization than those who use bladder catheterization assisted by a third party (Hunt et al. 1984).

Specialists indicate that self-catheterization training should begin after about six years of age, when children have the cognitive abilities and manual dexterity to self-catheterize (Stein et al. 2007; Edwards et al. 2004; Association for Continence Advide 2003; Hannigan 1979). Nevertheless, not all patients with SB at this age have the maturity and intellectual performance compatible with performing self-catheterization (Association for Continence Advide 2003). In addition to cognitive deficit, other factors can negatively impact self-catheterization. For example, motor deficit and orthopedic deformities can reduce patient agility during the procedure, affecting for example, undressing and positioning lower members, sitting correctly due to control of shaky trunk, visualizing the urethral meatus, and getting to the bathroom on time (Costa & Carvalho 2006). On the other hand, recent advances in the training of self-catheterization have shown that serious deficiency, including low intellectual development, is not necessarily an insurmountable obstacle to learning the procedure (Oakeshott & Hunt 1992; Robinson et al. 1985).

A Canadian study with a high sample of 912 patients with traumatic and non-traumatic medullary lesions states that bladder self-catheterization protects against UTI, while catheterization done by third parties (assisted catheterization) can contribute to UTI. This study also revealed a higher rate of UTI in women than in men, in addition to corroborating studies that maintain that lower rates of UTI are associated with adequate frequency of catheterization and the use of a hydrophilic catheter (Woodbury et al. 2008).

There are some studies that address the different forms of teaching bladder catheterization to children with SB; however, the training of self-catheterization continues to be a challenge for health professionals, especially nurses (Segal et al. 1995). The integration of patients, their family members and the training team is essential for creating support to promote the acceptance and adherence to IC throughout the patient's lifetime (Stein et al. 2007; Borzyskowski et al. 2004). Participating in conjunction with other patients in leisure programs and association courses, such as ASBH in Germany, increases commitment to IC. This can reduce fears of IC

implementation and preoccupation with social acceptance due to incontinence (Stein et al. 2007).

2.6. Participation, autonomy and self-care with SB

The focus of rehabilitation for people with an incapacitating, chronic condition is changing from a biomedical perspective to a perspective that centers on the individual. Cardol, 2002, states that "the ultimate goal of rehabilitation is to acquire and retain the highest possible level of autonomy, with the aim of maximizing participation" (Cardol et al. 2002).

Autonomy and social participation are fundamental criteria in rehabilitation results. The conceptions of autonomy vary between individuals and cultures, but a distinction can be made between autonomous decision-making (capacity to make decisions without external interference) and autonomous execution (capacity to act as one wills). Autonomous decision-making can increase throughout the lifetime of the individual, while autonomous execution declines. As a result, autonomy is not something static but rather develops throughout the lifetime of an individual (Cardol et al. 2002).

Originating from the Latin *participatio*, participation is action, the effect of participating, taking part, intervening, being part of. According to Cardol, in the context of rehabilitation, authentic social participation requires as a prerequisite autonomous execution sufficient to communicate and autonomous decision-making sufficient to be an authentic communicator. In rehabilitation, however, an ideal state of autonomy should not be sought. People should have the opportunity to choose what they will do themselves and what others will do. Thus, in light of autonomy, understanding the individuality of people, participation should be seen primarily in relation to the preferences of an individual rather than his/her overall abilities (Cardol et al. 2002). Hammel points out that participation does not occur in a vacuum, but that the environment influences social participation in a dynamic way (Hammel et al. 2008).

Self-care is a process that aims to improve human life, combining daily routines with internal and external factors that are part of the life of an individual; such as making the decision to take care of oneself and to be self-reliable, seeking to rationally integrate everything that impacts one's quality of life (Oliveira et al. 2011).

Although social integration should be an objective in the orientation of individuals with SB, many young people and adults feel restrained in their participation experience. The severity of SB is negatively related to this participation. Some of the perceived obstacles include: long-distance travel, accessibility, physical disabilities, emotional barriers, financial limitations and confinement to a wheelchair (Barf et al. 2009). Other difficulties in participation experienced by adolescents with MMC are primarily related to self-care (including self-catheterization), mobility, place of residence, recreation and employment, as well as responsibilities, such as domestic chores, decision-making, money management and engagement in activities with same-age peers (Buffart et al. 2009).

Successful adjustment to disability is based on the ability of the child to cooperate with the treatment and, therefore, there are physical and psychological implications on quality of life (Borzyskowski et al. 2004).

A Dutch study with 179 individuals with SB between 16 and 25 years of age indicated that only 16% were living independently, more than one third of the participants were in a special high school, 53% of those who finished high school did not have regular work, and 71% did not have a partner (Barf et al. 2009).

In general, SB does not seem to be a determiner of satisfaction in life. According to a Dutch study of young people with SB about the level of life satisfaction, a great majority were satisfied with life, only 24% stated being dissatisfied, compared with 28% in the general population. The highest percentages of dissatisfaction were related to financial situation (44%), relationship with a partner (49%) and sex life (55%). Contact with family and friends represented the lowest percentages of dissatisfaction, only 15 to 17% (Barf et al. 2007).

Neurological commitment of patients with SB can compromise self-care. In adolescence, the transfer of responsibilities for patients with SB is necessary and generally associated with conflicts and impasses. Only one third of adult patients are able to be totally responsible for their health-related care (Stein et al. 2007). In order to improve family relationships, self-catheterization, as part of self-care, can be an alternative since studies with families note psychological problems in mothers of patients with SB who carry the burden of daily care activities while they are caring for the child (Borzyskowski et al. 2004).

It is essential for youth with MMC to develop self-management skills that seek to reduce vulnerability and achieve self-sufficiency for the transition to adulthood (Sawin et al. 2009). However, Davis concluded that adolescents with MMC experience a delay of about two to five years in the acquisition of skills essential to autonomy, when compared with other adolescents in the same age range (Davis et al. 2006). Other studies also point out that patients with MMC experience slow development in independence in self-care activities, being close to 60 to 69% that need some kind of assistance (Collange et al. 2008; Schoenmakers et al. 2005). Parents of pre-adolescents with MMC attribute difficulties with self-care (self-catheterization, intestinal re-education, care of the skin and self-medication), motivational factors, attention and memory (Holmbeck et al. 1998). One study conducted with 40 Brazilians with SB showed that the patients with a thoracic level lesion experience the poorer functional results in personal care than those with the lumbar or sacral levels. When associated with symptomatic hydrocephalus, the limitation was even more accentuated (Collange et al. 2008).

With all that has been presented to this point, taking into consideration the entire context involved in the rehabilitation and use of IC by people with SB, the researcher was motivated to study catheterization at a deeper level, in search of understanding how to simplify, transpose difficulties and transform realities, through scientific collaboration among countries and international exchange experiences. Thus the present study set out to examine, describe and compare the factors involved in the use of IC by

people with SB in Brazil and Germany, and later raise suggestions for the exchange of information about IC between the two countries.

3. OBJECTIVES

In this section, the overall objetive and specific objectives of this study will be presented.

3.1. Overall objective:

The primary objective of this study is to examine, describe and compare the technical, biopsychosocial and family-related factors associated with the use of intermittent bladder catheterization in German and Brazilian individuals with spina bifida.

3.2. Specific Objectives:

- Characterize from a biopsychosocial perspective German and Brazilian individuals with spina bifida who use IC.
- Describe and compare the variables related to the IC technique currently used in both countries.
- Describe and compare the main difficulties related to IC reported by Brazilian and German patients and their family members.
- Identify factors related to the use or non-use of IC.
- Identify the predictive factors for the use of self-catheterization.
- Identify the factors that correlate with the acquisition of vesical continence after the introduction of IC.
- Identify the factors that influence the occurrence of urinary tract infection (UTI) in patients who use IC.
- Develop considerations and suggestions for Brazil and Germany in the context of rehabilitation of individuals with SB and IC, based on experiences and cultural differences observed during the study.

4. METHOD

The factors involved in the performance of intermittent bladder catheterization for young Brazilians and Germans with SB will be described, correlated and evaluated in this study. It is a quantitative, descriptive, correlational study, composed of two phases. The first was conducted in Brazil between 2008 and 2009, and the second in Germany between 2010 and 2011. The methodological path that was followed in each country is reported below:

4.1. Literature

The databases PUBMED/ MEDLINE, WORDCAT, EBSCO, ERIC, BVS, BDENF, LILACS, SCIELO, COCHRANE, IBECS, PsycINFO, PSYNDEX, SCOPUS, as well as the collections in the libraries of the Sarah Network of Rehabilitation Hospitals and the Technical University of Dortmund, were consulted between January 2008 and October 2011. The descriptors used in this study were: spina bifida, spinal dysraphism, myelomeningocele, bladder catheterization, intermittent catheterization, urinary tract infection, urinary incontinence, rehabilitation, participation, autonomy, quality of life and urological treatment.

4.2. Location of Study

4.2.1 Location of the study in Brazil

The first phase of the study occurred in Brazil in the city of Belo Horizonte, Minas Gerais. Data were collected at the Belo Horizonte site of the Sarah Network of Rehabilitation Hospitals (www.sarah.br). The Sarah Network, comprised of nine hospitals in different regions of Brazil, is a model for neurological rehabilitation

in Latin America and, further, for the treatment of patients with SB. This is a free public service accessible to all Brazilians, across all social classes.

The Belo Horizonte site has a capacity of 125 beds and serves approximately 600 outpatient clients per day. Nursing care is provided exclusively by about 100 nurses, whose minimum education is a college degree, and 20 nursing assistants. The majority of care is done in teams composed of nurses, psychologists, pediatricians, physical therapists, speech therapists, hospital educators, physical educators and nutritionists. Currently, the Belo Horizonte site has approximately 1,130 patients diagnosed with SB and 900 of these have MMC. The total number of patients with SB in all units of the network is 5,462 patients and 4,973 of these have MMC.

4.2.2 Location of the study in Germany

The data collection in Germany was conducted through an online questionnaire which allowed for data to be collected from different regions of the country.

The study was supported by the School of Rehabilitation Sciences, University of Dortmund, the ASBH (Association for Spina Bifida and Hydrocephalus) and Sternchenforum (www.sternchenforum.de).

ASBH, founded in Germany in 1966, is a nationwide organization of mutual aid whose objectives are to inform, advise and cooperate with patients and their families who have congenital spinal cord disorders (spina bifida) and hydrocephalus. The Association is headquartered in Dortmund and has the support of approximately 75 regional groups and associations composed of individuals with SB, their parents, relatives, and volunteers. ASBH currently has approximately 4,000 members throughout Germany. The Sternschenforum, which operates in collaboration with ASBH, is also an online, self-help forum for families and people with SB and/or HC.

4.3. Ethical aspects

Brazil

This study was authorized by the board of the rehabilitation hospital (Sarah Network - Belo Horizonte site). Data collection began only after the consent form for participation in scientific research were signed (Appendix 1) by the patient, if 18 or older, or by the person responsible if the patient was younger than 18 years of age (Brazil - Ministry of Health 1996).

Germany

In Germany, the research project was initially approved by the committee of professors at the School of Rehabilitation Sciences, University of Dortmund, and the board of directors of ASBH (Association of Spina Bifida and Hydrocephalus). For the collection of data during the pilot phase, the consent form for participation in scientific research were printed by the patient or person responsible and signed (Appendix 2). For the data collection via the online questionnaire, a virtual consent form for participation in scientific research (Appendix 3), consisting of one page of explanation of the study and request for permission to use the data, was inserted.

4.4. Sample

Study participants were Brazilian and German patients diagnosed with spina bifida and experience using IC.

A specific age group was not stipulated because the study aimed to broadly cover all individuals who use IC, while utilizing the variation in age to better understand the context of IC in both countries.

4.4.1. Criteria for inclusion in the samples:

Brazilian and German patients diagnosed with spina bifida who use or have used IC.

4.4.2. Exclusion criteria of the samples:

Patients who had never used intermittent catheterization, as well as patients and those responsible for them did not agree to participate in the study.

In the German sample participants were excluded if they did not complete the entire virtual questionnaire.

4.4.3. Sample size

The sample was calculated using the Freeman formula n = 10 * (k +1) for logistical regression, where k is the maximum number of independent variables (Freeman 1987). Thus, the sample was comprised of 200 patients, 100 in Brazil and 100 in Germany.

4.5. Procedures for data collection

Brazil

The Brazilian questionnaire (Appendix 4) was prepared by a team consisting of one psychologist, two nurses and two pediatricians, all with experience in the rehabilitation of patients with SB. As a base for the development of the questionnaire, the protocol for urological follow-up of patients who have used bladder catheterization was used. The questionnaire was validated through the process of daily care of inpatients and outpatients at the hospital.

The Brazilian sample consisted of 100 patients with open SB and was selected according to the sequence of appointments scheduled by the hospital until 100 individuals were interviewed.

Participants and those responsible for them responded to the questionnaire (Appendix 4), which was administered by the same team responsible for its development.

Germany

This section will report the trajectory followed by the researcher in Germany through to the completion of data collection. The first contacts with the German researchers began in mid-2009. For approximately one year, the planning and feasibility study were conducted in Germany.

In July 2010, the researcher moved to the city of Dortmund, entering the doctoral program at the School of Rehabilitation Sciences, University of Dortmund. At that time, she began to have personal contact with the culture and intensive study of the German language (7 to 9 hours a day), including class time and personal study. Meetings with patients with SB began at the headquarters of the Association of Spina Bifida and Hydrocephalus in Dortmund. After sharing the research objectives with the board of ASBH, the following action plan was developed:

Step 1: field research. In this stage, the researcher sought to become familiar with the German system of rehabilitation and how the patient population uses the IC technique. She completed internships in some German rehabilitation centers, including Stuttgart and Gerlingen Kliniken Schmieder, which specializes in neurological rehabilitation and has about 1,000 beds, plus a day hospital and outpatient care. The researcher was also an intern at the Hegau-Jugendwerk hospital and rehabilitation center in Gailingen, which specializes in neurological rehabilitation of children, adolescents and young adults. Later, the researcher followed the work of the nurses of the companies producing

catheters, who are specialists in providing training for intermittent bladder catheterization.

Step 2: Translation and adaptation of the questionnaire. In this phase, the questionnaire previously used in Brazil was translated and adapted to fit the German reality. The translation was done by the researcher in conjunction with a German professor fluent in Portuguese, as well as a Brazilian teacher of German and three German university students of child development, specializing in rehabilitation. The adaptation of the questionnaire to the German reality was accomplished with the collaboration of German professionals: five nurses specialized in training of bladder catheterization to patients with SB, a neurologist and two educators with SB experience. During the adaptation of the questionnaire, the professionals initially responded to each question and later discussed it with the researcher, who then made changes to the questionnaire according to the suggestions made during this stage.

Step 3: Pilot testing. During this stage, three pilot tests of the translated and adapted questionnaire were conducted to test the research instrument with a small portion of the population before being administered (Marconi & Lakatos, 2005). The tests were conducted during the seminars sponsored by ASBH, where patients and their relatives participate in courses and leisure activities, in addition to IC training weekends sponsored by the catheter manufacturing firms. About 20 patients/relatives and seven professionals, mostly nurses, participated in this stage. Pilot test participants first attended a lecture by the researcher on the subject of research, and then they responded to the questionnaire, including their questions and suggestions for change. Finally, each participant had brief meeting with the researcher where they provided the feedback they recorded on the questionnaire. Later, all of the notes and suggestions were gathered, analyzed and incorporated into the instrument. The next step was to adjust the structure and visual presentation of the questionnaire.

Step 4: Construction of the online questionnaire. The pre-tested questionnaire was converted to an online platform (Survey Monkey) to facilitate access for patients and their families throughout Germany.

Step 5: Pilot test of the online questionnaire. After building the online questionnaire, a pilot test was conducted to verify that its functionality. This test was performed by university students in the area of child development from the School of Sciences of Rehabilitation, by a Brazilian statistician from the local hospital of study and by a psychologist/professor at the University of Dortmund.

Step 6: Dissemination of the study. In this stage, strategies to promote the study were implemented. For example, publication of the study proposal/invitation in the ASBH magazine, promotion in specialized forums targeting patients with SB and their families, and posting in the most popular social networks used by young people. In addition to lectures on the status of intermittent catheterization in Brazilian patients with SB and on the research proposal, the study was promoted during meetings about IC training with relatives and patients organized by ASBH and by catheter manufacturers.

Step 7: Data collection. Data was collected using the online questionnaire (Appendix 3). The online questionnaire page had about 150 hits and of these 100 patients answered the questionnaire completely. Data collection took place over a period of about 60 days and was stopped when the goal of 100 complete questionnaires was reached. This allowed the researcher to pair the German sample with the Brazilian sample, in accordance with the projected study sample.

4.6. Description of study variables

This study sought to investigate the relationship between the current *use of IC, method of catheterization, acquisition of urinary continence after IC*, and the *number of UTIs* (dependent variables) to those described in the questionnaire presented in Appendices 3 and 4 (independent variables).

4.6.1. Dependent variables

Four response variables were analyzed as described below:

1) Model 1 – *Use of IC* - this type of response variable was binary (yes / no) - and defined as follows:

- Yes: uses intermittent bladder catheterization;

- No: does not use intermittent bladder catheterization.

2) M odel 2 – *Self-catheterization*: This type of response variable was binary (yes / no) - assisted catheterization is used (no) or self-catheterization (yes) - and defined in the following manner:

- Yes: uses self-catheterization - realization of intermittent bladder self-catheterization with no assistance from others, or uses IC with a need for supervision only in relation to time schedule and/or washing (self-catheterization with assistance or supervision) (Association for Continence Advide, 2003).

- No: does not use self-catheterization, uses assisted catheterization – IC performed by a third party, without the patient's participation, or with minor patient participation for technical requirements, such as holding or removing the catheter, washing the genitalia, among others (Association for Continence Advide, 2003).

3) Model 3 - *Urinary tract infection (UTI)*: In this study, UTI was considered as a guide for patients and family members who participated in the survey, the occurrence of bacteriuria (more than 100,000 colonies / ml) in combination with one or more of the following findings: fever (greater than or equal to 38°), leukocytosis, flank or suprapubic pain, changes in habit of bladder emptying, nausea, vomiting, increase of

muscle spasms, appearance or intensification of symptoms of dysreflexia and exclusion of other causes for these findings.

This variable was classified into two categories:

- UTI before: number of episodes of symptomatic UTI in the year before the beginning IC;

- UTI after: number of episodes of symptomatic UTI in the year after using IC;

4) Model 4 - *Acquisition of urinary continence after IC*: this type of response variable was binary (yes / no) - total or partial continence and incontinent, defined as follows:

- Yes: total or partial continence – does not have any urinary leakage or has low level loss with the need to use small sanitary pads.

- No: incontinent - has frequent leakage of urine requiring the use of diapers at all times.

4.6.2. Independent Variables

The independent variables can be viewed in the questionnaire itself (Appendices 3 and 4).

4.6.3. Classification of variables

In this section, the classifications of the variables in the study will be elaborated.

– *Mobility*: The classification of mobility was different in the two samples, since the

Brazilian sample was rated by rehabilitation professionals, which was not possible in the German sample because participants responded to the questionnaire online.

Therefore, the Brazilian sample was classified using the ambulation classification according to the criteria of Hoffer and Findley, which has been used in the Sarah Network of Rehabilitation Hospitals (Findley et al., 1987, Hoffer et al. 1973; Palhares, 2000). The classification is divided into four categories:

1. No ambulation: under no circumstances do patients walk by themselves; they use a wheelchair full-time.
2. Non-functional ambulation: the patient walks about with or without the aid of braces and / or mobility assistance, only when exercising, and therefore only on occasion. Uses a wheelchair as a means of transportation within and outside the home.

3. Household ambulation: the patient walks about with or without the aid of braces or mobility assistance, at home and at school (short distances), requiring a wheelchair for long distances in the community.
4. Community ambulation: the patient walks about with or without assistance or orthosis and / or mobility assistance, and does not need a wheelchair under any circumstances.

Since the German sample, both patients and their families, answered the questionnaire on their own, it was decided that they be questioned about the resources used for mobility using a multiple choice question format. The following possible answers were provided: walk without assistance, walk with braces, wheelchair, crutches/canes, walker, other. The patient who reported using a wheelchair full-time was considered wheelchair dependent / non-ambulatory because he/she depended constantly on the wheelchair as a means of mobility.

– *Education level*: since the school systems in Brazil and Germany have different classifications, the analysis required the creation of seven categories, divided according to years of schooling:

1. Pre-school/ kindergarten/ early childhood education, or not school age or no schooling.
2. 1 to 5 years of schooling: for the period from 1st to 5th year in Brazil and *Grundschule* in Germany.
3. 6 to 12 years of schooling: for the period from 6th to 12th year in Brazil, and refers to *Hauptschule, Realschule* and *Gymmasium* in Germany.
4. Special school: education aimed at people with special needs, and refers to *Sonderschule* in Germany.
5. Technical education / vocational training: technical high school, refers to *Berufsschule* in Germany.
6. Technical college (technologist): higher vocational education, refers to *Fachhochschule* in Germany.
7. University: higher education.

– *Understanding of catheterization by the primary person responsible:* the understanding of the German sample was evaluated by the study participants themselves, and the Brazilian sample was evaluated by professional staff of the hospital study site. The level of understanding was classified into four categories:

1. Excellent or good understanding: knows the test results, the indication for the procedure and the risks involved.
2. Reasonable: understands the most relevant aspects of the tests, procedures and risks involved.
3. Low: only partially understands, confuses the data.
4. None: does not understand anything about IC.

– *Substances used in the performance of IC*: substances used to clean the genitalia before the introduction of the catheter were classified into four categories, in order to facilitate the analysis of data:

1. Disinfection: patients who reported using disinfectant / antiseptic substances, for example: Octenidine dihydrochloride, Polyhexanide solution and Chlorhexidine solution;
2. Washing: patients who reported using sanitizing cleansers, for example: water, sterile water, water and soap, and moist towelettes;
3. Disinfection or washing: patients who reported using desinfectants or sanitizers.
4. No cleaning: patients who reported not performing any cleaning.

4.6.4. Additional variables of the German sample

The study exaamined more variables in the German sample, including: patient occupation, resources necessary for self-catheterization, substances used in cleaning or disinfecting the genitalia before IC, location where IC is performed, degree of satisfaction with IC, difficulties with the IC from the perspective of the patient and their parents (open-ended question), training previous to performing for self-catheterization and desire for such training, and method used to function the bowel. However, these variables were not subject to comparison, and were only described.

4.7. Data analysis

The data were organized in a database using SPSS statistical software (Statistical Package of Social Science), version 19.0.

The mean values (m) and median values (md) were exhibited with their respective standard deviation (SD) 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 always greater than 0.5.

For nominal variables, contingency tables and Yates' chi-square or Fisher's Exact were used. For ordinal and interval variables with few integer values, the Mann-Whitney U-test was used for two independent samples, and the Kruskal-Wallis H-test for more than two independent samples. Where the Student's t-test was used, the p-value was chosen according to the significance of the Levene test for equality of variances of independent samples. When the ratio between two samples was greater than the ratio 1:5, the p-value and respective 99% confidence intervals (CI 99%) were calculated using the *Monte Carlo* method with 10,000 or 100,000 interactions between samples.

Bilateral statistical tests were the preferred choice, and the use of unilateral tests was was clearly stated in the text. The probability of minimal significance for decision-making was 0.05.

Multivariate analysis of the explanatory variables in the use if IC, the IC method, the number of UTIs before and after the use of IC and the acquisition of continence after IC:

The process of selecting variables, for the construction of the multivariate model, took place by running statistical tests between each independent variable and the dependent variable of interest. Variables with p-values less than or equal to 0.25 were selected as possible candidates.

The final multivariate logistical model was the result of selection of these variables using the SPSS backward method (likelihood ratio), using the probabilities of significance of 0.05 for entry and 0.10 for removal of the variable.

The explanatory model of the number of UTIs before and after the use of IC was developed using Analysis of Variance (ANOVA) for repeated measurements.

Previously, the M-Box test was run to check the equality of the covariance matrix of the number of UTIs before and after.

In order to manage the bibliographical references for the literary review of this study, the Citavi program was used.

4.8. Funding of the study

In Brazil, in the first phase, this study was supported by the SARAH Network of Rehabilitation Hospitals, especially by the unity of Belo Horizonte – MG.

In the second phase in Germany, the study relied on the collaboration of KAAD (Catholic Academic Service International), an institution that assisted the study through a doctoral scholarship for the researcher.

5. RESULTS

In this section, the results of this study will be presented. They have been organized into two major parts:

1) Descriptive and comparative analysis of the variables evaluated in the 200 patients and divided between the Brazilian sample and the German sample in order to characterize and understand the populations studied;

2) Advanced statistical analysis with selected variables, divided into four models, aimed at reaching the objectives proposed by the study.

Disclosure of the data will occur in the following sequence:

5.1. Descriptive and comparative analysis

5.1.1. Socio-demographic and health variables:

- *Profile of the individuals* (age, gender, education level, location of SB, presence of HC, presence of VP shunt and mobility).
- *Profile of key person responsible for catheterization* (identification of the primary person responsible, the one who answered the questionnaire and questions regarding education level).

5.1.2. Variables related to catheterization:

- *Variables related to family structure and previous history with IC* (if another person performs IC, age at the beginning of IC use, and first method of catheterization).
- *Variables related to IC technique (*current method of catheterization, age at first assisted catheterization as well as age at time of self-catheterization, resources for self-catheterization and daily frequency of IC).

- *Variables related to the materials used in* IC (substance used for washing genitalia, disposal and type of catheter).
- *Health variables* (medical indication of IC, UTI before IC, UTI after IC, use of medication, medications taken, reasons for irregular use of medications, and continence after IC).
- S*ocial variables* (objectives for person responsible for IC, understanding of indication of IC, performance of IC away from home, and how IC materials are acquired).
- *Variables related to difficulties with IC* (discontinuation of IC, reasons for discontinuation of IC, technical difficulties, home-related difficulties and emotional barriers).

5.1.3. Variables exclusive to the German sample: (location of performance of IC, resources needed for self-catheterization, occupation, prior training and desire to learn self-catheterization, report on difficulties from the viewpoint of patients and their parents, and method for emptying the bowel).

5.2. Advanced statistical analysis

5.2.1. Factors related to using or not using IC: model 1**.**

5.2.2. Predictive factors for self-catheterization: model 2.

5.2.3. Factors related to the occurrence of UTI: model 3.

5.2.4. Factors related to the acquisition of urinary continence after IC: model 4.

5.1. Descriptive and comparative analyses

This analysis will describe all the variables collected in the study, which are divided according to the topics relevant to the research, in order to characterize the Brazilian and German individuals with spina bifida who use IC. The values of the variables are presented according to the total sample and also divided according to nationality in order to provide the reader with an overview, as well as an initial possibility of comparison between Brazilian and German samples.

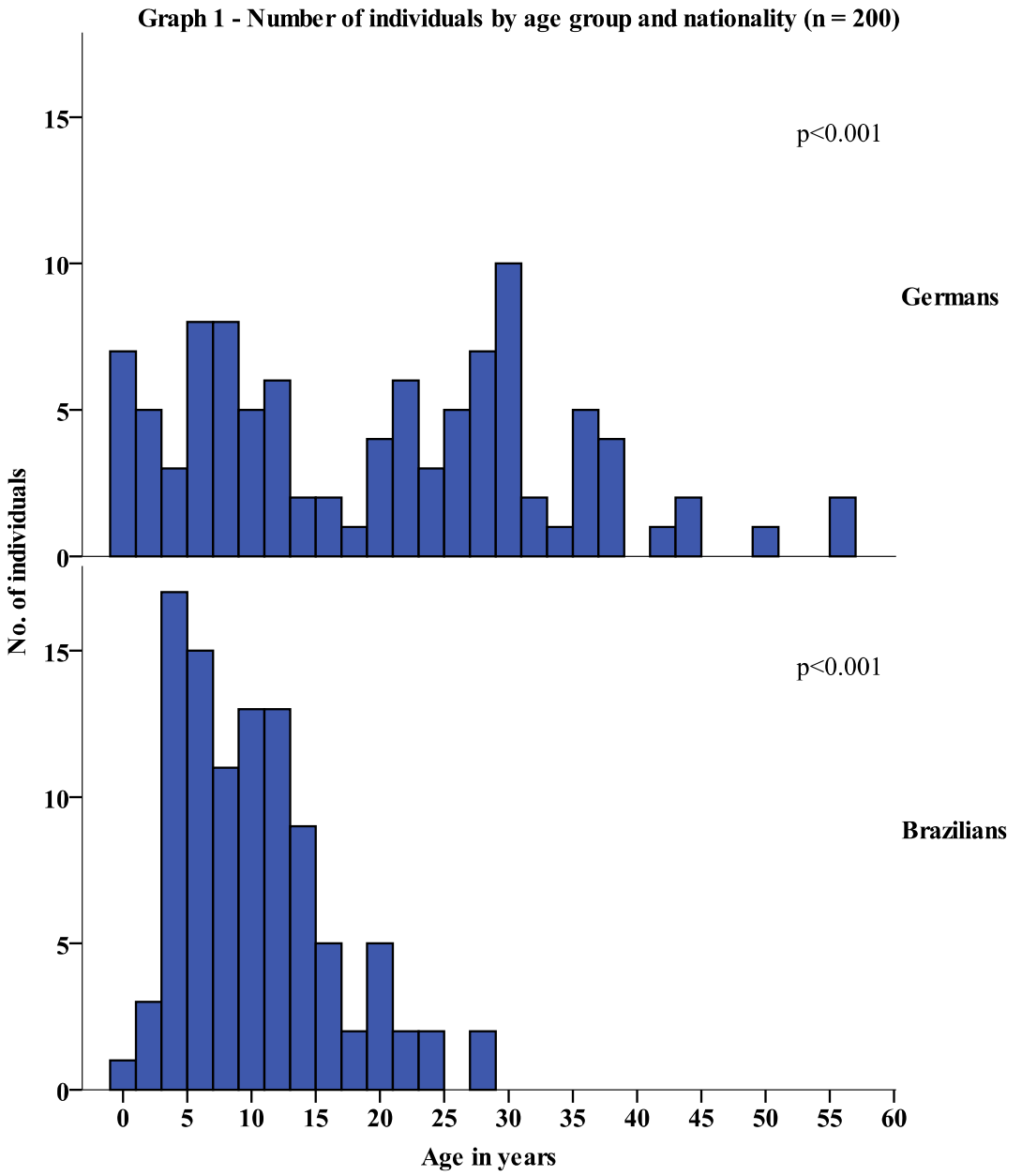
The sample was comprised of 200 participants, equally divided into 100 Brazilians and 100 Germans. The Brazilian data collection was conducted 100% through a printed questionnaire. The German sample was collected 100% through an online questionnaire.

5.1.1. Socio-demographic and health variables

In this section we will describe the main socio-demographic variables of the study sample, emphasizing the distribution of data according to nationality.

– *Profile of individuals*:

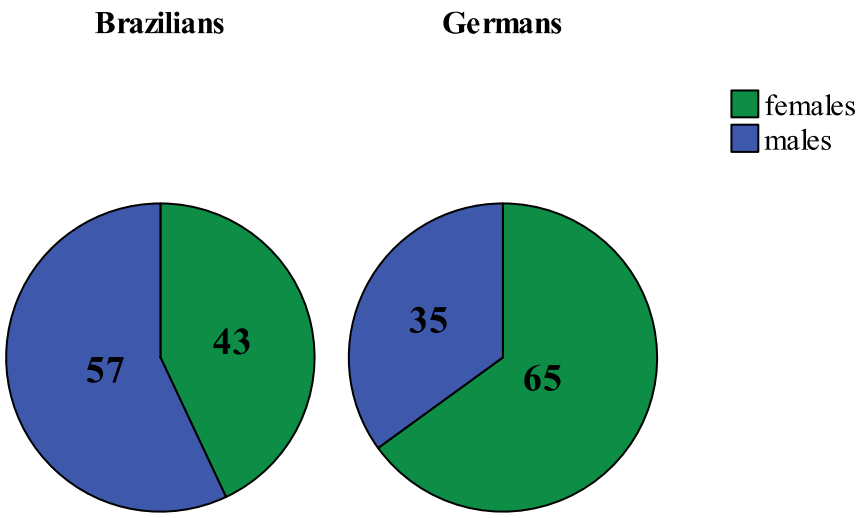
The age of the total sample ranged from 0 to 55 years old, with a median of 11 (6.0; 22.0) years and a mean of 14.5 (11.5). The age of the Brazilians varied between 0 and 28 years of age, with a median age of 9 (5.5, 13.0) and a mean of 9.9 (6.0). The age of the Germans ranged from 0 to 55, with a median age of 20 (7.0, 29.0) years and a mean of 19.2 (13.7). The ages of the sample are presented in the histogram below (Graph 1)



As noted in the histogram displaying age, the Brazilian sample was composed of children, adolescents and young adults, whereas the German sample had a population that included children, adolescents and adults. Therefore, the Brazilian sample represented a younger population than the German sample (Student's t-test, $p < 0.001$, Levene test, $p < 0.001$). In this aspect, the German sample was more representative because it included almost all age categories, with two modes (0 to 20 and 20 to 45), indicating that two populations are in the same sample.

Regarding gender, the total sample consisted of 108 females and 92 males. The Brazilian sample had 43 women and 57 men, and the German sample had 65 women and and 35 men (Graph 2).

Graph 2 - Number of individuals by gender and nationality (n = 200)



(p=0.003)

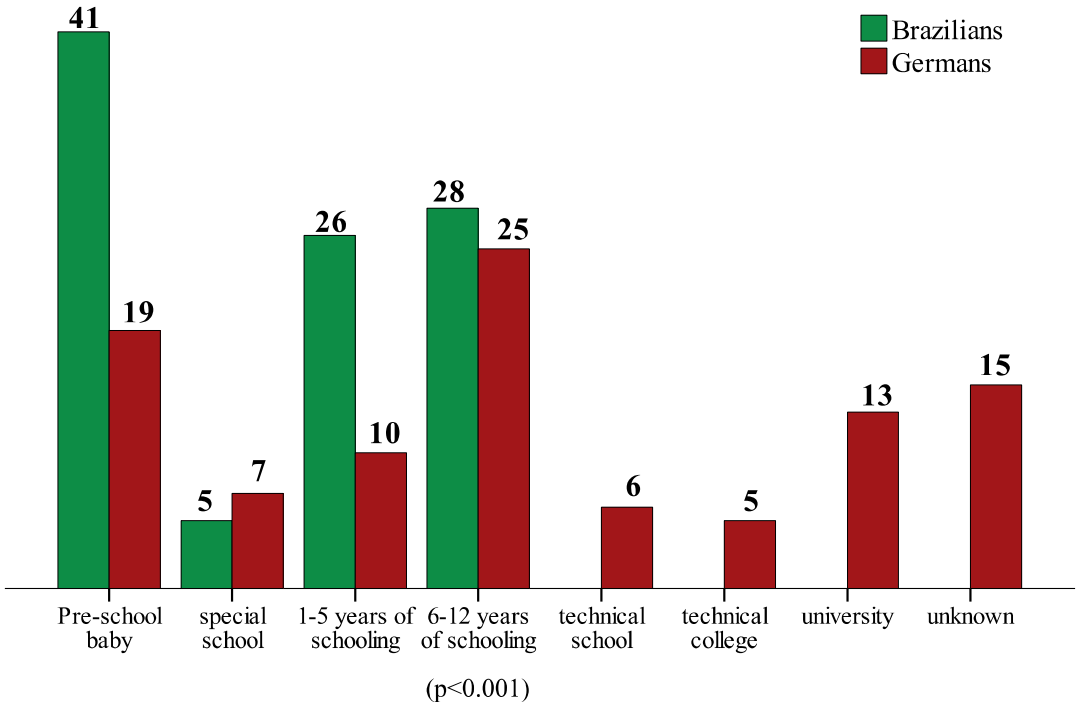
As noted in the graph above, there was a difference in the distribution of the Brazilian and German samples in relation to the gender of the individuals (Chi-square test, p=0.003). The Brazilian sample was predominantly male and the German sample primarily female.

Regarding education level, a matching of the schooling levels in Germany and Brazil was done, as previously described in the methodology of the study (p. 79) and displayed in Table 5 and Graph 3.

Table 5 – Education level of the patients and their nationality (n = 200)

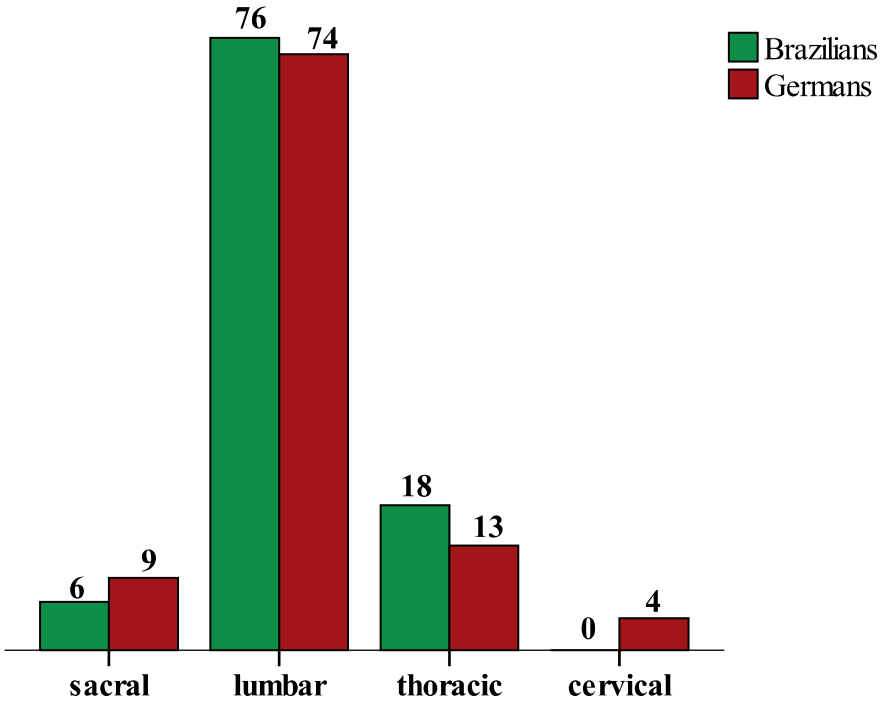
Education level	Brazilians	Germans	P-value	Total
Pre-school / non-school age	41	19	<0.001	**60 (30.0%)**
Special schooling	5	7	0.551	**12 (6.0%)**
1 to 5 years of schooling	26	10	0.002	**36 (18.0%)**
6 to 12 years of schooling	28	25	0.630	**53 (26.5%)**
Technical high school	0	6	<0.001	**6 (3.0%)**
Technical college (technologist)	0	5	<0.001	**5 (2.5%)**
University	0	13	<0.001	**13 (6.5%)**
Unknown	0	15	<0.001	**15 (7.5%)**
Total	**100**	**100**	**-**	**200 (100.0%)**

Graph 3 - Distribution of the sample by education level of patients and nationality (n=200)



There were 41 Brazilians and 19 Germans in pre-school / non-school age / baby, 5 Brazilians and 19 Germans attending special schools, 26 Brazilians and 10 Germans with 1-5 years of schooling, 28 Brazilians and 25 Germans with 6 to 12 years of schooling, 6 Germans and no Brazilians pursuing a technical education (technical high school), 5 Germans and no Brazilians as technologists (technical college). There were no Brazilian university students and 13 German students. In the German sample, 15 participants did not report their education level. Schooling in the two samples has a different distribution, being higher in the German sample than in the Brazilian sample (Mann-Whitney U-Tests, p <0.001). There was a predominance of “pre-school” and “1-5 years of schooling” in the Brazilian sample, and people with “13 or more years of schooling” in the German sample (Mann-Whitney U-Tests, p <0.001). There was a balance in the distribution between the categories "special school" and "6 to 12 years of schooling". The participants were classified according to the location of the SB (Graph 4).

Graph 4 - Number of individuals by level of spina bifida and nationality (n = 200)

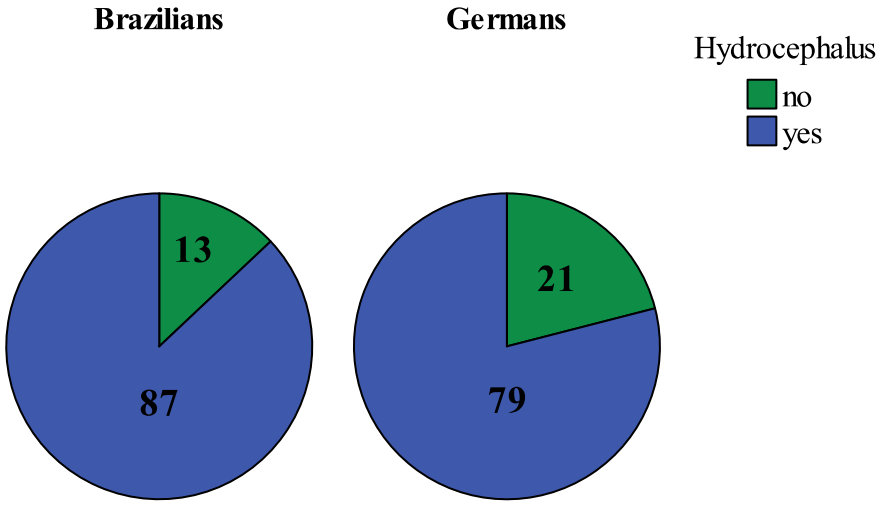


(p=0.153)

According to the graph above, the Brazilian and German samples have a uniform distribution in relation to the location of the spina bifida (Exato de Fisher, p=0.153). At the cervical level, there were 4 Germans and 0 Brazilians. At the thoracic level, there were 18 Brazilians and 13 Germans. At the lumbar level, there were 76 Brazilians and 74 Germans. And finally, at the sacral level, there were 6 Brazilians and 9 Germans.

The sample distribution was run for the presence of hydrocephalus (Graph 5) and the use of ventriculoperitoneal shunt (Table 6).

Graph 5 - Number of individuals by presence of hydrocephalus and nationality (n = 200)



(p=0.133)

Table 6 – Sample distribution for the presence of hydrocephalus, use of ventriculoperitoneal shunt and nationality (n = 200)

Nationality			Shunt**		Total
			no	yes	
Brazilian	HC*	no	13	0	13
		yes	16	71	87
	Total		**29**	**71**	**100**
German	HC*	no	21	0	21
		yes	7	72	79
	Total		**28**	**72**	**100**

* Chi-square test, p=0.188, the samples exhibited similar distribution for HC.

** Chi-square test, p=1.000, the samples exhibited similar distribution for VP shunt.

Hydrocephalus associated with SB was found in 166 patients (83.0%), with the Brazilian sample having 87.0% of the patients with HC and the German sample having 79% of the patients with HC (Graph 4). Out of these 87 Brazilian patients with HC, 71 (81.6%) use a ventriculoperitoneal shunt. In the German sample, of the 79 patients with HC, 72 (91.1%) use a ventriculoperitoneal shunt (Table 6). The difference in the distribution of HC in the two samples was not statistically significant (Chi-square test, p=0.188). The use of the VP shunt also did not show a difference in distribution by nationality (Chi-square test, p=1.000). Looking at each category separately, HC without a shunt was predominant in the Brazilian sample (Brazilian = 16.0% and German = 7.0%, z-test between two proportions, p=0.044). The condition for the use of the VP shunt was the presence of HC. The mean age of patients who used the VP shunt was 12.5 (14.2) years, lower than the mean age of patients who did not use the VP shunt which was 19.6 (9.6) years (teste t-Student, p=0.001; teste de Levene, p<0.001).

The mode of ambulaton of the Brazilian sample was evaluated according to the

ambulation classification (Table 7), as described in the methodology for the classification of the variables.

Table 7 – Distribution of the Brazilian sample according to gait classification

(n = 100)

Gait classification	**n***	**%**
Non- ambulatory	42	42.0
Ambulation at home	18	18.0
Ambulation in community	31	31.0
Non-functional ambulation	6	6.0
Classification not determined due to age	3	3.0
Total	**100**	**100.0**

*Student's t-test, $p<0.001$, the sample presented a different distribution in relation to the ambulation classification.

There were 42 patients who were classified as non-ambulatory, with 18 patients having household ambulation, 31 patients with community ambulation, 6 patients classified with non-functional ambulation, and 3 patients were not classified due to their young age. The Brazilian sample had a different distribution in relation to the gait classification (Student's t-test, $p <0.001$).

The form of ambulation of the German sample was divided according to the necessary assistance for ambulation reported by patients (Table 8). Unlike the Brazilian sample, there was no gait classification reported by professionals.

Table 8 – Distribution of the German sample by support used for ambulation (n = 100)

Ambulation assistance	n	%
Ambulation without assistance	13	13.0
Wheelchair dependent (non-ambulatory)	41	41.0
Many types of assistance used (canes, crutches, walker, wheelchair)	35	35.0
Ambulation-assistance not determined due to age	11	11.0
Total	**100**	**100.0**

* Student's t-test, $p<0.001$, sample presented a different distribution in relation to the distribution for assisted ambulation.

There were 13 German patients who reported walking without any type of assistance, 41 patients (non-ambulatory) who used a wheelchair exclusively for ambulation, 35 patients used various mobility aids (canes, crutches, walker and wheelchair) and 11 patients were babies, thus the form of ambulation by ambulation assistance could not be determined due to their young age. The German sample showed a different distribution in relation to the distribution ambulation assistance (Student's t-test, $p <0.001$).

Even though the ambulation classification was not the same in both samples, the data showed that 42.0% of Brazilian individuals are "non-ambulatory", using a wheelchair full-time to get around. A similar frequency was also observed in the German sample with 41.0 % of individuals being totally dependent on a wheelchair for ambulation (z-test, $p=0.885$).

Table 9 – Level of spina bifida and use of wheelchair as the only form of ambulation (n = 197)

Location of SB	Use of wheelchair		P-value*	Total
	no	yes		
sacral	93.8% (15)	6.2% (1)	<0.001	**100.0% (16)**
lumbar	64.0% (96)	36.0% (54)	<0.001	**100.0% (150)**
thoracic	9.7% (3)	90.3% (28)	<0.001	**100.0% (31)**
Total	**57.9% (114)**	**42.1% (83)**	**-**	**100.0% (197)**

* Fisher's Exact, p<0.001, the distribution of wheelchair use varied according to SB level.

Thus, considering the total sample, 83 participants were wheelchair-dependent on a full-time basis. By comparing the level of the lesion in three categories (sacral, lumbar and thoracic) with the full-time use of a wheelchair, there was a difference in the distribution of the sample (Fisher's Exact test, p <0.001). Of the patients with the lesion at the thoracic level 90.3% were wheelchair dependent. For those with the lesion at the lumbar and sacral levels, 36.0% and 6.2% were wheelchair dependent, respectively (Table 9). By calculating the odds ratio using the logistical regression, it was possible to verify that an individual with SB at the thoracic level was approximately 14.2 times more likely to use a wheelchair full-time, that is, to be non-ambulatory (Table 10).

Table 10 – Effect of the variable level of spina bifida on full-time use of a wheelchair

Variable	Coefficient	Standard Error	Wald Statistic	P-value	Odds Ratio	95%CI for OR	
						Inferior	Superior
Level of SB	2.655	0.538	24.357	<0.001	14.222	4.955	40.815
Constant	-5.863	1.121	27.339	<0.001	0.003	-	-

– *Profile of the key person responsible for catheterization:*

The people who responded to the questionnaire were distributed according to Table 11.

Table 11 – Number of individuals according to the person who completed the questionnaire and by nationality (n = 200)

Person	Brazilians	Germans	P-value	Total
mother	72	43	<0.001	115 (57.5%)
patient	20	49	<0.001	69 (34.5%)
father	7	6	0.774	13 (6.5%)
grandparents	1	1	1.000	2 (1.0%)
other	0	1	0.314	1 (0.5%)
Total	**100**	**100**	**-**	**200**

Between the two samples, 69 questionnaires were completed by the patients themselves and 131 were completed by other people. The majority of the questionnaires were completed by mothers (115), followed by the patients themselves (69), fathers (13), grandparents (2), others (2). In the Brazilian sample, 20.0% of the questionnaires were completed by the patients and 80.0% were completed by "other person", including 72

mothers, seven fathers and one grandmother. In the German sample, 49.0% of the questionnaires were completed by the patient, while the "other person" category had 51.0% (43) mothers, 6 fathers, 1 grandfather and one other. There was a different distribution of the questionnaire respondents between the Brazilian and German samples (Fisher's Exact test, p <0.001). It can be noted that, in the German sample, there was a balance between the number of questionnaires completed by patients, 49%, and those completed by another person 51.0% (z-test, p=0.769). In the Brazilian sample, most of the questionnaires (72.0%) were completed by the mothers (z-test, p<0.001).

According to the key person responsible for catheterization, the samples were divided and distributed as outlined in Table 12.

Table 12 – Key person responsible for catheterization and nationality (n = 200)

Person Responsible	**Brazilians**	**Germans**	**P-value***	**Total**
mother	71	42	<0.001	**113 (56.5%)**
patient	22	54	<0.001	**76 (38.0%)**
father	3	3	1.000	**6 (3.0%)**
grandparents	4	0	0.041	**4 (2.0%)**
siblings	0	1	0.314	**1 (0.5%)**
Total	**100**	**100**	-	**200 (100.0%)**

*Fisher's Exact test, p<0.001, the samples had a different distribution in relation to the key person responsible for IC.

In the Brazilian sample, the primary persons responsible for performing IC were: 22 patients, 71 mothers, 3 fathers and 4 grandparents. In the German sample, those responsible for the procedure were: 54 patients, 42 mothers, 3 fathers and 1 brother. The samples had a different distribution regarding the key person responsible for IC

(Fisher's Exact test, p <0.001). In the Brazilian sample, in the majority of cases (71.0%), mothers were responsible (z-test, p <0.001), whereas in the German sample, the patients themselves, in 54% of cases, were principally responsible for IC (z-test, p=0.368). Mothers were primarily responsible for IC in the Brazilian sample (71.0%, z-test, p<0.001), whereas in the German sample, the patients themselves were responsible (54.0%, z-test, p=0.368).

The level of education of the key person responsible for assisted IC was evaluated and can be observed in Table 13.

Table 13 – Education level of key person responsible for assisted catheterization and nationality (n = 124)

Education level	**Brazilians**	**Germans**	**P-value**	**Total**
1 to 5 years of schooling	23	0	<0.001	**23 (18.5%)**
6 to12 years of schooling	46	17	<0.001	**63 (51.0%)**
Technical high school	0	6	0.011	**6 (4.8%)**
Technologist (technical college)	0	9	0.001	**9 (7.2%)**
University	7	12	0.266	**19 (15.3%)**
Illiterate	2	1	0.560	**3 (2.4%)**
Other	0	1	0.314	**1 (0.8%)**
Total	**78**	**46**	**-**	**124 (100.0%)**

There were a total of 124 key persons responsible for assisted IC. In the "1 to 5 years of schooling" category, there were 23 Brazilians and 0 Germans. In the "6 to 12 years of schooling" category, there were 46 Brazilians and 17 Germans. In the "technical high school" category, there were 0 Brazilians and 6 Germans. In the "technical college" category, there were 0 Brazilians and 9 Germans. In the "university" category, there were 7 Brazilians and 12 Germans. In the "illiterate" category, there were 2 Brazilians and 1 German. And in the "other schooling" category, there was 1 German. According

to the table, it can be noted that the German key persons responsible for assisted IC have a higher level of education than the Brazilian key persons responsible for IC (Mann-Whitney U-Tests, p=0.001).

5.1.2. Variables related to catheterization

This section describes the relevant variables necessary for understanding how IC is performed in both countries.

– *Variables related to family structure and previous history with IC*

The ages of the two samples when IC was begun were similar (Student's t-test, p=0.197, Levene test, p <0.001), the median in the total sample was 4 (1.0, 7.7) years, and the mean was 6.2 (8.4) years. In the Brazilian sample, the median was 5 (2.0, 7.0) years and the mean was 5.16 years (3.9) years. In the German sample, the median was 2 (0.0, 9.0) years and the mean was 7.2 (11.2) years. In this case, the values of standard deviation (SD) were very high, so the median brings more clinical significance since the mean was influenced by extreme values. . In the German sample, the value of the standard deviation exceeded the mean value, so for this sample, the median provided greater clinical significance. Approximately 45.5% of patients started IC at three years of age or younger.

According to the initial method of catheterization, 165 patients started with assisted catheterization, 28 with assisted self-catheterization and only 7 started with self-catheterization (Table 14). Of those who started wtih assisted catheterization, 96 were Brazilians and 69 were Germans; 2 Brazilians and 26 Germans began with assisted/supervised self-catheterization; and 2 Brazilians and 5 Germans chose fully independent self-catheterization.

Although the distribution of the initial method of catheterization was different according to nationality (Fisher's Exact test, p<0.001), Table 14 shows that assisted

catheterization was predominant in the two samples as the initial method of IC. In contrast, 31% of Germans began with this procedure with the intention of switching to self-catheterization.

Table 14 – Initial method of catheterization and nationality (n = 200)

Initial method of IC	**Brazilians**	**Germans**	**P-value***	**Total**
Assisted catheterization	96	69	0.035	**165 (82.5%)**
Self-catheterization with assistance	2	26	0.001	**28 (14.0%)**
Self-catheterization	2	5	0.103	**7 (3.5%)**
Total	**100**	**100**	**-**	**200 (100%)**

Participants were asked if there were another person who could be trained to perform IC if needed. A total of 71.0% (70 Brazilians and 72 Germans) responded affirmatively, that there was someone. Those who responded that there was no one totalled 29.0% of the sample (30 Brazilians and 28 Germans). The was a similar distribution of the samples in relation to the existence of another person to perform IC when necessary (yes/no) (Chi-square test, p=0.876). The description of who these people were is outlined in Table 15.

Table 15 – Others who are able to assist in IC procedure if necessary (n = 142)

Person	Brazilians	Germans	P-value	Total
Father	23	40	0.008	**63 (44.4%)**
Mother	28	30	0.755	**58 (40.8%)**
Grandparents	4	22	<0.001	**26 (18.3%)**
Caregiver/Health professional	2	24	<0.001	**26 (18.3%)**
Uncles/Aunts	10	9	0.809	**19 (13.4%)**
Siblings	12	6	0.136	**18 (12.7%)**
Patient	5	6	0.756	**11 (7.7%)**
Other relative (cousin, niece)	7	0	<0.006	**7 (4.9%)**
Partner	0	4	<0.041	**4 (2.8%)**
Educators/teachers	0	4	<0.041	**4 (2.8%)**

As outlined in the previous table, when asked who the other person would be to perform IC, mothers were chosen by 28 Brazilians and 30 Germans, fathers were chosen by 23 Brazilians and 40 Germans, siblings were chosen by 12 Brazilians and 6 Germans, grandparents were chosen by 4 Brazilians and 22 Germans, uncles/aunts were chosen by 10 Brazilians and 9 Germans, the patient him/herself was chosen by 5 Brazilians and 6 Germans, a caregiver or health professional was chosen by 2 Brazilians and 24 Germans, other relatives such as cousin or niece were chosen by 7 Brazilians and 0 Germans, a partner was chosen by 0 Brazilians and 4 Germans, a teacher/educator was chosen by 0 Brazilians and 4 Germans. It is apparent that more Germans have the support of health professionals/caregivers, grandparents, partners and teachers to perform IC than Brazilians (z-test, $p < 0.001$); however, Brazilians have the support of other relatives, such as siblings, cousins and nieces (z-test, $p < 0.004$).

– *Variables related to the technique of IC:*

Regarding the current catheterization of the sample participants, 188 (94%) were using IC at the time, with 94 being Brazilian and 94 German. Also, 12 (6%) of these had performed IC, 6 being Brazilian and 6 German. In relation to the variable "currently use IC", yes or no, the distribution of the sample participants was exactly the same (Chi-square test, p=1.000). The Graph 6 and Table 16 outlines the distribution of the current method of catheterization according to nationality.

Graph 6 - Current method of catheterization and nationality (n = 200)

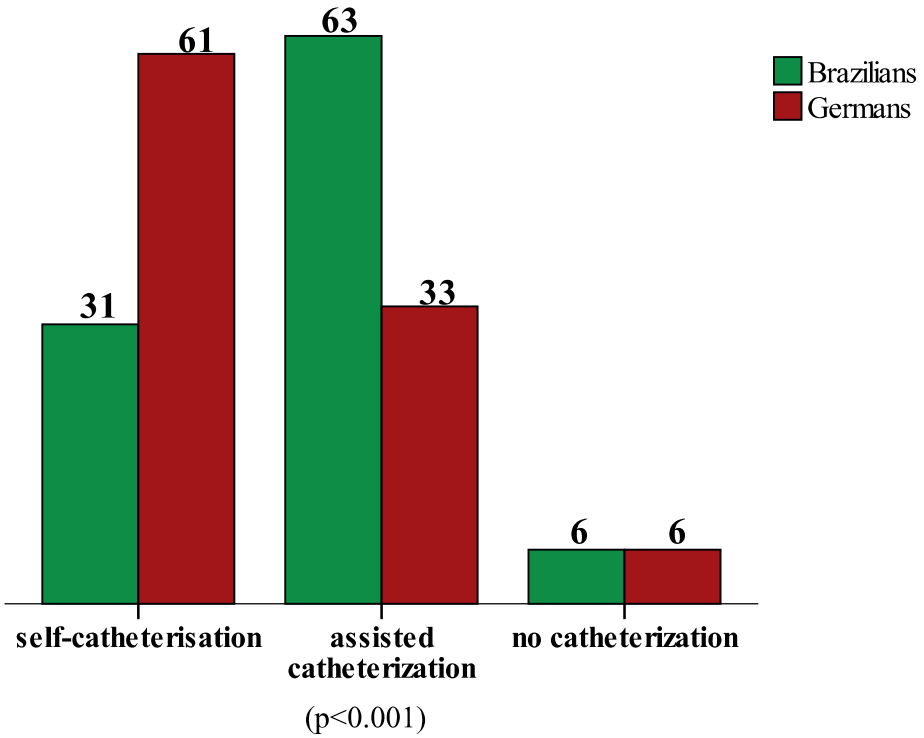


Table 16 – Current method of catheterization and nationality (n = 200)

Method of catheterization	Brazilians	Germans	P-value	Total
Self-catheterization	22	53	<0.001	**75 (37.5%)**
Self- catheterization with assistance	9	8	0.799	**17 (8.5%)**
Assisted catheterization	63	33	<0.001	**96 (48.0%)**
Does not use catheterization	6	6	1.000	**12 (6.0%)**
Total	**100**	**100**	**-**	**200 (100.0%)**

The method of catheterization used at the time of interview had a different distribution in the two samples (Table 16 and Graph 6; Chi-square test, p<0.001). The predominately used type of catheterization for Brazilians was assisted catheterization (63.0%), and for Germans it was self-catheterization (61.0%). One factor that could explain this distribution would be the older age of the Germans (p <0.001, see page 80, Graphic 1). Of the 12 patients who were not using IC, 8 patients had previously used assisted catheterization and 4 patients had used self-catheterization.

For the entire sample, the age at the beginning of training for self-catheterization with assistance or under supervision had a median of 9.5 (7.7, 12.0) years of age and a mean of 11.0 (5.6) years (Table 17). In the Brazilian sample, this age ranged from 6 to 21 years, with a mean of 10.7 (3.9) years and median of 10.0 (8.7, 12.0) years. In the German sample, the age ranged from 6 to 27 years with a median of 7.5 (6.0, 20.5) years and a mean of 11.7 (8.6) years. The distribution of the samples according to age when beginning self-catheterization with assistance was similar (Student's t-test, p=0.755, Levene's test, p=0.007). The following table exhibits the mean and median ages at the beginning of self-catheterization with and without assistance.

Table 17 – Distribution of the mean and median ages at the beginning of self-catheterization with and without assistance (ISC)

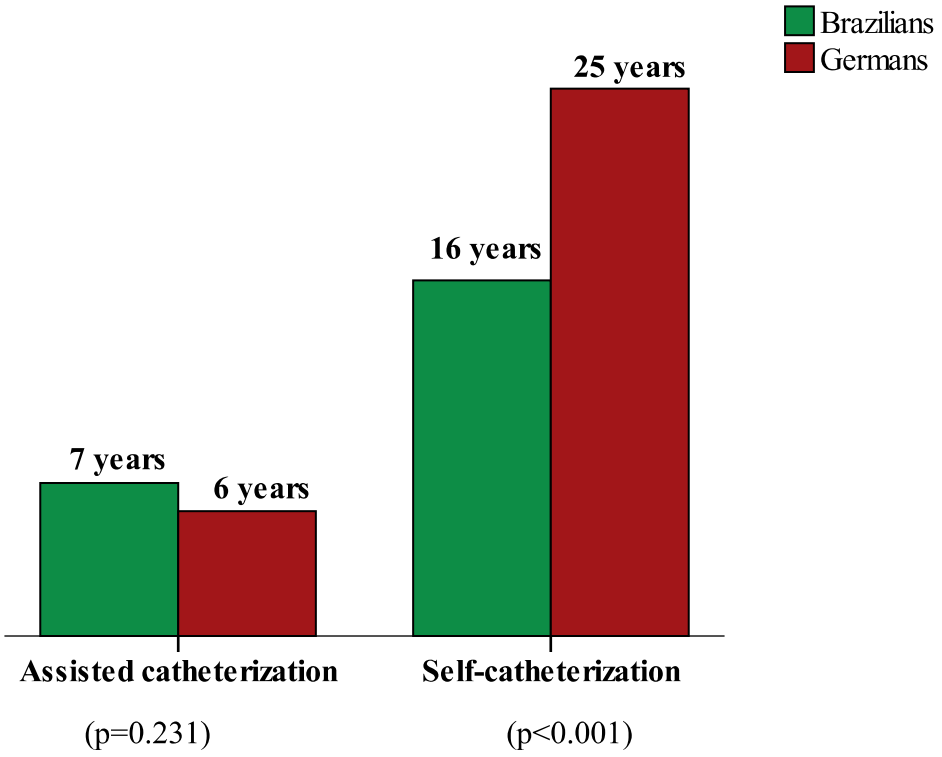
Statistic	**Brazilians**		**Germans**		**Total**	
	Age ISC **with** assistance	Age ISC **without** assistance	Age ISC **with** assistance	Age ISC **without** assistance	Age ISC **with** assistance	Age ISC **without** assistance
Mean	**10.7**	**12.1**	**11.7**	**14.6**	**11.0**	**13.9**
SD	3.9	3.6	8.6	10.2	5.6	8.8
Median	**10.0**	**12.0**	**7.5**	**11.0**	**9.5**	**11.0**
Q1; Q3	8.7; 12.0	9.7; 14.0	6.0; 20.5	8.2;15.7	7.7; 12.0	9.0; 15.0

The age at the start of self-catheterization was similar in the two samples (Student's t-test, p=0.118, Levene's test, p=0.004). Therefore, self-catheterization was begun at a median age of 11 (9.0, 15.0) years and a mean of 13.9 (8.8) years. In the Brazilian sample, age also varied between 6 and 21 years, with a mean of 12.1 (3.6) years and a median of 12.0 (9.7, 14.0) years. In the German sample, the range was greater, between 4 and 48 years old, with a median of 11.0 (8.2, 15.7) years and a mean of 14.6 (10.2), the standard deviation exceeded the average by more than 50%, so the median would be a more representative measure of central tendency of the German sample.

Graph 7 demonstrates that, considering the current mean ages of patients who use self-catheterization, the resulting mean is 16.3 (5.3) years in the Brazilian sample and 25.1 (10.1) years in the German sample. Thus, the mean age of participants who currently use self-catheterization was different in the two samples (Student's t-test, p<0.001, Levene's test, p=0.002). However, the mean age of patients who currently use assisted catheterization did not have a statistically significant difference (Student's t-test, p=0.231, Levene's test, p=0.132) as the German sample had a mean of 5.7 (5.6) years and the Brazilian sample mean was 7.0 (3.6) years. These values conclude that patients who use self-catheterization are older, 22.2 (9.7) years, than those who use assisted

catheterization, 6.6 (4.4) years, independent of nationality (Student's t-test, p<0.001, Levene's test, p<0.001).

Graph 7 - Current mean age by method of catheterization and nationality



In the overall sample, the difference in age between male and female patients was not statistically significant regarding assisted catheterization (Student's t-test, p=0.669, Levene's test, p=0.684). Furthermore, there was no relationship between the method of catheterization and gender in the Brazilian sample (n = 93, Yates' chi-square=1.968, degrees of freedom = 1; p=0.161) nor in the German sample (n = 94, Yates' chi-squar = 1.068, degrees of freedom=1, p=0.301). As a result, no relationship was confirmed between gender and method of catheterization in the sample distribution by nationality.

Regarding the minimum daily frequency of performing IC, the mean was 4.5 (1.0) times per day. In the Brazilian sample, this frequency had a mean of 4.3 (0.9) times per day, and the Germany sample had a mean frequency of 4.6 (1.1) times per day. The

distribution of minimum daily frequency of IC was different in the two samples (Student's t-test, p=0.015, Levene's test, p=0.124), although this piece of data is not significant in clinical practice.

– *Variables related to the materials used in* IC:

The German sample reported using 100% disposable catheters. This data was not obtained in the Brazilian sample. Regarding the type of catheter used, the Brazilian and German populations use completely different catheters (Table 18).

Table 18 – Type of catheter used and nationality (n = 200)

Nationality	Type of catheter	n	%
Brazilians	plastic	78	78.0
	metal	18	18.0
	metal or plastic	4	4.0
	Total	**100**	**100.0**
Germans	with hydrophilic coating	60	60.0
	with gel	31	31.0
	with gel and with hydrophilic coating	4	4.0
	other catheters	3	3.0
	uncoated	2	2.0
	Total	**100**	**100.0**

The Brazilian participants used uncoated plastic catheters (78.0%), metal catheters (18.0%) and both plastic and metal catheters (4.0%). German participants used hydrophilic-coated catheters (60.0%), catheters with gel (31.0%), uncoated plastic

catheters (2.0%), catheters both with gel and hydrophilic coating (4.0%), and other catheters (3.0%).

In the German sample, the substances used for the cleaning or disinfection of the genitalia before the introduction of the catheter (Table 19) were: Octenisept (55.0%), water (17.0%), soap and water (10.0%), Protosan (8.0%), sterile water (7.0%), moist towelette (4.0%) and chlorhexidine alcoholic solution (1.0%). A total of 15.0% of the German participants reported not engaging in any type of genital hygiene before catheterization. In the Brazilian hospital where the data for this study was collected, patients are recommended to wash the genitalia with water and soap, preferably pH-balanced.

Table 19 – Distribution of the German sample regarding substance used in cleaning genitalia before catheterization (n = 96)

Substance	**n**	**%**
Octenidine dihydrochloride solution	55	57.3%
Water	17	17.7%
No cleaning	15	15.6%
Soap and water	10	10.4%
Polyhexanide solution	8	8.3%
Sterile water	7	7.3%
Moist Towelette	4	4.2%
Chlorhexidine solution	1	1.0%

Based on the substances used in performing IC, the German sample was divided according to the type of cleaning they practiced (Table 20).

Table 20 – Distribution of the German sample by cleaning method in performing IC

(n = 96)

Cleaning method	n	%	P-value
Disinfection	47	49.0	0.766
Washing	24	25.0	<0.001
Disinfection and washing	15	15.6	<0.001
No cleaning	10	10.4	<0.001
Total	**96**	**100.0**	**-**

Disinfection was the predominant method in the German sample (49.0%), followed by washing (25.0%). Those who followed both of these cleaning methods totalled 15.6% and those who did not clean totalled 10.4%.

– *Health variables*

The primary medical indications for IC reported by patients (Table 21) were urinary incontinence (80), high intravesical pressure (62), UTI (38), high residual volume in bladder (36), vesicoureteral reflux (28), hydronephrosis (22), unknown indication (24), and other indications (4).

Table 21 – Sample distribution by indications for performing catheterization and by nationality

Medical indications for IC	Brazilians	Germans	P-value	Total
Incontinence	19	61	<0.001	**80 (40.0%)**
High intravesical pressure	36	26	0.124	**62 (31.0%)**
UTI	4	34	<0.001	**38 (19.0%)**
High residual volume	0	36	<0.001	**36 (18.0%)**
Vesicoureteral reflux	13	15	0.683	**28 (14.0%)**
Hydronephrosis	22	0	<0.001	**22 (11.0%)**
Unknown	19	5	0.001	**24 (12.0%)**
Others	0	4	0.041	**4 (2.0%)**

As the table above demonstrates, medical indications for performing IC were divided as follows: due to urinary incontinence – reported by 19 Brazilians and 61 Germans; due to high intravesical pressure – reported by 36 Brazilians and 26 Germans; due to UTI – reported by 4 Brazilians and 34 Germans; due to elevated residual volume – reported by 0 Brazilians and 36 Germans; due to vesicoureteral reflux – reported by 13 Brazilians and 15 Germans; due to hydronephros – reported by 22 Brazilians and 0 Germans; due to other causes – reported by 4 Germans. There were 19 Brazilian participants and 5 German participants who reported not knowing the medical indication for IC.

Therefore, the primary medical indications for IC in the German sample were incontinence, high residual volume and UTI, while in the Brazilian sample, the key indications were high intravesical pressure, hydronephrosis and incontinence. There was a difference between the Brazilian and German samples in relation to the primary medical indications for IC reported by participants (Chi-square test, $p<0.001$), only the indications of high intravesical pressure (z-test, $p=0.124$) and vesicoureteral reflux (z-test, $p=0.683$) had a similar distribution.

The following table shows the distribution of the samples according to the annual number of UTI episodes before and after the use of IC.

Table 22 – Annual episodes of UTI before and after use of IC (n = 200)

Nº of UTIs	**Before***		**After****		**Total**	
	Brazilians	**Germans**	**Brazilians**	**Germans**	**Before**	**After**
0	35	21	69	25	**56**	**94**
1	16	10	21	22	**26**	**43**
2	13	13	8	18	**26**	**24**
3	7	6	0	7	**13**	**7**
4	4	3	1	5	**7**	**6**
5 +	23	26	0	9	**49**	**9**
Don't know	2	21	1	14	**23**	**15**
Total	**100**	**100**	**100**	**100**	**200**	**200**

* Mann-Whitney U-Tests, p=0.110, there was on difference in relation to the number of UTIs before IC between the samples.

** Mann-Whitney U-Tests, p<0.001, there was no difference in relation to the number of UTIs after IC between the samples.

There was no statistical difference in the number of UTIs before catheterization between the Brazilian and German samples (Mann-Whitney U-Tests, p=0.110); however, after IC, there was a statistically significant difference in relation to the number of UTIs between the Brazilian and German samples (Mann-Whitney U-Tests, p <0.001).

For the calculation of mean UTIs, only those patients who had responded to both questions (no. UTIs before IC and no. of UTIs after IC) were considered, and these totaled 171 participants (97 Brazilians and 74 Germans). Considering the total sample mean UTI before IC was 2.8 (3.0) episodes per year, the mean UTI after IC was 1.1 (1.7) episodes per year. In the German sample, the mean UTI before catheterization was

3.2 (3.1) per year and after catheterization was 1.9 (2.2) per year. In the Brazilian sample, the mean UTI before catheterization was 2.4 (2.8) per year and after IC was 0.4 (0.7) per year.

The analysis of the paired samples shows that the mean of UTI episodes before catheterization was different than the mean of UTI episodes after catheterization, both in the Brazilian sample ($p<0.001$) and in the German sample ($p<0.001$; Graph 8). Later, in the advanced statistical analysis, the factors that affect the number of UTI before and after IC will be analyzed.

Graph 8 - Mean UTI before and after IC and nationality

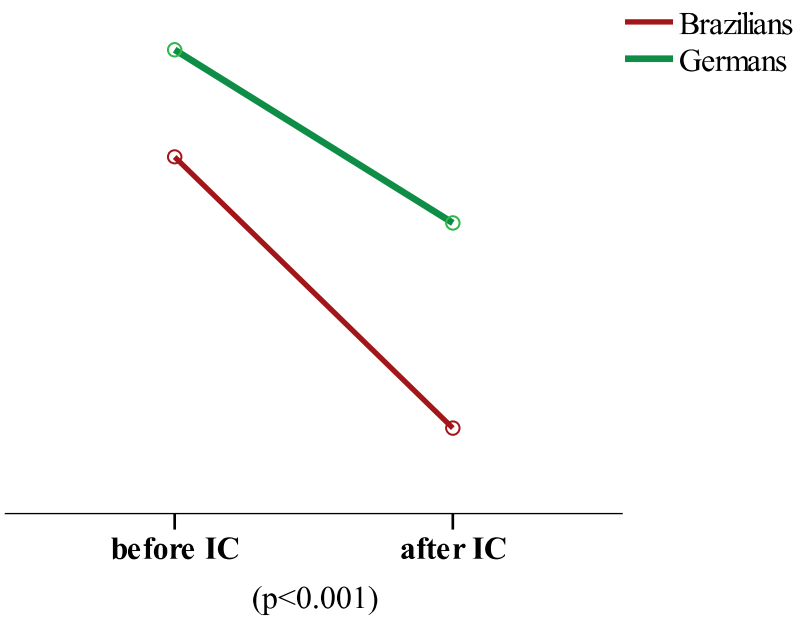


Table 23 – Sample distribution by no. of UTIs after IC and by nationality (n = 171)

UTI after IC	Brazilians	Germans	P-value	Total
No UTI	27	9	0.008	36 (21.0%)
Fewer UTIs	57	31	0.026	88 (51.4%)
Same UTIs	3	19	0.001	22 (13.0%)
More UTIs	10	15	0.075	25 (14.6%)
Total	**97**	**74**	**-**	**171 (100.0%)**

Considering the number of UTIs in the year before using IC and the year following, as shown in Table 23, the sample was distributed according to the number of UTIs after IC. The effective rate of catheterization was 72.4%. Only 14.6% showed an increase in the number of UTIs after catheterization, and 13.0% maintained the same frequency of UTI.

Survey participants were distributed in relation to the use of medication, with 171 individuals reporting medication use and 29 individuals reporting no use of medication. Among the Brazilians, 96.0% use medicationand 4.0% do not use. Among the Germans, 75.0% use medication and 25.0% do not use. Thus, there was a difference in the distribution of the samples in relation to the use of medication (Chi-square test, $p<0.001$) as the percentage of Brazilian participants (96.0%) using medication was higher than that of German participants (75.0%) (z-test of proportions, $p<0.001$). The following table describes the drugs used by participants by nationality.

Table 24 – Medications used and nationality (n = 171)

Medication	Brazilians	Germans	P-value	Total
Oxybutynin	92	36	<0.001	**128 (74.8%)**
Prophylactic antibiotics	3	20	<0.001	**23 (13.4%)**
Cranberry	0	19	<0.001	**19 (11.1%)**
Propiverine	0	17	<0.001	**17 (10.0%)**
Imipramine	14	0	<0.001	**14 (8.2%)**
Trospium chloride	0	6	0.010	**6 (3.5%)**
Methionine	0	4	0.039	**4 (2.3%)**
Doxazosin	1	2	0.449	**3 (1.7%)**

As the previous table shows, the use of antibiotics for the prophylaxis of UTI was more frequent in the German sample (20.0%) than in the Brazilian sample (3.0%) (z-test, p<0.001). The use of cranberry, propiverine, trospium chloride and methionine were only reported by the Germans, and the use of imipramine was only reported by Brazilians. Oxybutynin was the drug most used by participants across the sample (96.0% of Brazilians and 36.0% of Germans).

Only 20 patients, 10 Brazilian and 10 German, reported irregular use of medications. Table 25 shows the justifications given by the participants.

Table 25 – Reasons for irregular use of medication (n = 20)

Reasons	Brazilians	Germans	P-value	Total
Side effects	4	3	0.637	**7 (35.0%)**
Financial difficulty	2	2	1.000	**4 (20.0%)**
Forgetfulness	3	0	0.038	**3 (15.0%)**
Uncertainty of dosage and intervals	0	2	0.113	**2 (10.0%)**
Other	1	3	0.248	**4 (20.0%)**

According to the previous table, side effects (35.0%) were the principle reason for the irregular use of medication, followed by financial difficulties (20.0%), forgetfulness (15.0%) and not knowing correct medication doses and intervals (10.0%). Other reasons were reported by 4 (20.0%) patients.

Table 26 shows the distribution of the sample according to the acquisition of urinary continence after using IC and by nationality.

Table 26 – Continence after IC (n = 200)

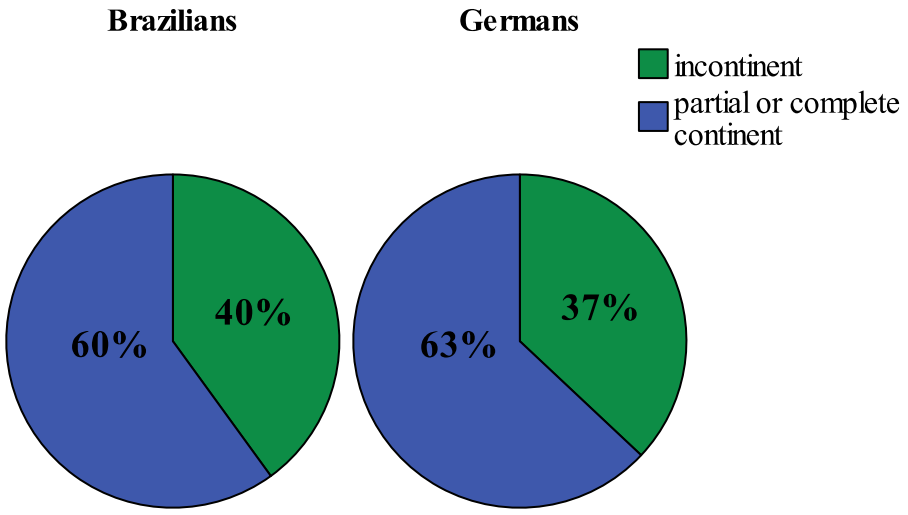
Continence	Brazilians	Germans	P-value	Total
No	40	37	0.662	77 (38.5%)
Partial	42	41	0.885	83 (41.5%)
Yes (total)	18	22	0.478	40 (20.0%)
Total	**100**	**100**	**-**	**200 (100%)**

According to Table 26, 61.5% of patients achieved partial or complete continence and 38.5% remained incontinent after IC. The distribution of the variable "continence after

IC" was similar across the two nationalities (Student's t-test, p=0.507; Levene's test, p=0.929).

In the following graph, the sample was divided by nationality and acquisition of urinary continence after CI, using the categories *partial continence* and *complete continence*. With this new categorization, the samples also had a similar distribution (Student's t-test, p=0.665; Levene's test, p=0.390).

Graph 9 - Distribution of sample by acquisition of continence after IC and nationality (n = 200)



(p=0.665)

– *Social variables*

This section will describe the social variables that were involved with the use of IC by the participants in this study.

The participants were questioned about the objectives of the person responsible for the technique of IC (Table 27).

Table 27 – Objectives of person responsible for IC technique (n = 200)

Objective	Brazilians	Germans	P-value	Total
Renal preservation	52	78	<0.001	**130 (65%)**
Continence	45	57	0.087	**102 (51%)**
Prevention of UTI	24	74	<0.001	**98 (49%)**
Bladder treatment	8	0	0.003	**8 (4%)**
Other	3	1	0.311	**4 (2%)**
Unknown	1	0	0.314	**1 (0.5%)**

As shown in the previous table, the main objectives of the person responsible for performing of IC were renal preservation (65.0%), followed by urinary continence (51.0%) and prevention of UTI (49.0%). The objective of continence was similar in the two samples (z-test, p=0.089); however, all the other objectives (renal preservation, UTI prevention and bladder treatment) had a statistically different distribution according to nationality (z-test, p<0.001). The objective of UTI prevention was higher in the German sample (74.0%) than in the Brazilian sample (24.0%) (z-test, p<0.001).

As outlined in Table 28, the medical indication understanding of the procedure by the key person responsible for the IC technique includes understanding tests and the risks involved. It should be noted that, in the Brazilian sample, understanding was evaluated and classified by professionals, and in the German sample, the participant conducted a self-assessment, as explained in the methodology.

Table 28 – Understanding of key person responsible for IC technique (n = 200)

Understanding	Brazilians	Germans	P-value	Total
excellent/good	41	78	p<0.001	**119 (59.5%)**
reasonable	45	19	p<0.001	**64 (32.0%)**
poor	13	2	0.002	**15 (7.5%)**
none	1	1	1.000	**2 (1.0%)**
Total	**100**	**100**	**-**	**200 (100.0%)**

According to the previous table, excellent or good understanding was predominant (59.5%), followed by reasonable (32.0%), poor (7.5%) and none (1.0%). There was a difference between the two samples in the classification of understanding by the person responsible for the IC technique (Mann-Whitney U-Tests, p<0.001).

In the Brazilian sample, 45.0% were classified as having reasonable understanding, 41.0% excellent or good understanding, 13.0% poor understanding, and 1.0% no understanding. In the German sample, 78.0% of participants assessed themselves as having excellent understanding, 19.0% reported reasonable understanding, 2.0% reported poor understanding, and 1% no understanding.

In the overall sample, there was no statistically significant difference between understanding of IC when it was administered by the patient him/herself or by another person (Mann-Whitney U-Tests, p=0.217), for example, the mother. There was also no difference between the group who performed self-catheterization and the group who used assisted catheterization (Mann-Whitney U-Tests, p=0.732). However, it was observed that the participants who had excellent or good understanding about IC had lower rates of discontinuation (temporary interruption) of the procedure than those who had reasonable, poor or no understanding (Mann-Whitney U-Tests, p=0.004).

The following table shows the distribution of the samples according to the performance of IC in venues outside the home.

Table 29 – Performance of IC away from home (n = 200)

IC away from home	Brazilians	Germans	Total
yes	81	94	**175 (87.5%)**
no	19	6	**25 (12.5%)**
Total	**100**	**100**	**200 (100.0%)**

According to Table 29, the majority of participants (87.5%) perform IC away from home. However, the distribution of the samples in relation to this variable was different (Yates' chi-square test, p=0.010), with the Germans (94.0%) performing catheterization away from home more frequently than the Brazilians (81.0%).

As outlined in the following table, the Brazilian participants were asked about the existence of financial difficulties regarding the acquisition of materials required to perform IC.

Table 30 – Distribution of Brazilian sample according to financial difficulty in the acquisition of IC materials (n = 100)

Financial Difficulty	n	%
no	42	42
Receives donated material	31	31
yes	27	27
Total	**100**	**100**

According to Table 30, 31.0% of the Brazilian patients receive IC materials free of charge from the public health system, 27.0% cited financial difficulties in the acquisition of necessary materials and 42.0% bought the materials without difficulties.

The form of acquisition of IC materials by German patients was adapted to the reality of the national health care system. Individuals were questioned whether they had any problems receiving the IC materials through their health insurance program (Table 31).

Table 31 – Distribution of the German sample by the existence of problems in receiving IC materials through health insurance (n = 100)

Problem	**n**	**%**
Yes	13	13
No	87	87
Total	**100**	**100**

The majority of German participants in the study (87.0%) reported receiving the IC material through their health insurance program without problems, while 13.0% reported having some type of problem receiving the material.

However, according to Tables 30 and 31, the German participants (87.0%) received more financial assistance from the health care system in relation to the acquisition of the IC material than the Brazilian participants (31.0%; Student's t-test, p <0.001).

– *Variables related to difficulties with IC*

This section describes the variables that were intended to identify the difficulties of individuals in both countries regarding the performance of IC.

When asked about difficulties during performance of the IC technique, 41 participants – 23 Brazilians and 18 Germans – reported difficulties in performing catheterization, which are described in Table 32. The difference in the distribution of technical difficulties with IC in the two samples was not statistically significant (z-test, p=0,380).

Table 32 – Technical difficulties with IC (n = 41)

Technical difficulties	Brazilians	Germans	Total
Restlessness of child during IC	8	5	**13 (31.7%)**
Positioning and torso control	3	8	**11 (26.8%)**
Sphincter resistance	7	3	**10 (24.4%)**
Visualization of urethral meatus	2	6	**8 (19.5%)**
Urethral sensitivity / pain	3	2	**5 (12.2%)**
Other	3	0	**3 (7.3%)**

The main technical difficulties described in the preceding table include: restless behavior of the child during the procedure (31.7%), poor positioning and torso control during IC (26.8%), sphincter resistance during insertion of the catheter via urethral meatus (24.4%), visualization of the urethral meatus in order to insert the catheter (19.5%), urethral pain / sensitivity during the procedure (12.2%), and other difficulties (7.3%). The mean age of the participants where the difficulty "restless child during IC" was reported was 4.2 (3.7) years. Difficulty visualizing the urethral meatus was reported by six female participants and two male participants.

Home-related barriers to performing IC were not reported as a difficulty by 89.0% of the participants in the sample, but 11.0% did report them as a barrier to performing IC, of which 17 were Brazilians and 5 were Germans. The sample showed a different distribution for home-related barriers according to nationality (Chi-square test, p=0.013; Table 33).

Table 33 – Home-related difficulties in performance of catheterization (n = 22)

Home-related difficulty	Brazilians	Germans	Total
Inadequate bathroom	16 (72.7%)	4 (18.2%)	**20 (90.9%)**
Lack of privacy	1 (4.5%)	2 (9.0%)	**3 (13.5%)**
Lack of running water	1 (4.5%)	0	**1 (4.5%)**
Other	1 (4.5%)	0	**1 (4.5%)**

* Chi-square test, p=0.013, The sample shows a different distribution of home-related barriers according to nationality.

Of the participants who reported home-related difficulties, an inadequate bathroom was the main difficulty reported (90.9%), of which 16 were Brazilian and 4 were German. Other difficulties cited were lack of privacy (13.5%), lack of running water (4.5%) and other difficulties (4.5%).

When asked about the existence of feelings or ideas that hinder the key person responsible for performing the procedure, 69 Brazilians and 86 Germans denied their existence, yet 31 Brazilians and 14 Germans reported emotional difficulties, as described in Table 34

Table 34 – Feelings that hinder the performance of IC (n = 45)

Feeling	Brazilians	Germans	Total
Fear	13 (28.9%)	2 (4.4%)	15 (33.3%)
Shame/ embarrassment	3 (6.6%)	7 (15.5%)	10 (22.2%)
Insecurity	2 (4.4%)	4 (8.8%)	6 (13.3%)
Distress	4 (8.8%)	1 (2.2%)	5 (11.1%)
Strangeness	1 (2.2%)	1 (2.2%)	2 (4.4%)
Worry	2 (4.4%)	0	2 (4.4%)
Self-pity	2 (4.4%)	0	2 (4.4%)
Demotivation	2 (4.4%)	0	2 (4.4%)
Nonconformity	2 (4.4%)	0	2 (4.4%)
Other	5 (11.1%)	2 (4.4%)	7 (15.5%)

A larger number of individuals (31) from the Brazilian sample reported feelings that hinder the performance of IC than from the German sample (14) (z-test, p=0.003). Among the reported feelings were fear (15), shame (10), insecurity (6), distress (5), self-pity (2), demotivation (2) and nonconformity (2). Other feelings, such as anxiety, embarrassment, impatience, anger and sadness, were reported by 7 participants. The sentiment that was predominant in the Brazilian sample was fear (28.9%) (Fisher's Exact test, p=0.005), the second most frequently reported feeling was embarrassment, which had a statistically similar distribution between the German sample (15.5%) and the Brazilian sample (6.6%) (Fisher's Exact test, p=0.330). The mean age of the participants who reported fear was 8.1 (6.1) years, and the mean age of the participants who reported shame was 20.0 (12.9) years.

Participants were asked about the discontinuation of IC for a period of time after beginning the procedure (Table 35).

Table 35 – Sample distribution of the discontinuation of IC and nationality (n = 200)

Discontinuation of IC	Brazilians	Germans	P-value	Total
None	79	81	0.723	**160 (80.0%)**
Once	17	5	0.005	**22 (11.0%)**
More than once	4	14	0.012	**18 (9.0%)**
Total	**100**	**100**	**-**	**200 (100.0%)**

According to the previous table, the majority of patients (80.0%) reported never having discontinued the procedure, 11.0% reported having one interruption and 9.0% had interrupted IC more than once. There is a similarity in the distribution of the Brazilian and German responses since 79.0% of Brazilians and 81.0% of Germans had never interrupted IC, and 21.0% of Brazilians and 19.0% of Germans stopped the procedure one or more times (Chi-square test, p=0.724).

The main reasons cited for temporary discontinuation of the procedure are described in the following Table 36.

Table 36 – Principle motives for discontinuing IC (n = 40)

Motives for discontinuing IC	Brazilians	Germans	Total
Incontinence despite IC	2	7	**9 (22.5%)**
Difficulty in organizing daily routine	1	6	**7 (17.5%)**
UTI	2	5	**7 (17.5%)**
Lack of motivation	2	4	**6 (15.0%)**
Pain	4	2	**6 (15.0%)**
Resistant behavior of the child	3	2	**5 (12.5%)**
Hematuria	2	2	**4 (10.0%)**
Continence without IC	1	3	**4 (10.0%)**
Maternal problems	4	0	**4 (10.0%)**
Financial difficulty	2	1	**3 (7.5%)**
Technical difficulty	0	3	**3 (7.5%)**
Discontinuation of medication	1	0	**1 (2.5%)**
Indication to stop by other health service	1	0	**1 (2.5%)**
Other	4	3	**7 (17.5%)**

The reasons that led participants to stop IC for a period of time included: incontinence despite IC (22.5%), difficulty in organizing daily routine (17.5%), UTI (17.5%), lack of motivation (15.0%), pain (15.0%), resistant behavior of the child to the procedure (12.5%), bleeding during IC (10.0%), continence even without using IC (10.0%), problems with the mother who was responsible for IC (10.0%), financial difficulty (7.5%), technical difficulty (7.5%), discontinuation of medication (2.5 %), medical recommendation to stop (2.5%) and other reasons (17.5%).

In the Brazilian sample, the most frequent reasons for discontinuation of IC were pain (4), maternal problems (4) and resistant behavior of the child (3). Yet in the German

sample, the most common reasons were incontinence despite IC (7), difficulty in organizing daily routine (6), UTI (5) and lack of motivation (4). The next section will describe the variables unique to the German sample, including answers to an open-ended question about difficulties with IC.

The following table shows a summary of the distribution of the difficulties associated with IC according to the patients who currently use IC (yes or no).

Table 37 – Distribution of difficulties related to performance of IC

Difficulties	**Use IC**		**P-value***
	Yes (n = 188)	**No (n = 12)**	
Discontinuation of IC	16.5% (31)	75% (9)	<0.001
Emotional	20.2% (38)	58.3% (7)	0.006
Technical	18.6% (35)	50.0% (6)	0.018
In acquision of IC materials	39.4% (74)	66.7% (8)	0.075
Home-related	11.2% (21)	8.3% (1)	1.000

*P-values according to Fisher's Exact test

The distribution of the sample according to difficulties with IC and the use or non-use of IC reveals that emotional difficulties (Fisher's Exact test, p=0.006), technical difficulties (Fisher's Exact test, p=0.018) and discontinuation of IC (Fisher's Exact test, p<0.001) were higher in patients who did not use IC than those who did. Yet home-related difficulties (Fisher's Exact test, p=1.000) and difficulty in acquiring the material for IC (Fisher's Exact test, p=0.075) showed no statistically significant difference between participants who used or did not use IC.

5.1.3. Variables exclusive to the German sample

This section describes the variables that were collected exclusively in the German population in order to better understand the context of spina bifida and IC in that country.

In relation to the resources needed for self-catheterization with and without assistance, 11 patients reported needing a mirror, and 3 reported using some other positioning aid during the procedure. Also, 11% of the German patients reported using an intravesical via to administer medication.

The German individuals were asked about the location where they perform IC, which is described in Table 38.

Table 38 – German sample distribution according to the location where the IC is performed (n = 93)

Location	n	%
Toilet	46	49.5%
Bed	30	32.3%
Wheelchair	19	20.5%
Baby changing table	12	12.9%
Stretcher	4	4.3%
Other	5	5.4%

The main location where the German patients perfrom IC is on the toilet (49.5%), other locations cited were bed (32.3%), wheelchair (20.5%), changing table (12.9%), stretcher (4.3%) and 5.4% cited other locations for performing IC.

The German sample participants were also asked about their current occupation (Table 39).

Table 39 – Current occupation of individuals in German sample (n = 100)

Occupation	n	%
student	37	37
employed	24	24
baby and/or pre-schooler	19	19
no occupation	10	10
university student	8	8
retired / on a pension	2	2
Total	**100**	**100**

According to the previous table, the distribution of the German sample was diverse in terms of the occupation of the individuals (Chi-square test, $p<0.001$). A large number of the German individuals classified their current occupation as high school students (37.0%), 24.0% reported being employed, 19.0% attended pre-school and /or were infants, 10.0% did not work or were unemployed at the time, 8.0% were university students and 2.0% were retired pensioners. Together, the categories of high school student and university student represent 45.0% of the German participants.

The German sample was evaluated according to the degree of satisfaction with IC as is described in Table 40.

Table 40 – Level of satisfaction with IC in the German sample (n = 89)

Level of satisfaction	**n**	**%**
Very satisfied	43	48.3
Mostly satisfied	31	34.8
Moderately satisfied	11	12.4
Somewhat satisfied	2	2.2
Not satisfied	2	2.2
Total	**89**	**100**

According to the previous table, combining the levels very satisfied and mostly satisfied, about 83.1% of the German patients are represented. There were 12.4% of the participants who reported being moderately satisfied and only 4.5% were somewhat or not satisfied with IC. It appears that most of the German individuals are very or mostly satisfied with the procedure.

In the German sample, 81 participants reported having received previous training to perform the self-catheterization. Of the patients who do not use self-catheterization, 14 indicated a desire to learn how to self-catheterize.

The German questionnaire was concluded with an open-ended question directed primarily to the patient and then to family members, with the goal of enabling the participant to express something that had not been previously considered in the questionnaire. This question asked them to express, in general way, all the difficulties and conflicts involved with the use of IC. This question was answered by 24 patients and 18 family members. Responses were examined and classified according to the central idea of the response, and are presented in the following tables:

Table 41 – Conflicts and difficulties of patients in the German sample relating to IC (n = 24)

Responses:	**n**
Incapaciity or motor difficulty in performing self-catheterization	5
Regularity and time spent with the procedure	5
Restless behavior of the patient during the procedure	5
Technical difficulty and complexity of the procedure	4
Difficulty with positioning for IC	3
Lack of adapted infrastructure in restrooms outside the home	3
Consciousness of difference/disability	2
Shame/embarrassment	2
Difficulty with the catheter, sensitivity and bleeding	1
Puberty and conflicts with parents in regards to IC	1
Fear of transfer of germs into the bladder via catheter	1
Combining sleep patterns with IC	1
Lack of tactile sensation and pain	1
Nervousness related to a lack of acceptance in relation to IC	1

Among the most frequent responses by patients are: motor incapacity for self-catheterization (5); frequency and time spent on the procedure (5); restless behavior of the patient during IC (5); technical difficulty and complexity of the procedure (4); difficulty in positioning for IC (3); non-adapted infrastructure in restrooms outside the home (3), among others.

Table 42 – Conflicts and difficulties of the German sample and their families regarding IC (n = 17)

Responses:	**n**
Lack of infrastructure of restrooms outside the home	6
Regularity, organization and time spent on the procedure	5
Too much work	2
Technical difficulty and complexity of procedure	2
Difficulty in social settings	2
Difficulty with positioning during IC	1
Difficulty in maintaining privacy of IC outside the home	1
Difficulty making the patient responsible for the procedure	1
Restless behavior of the patient during procedure	1
Need for two people to perform IC	1
Incontinence even after IC	1
Difficulty with involvement of the father during menstral period of the patient	1
Difficulty in catheterizing a newborn patient	1

The most common responses from the German sample were: lack of adapted infrastructure in bathrooms away from home (6); regularity and time spent on the procedure (5); too much work (2); technical difficulty and complexity of procedure (2); difficulty in social settings (2).

The German participants were also asked about the resources used to empty the bowel, since fecal continence and bowel function are part of the context of vesicointestinal re-education in the rehabilitation of patients with SB. There were 88 participants who answered this question (Table 43).

Table 43 – Distribution of German sample regarding the method used in emptying the bowel (n = 88)

Resources used	n	%
Rectal irrigation	26	29.5%
Digital rectal stimulation	24	27.3%
Toilet training	11	12.5%
Laxatives	11	12.5%
Suppository/mini-enema	10	11.4%
Intestinal/colon massage	5	5.7%
Other	1	1.1%
None	20	22.7%

As outlined in the previous table, the distribution of the German sample was different in relation to the methods used for emptying the bowel. For intestinal emptying, 29.5% of the German patients use rectal irrigation, 27.3% use digital rectal stimulation, 12.5% use toilet-training, 12.5% use laxatives, 11.4% use a suppository or mini-enema, 5.7% use intestinal or colonic massage, 1.1% use some other means, and 22.7% stated they do not use any means to aid their intestinal functioning.

5.2. Advanced statistical analysis

5.2.1. Factors related to using or not using IC

The analysis of factors that influence using or not using IC was conducted with a multivariate logistical regression. Thus, in this model, 1 was considered the dependent variable use IC (yes or no), where:

- 0 = no, do not use IC.
- 1 = yes, use IC.

The participants were divided into two groups: those that use IC (n = 188) and those who do not currently use IC (n = 12). Since the ratio between the groups was higher than 1:5, the Monte Carlo method was used to estimate the p-values and their respective 99% confidence intervals (CI99%). The following table shows the p-values and an analysis of the statistical significance of each variable. When the p-value was less than or equal to 0.25, the variable was tested in the logistical model, otherwise it was discarded.

Table 44 – Test of the possible variables related to using IC

Defined variable	Test	P-value (CI99%)	Univariate Analysis
Discontinuation of IC	Mann-Whitney	< 0.001 [b]	Significant
Technical difficulty	Fisher's Exact	0.018 [a]	Significant
Difficulty in receiving IC material	Fisher's Exact	0.075 [a]	Significant
Emotional difficulty	Fisher's Exact	0.011 [a]	Significant
Frequency of IC	Mann-Whitney	0.116 (0.108-0.125) [b]	Possibly significant
Gender	Fisher's Exact	0.231 [a]	Possibly significant
Level of SB	Fisher's Exact	0.134 (0.125-0.143) [a]	Possibly significant
Hydrocephalus and VP shunt	Fisher's Exact	0.122 (0.113 – 0.130)[b]	Possibly significant
Nationality	Fisher's Exact	>0.999 [a]	Not significant
Current age	Mann-Whitney	0.818 (0.808-0.828) [b]	Not significant
Age when started to use IC	Mann-Whitney	0.355 (0.343-0.368) [b]	Not significant
UTI before IC	Mann-Whitney	0.779 (0.768-0.790) [b]	Not significant
UTI after IC	Mann-Whitney	0.559 (0.546-0.571) [b]	Not significant
Hydrocephalus	Fisher's Exact	0.433 [a]	Not significant
Difficulties at home	Fisher's Exact	1.000 [a]	Not significant

(a) Exact results were provided instead of MC results.

(b) P-values and CI99% estimated using Monte Carlo method.

According to Tables 44 and 45, it can be noted that the variables related to technical difficulty (p=0.018), receiving IC material (p=0.075), emotion (p=0.011), and

discontinuation of IC (p<0.001) were significant. However, the biological and demographic variables, such as age (p=0.818), UTI after IC (p=0.559) and hydrocephalus (p=0.433), were not significant.

Table 45 – Distribution of difficulties related to IC

Difficulties	**Use IC**		**P-value***
	Yes (n = 188)	**No (n = 12)**	
Discontinuation of IC	16.5% (31)	75% (9)	<0.001
Emotional	20.2% (38)	58.3% (7)	0.011
Technical	18.6% (35)	50.0% (6)	0.018
Acquiring IC material	39.4% (74)	66.7% (8)	0.075
Home-related	11.2% (21)	8.3% (1)	1.000

*P-values according to the Fisher's Exact Test

Regarding Table 44, it is important to note that the univariate logistical model between use IC and do not use IC and the variable *Discontinuation of IC* (never; once; more than once) indicated that the categories "once" and "more than once" were similar (Table 46; p=0.428) and, for this reason, they were grouped together into the category "at least once".

Table 46 – Result of the logistical model between using IC or not using IC, and discontinuation of the procedure

Categories	Coefficient	SE	Wald	df	Significance*	Odds Ratio
Never	2.348	0.860	7.454	1	0.006	10.47
Once	-0.629	0.793	0.628	1	**0.428**	0.53
Constant	1.609	0.632	6.476	1	0.011	5.00

Standard error (SE) and degrees of freedom (df).

* Significance in relation to base category (more than once).

The regression *"Backward Stepwise (Likelihood Ratio)"* for the logistical model initially included all of the variables classified as significant or possibly significant ($p < 0.25$). Those that were not statistically significant for the model ($p > 0.10$) were excluded one by one until the final model was created with the coefficients, shown in the following table, having the value $\ln(P_1/1-P_1)$, where P_1 is the probability of the person using IC and ln(.) is the Neperian logarithm of the ratio between chances.

Table 47 – Effect of independent variables on using IC

							CI 95.0% for OR	
Variables	B	S.E.	Wald	df	Sig.	OR	Lower	Upper
Discontinuation of IC	2.219	0.745	8.866	1	0.003	9.195	2.135	39.608
Technical difficulty	1.690	0.708	5.699	1	0.017	5.419	1.353	21.697
Daily frequency of IC	0.466	0.275	2.872	1	0.090	1.594	0.930	2.734
Constant	-1.424	1.189	1.435	1	0.231	0.241	-	-

*P-value of the Hosmer and Lemeshow test: 0.848. R^2 Nagelkerke = 0.330;

**Initial -2LL = 84.851; Final -2LL = 60.762 (LL=Log Likelihood)

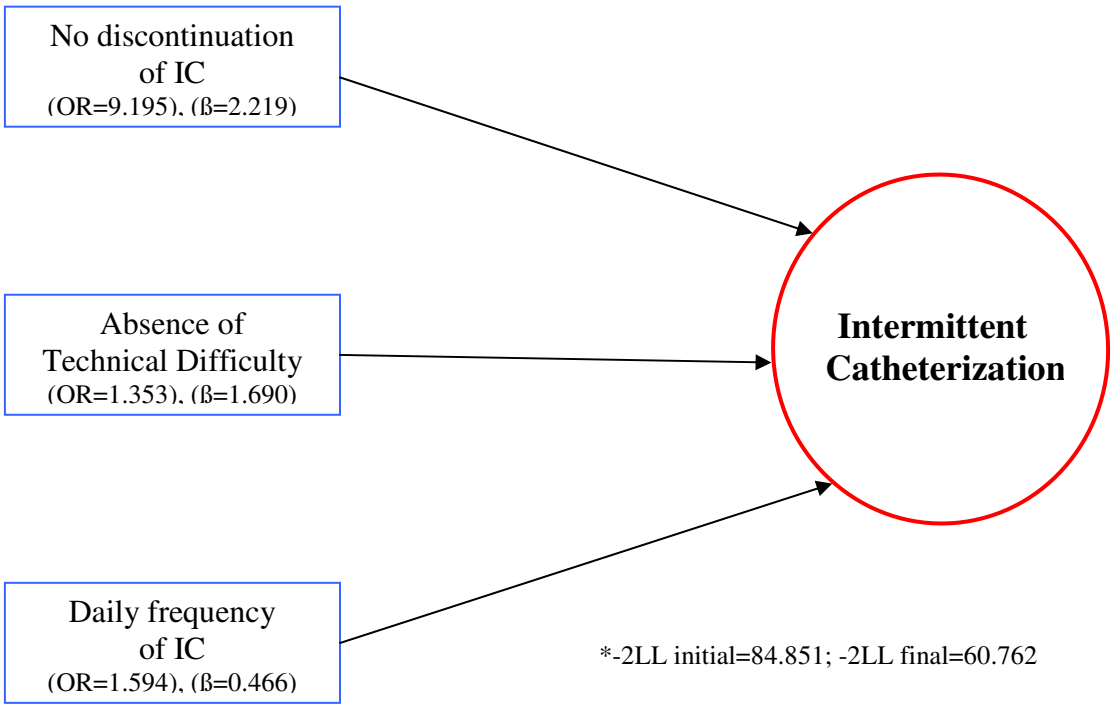
Model 1:

$$\text{Ln}\,(P_1/1\text{-}P_1) = -1.424 + 2.219 * \underset{(0=\text{yes};\ 1=\text{no})}{\textit{discontinuation of IC}} + 1.690 * \underset{(0=\text{yes};\ 1=\text{no})}{\textit{technical difficulty}} + 0.466 * \underset{(\text{whole n}^{o}.:\ 0,1,2,3,\ldots)}{\textit{IC frequency}}$$

The coefficient for discontinuation of IC indicates that no discontinuation (*discontinuation of IC=1 and other values equal to zero*) was the variable that contributed the most to increasing the likelihood of using IC. Not having technical difficulty also contributed positively toward maintaining IC, increasing up to 5.4 times the odds of performing the IC. Finally, the model indicates that increasing the frequency of catheterization creates a greater likelihood of the patient using IC. The strength of the model can be seen in the reduction of the likelihood ratio (Initial -2LL = 84.851; Final -2LL = 60.762, LL=Log Likelihood) and on the R^2 Nagelkerke (R^2=0.330). The following graph shows the logistical regression of model 1:

Figure 1 – Logistical Regression: Model 1

Factors related to using or not using IC



The statistical analysis of using or not using IC shows that the discontinuation of IC was more related to the difficulties in doing it than to demographical and biological factors. Out of the 12 patients who were not currently using IC, 8 patients had previously used assisted catheterization, while the rest had used self-catheterization.

5.2.2. Predictive factors for self-catheterization

The current method of catheterization was analyzed in order to identify possible predictive factors for self-catheterization (model 2). For this model, using self-catheterization (0) or assisted catheterization (1) was considered a dependent variable, with its coding as follows:

- 0 = does not use self-catheterization (assisted catheterization).
- 1 = uses self-catheterization.

To begin, patients were selected if they were using IC and were 6 years of age or older (n = 148), since this is the time when the individual begins to have the capacity to self-catheterize. The participants were divided into two groups: those that use self-catheterization (92) and those who do not use self-catheterization, but do use assisted catheterization (56). The following table shows an analysis of the statistical significance between each defined variable and the use of self-catheterization (yes/no). According to the criteria, if the p-value was less than or equal to 0.25, the variable was included in the logistical model, otherwise, it was discarded.

Table 48 – Test of the variables possibly related to the use of self-catheterization in patients who use IC and who are 6 years or older (n = 148)

Variable	Test	P-value	Statistical significance
Nationality	Chi-square	< 0.001	Significant
Age	t- Student	< 0.001	Significant
HC	Chi-square	< 0.001	Significant
VP shunt	Chi-square	< 0.001	Significant
Education level	Mann-Whitney	< 0.001	Significant
Lesion level	Chi-square	0.006	Significant
Wheelchair dependent	Chi-square	0.075	Possibly significant
Gender	Chi-square	1.000	Not significant
Understanding of IC	Mann-Whitney	0.906	Not significant
Technical difficulty	Chi-square	0.753	Not significant
Home-related difficulties	Chi-square	0.272	Not significant
Emotional difficulties	Fisher's Exact	0.549	Not significant
Difficulty acquiring IC material	Chi-square	0.054	Not significant
Discontinuation of IC	Chi-square	0.298	Not significant

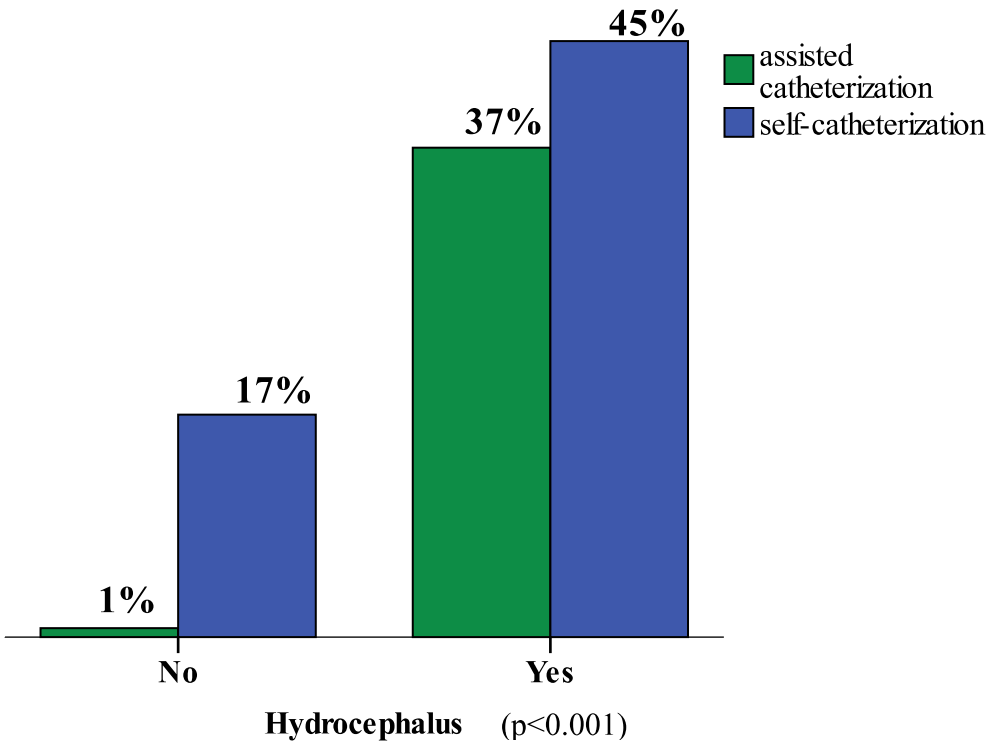
Regarding the previous table, it is important to clarify that the univariate logistical model between the variable response and the variable *SB level* (sacral, lumbar, thoracic and cervical) identified that the *sacral* category was similar to the *lumbar* category (p=0.723), which also occurred with the *thoracic* and *cervical* categories (p=0.681). As a result, they were grouped together, thus reducing the SB level to *sacral or lumbar* and *thoracic or cervical* (Table 48). For the same reason, education level was regrouped and composed of the following: the categories *pre-school, not school age, special school* and patients with *1 to 5 years of schooling* were grouped to form the

category *Education Level A* (up to 5 years of schooling; p=0.067). The category *6 to 12 years of schooling* formed category *Education Level B*, and the categories *technical high school, technical college and university students* were grouped together to form *Education Level C* (with 13 or more years of schooling; p=0.465).

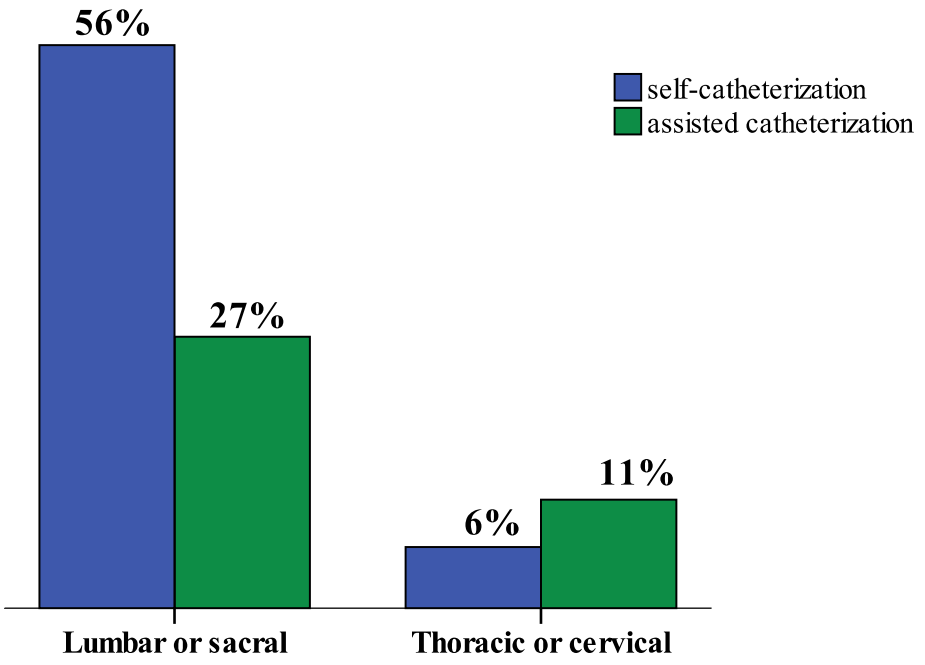
According to Table 47, in contrast to model 1, it can be noted that the variables related to technical difficulties (p=0.753), difficulty receiving IC material (p=0.054), emotional difficulties (p=0.549) and discontinuation of IC (p=0.298) were not significant. On the other hand, the biological and demographical variables of nationality (p<0.001), age (p<0.001), hydrocephalus (p<0.001), education level (p<0.001), VP shunt (p<0.001) and SB level (p=0.006) were significant.

A series of 4 graphs (graphs 10, 11, 12 and 13) will illustrate the individual interaction between the independent variables that were significant and the variable response.

Graph 10 - Distribution of individuals 6 years and older, by method of IC and presence of hydrocephalus (n = 148)

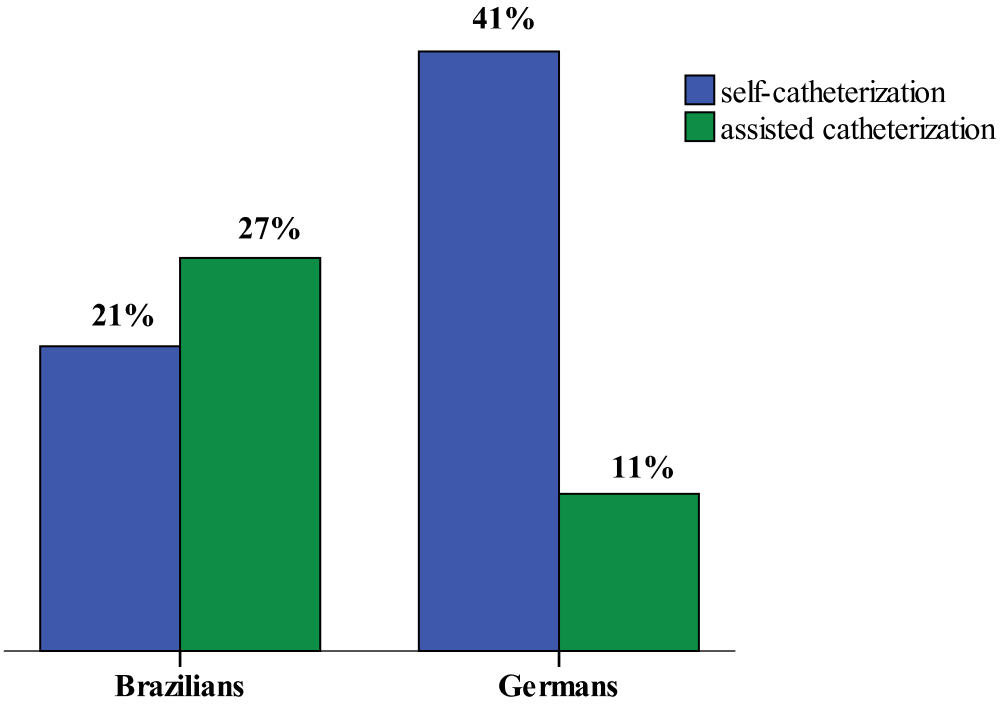


Graph 11 - Distribution of individuals 6 years and older, by method of IC and level of spina bifida (n = 148)



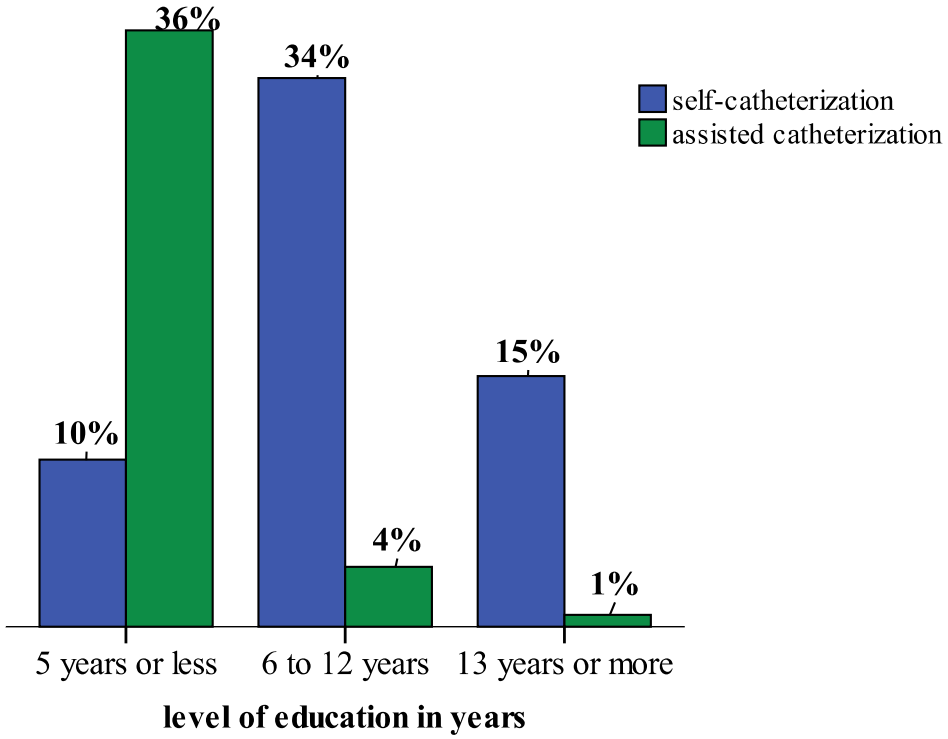
(p=0.006)

Graph 12 - Distribution of individuals 6 years and older, by method of IC and nationality (n = 148)



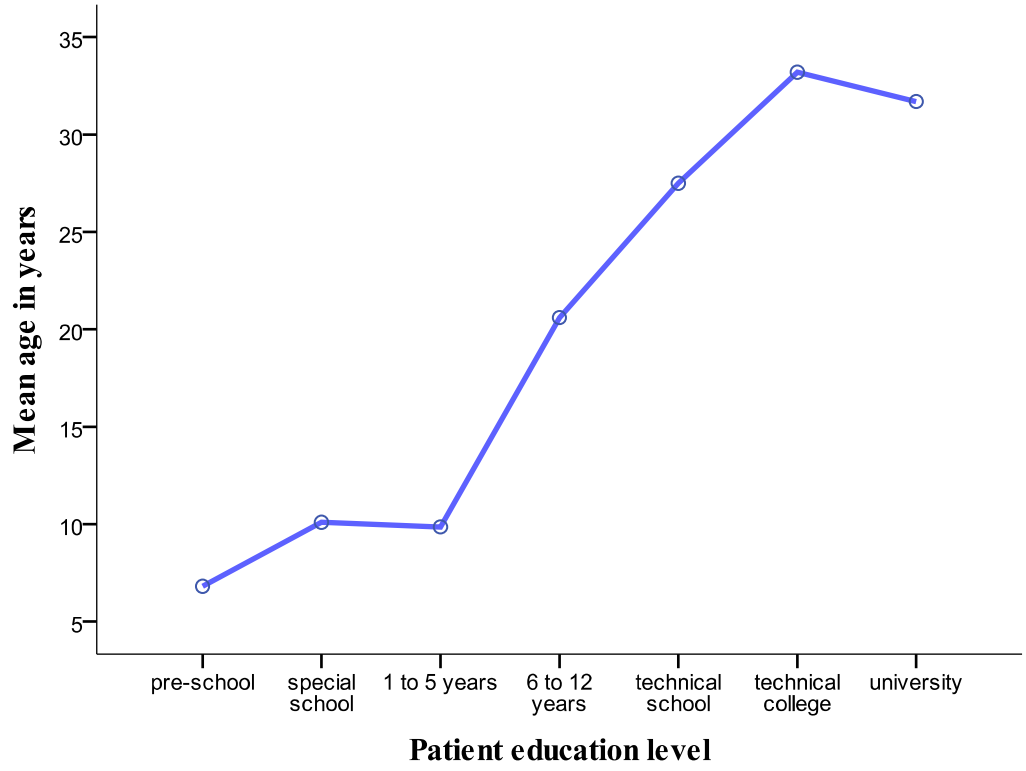
(p<0.001)

Graph 13 - Distribution of individuals 6 years and older, by method of IC and the level of education (n = 137)



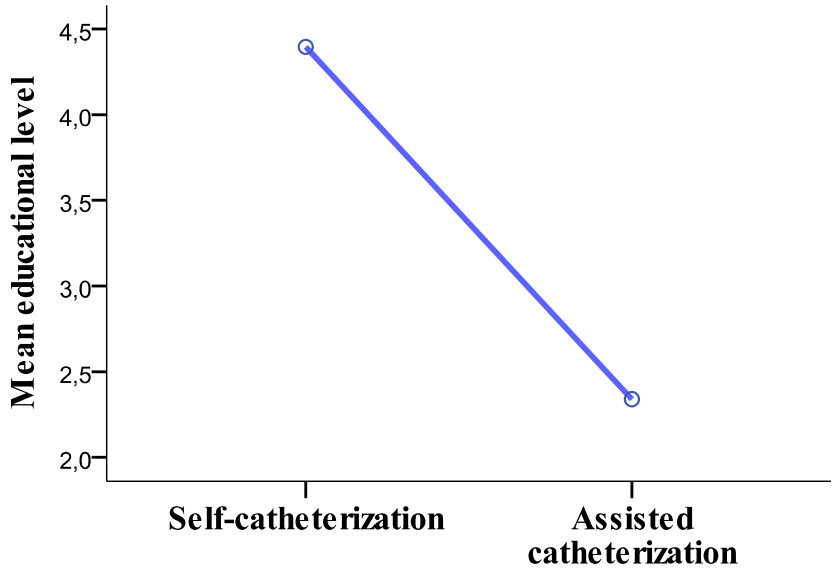
Despite education level and age being significant, in order to explain the use of self-catheterization, a graphic analysis (graph 14) proved there is a correlation between these variables. For this reason, we excluded age from the logistical model in order to test the effect of education level on the use of self-catheterization.

Graph 14 - Distribution of sample by education level and mean age (n = 148)



The next two graphs (15 and 16) portray average education level according to the method of catheterization and nationality.

Graph 15 - Method of catheterization and mean level of education



Graph 16 - Nationality and mean level of education

The table below shows the coefficients of the logistical model $\ln(P_2/1-P_2)$, where P_2 is the probability that the person will use self-catheterization.

Initially, the model included the variables below, in addition to VP shunt and if the person was or was not in a wheelchair (full-time wheelchair user). However, these latter variables were excluded by the *"Backward Stepwise (Likelihood Ratio)"* method.

Table 49 – Effect of the independent variables on the use of self-catheterization

Variables	B	S.E.	Wald	DF	Sig.	OR	CI 95.0% for OR Lower	Upper
Nationality	0.978	0.564	3.014	1	0.083	2.660	0.881	8.029
HC	2.247	1.194	3.538	1	0.060	9.459	0.910	98.307
SB level	1.709	0.756	5.106	1	0.024	5.525	1.254	24.334
Education Level A (up to 5 years)	-	-	34.520	2	0.000	-	-	-
Education Level B (6 to 12 years)	3.526	0.638	30.519	1	0.000	33.996	9.730	118.784
Education Level C (13 years or more)	3.744	1.201	9.710	1	0.002	42.247	4.010	445.052
Constant	0.704	1.169	.362	1	0.547	2.022	-	-

*P-value of the Hosmer and Lemeshow Test: 0.905. R^2 Nagelkerke = 0.662;

**Initial -2LL = 185.335 ; Final -2LL = 92.826 (LL=Log Likelihood)

Therefore, model 2 will be:

$$\text{Ln}\,(P_2/1\text{-}P_2) = 0.704 + 0.978^{*}\textit{nationality} + 2.247^{*}\textit{hydrocephalus} + 1.709^{*}\textit{SB level}$$

(0=Brazilian; 1=German) (0=yes; 1=no) (1=sacral or lumbar; 0= thoracic or cervical)

$$+\ 3.526^{*}\textit{Education Level B} + 3.744^{*}\textit{Education Level C}$$

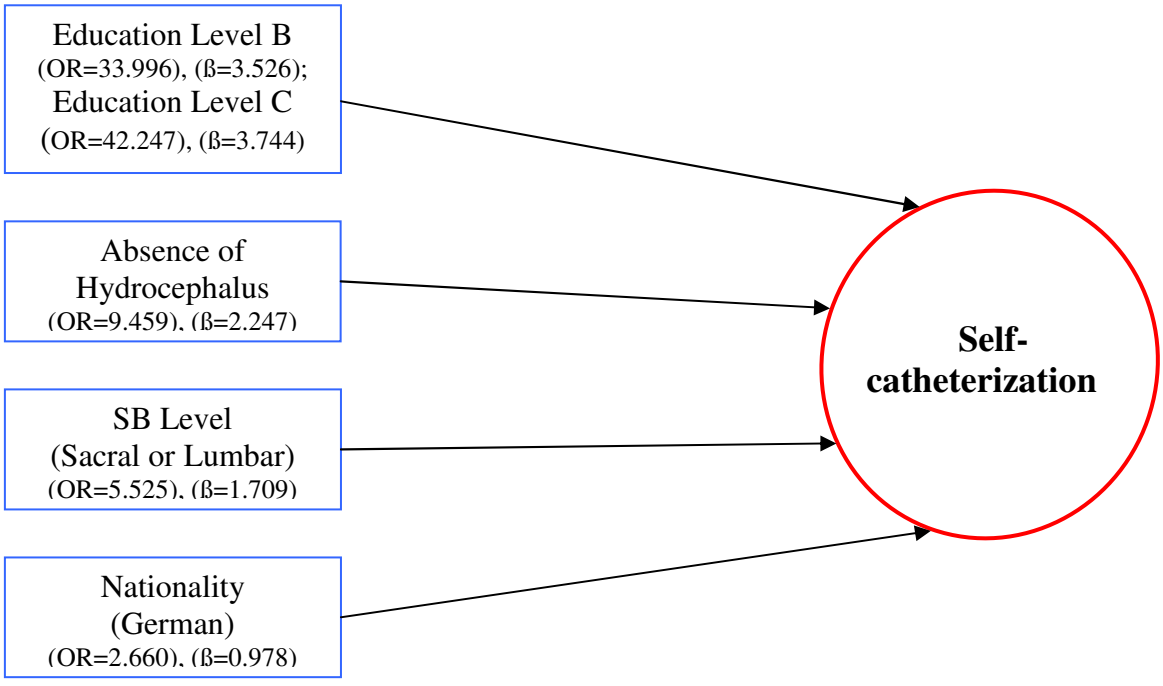
(1=6 to 12 years; 0=opposite case) (1=13 years or more; 0=opposite case)

Maintaining the other variables unchanged, the model indicates that, the higher the education level, the greater the likelihood of using self-catheterization. Not having hydrocephalus positively affected the use of self-catheterization, and the individual who does not have HC has up to 9.5 times greater likelihood of using self-catheterization. Model 2 also shows that the lower the lesion level, the greater the likelihood the

individual will use self-catheterization, and that having the lesion in the lumbar or sacral levels increases the chances of using self-catheterization up to 5.5 times. Finally, the coefficient of nationality indicates that being German increased the likelihood of using self-catheterization by up to 2.6 times. The considerable strength of the model can be seen in the reduction of the likelihood ratio (Initial -2LL = 185.335; Final -2LL = 92.826, LL=Log Likelihood) and on R^2 Nagelkerke (R^2=0.662). The logistical regression of model 2 can be viewed in the following graph.

Figure 2 – Logistical Regression: Model 2

Predictive factors for self-catheterization



*2LL initial = 185.335; -2LL final = 92.826

5.2.3. Factors related to the occurrence of UTI episodes

In model 3, the number of UTIs before and the number of UTIs after were considered dependent variables. In order to conduct this analysis, the UTI episodes were considered between the range of 0 and 9 or more UTI episodes per year.

UTI was evaluated at two different moments:

- UTI before: number of symptomatic UTI episodes per year before IC (Y1).
- UTI after: number of symptomatic UTI episodes per year after IC (Y2).

According to the prior data in the descriptive analysis, the number of UTIs before was higher than the number of UTIs after IC (Mann-Whitney U-tests, $p<0.001$).

An ANOVA was done for repeat measurements, in order to evaluate the effect of the variables gender, IC method and nationality (independent variables, Table 50) on the behavior of the dependent variables UTI before and UTI after. The number of persons in each category of the independent variables was different, making the ANOVA a case of unequal samples (unbalanced ANOVA). Only those participants who could report the number of UTIs before and after IC were considered. Those who did not know or could not remember were excluded from the analysis, leaving a total of 171 participants.

Table 50 – Relationship and coding of the independent variables (n = 171)

Variable	Code	Description	Nº persons
Nationality	1	Brazilian	97
	2	German	74
Gender	1	feminine	85
	2	masculine	86
Current method of catheterization	1	self-catheterization	73
	3	assisted IC	87
	4	does not use IC	11

The next table shows that the observed variation in the number of UTIs, for each subject, occurred only once due to the difference between the before and after moments ($F=15.07$; $p<0.001$), without any interaction with the independent variables.

Table 51 – Variation of the number of UTIs associated to the before and after moments in relation to the independent variables

Source	Type III Sum of Squares	DF	Mean Square	F	Sig.
Moment	57.453	1	57.453	**15.070**	0.000
Moment * Nationality	5.837	1	5.837	1.531	0.218
Moment * Gender	0.913	1	0.913	0.239	0.625
Moment * Current IC method	20.991	2	10.496	2.753	0.067
Moment * Nationality * Gender	0.378	1	0.378	0.099	0.753
Moment * Nationality * Current IC method	8.140	2	4.070	1.068	0.346
Moment * Gender * Current IC method	9.897	2	4.949	1.298	0.276
Moment * Nationality * Gender * Current IC method	3.765	2	1.883	0.494	0.611
Error (Moment)	606.148	159	3.812	-	-

It can be noted in the following table that, with the exception of the last two lines, all of the p-values were significant. This means that nationality, gender and IC method, individually, influence the number of UTIs. Nationality influenced the number of UTIs, but this influence depended on two variables: gender ($p=0.011$), that is, it was different for men than for women, and IC method ($p=0.025$), that is, it was different for patients who used self-catheterization/assisted IC than for those who did not use IC.

Table 52 – Interaction between the independent variables in model 3

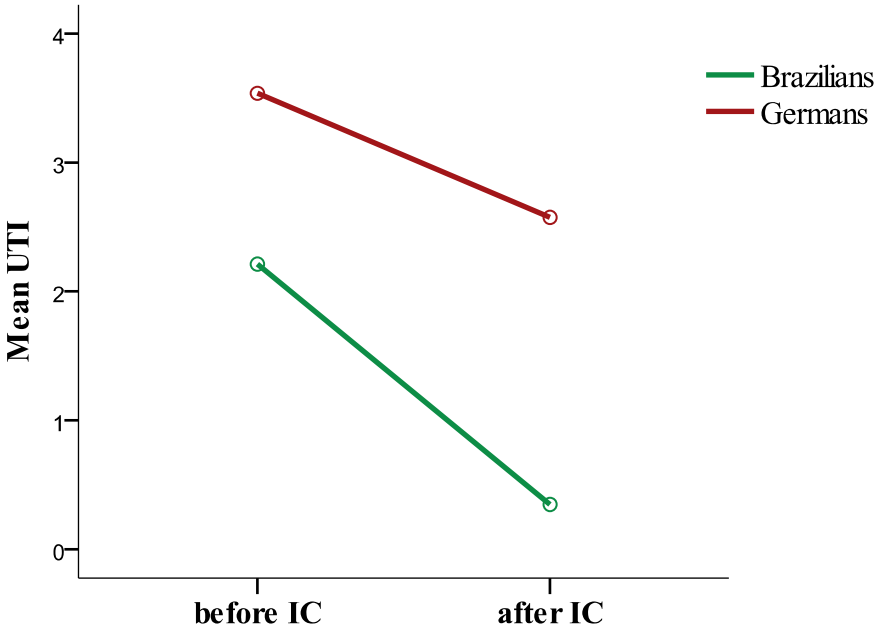
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	270.356	1	270.356	86.155	**0.000**
Nationality	45.352	1	45.352	14.452	**0.000**
Gender	14.678	1	14.678	4.678	**0.032**
Current IC method	24.670	2	12.335	3.931	**0.022**
Nationality * Gender	20.930	1	20.930	6.670	**0.011**
Nationality * Current IC method	23.822	2	11.911	3.796	**0.025**
Gender * Current IC method	6.399	2	3.199	1.020	0.363
Nationality * Gender * Current IC method	17.232	2	8.616	2.746	0.067
Error	498.944	159	3.138	-	-

The following graphs provide a more didactic perspective of the results obtained from the analysis.

In the first graph, there is no statistical difference in the number of UTIs before catheterization between the Brazilian and German samples (Yates' chi-square, p=0.655); however, after IC, there was a significant statistical difference in relation to the number of UTIs between the Brazilian and German samples (Mann-Whitney U-tests, p<0.001). In the German sample, the mean UTI before catheterization was 3.2 (3.1) per year and after catheterization it was 1.9 (2.2) per year. In the Brazilian sample, the mean UTI before catheterization was 2.4 (2.8) per year and after IC it was 0.4 (0.7) per year. The analysis for the paired samples shows that the mean UTI episodes before catheterization was different than the mean UTI episodes after catheterization, for both the Brazilian sample (p<0.001) and the German sample (p<0.001).

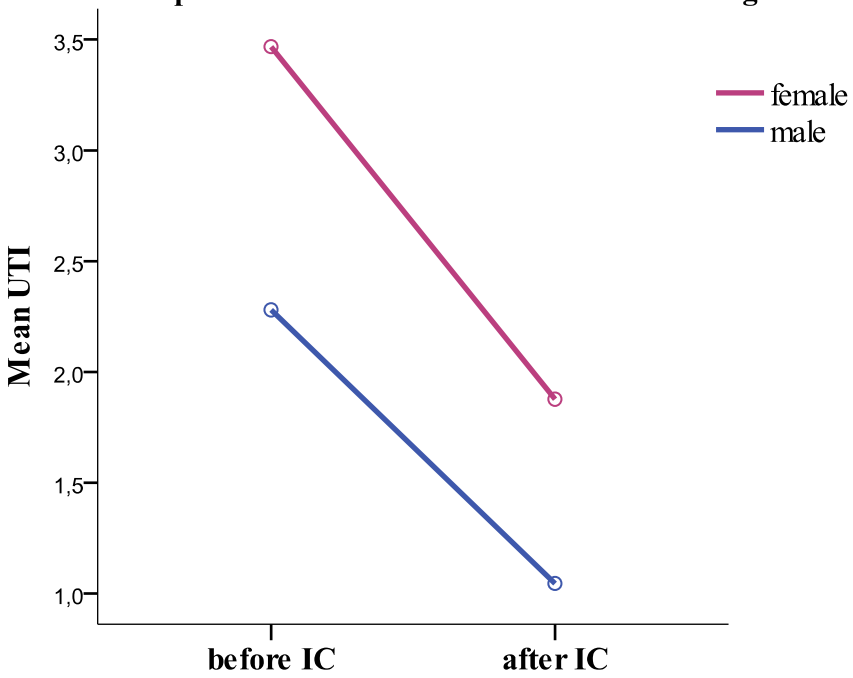
The following three graphs present the mean UTI before and after IC, related to the variables nationality, gender and method of catheterization. All were generated using ANOVA.

Graph 17 - Mean UTI before and after IC and nationality



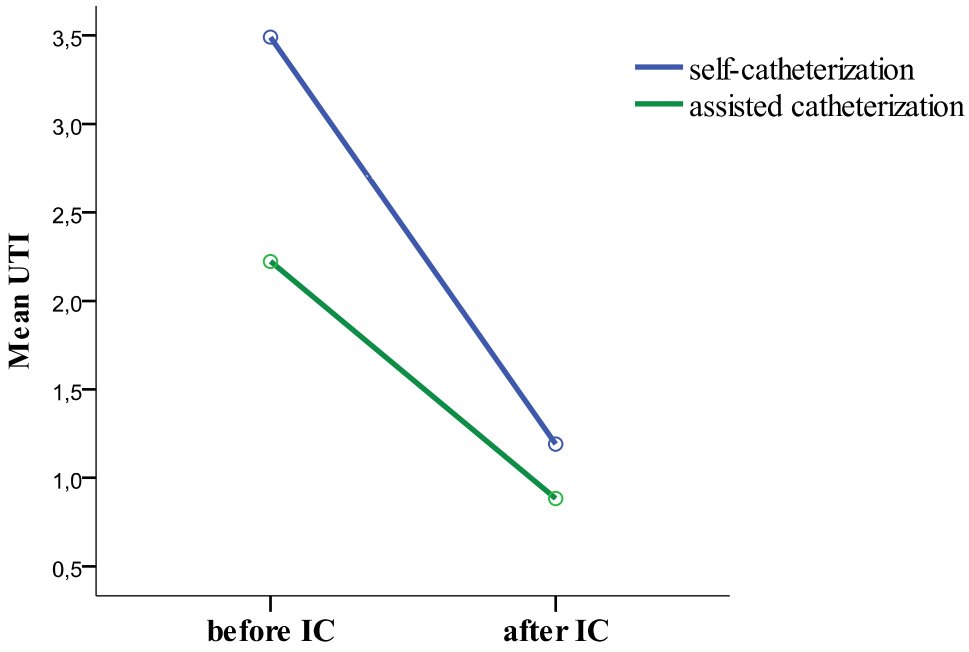
This graph shows there was a difference between the number of UTIs before and after, related to gender. In comparison with the men, the women had a higher number of UTIs before and after.

Graph 18 - Mean UTI before and after IC and gender



In the following graph, we can see the difference in the mean UTI according to the method of catheterization.

Graph 19 - Mean UTI before and after IC and method of catheterization



The following table shows the means of UTIs before and after IC, distributed by IC method.

Table 53 – Mean number of UTIs before and after IC by IC method

IC type	Before (dp)	After (dp)	Mean
Self-catheterization (n = 73)	3.45 (3.14)	1.34 (1.80)	2.40
Assisted IC (n = 87)	2.13 (2.56)	0.67 (1.04)	1.40
Does not use IC (n = 11)	3.27 (3.98)	2.45 (3.53)	2.87
Mean (n = 171)	2.77 (2.97)	1.07 (1.70)	2.22

Since the ANOVA detected differences between the number of UTIs between the IC groups, it is worth knowing how these groups compare two by two. Using the Games-Howell test for unequal variances, it was possible to detect a difference only between those who practiced self-catheterization and those who used assisted catheterization (p=0.002), regarding the reduction in the number of UTIs. Those who practiced self-catheterization had a higher reduction in the initial number of UTIs, compared with those who used assisted catheterization (Graph 19, Table 53 and 54).

Table 54 – Results of the Games-Howell test in the comparison of IC methods

Methods compared	Difference between means	Standard error	P-value
Assisted IC - self-catheterization	-1.00	0.284	**0.002**
Does not use IC – self-catheterization	-0.47	1.110	0.908
Does not use IC – Assisted IC	+1.47	1.097	0.407

The type of substance used to wash the genitalia was only collected in the German sample, thus the analysis of substance and number of UTIs was only conducted for the Germans. The categories used for cleaning were: disinfection (for patients who reported using these substances: octenidine, polyhexanide and chlorhexidine), washing (for patients who reported using: potable water, sterile water, water and soap, and moist toilettes), disinfection and washing (patients who alternated the form of cleaning), and no cleaning (patients who neglected to do any kind of cleaning before inserting the catheter). Thus, the number of UTI episodes per year after performing IC was evaluated according to the type of cleaning used by the participants. There was no difference observed in the distribution of the number of UTIs in relation to the cleaning (p=0.365, Kruskal-Wallis test for independent samples).

There was also no significant statistical difference observed between the disinfection and the washing related to the mean UTI per year after IC (Student's t-test, p=0.596; Levene's test, p=0.495), as there was no difference between disinfection and any forms of cleaning before IC (Student's t-test, p=0.116; Levene's test, p=0.380). The means of the number of episodes of UTIs per year after IC can be observed in the following table.

Table 55 – Distribution of the German sample according to the type of cleaning done and the mean of UTI episodes per year after IC (n = 83)

Cleaning	n	Mean UTI
Disinfection	39	2.0/year
Washing	20	1.7/year
Disinfection and Washing	14	2.28/year
No cleaning	10	0.9/year

5.2.4. Factors related to the acquisition of urinary continence after IC

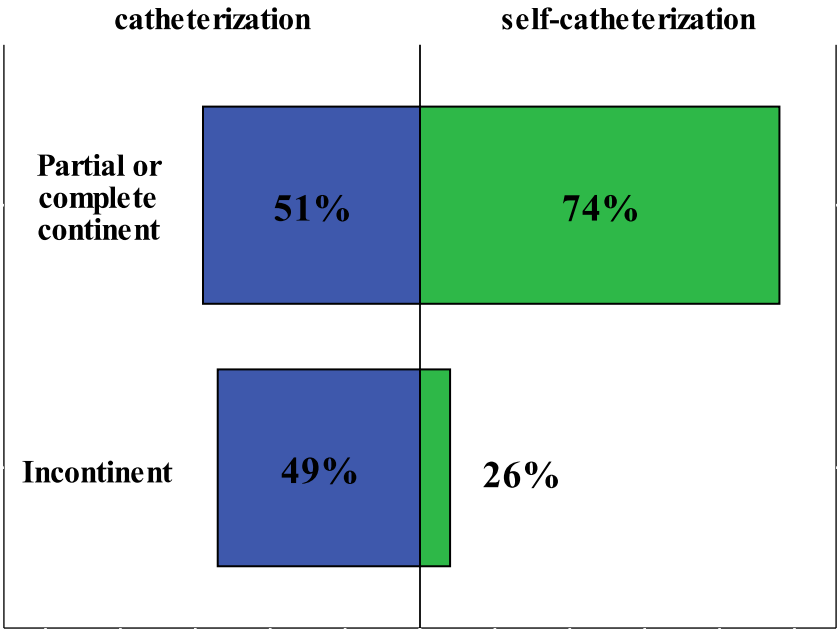
In the analysis of model 4, the dependent variable acquisition of continence after IC (complete or partial continence and incontinence) was considered, where:

- 0 = incontinent.
- 1 = partially or completely continent.

For the logistical regression of model 4, 188 patients who had used IC were considered; those who had not used IC were removed from the analysis. Out of the 188 participants, 62.2% (117) achieved complete or partial continence, and of these 56 were Brazilian and 61 were German. The remaining 37.7% (71) did not achieve continence after IC, and of these 38 were Brazilian and 33 were German. The distribution of the dependent variable was similar in the two nationalities (p=0.547). There was no association observed between acquisition of continence after IC and nationality. Similarly, according to the sample, urinary continence was not associated to variation in gender (p=0.401) and the presence of hydrocephalus (p=1.000).

The following graph shows the distribution of the sample of 188 patients who use IC according to acquired continence after using IC and the method of catheterization. It can be noted that the sample distribution was statistically different from the continence between the patients who use assisted IC and those who self-catheterize (Chi-square test; p=0.002).

Graph 20 - Distribution of individuals who use IC by method of catheterization and acquisition of continence (n = 188)



(p=0.002)

The following table shows the statistical significance between each defined variable and the acquisition of continence after IC (yes/no). When the p-value was less than or equal to 0.25, the variable was included in the logistical model, otherwise, it was discarded.

Table 56 – Variables related to the acquisition of continence after IC

Variable	Test	P-value	Statistical significance
Age	Students t-test	**0.022**	Significant
Current IC method	Chi-square	**0.002**	Significant
Frequency of IC	Student's t-test	**0.002**	Significant
Nationality	Chi-square	0.547	Not significant
Gender	Chi-square	0.401	Not significant
UTI after IC	Student's t-test	0.371	Not significant
Wheelchair dependent	Chi-square	1.000	Not significant
Level of lesion	Fisher's Exact	0.526	Not significant
HC	Chi-square	1.000	Not significant
Use of medication	Chi-square	0.932	Not significant
Oxybutynin	Fisher's Exact	0.287	Not significant
Discontinuation of IC	Chi-square	0.258	Not significant

Regarding the previous table, it is important to note that the variables that were significant were age (p=0.022), IC method (p=0.002) and frequency of IC (p=0.002). However, the variables nationality (p=0.547), gender (p=0.401), UTI after IC (p=0.371), wheelchair dependent (p=1.000), level of lesion (p=0.526), HC (p=1.000), use of medication (p=0.932), oxybutynin (p=0.287) and discontinuation of IC (p=0.258) were not statistically significant in relation to the variable response.

Next, the *"stepwise backward"* regression was conducted for the logistical model. In the first step, all of the possible defined variables of the model were found, with the non-significant variables, among the candidates for exclusion (p>0.100), removed and the SPSS executing the next step and not considering that variable. This step by step

process was followed until the final model included the variables "*age", "IC method",* and *"frequency of IC"*.

The following table shows the coefficients of the final model of the logarithm, $\ln(P_4/1-P_4)$, where P_4 is the probability that the person will acquire complete or partial continence after using IC.

Table 57 - Effect of predictors variables in the acquisition of continence after CI

							CI 95.0% for OR	
Variables	**B**	**S.E.**	**Wald**	**df**	**Sig.**	**OR**	**Lower**	**Upper**
Frequency of IC	0.542	0.177	9.429	1	0.002	1.720	1.217	2.431
Method of IC	1.079	0.325	11.043	1	0.001	2.942	1.557	5.559
Constant	-2.390	0.815	8.604	1	0.003	0.092	-	-

* test Hosmer and Lemeshow, p=0.427. R2 Nagelkerke = 0.146;

**-2LL initial = 249.253 ; -2LL final =227.869 (LL=Log Likelihood)

Model 4 will therefore be the Neperian logarithm of the ratio between the probability of acquiring continence after IC and the probability of not acquiring continence after IC:

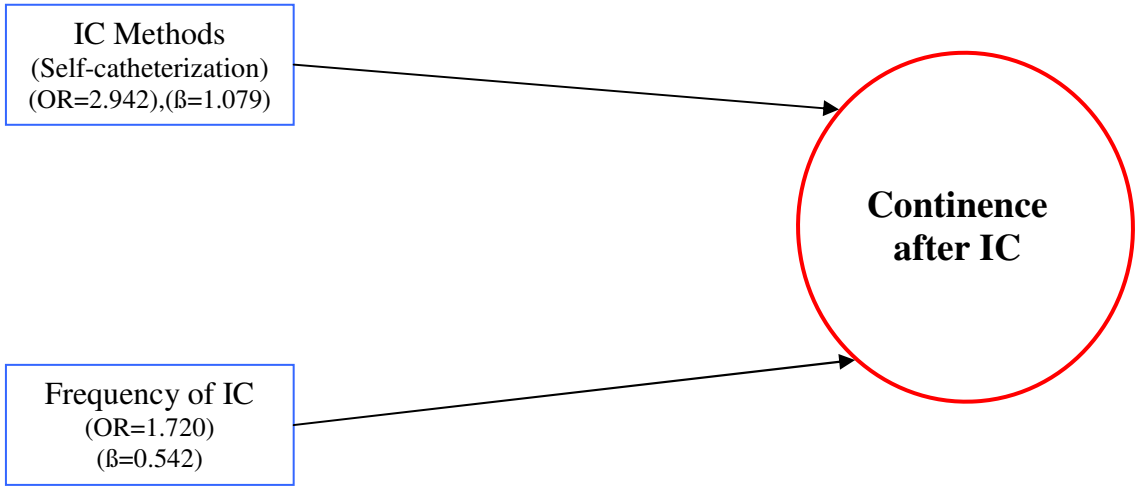
$$\text{Ln}(P_4/1-P_4) = -2.390 + 0.542 * \textit{frequency of IC} + 1.079 * \textit{method of IC}$$

(whole nº.: 0,1,2,3,...) (0=assisted catheterization; 1=self-catheterization)

The coefficient of frequency of IC indicates that increasing the frequency of IC increases the likelihood that the patient will acquire continence with IC. Using self-catheterization can increase the likelihood of acquiring continence (partial or complete) by up to 2.9 times, in relation to someone who uses assisted catheterization. The logistical regression of model 4 is shown as follows:

Figure 3 – Logistical Regression: Model 4

Factors related to the acquisition of continence after IC



*-2LL initial= 249.253; -2LL final =227.869

6. DISCUSSION

In this section, the results of the data analysis will be summarized and discussed in light of current scientific literature. To begin the discussion, two relevant aspects of the study should be highlighted. The first is the sample size (200 participants), and the second is that, in the literary review, there was not one similar study found about the factors involved in the use of IC by patients with SB, considering two countries on different continents. The uniform distribution of the sample with respect to the nationality of the participants (100 Brazilians and 100 Germans) was a factor that contributed to the data analysis.

A specific age range was not stipulated for participation in the research since the study sought to include a wide sample of individuals who use IC, also using the variation in age to understand the context of IC in the two countries. The total sample was comprised of young people with a mean age of 14 years. However, the profile of the Brazilian sample was younger, with a mean age of 10 years, varying between 0 and 28 years. The profile of the German sample was more adult-oriented, with a mean age of 19 years and a variation of 0 to 55 years. This different distribution of the sample in relation to age influenced other variables and contributed to understanding the predictive factors for self-catheterization, which will be discussed later. It should be noted that the young profile of the Brazilian sample reflected the reality of 1,130 patients with SB registered with the hospital of study and who have a mean age of 13.7 (9.1) years. It suggests that this difference in age within the sample reflected what also happens in the general population, as the lifespan of the German population is longer than that of the Brazilian population (DESTATIS 2009; IBGE 2009).

Furthermore, it was stated that in Germany there is a generation of adults with SB while, in Brazil, this generation has just begun to develop in recent years. This difference may also suggest that the treatments for SB, such as surgical correction for MMC, the use of a shunt to treat hydrocephalus and the use of clean intermittent vesical catheterization to prevent renal deterioration, were initiated and standardized in

Germany. As a result, life expectancy of individuals with SB increased in Germany, thus creating this generation of adults in Germany before Brazil.

As recorded in literature, the general sample showed a higher frequency of the female gender (Henriques & Pianetti 2011); however, the Brazilian sample was predominantly male (57%), while the German sample had a greater number of females (65%).

The education level of the patients was higher in the German sample, related to the difference in age between the Germans and the Brazilians, which can reflect what happens in the general population since Germany has higher education rates than Brazil (DESTATIS 2009; IBGE 2009). A similar piece of data can also be ascertained in the higher level of education of the Germans responsible for assisted IC than for those in Brazil.

The distribution according to the level of SB was uniform in relation to nationality – 75% of the patients had the lesion at the lumbar level, 15.5% at the thoracic level, 7.5% at the sacral level, and 4% at the cervical level. The predominance of the lumbar level corroborates with literature that shows a consensus stating that this region, between the fifth lumbar vertebrae (L5) and the first sacral vertebrae (S1), is where the majority of spinal dysraphisms lie (Zambelli 2006; Rintoul et al. 2002; Plese & Ciquini Junior 1996). Requeijo (2008) found a predominance of lumbar lesions in 75.5% of cases, followed by thoracic lesions in 15.6%, cervical in 6.7% and finally, sacral in 2.2%. These results are very close to those found in this study (Requeijo 2008). Castro et al. (2010) observed a rate of 85% of lesions at the lumbosacral level in Brazilian patients (Castro et al. 2010), which is similar to that found in this research, 82.5% between the lumbar and sacral levels.

Hydrocephalus was present in 83% of the participants in this study, which is similar to the rates reported in previous studies that indicate the presence of HC in close to 80 to 90% of patients with MMC (Perry et al. 2002; Bowman et al. 2001; Fletcher et al. 1992). Naturally, the condition for the use of the VP shunt was the presence of HC. Out of the patients who had HC, 86% used the VP shunt. For these individuals, it was

verified that the mean age was less than those who did not use the shunt. This could be related to the recent development of shunts that are more modern and effective, and to the standardization of medical policies for the treatment of HC (Zambelli 2006; Boockvar et al. 2001). Zambelli (2006) found that, of the 78.6% cases of HC that were associated with SB, 76.6% used the VP shunt (Zambelli 2006). Bowman et al. verified in their study of patients with MMC above 20 years of age that 86% used a shunt for the treatment of HC, and of these, close to 95% had already been subjected to at least one shunt revision (Bowman et al. 2001).

Despite the fact that the form of classifying ambulation was different in the two samples, a similarity was observed in the distribution of the non-ambulatory patients who depend on a wheelchair for movement, representing 41% of the Brazilian individuals and 42% of the German individuals. These data agree with recent studies of patients with SB. A German study in the city of Luebeck reported that 41% of participants depended on a wheelchair (Amari et al. 2010). In a Dutch study of 179 young adults with EB, 39% used a wheelchair full-time (Barf et al. 2009). An Irish study with 237 patients revealed that 36% were wheelchair dependent (McDonnell & McCann 2000). In this study, it was also observed that wheelchair dependency as a form of ambulation is associated with the lesion level. Considering the sacral, lumbar and thoracic levels, the higher the region of the lesion, the greater the likelihood of wheelchair dependency, according to the writings of other authors (Amari et al. 2010; Barf et al. 2009). With respect to the entire sample studied, the patient with the thoracic level of SB had approximately 14 times greater chances of depending on a wheelchair for ambulation.

A study of young people with SB revealed that the use of a wheelchair on a full-time basis is associated with a reduction in quality of life, but that psychological stress and self-management issues are predominant and independent of the individual's mobility (Dicianno 2009). Serious physical disability is not a contra-indication or insurmountable obstacle for using IC, since many patients who are wheelchair dependent are able to master the technique of self-catheterization (Oakeshott & Hunt 1992). It should be

noted that, in this study, the influence of the use of a wheelchair on the use of self-catheterization was not observed.

Intermittent bladder catheterization

In the two samples, assisted catheterization was the predominant choice as the initial method of catheterization. This is in line with the recommendation of early initiation of catheterization at an age when the individual is too young to move directly to self-catheterization (Clayton et al. 2010; Stein et al. 2007; D'Ancona & Silva Jr. 2007). The mean age for initiating IC throughout the entire sample was 6.2 years, similar to the mean of 6.9 years, which was found by the German researcher van Gool, who studied 61 children with MMC (van Gool et al. 1991). Despite 45.5% of the patients having started IC at three years of age or less, and considering the orientation of current urological policies for the neurogenic bladder in SB, which emphasize the benefits and recommend early initiation of the procedure, the mean age of about six years for the initiation of IC is considered high (Stöhrer et al. 2009; AWMF 2009; Brazilian Society of Urology 2006; European Association of Urology 2006). Studies reveal that children who are born with SB can probably keep their kidneys for their entire lives if they begin appropriate urological treatment soon after birth, including IC (Dik et al. 2006).

With respect to the current method, 92 participants used self-catheterization, of which 17 used it with assistance. The remaining 96 participants used assisted IC. There was a difference in the distribution of the samples according to nationality, since in reality the majority of Germans use self-catheterization (61%) and the majority of Brazilians use assisted IC (63%). The factors that influence the current method of catheterization will be discussed later.

The person deemed responsible for catheterization is the one who is in charge of both the technique, as well as the time schedule and other organizational factors involved in the procedure. In the German sample, the primary responsibility for IC was assigned to the patient him/herself (54%) and in second place were mothers (42%). In the Brazilian sample, however, the primary responsibility went to the mother (71%). These figures

were reflected in the current method of catheterization, with a higher rate of Germans using self-catheterization and a higher rate of Brazilians using assisted catheterization. In both the German and Brazilian samples, the one responsible for assisted catheterization was usually the mother. In the absence of the mother, the father became the first choice when it was necessary to have someone else perform the procedure. Other studies confirm the higher responsibility of mothers in the care of children with SB, including IC (Gaiva et al. 2009; Osterlund et al. 2005; Furlan 2003). Martins (2008), after studying the profile of Brazilian caregivers of children with SB, stated that the majority were mothers, with a low education level, low monthly income and financial difficulties (Martins und Soler 2008). In Brazil, the economic situation of families with sick members, primarily when they are children, is very often made worse. As a result, mothers leave their paid work to take care of their child (Furlan 2003).

The training of various people for the use of IC is essential. The connection between the patient, family and network of support, building an IC support team of skilled people, helps build commitment to the procedure throughout the patient's life (Stein et al. 2007; Borzyskowski et al. 2004). With respect to the person who would be trained to perform IC if necessary, this study shows that, in addition to immediate family members (father, mother and siblings), grandparents, aunts and uncles, the Germans include health professionals (24%), educators and even partners as alternatives. On the other hand, Brazilian participants include other relatives, such as cousins and nieces, and only 2% of the Brazilians would include a caregiver or health professional. This data shows the differences between family support networks and may also have been affected by the different economic situation in the two countries, as the Germans have greater financial means and access to public health insurance to be able to hire professionals to aid in the care.

The data analysis shows that the participants who use self-catheterization are older than those who use assisted IC, independent of nationality. The mean age of the iniatiation of self-catheterization training under supervision/with assistance was 11 years and for self-catheterization was 14 years. In the two samples, the training for self-

catheterization was initiated at a minimum of six years of age. This was in line with what various authors have recommended, that children without serious cognitive difficulties are able to learn self-catheterization beginning at six years of age, although they continue to require adult supervision to ensure reliability. They also suggest that better results could be obtained if self-catheterization training were started before seven years of age (Stein et al. 2007; Edwards et al. 2004; Association for Continence Advide 2003; Delisa 2001; Hannigan 1979).

The mean of minimum IC frequency in the overall sample was 4.5 times per day. In the Brazilian sample, this frequency had a mean of 4.3 times per day, and in the German sample, the mean frequency was 4.7 times per day. Even though the Student's t-test indicated a different distribution for IC frequency in the two samples ($p<0.015$), in practice, the use of IC 4 to 5 times per day is what is cited in literature. Therefore, there is no difference in the clinical significance of the procedure. This frequency of IC usage is within the recommended norm, which suggests catheterization 4 to 6 times per day, varying with bladder capacity and volume of urine loss (Newman & Willson 2011; AWMF 2009). Lapides advised that IC frequency should be sufficient to avoid over-stretching the bladder and is an essential factor for the procedure's effectiveness in preventing urinary tract complications, even more important that the sterility of the materials used in the technique (Lapides et al. 2002).

The type of catheter used and the form of disposal are completely different in the two countries. In Germany, 100% of the participants stated using disposable, single-use catheters. In Brazil, it is common to re-use the catheter. The most common type of catheter used by the German participants was a hydrophilic-coated catheter (60%) or gel-coated catheter (31%). Yet in Brazil, the most commonly used catheter was the plastic (PVC), non-coated (78%) or metallic catheter (18%).

The type of catheter was an interesting point of study because it reflected the economic contrast between the two countries. The mean cost of the coated catheter used by the Germans is €2.70. For the patient who performs IC four times per day, the monthly cost would be approximately €324.00. All of the individuals in the German sample receive

catheters through the German health plan, although 13% reported having problems receiving their reimbursement.

In Brazil, the pre-lubricated catheters are not distributed by the Unified Health System (SUS) (Martins et al. 2009). The metallic catheter is donated by the rehabilitation hospital where this study was conducted. It can only be used by women and it can be re-used as long as it does not show any microscopic changes. This catheter has been used less often. The plastic catheter, made of PVC (polyvinyl chloride), is reused for up to one week. The Municipal Secretary of Health in Belo Horizonte donates 30 catheters per month to children up to five years of age and seven catheters per month to those over five years (Schmiemann et al. 2010). The donation policy for catheters varies with the municipal health policies of each city. In some Brazilian municipalities, patients manage to receive a donated catheter for each procedure. The price of one catheter, when purchased in stores that specialize in hospital materials, is approximately R$0.50 or 0.20€, plus the cost of the lubricant gel of about R$5.00 or 2.00€ per tube of 30g. Thus, the minimum monthly cost for re-used catheters would be R$3.50 or 1.40€. When disposing of the catheter after each use, the monthly cost becomes R$60.00 or 24.00€, plus R$20.00 or 8.00€ for four tubes of lubricant gel. In accordance with the Secretary of Planning and Management, the city of Belo Horizonte pays R$0.30 or 0.12€ for each urethral probe no. 12 and R$0.79 or 0.37€ for each tube of lubricant gel (Register of medication prices – act 4, process: 04.000516.08.54).

Unit values of catheters and lubricant gel, monthly cost and minimum Brazilian salary (per month) can be seen in Table 58.

Table 58 – Unit values of catheters and lubricant gel, monthly cost and minimum Brazilian salary (per month)

	PVC Catheter		**Pre-lubricated Catheter**	**Lubricant gel**
	Weekly re-use	**Single use**		
Per unit cost	0.20€[a]	0.20€[a]	2.70€[b]	2.00€ [a]
Monthly cost	**1.40€**[a]	**24.00€**[a]	**324.00€**	**8.00€** [a]
Unit cost for the municipality of BH	0.12€	0.12€	-	0.37€
Monthly cost for the city of BH	0.84€	14.4€	-	1.48€
% of Brazilian minimum salary[c]	0.64%	11.0%	148.62%	3.67%

(a) Values in euros, as found in Belo Horizonte (BH) - 2011 (money conversion: 1.00€ = R$2.50).

(b) Value per catheter paid by German health plans.

(c) Minimum Brazilian salary (per month) valid since 01/03/2011 (R$545.00 = 218.00€).

According to the above table, converting these values into equivalent percentages of the minimum Brazilian salary (per month), it can be verified that the use of the hydrophilic catheter generates a monthly cost of about 1.5 minimum Brazilian salaries. Thus, this is an unviable option right now for Brazilian families. Yet, the PVC single-use catheter (disposable) equates to 11% of the minimum Brazilian salary when financed by the patient him/herself, and 6.6% of the minimum salary with financing from the municipal government of Belo Horizonte. Thus, the PVC disposable catheter could be a possible middle option. Between the sterile technique and the clean technique with re-usable catheter, it is more viable from an economic perspective and more practical and useful as a prophylactic means for dealing with complications associated with IC. Various international urological and rehabilitation associations encourage the use of a new catheter after each procedure as a means to assist UTI prophylaxis (Newman & Willson 2011; Woodbury et al. 2008; European Association of Urology 2006; Association for

Continence Advide 2003). Not included in the cost is the immeasureable comfort and practicality of using the disposable catheter, which makes the procedure easier by eliminating the stages of washing, drying and storing the catheter. Costa (2006) has already reported that the use of the disposable catheter was a factor that facilitated IC, as reported by mothers who complained about the time spent washing the catheter and the fear of contamination when re-using it (Costa & Carvalho 2006).

In an effort to reduce bacteriuria in patients who use IC, various researchers suggest some changes during the performance of catheterization, despite the fact that there are very few studies related to this issue. Some researchers advise that the person performing catheterization should not touch the distal part of the catheter that is inserted into the bladder during the procedure (Stein et al. 2007). Others suggest that the catheter that is to be re-used should be dried after washing since the drying process reduces the bacterical count on the catheters (Schlager et al. 2001). However, in reality, there are no studies with random, controlled clinical trials to teach the ideal cleaning method for re-used catheters. *A priori*, in accordance with the instructions provided by manufacturers on the packaging, all catheters are single-use and no manufacturer takes responsibility or possesses a standard protocol for the re-use of catheters (Newman & Willson 2011; Pannek et al. 2006).

To continue the discussion about the differences between catheters, as previously noted, some researchers claim that the rate of difficulty is the same between the hydrophilic catheters and the PVC catheters (Lindehall et al. 2007; Campbell et al. 2004 However, there are also various studies that report that the benefits of hydrophilic catheters include the reduction of complications (related to IC), as well as practicality, comfort and patient preference (Cardenas et al. 2011; Stensballe et al. 2005; Hudson & Murahata 2005; Hedlund et al. 2001; Waller et al. 1995).

Another difference was in the type of substance used to clean or disinfect the genitalia before inserting the urethral catheter. The majority of German participants (64) reported using antiseptic substances (octenidine and polyhexanide), in accordance with the recommendations of the German Society of Urology (AWMF 2009). About 18

patients reported washing only with potable or sterile water, 15 patients reported not cleaning before inserting the catheter, and only 10 patients washed with water and soap. In Brazil, the majority of patients are oriented to wash with water and, preferably, a pH-balanced soap (Costa & Carvalho 2006; Martins 2004). They say 'preferably' neutral soap because not all Brazilian families have the means to buy this soap as it is more expensive than regular soap.

Regarding the substances used by the Germans, the study verified that 49% of the German participants exclusively used the aseptic technique recommended by the AWMF, 15.6% used the aseptic technique and the clean technique, 25% used the clean technique with the single-use catheter, and 10.4% reported not washing and thus there was no technique classification for them. It was also noted that, despite the recommendations of the AWMF. Many German participants prefer not to use antiseptic substances on a regular basis, thus using the clean technique with the single-use catheter. Some researchers say that there are not enough studies yet to standardize an ideal substance for the cleaning and disinfection of the urethral meatus before probing; however, all of them are definite in their recommendation of cleaning the genitalia before catheterization (AWMF 2009; Moore et al. 2006). The relationship between the substances used for cleaning the genitalia and the mean UTI per year were analyzed and will be discussed later.

The Brazilians used medications more frequently (96%) than the Germans (75%); however, 20% of the Germans reported using prophylactic antibiotics while, in the Brazilian sample, only 3% reported this practice. Another study of Brazilian children with MMC found a similar rate of 94.5% having used medication associated with using IC, with oxybutynin being the most common (Costa & Carvalho 2006). The fact that all the Brazilian patients use the same health services and receive similar medical care may have contributed to the prescribed medications and the medical indication of IC. However, the Germans use different health services, which could have contributed to the use of a high variety of medications and medical indications of IC. Even though oxybutynin is the most prescribed medication in both countries, some medications used

by the Germans are not yet commonly prescribed in Brazil, such as cranberry (recently more widespread), propiverine, trospium, and methionine (Castro et al. 2010).

A small portion (10%) of participants reported using medication on an irregular basis. Among patients' reasons for this irregular use were side effects, financial difficulty, forgetting to take it, and not understanding the doses and intervals. The side effects of oxybutynin, primarily, are already known in literature as being the primary cause for the discontinuation of medication (Cintra 2010; Aslan & Kogan 2002; Ferrara et al. 2001). Financial difficulty, especially in Brazil, was reported various times throughout this study and in previous studies as a complicating factor for using IC (Martins et al. 2009; Martins & Soler 2008; Costa & Carvalho 2006). Forgetting to take medicine and not understanding the doses and intervals of medications show the need for the one who is responsible for IC, be it the patients themselves or family members, to be better oriented and trained on the administration of drugs. An important alternative would be the use of learning strategies that facilitate the creation of this daily routine for the individual.

The three key medical indicators for IC in the German sample were: urinary incontinence (61%), elevated residual volume (36%), and UTI (34%). In the Brazilian sample, the three key indicators were elevated intravesical pressure (36%), hydronephrosis (22%) and urinary incontinence (19%). The indications for IC in both samples showed coherence between the two primary objectives of bladder catheterization highlighted in the urological policies of the two countries, the protection of the urinary tract and urinary continence (AWMF 2009; Brazilian Society of Urology 2006; European Association of Urology 2006).

The objectives of the person primarily responsible for the IC procedure were also in line with the objectives for treatment of the neurogenic bladder (AWMF 2009; Brazilian Society of Urology 2006). The first objective in both countries was renal preservation (65%). UTI prevention was in second place in Germany (74%) and third place in Brazil (24%). Urinary continence was in second place in Brazil (45%) and third place in Germany (57%). Another Brazilian study noted that 40% of mothers responsible for

assisted IC for children with MMC had the objective of bladder continence with the procedure (Costa & Carvalho 2006).

Despite the difference in the assessment of understanding of IC in relation to medical indication of the procedure, and the tests and risks involved, the majority (91.5%) of participants in the study were assessed as good/excellent or reasonable understanding. Also, the degree of understanding was higher in the German sample than in the Brazilian. There was no difference in the understanding of IC in relation to the key person responsible for the procedure, nor in relation to the actual method of catheterization (self-catheterization or assisted catheterization). However, it was observed that the participants who had excellent or good understanding about IC had lower rates of discontinuation (temporary) of the procedure. Researchers highlight that good understanding of the procedure by all those involved with IC is essential for the treatment to be successful as it facilitates cooperation. This is particularly important with children since their commitment to any kind of long-term treatment program is considered unreliable (Borzyskowski et al. 2004; Edwards et al. 2004). It can be difficult to motivate children and adolescents to use IC when, in reality, the primary goal for them is to protect their kidneys over the long term and this is an 'invisible benefit'. Furthermore, they are not always able to think or be concerned about the future (Edwards et al. 2004). Therefore, despite few studies on this topic, this study verified that good or excellent understanding of the individual concerning the procedure contributed to lower rates of discontinuation of IC throughout his/her life.

Difficulties related to IC

This investigation reveals that, while IC is established in literature as an effective means to manage the neurogenic bladder in SB, and it is currently being used by the majority of patients (94%) in this study, there are still challenges as well as technical, home-related, emotional and financial difficulties with IC, faced by patients and their families on a daily basis. These can lead to discontinuation of the procedure.

The distribution of the sample according to the difficulties related to IC revealed that the patients that are not currently using IC have more emotional difficulties (58.3%), technical difficulties (50%) and discontinuation of IC (75%), in comparison with patients who use IC. Even though the majority (66.7%) of patients who do not use IC reported difficulty in acquiring IC material, there was no statistically significant difference in the distribution of this variable between the participants who use IC and those who do not.

The difficulties in performing the technique of IC were reported by 41 patients (20.5%). Among the difficulties cited were: restlessness of the child during performance of IC, the positioning and control of the torso during the procedure, sphincter resistance to insertion of the catheter, visualization of the urethral meatus, and urethral pain/sensitivity. The technical difficulties reported by participants in this study are aligned with those previously recorded by other researchers of IC (Clayton et al. 2010; Lindehall et al. 2007; Costa & Carvalho 2006; Borzyskowski et al. 2004; Furlan 2003; Oakeshott & Hunt 1992).

Costa (2006) and Furlan (2003) also noted that the movement of the child during the procedure was a complicating factor for the IC technique as reported by mothers (Costa & Carvalho 2006; Furlan 2003). The mean age of the participants who reported difficulty with "restlessness of the child during IC" was 4 years, showing that this is a difficulty that occurs with younger children. In the case of restlessness during IC, some resources are recommended by various authors to help the child remain calm and accept the procedure, for example, the use of toys and positive reinforcement (Segal et al. 1995; Neef et al. 1989; Hannigan 1979). Borzyskowski (2004), Lindehall (2004) and Costa (2006) reported that one of the difficulties with IC noted by the participants in their study included sphincter resistance related to pain and sensitivity (Costa & Carvalho 2006; Borzyskowski et al. 2004; Lindehall et al. 2004). Clayton also cites the difficulties of positioning and torso control faced by some patients when performing IC (Clayton et al. 2010).

Visualization of the urethral meatus was the most common difficulty among the female gender, clearly due to the anatomical characteristics of the female genitalia, which make visualization more difficult than for men. This is often observed during IC training. However, over time, women tend to overcome this difficulty. According to Lapides and his colleagues, after a period of time, upon perfecting this skill, women stop using a mirror and rely on touch to locate the urethral meatus. Another difference in female catheterization, as noted by these researchers was that, over time, some women also stop using lubricants, relying only on the natural lubrication of the female urethra to insert the catheter (Lapides et al. 1972). Newman et al. cites that the anatomical variations can complicate the visualization of the urethral meatus, emphasizing that this is a particular difficulty for obese individuals (Newman & Willson 2011).

Home-related difficulties were reported by the minority (11.5%) of patients, led by inadequacy of the bathroom, followed by lack of privacy. Inadequacy of bathrooms appeared as a difficulty, not only at home but also in public. In the open-ended question about difficultires in the overall context of IC, close to 8 German participants, including patients and family members, reported inadequate public bathroom infrastructure as a current difficulty for the performance of the procedure.

The toilet was the location for performing IC that was most reported by the German participants (49.5%). Thus, the bathroom was the preferred location for the performance of the procedure, as it is the place that most people use for spontaneous urination, as stated by Newman (Newman & Willson 2011). Woodbury (2008) warns that, during the daily lives of patients, such as at school or work, particularly for those with reduced mobility, lack of adapted public bathrooms can further increase the risk of UTI (Woodbury et al. 2008). Therefore, adequate and adapted bathrooms become important to facilitate the performance of the procedure, both at home and away from home. This should be emphasized during orientations and training for patients, as well as in public policies on accessibility. During home visits for IC training, health professionals should be attentive to bathroom appropriateness.

Despite the difficulties reported about bathroom inadequacy outside the home environment, the majority of participants in the study perform IC away from home, with the Germans (94%) doing so more often than the Brazilians (81%). The evaluation of the performance of IC away from home is relevant because it is an indicator of social participation, both for leisure and for integration into work and school. Previous studies show the comments of mothers who report difficulties with social life and leisure related to the use of IC (Borzyskowski et al. 2004).

Emotional difficulties related to IC were reported by 43 participants (21.5%), with the majority being Brazilian (72%). The primary feelings cited were: fear, shame/embarrassment, insecurity, distress, strangeness, worry, self-pity, demotivation, nonconformity in having to do the procedure. Fear was the predominant feeling in the Brazilian sample, while in the German sample, the predominant feeling was shame/embarrassment.

Even though there are few studies about the feelings of the person responsible for IC which complicate the performance of the procedure, some emotional difficulties reported by participants of the study can be observed in earlier studies (Sawin et al. 2007; Furlan 2003; Furlan et al. 2003). Costa (2004) also observed that patients reported fear of feeling pain during the insertion of the catheter, and shame when school colleagues find out about their using IC; different from the fear of hurting the child as reported by those responsible for assisted IC. However, these feelings did not hinder the use of the technique (Costa & Carvalho 2006).

Some researchers emphasize that emotional difficulties such as fear, insecurity, distress, strangeness, worry and self-pity can be reduced over time, primarily when IC is introduced early in the life of the individual, making it a natural part of daily life (Newman & Willson 2011; Pannek et al. 2006; Lindehall et al. 2004; Araujo 2000a). The observation of these researchers concurs with the mean age of 8 years for patients who reported fear, providing evidence that this feeling afflicts children more, as it was not observed in the adolescent or adult patients. Yet, the mean age of patients who reported shame or embarrassment related to IC was 20 years, which shows that this

feeling afflicts adolescents and young adults, and can be associated with sexuality, the work environment and social life.

With regard to the acquisition of material required to perform IC, as was stated previously, there is a difference between the two countries. In Germany, patients receive IC material through their health plan, despite some (13%) reporting problems in receiving their reimbursement. In Brazil, 42% reported not having financial difficulty in acquiring material, 27% reported receiving IC material through the government and 27% stated having financial limitations to acquire the material. These completely different scenarios show the discrepancy between the two countries with respect to receiving the resources required to perform IC. Costa (2006) and Araújo (2000a), who studied the interfering factors for using IC from the perspective of Brazilian caregivers and children with MMC, identified that financial support and IC material received from the government were factors that facilitated the use of the procedure (Costa & Carvalho 2006; Araújo 2000a). It should be noted that the economic situation of families with members who require special care often times is aggravated when the family caregiver leaves remunerated work to care for their relative (Furlan 2003). Therefore, financial aid to purchase IC materials is essential for many low-income families, particularly in Brazil.

When interviewed about the discontinuation of IC, the majority of patients (80%) reported never having temporarily discontinued the use of the procedure. However, 20% stated having discontinued IC at least once. There was no difference in the distribution of discontinuation or no discontinuation of IC in relation to nationality; however, as was discussed previously, it was observed that a higher level of understanding IC reduced the likelihood of discontinuation of the procedure.

The motives that caused patients (20%) to discontinue IC included: incontinence despite using IC, difficulty organizing daily routine to perform the procedure, existence of UTI, lack of motivation, experience of pain/sensitivity during the procedure, resistant behavior of the child to IC, hematuria, continence without IC, problems related to the mother, financial difficulty and technical difficulty. A significant number of the

motives related to discontinuation of the procedure also appeared in the answers of the German participants to the open-ended question about difficulties in the IC context, for example, difficulty with the regularity and time spent with IC reported by German participants (9%). Problems such as incontinence after IC, resulting in permanent use of diapers, difficulty in organizing time and daily routine, occurrence and fear of UTI, pain associated with urethral sensitivity, and lack of motivation were also cited by other researchers who have studied IC in individuals with SB (Costa & Carvalho 2006; Borzyskowski et al. 2004; Edwards et al. 2004; Furlan 2003).

Variables exclusive to the German sample

In the German survey, there were more questions than in the Brazilian questionnaire, in order to adapt the instrument to the German reality and also to further clarify the context of the study.

The current occupation of the German participants was studied. The majority (49.5%) were high school students, with the remainder being babies or in pre-school (19%), employed (24%), university students (8%), or unemployed/retired (12%). It was noted that the majority of the participants were currently engaged in some kind of year-round activity. The rate of unemployment of the German sample (10%) was higher than the general economically-active population in Germany which is 6.6%, but similar to the population of East Germany which is 10.4% (Federal Employment Agency, September 2011). This unemployment rate found contrasts former studies that reveal higher unemployment rates among individuals with SB (Cox et al. 2011). It is important to note, however, that the participants' type of employment was not specified, if they work in public spaces or in more protected environments.

Studies reveal that, among the factors associated with unemployment for people with SB include a lower coefficient of intelligence (IQ), dependence on another to get to work, HC, level of education, immobility, independence in self-care, and gender (women are more prone to being employed) (Van Mechelen et al. 2008; Magill-Evans et al. 2008). A Dutch study of 179 individuals between 16 and 25 years of age with SB

showed that only 16% were living independently, more than one third of the participants attended a special high school, 53% of those who finished high school did not have regular employment and 71% did not have a partner (Barf et al. 2009). A British study states that, in addition to the factors already described, there was a statistically greater frequency of incontinence in the group of unemployed patients with SB than in the group of employed patients (Tew et al. 1990). In the German sample, out of the 10 participants who reported being unemployed or not having an occupation, 6 were women and 4 were men. The 2 individuals who reported being retired were women. Unfortunately, the occupations of the patients in the Brazilian sample were not collected in order to make a comparison by nationality.

The majority of the Germans (83.1%) was very or mostly satisfied with IC, with the remainder (12.4%) being moderately satisfied and only a small portion (4.5%) being somewhat dissatisfied or not satisfied. Lindehall (2004) states that participants in his study exhibited a great emotion upon mastering the technique, principally self-catheterization (Lindehall et al. 2004). Despite not finding studies about the satisfaction of patients with SB in relation to IC, it does not seem to be a determining factor of life satisfaction. According to a Dutch study of youth with SB about the level of life satisfaction, the majority were satisfied with life and only 24% were not satisfied, in comparison with 28% in the general population. The higher percentages of insatisfaction were related to financial situation (44%), partner relationships (49%) and sex life (55%), and not to bladder catheterization (Barf et al. 2007).

Among the responses obtained from the German participants when questioned about conflicts and difficulties related to IC, the most common were the difficulty with regularity and time spent with IC, difficulty finding bathrooms away from home with an infrastructure suitable for performing IC, and difficulty with the restless behavior of children during the procedure. The difficulty of restlessness in children during the procedure was also cited by some Brazilian participants in answering the question about technical difficulties. The difficulty finding adequate bathrooms, restlessness in children, difficulty finding time for IC frequency and family conflicts related to IC were also cited by Furlan when studying the IC experience of Brazilian children and

adolescents with a neurogenic bladder. However, the researcher also found difficulties with finances, leisure and overburdened mothers providing care (Furlan 2003).

With respect to intestinal emptying, the most common practices in Germany have been intestinal irrigation (29.5%) and digital rectal stimulation (27.3%), in addition to toilet training and use of laxatives and suppositories (12.5%). Only 5 patients reported using intestinal/colonic massage anad close to 22.7% reported not using any method for emptying. In Brazil, the most commonly recommended method for emptying is intestinal massage, combined with toilet training with the Valsalva maneuver and digital rectal stimulation. Intestinal irrigation is not an observed practice in these patients.

Use of IC

When the data was collected, the majority of patients (94%) were using IC. After analyzing the variables that could justify the use of IC or not, it became clear that the variables related to the difficulties faced by patients and their family members were able to better explain the non-use of IC than the biological or demographic variables. There was no relationship between non-use of IC and the following demographic and biological variables: gender, nationality, current age, and age at the time of beginning IC, UTI episodes before and after IC, and hydrocephalus.

The temporary non-discontinuation of IC increased the likelihood that the participants would use IC by up to 9 times, since the individual who is always suspending the procedure for some period of time, even if for only a few hours or days, has a greater tendency to give up on using IC. Not having technical difficulties also positively affects the use of the technique, increasing the likelihood of using IC up to 5.4 times. The frequency of IC also appeared relevant as people who perform IC very few times in the day have greater chances of not using the procedure. Low IC frequency can therefore be a sign that the procedure is not going well and is about to be discontinued. Another factor that appeared to be important for the use of IC was the lack of emotional difficulties.

During training and monitoring of patients who use IC, activities that seek to reduce any motives to suspend the procedure and later discontinue it, should be prioritized. In this study, the primary motives that led to suspension of IC were incontinence despite IC, difficulty organizing time/daily routine around the regular times of IC, UTI, lack of motivation, pain and resistant behavior of children. The principal technical difficulties reported were restlessness of the child during the procedure, positioning difficulties and torso control, sphincter resistance, difficulty visualizing urethral meatus, and urethral pain/sensitivity.

It was noted that restless behavior of the child during the procedure and pain associated with urethral sensitivity were factors that were reported by study participants both as motives for IC discontinuation and as technical difficulties. Other studies about factors that lead to success with IC or to not using IC also cite these motives for discontinuation of the procedure and the technical difficulties reported by the participants of this study (Federal Employment Agency 2011; Clayton et al. 2010; Costa & Carvalho 2006; Borzyskowski et al. 2004; Furlan 2003; Oakeshott & Hunt 1992).

Self-catheterization

Out of the participants who used IC, 92 used self-catheterization and 96 used assisted catheterization. The method of catheterization that was used more at the time when the German participants were interviewed was self-catheterization (53%), while the majority of Brazilian participants used assisted catheterization (63%). After analyzing the mean ages of the patients who use self-catheterization and assisted catheterization, it was also noted that the patients who use self-catheterization are older (25 years in the German sample and 16 years in the Brazilian sample), independent of nationality, which shows that self-catheterization is affected by the maturity of the individual (Association for Continence Advice 2003).

With the intention of understanding the key predictive factors for self-catheterization, an analysis using logistical regression verified that the following variables influence the method of catheterization:

- Education level: it was observed that the greater the education level of the participant, the greater the chances of doing self-catheterization, demonstrating the importance of the individual's cognitive capacity in self-catheterization.
- Hydrocephalus: the participants who did not have HC had up to 9.5 times greater likelihood of using self-catheterization than those who had HC. Thus, not having HC was a predictive factor for self-catheterization. HC is also recognized as a predictive factor of cognitive difficulty in patients with SB (Verhoef et al. 2006; Hetherington et al. 2006; Amoedo 2005).
- Level of SB: the participants who had the lowest lesion level, sacral and lumbar levels, had close to 5.5 times greater likelihood of using self-catheterization than those who had lesions at the highest levels, such as thoracic and cervical levels.
- Nationality: in addition to being older and having higher education than the Brazilians, the Germans used self-catheterization more. The fact of being German can increase up to 2.7 times the likelihood of an individual with SB using self-catheterization.

The patients who used self-catheterization were older than those who used assisted catheterization. Age had a statistically significant influence over the variable *method of catheterization.*

It was noted that the biosocial variables explain better the use of self-catheterization than the variables related to difficulties with IC. Some factors did not affect the method of catheterization, such as gender, being female or male does not increase the chances of using self-catheterization. The variables related to difficulties involving IC also were not significant with respect to the method of IC, and use of a wheelchair on a full-time basis also was not a determining factor of self-catheterization. This concurs with the findings of Oakeshott (1992) who pointed out that serious physical disability is not a contraindication or insurmountable obstacle for using IC, since many people who are wheelchair dependent are able to master the technique of self-catheterization (Oakeshott & Hunt 1992).

In addition to being relevant to the health of the people with SB, as previously mentioned, self-catheterization contributes to the process of the individual becoming independent, helping him/her, not only physically but also psychologically, to gain control over his/her body, privacy, freedom and increased self-esteem (Edwards et al. 2004). The child with a learning disability is able to learn self-catheterization through repetition. Studies show that a life-long commitment to intermittent catheterization is higher for individuals who use self-catheterization than for those who use bladder catheterization assisted by a third party (Hunt et al. 1984). With respect to commitment to IC, it can be noted that the majority of participants (66.7%) who were not currently using IC had previously used assisted catheterization, while the remaining participants (33%) had used self-catheterization.

Urinary tract infections and IC

Before discussing the data related to UTI, it should be noted that the data were collected based on the answers of participants regarding the number of symptomatic UTI episodes in the last year, before and after vesical catheterization. In addition, laboratory exams and UTI longitudinal control were not done for the research participants.

The mean UTI before IC, which was about 3 episodes per year, became 1 episode per year after IC. Considering the number of UTIs in the last year before and after using IC, it can be said that the actual rate of catheterization was 72.4%, that is, these participants had lower UTI rates after IC. Only 14.6% showed an increase in the number of UTIs after catheterization, and 13% maintained the same UTI frequency. As with many other studies, this study concludes that the number of UTIs before IC is higher than after IC, confirming that IC works to reduce the episodes of UTI in individuals with a neurogenic bladder as a result of SB (Kari et al. 2009; Katrancha 2008; Jong et al. 2008; Oakeshott & Hunt 1992; van Gool et al. 1991; Lapides et al. 1972).

Among the factors that influenced the occurrence of UTI in the sample were: nationality (the Brazilians had lower rates of UTI than the Germans), gender (the women had

higher UTI rates than the men), and method (assisted catheterization was associated with lower rates of UTI than self-catheterization; however, self-catheterization had a greater reduction in the number of UTIs after IC in comparison with assisted catheterization).

Contrary to literature, this study found lower rates of UTI in participants who use assisted catheterization. However, those who practiced self-catheterization had a greater reduction in the initial number of UTIs compared with those who used assisted catheterization. It should be noted that these rates were affected by nationality, since the Brazilians use assisted catheterization more and have lower UTI rates, thus contributing to the lower UTI means found in assisted IC. A Canadian study with an extensive sample of 912 participants with traumatic and non-traumatic medullary lesions reports that bladder self-catheterization is a protective factor for UTI, while that catheterization performed by third parties (assisted catheterization) is a predictive factor for UTI. This same study also reported a higher UTI rate for women than for men, which was also observed in this current study (Woodbury et al. 2008). In the general population, as it is already known that women have a higher incidence of UTI than men, studies point out that 50 to 80% of women will have a UTI episode in their lifetime. The shorter urethra and the proximity of the urethral meatus to the perianal region are among the factors that lead to UTI in the female gender (Schmiemann et al. 2010).

With respect to substances used to clean the genitalia before probing, an analysis was conducted using only the German sample. The study did not require this data from the Brazilian sample since all of the participants came from the same institution and are all oriented to use water with soap, preferably pH-balanced. During this analysis, a statistically significant similarity was observed in the distribution of the number of UTIs between participants who use disinfection (with antiseptic substances), washing (with sanitizing substances), both at the same time, or no cleaning at all. Again, despite the fact that there are not enough studies to establish which is the ideal substance to clean the genitalia during IC, current studies do not note a difference in UTI rates and bacteriuria between disinfection with antiseptics and cleaning with other substances like water (sterile or potable) (Hooton et al. 2010; Al-Farsi et al. 2009; Willson et al. 2009;

Cheung et al. 2008; Webster et al. 2001). Thus, these findings contrasted the recommendation of the German Association of Urology (AEU) which indicates the use of antiseptic substances for the disinfection of the genitalia during IC with the aseptic technique.

It is worth noting that, during the study, some German nurses with experience in IC training, reported not trusting the effectiveness of antiseptic substances for the disinfection of genitalia in the prevention of UTI. Another fact that corroborates the findings of the German nurses and questions the effective use of anti-septic substances in IC as a preventive measure for UTI was the higher number of post-IC UTI episodes experienced by the study's German participants in comparison with the Brazilian participants, who do not use anti-septic substances.

Some data obtained in the German sample indicate a higher preoccupation with UTI by the German participants, for example, 74% have as an objective for IC the prevention of UTI, 20% use prophylactic antibiotics for UTI, 34% consider UTI as an indication for IC. These percentages were all higher than those from the Brazilian sample.

One piece of data that stood out in the analysis of UTI before and after IC was the higher rate of UTIs per year found in the German sample. Since nationality in the occurrence of UTIs did not have an impact in earlier studies, this information was discussed with some German and Brazilian IC specialists and some hypotheses were formulated to try to explain this difference:

1) Diagnosis of UTI: It is believed that the German participants are able to obtain UTI diagnosis more easily since they have better access to urine tests, which can be easily purchased in pharmacies. They also have better access to health services since everyone has national health care, as well as information about SB and UTI because the German participants participate in associations and virtual forums where they can obtain advice quickly about UTI. Furthermore, the Brazilian participants, unlike those from Germany, received the support of health professionals in completing questionnaires in order to clarify the

definition of symptomatic UTI. On the other hand, the Germans answered an online questionnaire where there was a description of symptomatic UTI.

2) Bacterial resistance: Professionals believe that the German sample may have a higher bacterial resistance, due to greater access and use of antibiotic therapy (a fact which was proven in the study, where 20% of the Germans stated using antibiotic prophylaxia while only 3% of the Brazilians), and also due to the constant use of antiseptic substances for cleaning the urethral meatus before introducing the catheter. Today, there is discussion about the existence of a possible link between the use of cationic biocides, such as the antiseptics also used for disinfecting the genitalia during IC, and the selection of resistant bacteria to antimicrobials. Therefore, it is recommended that antiseptics be used carefully, including the use of antibiotics (Weber & Rutala 2006; Tavares 2000; Russell et al. 1998).

Former investigations confirm that asymptomatic bacteriuria is present in about 70 to 81% of individuals with SB (Lindehall et al. 2004; Szucs et al. 2001; Schlager et al. 1995). After researching asymptomatic bacteriuria in participants with SB who used IC, Schlager suggested that patients who used IC frequently exhibited asymptomatic bacteriuria, but that this fact did not lead to renal deterioration and the participants remained clinically well. In line with international urological policies, she advised that the treatment of bacteriuria should only happen in cases where it offers real benefit to patients (AWMF 2009; European Association of Urology 2006; Brazilian Society of Urology 2006; Schlager et al. 1995).

Some means can aid the prophylaxia of UTI, such as the use of urinary acidifiers (L-methionine, cranberry, juices rich in vitamin C), adequate fluid consumption, increase in the dose of anticholinergics, review of the technique of catheterization (including cleaning the catheter when being re-used), increase in the frequency of catheterization (avoiding withdrawal of excessive residual volumes), use of disposable catheters and regularity of intestinal function (Newman & Willson 2011; Stein et al. 2007).

UTI in patients with EB remains a complication that is not completely understood. This fact takes us back to the ideas of Lapides (1972) about the probable causes of the reduction of UTI in people with a neurogenic bladder, which still apply today. The factor that contributes most to the reduction of symptomatic UTI in individuals who do IC is the daily frequency with which the procedure is done. This frequency is even more important than the sterilization of the materials used in the technique. This is due to the improved blood flow in the detrusor muscles, resulting from the complete emptying (of the bladder) and the reduction of intravesical pressure, making the bladder mucous membrane more resistant to infectious bactéria (Lapides 1972).

Acquisition of urinary continence after IC

Complete or partial continence achieved after IC was similar in the two nationalities, and 61.5% of the study participants achieved complete or partial continence. This percentage was similar to the percentage (62%) found by Jørgensen of Denmark in a study of 60 participants with spinal dysraphism (Jørgensen et al. 2010). Another study of Denmarkian patients with MMC found a rate of 48% achieving continence after IC (Magill-Evans et al. 2008). In this study, it is important to highlight that complete continence (without the necessity to use small disposable sanitary napkins) was achieved by only 20% and partial continence (small sporadic urine leakages and use of small disposable sanitary napkins) by 41.5% of participants. Those who were not able to achieve continence after IC, 38.5%. must also be considered, particularly at the time of IC orientation, with the objective of making families and patients aware of the expectation of urinary continence created by the procedure. It is important to have a positive attitude about the benefits of IC, but also realistic so that incontinence with IC does not lead to loss of motivation and abandonment of the procedure, as reported by 22.5% of the study participants who claimed this as one of the motives for discontinuing the technique. It is worth remembering that, among the criteria for successful IC in the acquisition of bladder continence, and already recognized in literature, are physiological factors, such as bladder capacity and bladder type, which were not investigated in this study.

According to the logistical regression applied, among the factors that influenced the acquisition of urinary continence in the studied sample were the method of catheterization and the frequency of IC. Using bladder self-catheterization increased up to 3 times the chances of achieving continence after IC. Increasing the number of times that IC was done per day (daily IC frequency) also appeared to contribute, up to 1.7 times per procedure performed, to the achievement of urinary continence. Considering the entire sample, the achievement of urinary continence after IC was not affected by gender, nationality, having HC or by the use of a VP shunt. Also, influence by the use of medications was not observed.

Self-catheterization provides the opportunity for the individual to understand more about his/her body and to control it better. It was noted in the nursing clinical practice that, when the patient uses self-catheterization, he tends to regulate the times and frequency of the procedure according to his routine. For example, when he goes to a party and consumes more liquids, he increases and adapts the times of IC so as not to experience urine leakages in a social environment. This finding of the study confirmed that self-catheterization contributes to achieving urinary continence and also to the social integration of the individual, since incontinence is a factor of significant stress and reduced integration and participation (Edwards et al. 2004).

Urinary continence is a practically unanimous goal for patients and family members, and for this reason it has been a subject of interest of various studies that are not only related to IC, such as in the areas of urological surgery and pharmacotherapy (Edwards et al. 2004). It is known that social continence in the individual with SB is not limited only to the bladder and urinary control, but also includes intestinal continence, both of which have a significant effect on patients' self-esteem, independence and social participation (Clayton et al. 2010). Continence is also associated to higher self-esteem in boys and girls with SB, thus efforts to promote continence can have a positive effect on a child's self-image (Moore et al. 2004). For younger patients, incontinence is a challenge primarily in the school environment, while for older patients, it represents fear of intimacy with a partner and of sexuality.

In summary, the limitations of the study include: tests for the evaluation of the cognitive capacity of the patients were not conducted, since the cognitive difficulties of patients with SB can interfere with learning the IC technique; the different method of completing the questionnaire in the two countries; the presence of variables in the German sample that were not collected in the Brazilian sample and therefore were not subject to comparison; the classification of different ambulation in the two countries, since in Brazil the evaluation of gait was conducted by professionals but in Germany this evaluation was not possible. The same occurred with the variable understanding of IC.

Limitations and positive aspects of the study

In summary, among the limitations of this study are:

- not conducting tests to evaluate the cognitive capacity of the patients, since the cognitive difficulties of patients with SB can interfere in the learning of the IC technique;
- the different method of completing the questionnaire in the two countries;
- the presence of variables in the German sample that were not collected in the Brazilian sample and for this reason could not be compared;
- the different classification of ambulation in both countries, since in Brazil the gait assessment was conducted by professionals and in Germany this assessment was not feasible, which also happened with the variable understanding about IC.
- not doing exams, such as the urodynamic study of the bladder to correlate the type of bladder with the acquisition of urinary continence after IC;
- determining the number of UTI episodes based on the reporting of study participants rather than a longitudinal monitoring.

Finally, it should be noted that one of the relevant aspects of the study was the large sample, comprised of individuals who live in two countries that are different in terms of socioeconomic and cultural aspects. Furthermore, the study sought to identify the possible factors involved in the use or non-use of IC and the use of self-catheterization

versus assisted catheterization, through the use of multivariate models, bilateral statistical tests and likelihood ratio tests.

The means of communication that was most effective in finding participants for the study in Germany was an online forum, which represented close to 50% of the visitors to the virtual questionnaire; the others participated through similar means. The utilization rate of the answers from the virtual questionnaire was 66% (100/151). Thus, we suggest that this new means of capturing data be used in future studies, primarily when involving different countries since it is a fast, inexpensive method with a good rate of answer utilization. The only disadvantage is that this method is more effective in developed countries since in underdeveloped or developing countries, like Brazil, the internet is not yet accessible by the entire population.

7. CONCLUSIONS

The identification and comprehension of technical and bio-psychosocial factors involved in intermittent bladder catheterization is fundamental for the preparation of more effective training strategies, as well as for the development of public policies that match the reality of patients with SB. Cooperative studies between different countries and cultures contribute to the understanding of the development and rehabilitation of people with SB. This facilitates information sharing and exchange of experiences, which can be applied in a practical way to the daily lives of individuals with SB and their families, in addition to supporting the work of IC training of health professionals, particularly nurses.

This study was able to achieve the objectives initially proposed for this specific sample through the use of statistically significant logistical regression models. However, it must be understood that, in order to understand IC in SB with the wide range of factors involved, more studies are needed to corroborate the findings outlined in this investigation.

In the literary review, there was no similar study found about the factors involved in the use of IC by patients with SB, across two countries on different continents. Until today, the studies have not yet clarified all of the questions about IC, primarily in relation to the type of catheter, the most appropriate substance for cleaning the genitalia, type of technique, among others. This can be partly attributed to the few studies in this area, particularly controlled, random studies.

This study identified factors that can help with the understanding of the different realities in Brazil and Germany in the context of IC. After studying and characterizing the bio-psychosocial aspects of the Brazilian and German participants of the study, it was noted that the majority of similarities were among the biological factors, while the differences appeared more often among social factors.

In summary, the similarities found in the distribution of the Brazilian and German samples were:

- level of spina bifida,
- presence of hydrocephalus,
- use of ventriculoperitoneal shunt,
- wheelchair dependency,
- initial method of catheterization (assisted catheterization was predominant as the initial method in both samples),
- mean age when beginning IC (6 years) and self-catheterization (11 years),
- minimum daily frequency of IC (between 4 and 5 times per day),
- acquisition of bladder continence after IC,
- existence of a second person who can perform IC if necessary,
- mean UTI before IC,
- temporary discontinuation of IC,
- technical difficulties.

On the other hand, the differences observed in the distribution of the Brazilian and German samples were:

- age (the Brazilian sample was younger than the German),
- gender (the German sample was predominantly female and the Brazilian predominantly male),
- education level (level of schooling was higher in both the German patients and key persons responsible for IC),
- current method of catheterization (in the German sample, self-catheterization was predominant; in the Brazilian sample, assisted catheterization),
- key person responsible for IC (in the German sample, the patient was predominant; in the Brazilian sample, the mother)
- type of catheter (the PVC catheter was preferred in Brazil; in Germany, the hydrophilic catheter)

- form of disposal of the catheter (in Germany, 100% of the patients used a disposable catheter),
- medication (Brazilians used medications more often; however, the Germans used prophylactic antibiotics more),
- mean UTI after IC (the Brazilians had a lower mean than the Germans),
- performance of IC away from home (the Germans performed IC more frequently away from home than the Brazilians),
- acquisition of material for IC (the Germans receive more financial support to acquire material than the Brazilians),
- home-related difficulties (the Brazilians reported more home-related barriers than the Germans),
- emotional difficulties (the Germans reported fewer emotional barriers than the Brazilians).

With respect to using or not using IC, the analysis indicated that the variables related to difficulties experienced by the patients and their family members were able to better explain the non-use of IC than the biological and demographic variables. Among the factors that had statistical significance, contributing to the non-use of IC by the participants, were: temporary discontinuation of the procedure, daily frequency of IC and technical difficulties, as well as emotional difficulties. It was also verified that a good or excellent understanding of the individual about the procedure contributed to lower rates of IC discontinuation throughout the patient's life.

The predictive factors for self-catheterization that were identified in the sample were: education level (6 years or more), absence of hydrocephalus, level of spina bifida (sacral or lumbar) and nationality (German). Age also affected the method of catheterization. In contrast to the results of the analysis of the use of IC, the variables that had the greatest influence on the use of self-catheterization were those related to biological and demographic factors.

The identification and comprehension of predictive factors for self-catheterization is essential for the development of more effective training strategies. Based on the

predictive factors observed in this study, it is recommended that training for self-catheterization consider the following: age of the individual, since maturity will influence the use of self-catheterization; education level, including cognitive difficulties associated with SB which are known as attention, memory, visuoconstructive and visuoperceptive deficits; demographic and cultural aspects, such as nationality, exemplified in this study through the more autonomous characteristic of the German participants; presence of HC, which is also a proven predictor of cognitive difficulties; and lesion level, for example since during patient training it can be observed that difficulty in controlling the torso exhibited by patients with a thoracic level lesion often complicates positioning and hand movement for the performance of self-catheterization.

This study corroborated previous studies by showing a higher number of UTIs before IC than after IC, thus concluding that IC can reduce the episodes of UTI in patients with a neurogenic bladder caused by SB. The factors that influenced the mean UTI before and after IC were: nationality (the Brazilians exhibited lower UTI rates than the Germans), gender (the women exhibited higher UTI rates than the men), and method of catheterization. Assisted catheterization was associated with lower UTI rates than self-catheterization; however, the patients who used self-catheterization had a reduction in the number of UTIs after IC in relation to those who used assisted catheterization.

The acquisition of urinary continence, according to this study, was influenced by the method of catheterization and by the daily frequency of IC. Self-catheterization increased the likelihood of acquiring urinary continence by three times. Self-catheterization allows the individual him/herself to understand and have greater control over his/her body, facilitating completion of the schedule and frequency of the procedure according to the personal daily routine. This finding of the study confirmed the contribution of self-catheterization to the acquisition of urinary continence and the resulting integration of the individual with SB, since incontinence is a factor of significant stress and restricted social participation. Other factors that should also be taken into consideration in the acquisition of continence, but were not investigated in this study, are bladder capacity and patient bladder type.

The preparation for transition to adult life for the person with SB begins in infancy. Thus, it is necessary to structure care from the beginning in order to initiate the development of the patient's autonomy, supported by the investment of the family, with the objective of maximizing opportunities for social participation. Self-catheterization plays a role in the context of autonomy in terms of self-care and participation. In addition to the health benefits, there are very relevant personal and social reasons for the individual with SB to do self-catheterization including: a) social integration, for example, at work and at school; b) preservation of intimacy, since only the individual touches his/her own genitalia; c) support of sexuality, allowing the person to do the procedure before and after sex, thus avoiding embarrassing situations with urine leakages; d) allowing the individual to control and be responsible for his/her own body helps the individual achieve independence; it is common to see a second person, usually the mother, responsible for a child's self-care activities, including IC. Furthermore, this study showed that controlling one's own body through self-catheterization increases the chances of vesical continence after IC.

In practice, professionals should look for orientations that contribute to the early participation of the child during IC training, such as using a semi-lying position during IC so that the child can see what is happening, resulting in a more active, participatory attitude. It has been observed very often that the child who remains lying down during the entire assisted IC procedure has a passive attitude about it. Then, when beginning training for self-catheterization, he/she does not know the steps of the technique due to having a passive position toward the procedure. The child should be stimulated to participate in catheterization in a progressive manner, according to his/her abilities, such as washing hands before the procedure, preparing necessary material, holding the materials (lubricant gel, urine collector) to assist the caregiver, later to hold the catheter after insertion, then remove the catheter, and so forth. It is important that the parents be oriented to encourage the child's participation in IC according to the phase of development of the child. During the performance of assisted IC, it is recommended that the caregiver explain what he/she is doing, interacting with the child through the actual care and training him/her step by step for future self-catheterization. It should be noted that, according to literature, even children with cognitive difficulties can learn

self-catheterization through repetition. Furthermore, patients and family members should be able to understand the diagnosis, test results, indication for IC, method of bladder catheterization, administration of medications, management of fluid consumption, symptoms and risks involved, including knowledge of asymptomatic bacteriuria, macroscopic urine assessment, as well as understanding the legislated social rights of each country.

Home visits for training of self-catheterization provide an excellent opportunity to get to know the reality of the patient, so that the nurse can offer individualized training according to the context in which the technique will be performed. Related to this is the possibility of forming groups that would consider not only IC training, but also self-care and daily life activities, encouraging patient autonomy and participation. Access to an interdisciplinary team for support during the step by step learning of IC is essential for training success. The work of the team, particularly the collaboration between the nurse and the psychologist, is very important, especially in the administration of tests to assess cognitive capacity, in the work for procedure acceptance and in the reduction of anxiety, as well as providing individualized, positive support.

In this way, children, adolescents and adults with SB and their families should be effectively supported to use IC, with the goal of overcoming difficulties related to the procedure as described in this study. This is key since these individuals require special care for their entire lives, primarily health-related, which imposes on them a different way of life than their same-age peers, often times complicating social participation.

In light of this, considering the journey that patients with SB follow to arrive at adult age, the goals for the future are essentially focussed on these individuals developing skills for autonomy and social participation. We recommend that more studies be conducted about the factors involved in IC for patients with SB, related to testing for cognitive assessment and new ways of improving training for self-catheterization, in addition to research that will improve the resources for acquisition of urinary continence, and about the effectiveness of substances used for cleaning the genitalia in the CI, preferably controlled, random studies.

7.1 Considerations and final suggestions

In line with some of the objectives of this study, in this final section, the author will make some suggestions and observations based on her study and experience in training patients with SB, particularly during the outline and development process of this study.

Considerations for Brazil

We recommend that, in Brazil, the clean intermittent catheterization technique with single-use catheter be used. This technique can be a mid-range option, between the sterile technique and the clean technique with reusable catheter. It is more viable from an economic perspective and more practical, comfortable and useful as a means of prophylaxis for complications associated with IC. The use of the disposable catheter has various advantages already outlined in this study. These include: the possibility of encouraging autonomy, which has immeasurable value for the individual with SB since it facilitates self-catheterization and commitment to the procedure; and because it eliminates steps of the technique such as cleaning, drying and storage of the catheter. Increasing life-long commitment to the procedure can avoid complications related to not using IC, such as hospital admission, urological surgeries and even hemodialysis, resulting in this being a more economical option over the long term. The majority of recent studies in developed countries have also advised against catheter re-use. For example, a recent, extensive Canadian study recommended technical policies for the use of IC, reporting that catheter re-use only be used in cases of extreme poverty, which is not the situation in Brazil. It should be noted that *a priori*, according to the instructions on packaging for probes supplied by manufacturers, all catheters are single-use and no manufacturer is responsible or has a standard protocol for catheter re-use.

We suggest that, when a catheter must be re-used, procedures should be studied, standardized and validated to show the steps for re-use, from cleaning to storage.

We recommend that Brazilian professionals involved in the rehabilitation of individuals with SB be attentive to the orientation of practices that will encourage patient

autonomy. They should also train parents to motivate their children in their search for social participation, beginning in the early years of rehabilitation and not waiting until the individual reaches adolescence. It should be emphasized that training for self-catheterization plays a key role in this objective of autonomy in self-care.

We suggest that associations of patients with SB and HC and their families be formed, following the example of the associations in Germany, and since there already exists a willingness for these countries to collaborate. These communities of mutual support have proven to be an opportunity for children, adolescents and families to get to know other people who are also having

We recommend the development of new products, in particular catheters, that facilitate the use of IC, in particular self-catheterization, but that are financially compatible with the economic reality in Brazil.

Considerations for Germany

During the bibliographical review, there was no German scientific study found about IC developed by the nursing field in that country. However, these are the primary professionals who are training patients for IC. The majority of studies conducted by nurses come from the United States, England and Canada. Thus, we suggest that the field of nursing in Germany be inserted into the academic environment of German universities in order to initiate and collaborate on the building of the science of nursing.

We recommend that controlled, random studies be conducted about the effectiveness and necessity of using antiseptic substances for the disinfection of genitalia before probing. In addition, there should be greater focus on the criteria for the use of prophylactic antibiotics, according to the policies already outlined from the German Association of Urology. Since the possibility of bacterial resistance was identified in the analysis phase of the study, where there was a higher number of UTI episodes after IC in the German participants, in addition to the German nurses noting a lack of effectiveness with anti-septic substances.

We recommend that attention be paid to the steps of the technique, particularly the washing of hands before and after the procedure, a step that can often be forgotten or neglected due to the availability of disposable catheters and with the protective message “do not touch”, where the patient does not need to touch the probe.

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APPENDIX 1 – Consent form for participation in scientific research (Brazil)

CONSENTIMENTO LIVRE E ESCLARECIDO PARA A PARTICIPAÇÃO EM PESQUISA CIENTÍFICA.

O presente projeto de pesquisa tem por objetivo traçar o perfil dos pacientes com diagnóstico de mielomeningocele que receberam indicação de realizar o cateterismo vesical intermitente limpo, visando orientar a equipe e qualificar as orientações prestadas às famílias e pacientes.

Os questionários aplicados serão registrados e posteriormente analisados pela equipe da reabilitação infantil do Hospital Sarah de Belo Horizonte composta por dois médicos, duas enfermeiras e uma psicóloga; orientados pela Dra Olímpia Leal de Oliveira.

Estou satisfatoriamente informado(a) e esclarecido(a) sobre o proposto estudo, sobre a forma de coleta de dados e objetivos, concordo com a participação de meu filho(a), ciente de que o mesmo terá o seu nome mantido em confidencialidade.

Estou ciente de que posso desistir de continuar participando do estudo, a qualquer momento, sem prejuízo no tratamento recebido por meu filho _____ _____ neste Hospital.

Belo Horizonte____ de _____ de 2008

_____

Assinatura do responsável

_____

Assinatura do pesquisador

APPENDIX 2 - Consent form for participation in scientific research (Germany – pilot phase)

technische universität
dortmund

fakultät
rehabilitationswissenschaften

Technische Universität Dortmund | D-44221 Dortmund

Soziale und emotionale Entwicklung
in Rehabilitation und Pädagogik

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Diktatzeichen	Aktenzeichen	Ort	Datum	Dienstgebäude/Raum
			04.05.2011	

Einverständniserklärung

Hiermit erkläre ich mich/wir uns damit einverstanden, dass sich mein/unser Kind _____ an der Studie „Deutsche und brasilianische Patienten mit der Diagnose Spina Bifida und ihre Familien - Vergleichsstudie zur Blasenkatheterisierung und psychosozialen Aspekten“ von Frau Fabiana Faleiros Santana Castro beteiligt.
In der Studie werden alle datenschutzrechtlichen Aspekte beachtet, d.h. die persönlichen Daten des Kindes werden vertraulich behandelt, anonym ausgewertet und nicht an Dritte weitergegeben.

_____
Ort, Datum

_____ _____
Name der Eltern Unterschrift der Eltern

Fabiana Faleiros Santana Castro _____
Name Wissenschaftliche Mitarbeiterin Unterschrift Wissenschaftliche Mitarbeiterin

Doktorandin bei Prof. Dr. Christoph De Oliveira Käppler an der Fakultät für Rehabilitationswissenschaften der Technischen Universität (TU) Dortmund
fabiana.faleiros@tu-dortmund.de, Handy: 0157 / 88626090.

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APPENDIX 3 – Online questionnarie and Consent form for participation in scientific research (Germany)

Fragebogen Spina Bifida - Deutschland/Brasilien

Die Fakultät für Rehabilitationswissenschaften der Technischen Universität (TU) Dortmund führt zur Zeit eine Studie zum Thema „Deutsche und brasilianische Patienten mit der Diagnose Spina Bifida und ihre Familien" durch.
Die erste Phase der Studie mit brasilianischen Patienten wurde bereits in Brasilien durchgeführt. Die nun geplante Fortsetzung des Projekts zum Vergleich mit der Situation in Deutschland wird es ermöglichen, den Blasenkatheterismus und die familiären Herausforderungen in beiden Ländern besser kennenzulernen, womit ein Austausch positiver Erfahrungen erreicht werden soll.
Mit Hilfe Ihrer Beteiligung könnten somit andere Patienten unterstützt werden, ihre Schwierigkeiten bei der Durchführung des intermittierenden Katheterismus zu überwinden und somit die Belastungen bei den Betroffenen und ihren Familien zu vermindern.
Wir würden uns daher sehr freuen, wenn Sie den Fragebogen zu Ihren Erfahrungen beantworten könnten.

Wir bedanken uns herzlich für Ihre Unterstützung!

Fabiana Faleiros Santana Castro
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Tel.: 0231 / 755-4578

***1. Geburtsdatum des Patienten:**

TT MM JJJJ
z.B: 18/08/1985 ☐ / ☐ / ☐

***2. Geschlecht des Patienten:**

◯ weiblich
◯ männlich

***3. Welcher Grad der Spina Bifida liegt vor?**

◯ Halswirbelsäule
◯ Brustwirbelsäule
◯ Lendenwirbelsäule
◯ Sakral

***4. Liegt Hydrocephalus vor?**

◯ Nein
◯ Ja

5. Hat der Hydrozephalus ein Shunt-Ventil?

◯ Nein
◯ Ja

Fragebogen Spina Bifida - Deutschland/Brasilien

***6. Welche Mobilitätshilfen werden benutzt (Mehrfachantworten möglich)?**

- ☐ Gehen ohne Hilfe
- ☐ Gehen mit Orthese
- ☐ Rollstuhl
- ☐ Krücken
- ☐ Rollator
- ☐ Sonstiges (bitte angeben)

***7. Was macht der Patient derzeit?**

- ◯ geht in Kindergarten
- ◯ geht zur Schule
- ◯ ist in einer Ausbildung
- ◯ ist berufstätig
- ◯ trifft nicht zu
- ◯ Sonstiges (bitte angeben)

***8. Welche Schule/Bildungseinrichtung wird vom Patient derzeit besucht?**

- ◯ Grundschule
- ◯ Hauptschule
- ◯ Realschule
- ◯ Gymnasium
- ◯ Sonder-/Förderschule
- ◯ Fachschule
- ◯ Berufsschule/Lehre
- ◯ Universität
- ◯ Sonstiges (bitte angeben)

9. Welche Ausbildung macht der Patient derzeit, bitte angeben:

10. Welcher beruflichen Tätigkeit geht der Patient derzeit nach, bitte angeben:

Page 2

Fragebogen Spina Bifida - Deutschland/Brasilien

11. Hat der Patient die Schule davor mit einem Abschluss verlassen?

- ◯ Nein
- ◯ Ja

12. Welchen Schul-/Bildungsabschluss hat der Patient, bitte angeben:

***13. Wird derzeit Katheterisierung durchgeführt?**

- ◯ Nein
- ◯ Ja

***14. Wurde Katheterismus schon einmal beim Patienten durchgeführt?**

- ◯ Ja
- ◯ Nein

15. Wie lange wurde der Katheterismus durchgeführt?

***16. Wer ist hauptverantwortlich für die Katheterisierung?**

- ◯ Patient
- ◯ Mutter
- ◯ Vater
- ◯ Geschwister
- ◯ Großeltern
- ◯ Onkel/Tante
- ◯ Gesundheits- oder Pflegepersonal
- ◯ Sonstige (bitte angeben)

Fragebogen Spina Bifida - Deutschland/Brasilien

***17. Was ist die höchste Schulbildung des Hauptverantwortlichen für die Katheterisierung:**

- ◯ Grundschule
- ◯ Hauptschule
- ◯ Realschule/Volksschule
- ◯ Gymnasium
- ◯ Sonder-/Förderschule
- ◯ Fachschule
- ◯ Berufsschule/Lehre
- ◯ Universität
- ◯ Sonstiges (bitte angeben)

***18. Gibt es andere (Ersatz-)Personen, welche die Katheterisierung im Bedarfsfall vornehmen können?**

- ☐ Nein
- ☐ Patient
- ☐ Mutter
- ☐ Vater
- ☐ Geschwister
- ☐ Großeltern
- ☐ Onkel/Tante
- ☐ Gesundheitsberufe oder Pflegepersonal
- ☐ Sonstige (bitte angeben)

***19. Hauptsächliche Indikationen zum Katheterismus (Mehrfachantworten möglich):**

- ☐ Rezidivierende Harnwegsinfekte
- ☐ Hydronephrose
- ☐ Inkontinenz
- ☐ Vesikoureteraler Reflux
- ☐ Hoher intravesikaler Druck
- ☐ Hohe Restharnmenge
- ☐ Unbekannt
- ☐ Sonstiges (bitte angeben)

Fragebogen Spina Bifida - Deutschland/Brasilien

***20. Harnwegsinfekte vor dem Katheterismus (Definition von Harnwegsinfektionen: Vorkommen von Bakteriurie (mehr als 100.000 KBE / ml) in Kombination mit einem oder mehreren der folgenden Symptomen: Fieber (höher oder gleich 38°C), Leukozytose, Flankenschmerzen oder suprapubischen Bereich, Veränderungen in der Gewohnheit der Blasenentleerung, Übelkeit, Erbrechen, Muskelkrämpfe, Auftreten oder Intensivierung der Dysreflexiesymptome und Ausschluss anderer Ursachen für diesen Befund).**

◯ unbekannt ◯ nicht einmal im Jahr ◯ einmal im Jahr ◯ zweimal im Jahr ◯ dreimal im Jahr ◯ viermal im Jahr ◯ fünfmal im Jahr

◯ (bitte angeben) mal im Jahr

***21. Alter (in Jahren) bei Beginn des Katheterismus:**

◯ unbekannt

◯ im ersten Lebensjahr

◯ im Alter von (bitte angeben) Jahren

***22. Erste Katheterisierungsmethode, mit der begonnen wurde:**

◯ Fremd-Katheterismus

◯ Selbstkatheterismus mit Aufsicht

◯ Selbstkatheterismus allein

***23. Kam es schon vor, dass die Katheterisierung schon für einige Tage oder länger unterbrochen wurde?**

◯ Nein

◯ Einmal

◯ Mehrmals

Fragebogen Spina Bifida - Deutschland/Brasilien

***24. Die wichtigsten Gründe für den Abbruch der Katheterisierung (bis zu 3, die aktuellsten):**

- ☐ Finanzielle Schwierigkeiten
- ☐ Schwierigkeiten mit der Technik des Katheterismus
- ☐ Schmerzen
- ☐ Blutungen während der Katheterismus
- ☐ Kontinenz ohne Katheterismus
- ☐ Inkontinenz trotz Katheterismus
- ☐ Schwierigkeiten in der Alltags-Organisation
- ☐ Oppositionelles Verhalten/Widerstand
- ☐ Harnwegsinfektion(en)
- ☐ Unterbrochene Medikation
- ☐ Fehlende Motivation
- ☐ Von einem Gesundheitsdienst zum Aufhören aufgefordert
- ☐ Sonstiges (bitte angeben)

***25. Derzeit findet beim Patienten statt:**

- ☐ Selbstkatheterismus
- ☐ Selbstkatheterismus mit Aufsicht
- ☐ Fremd-Katheterismus
- ☐ kein Katheterismus

***26. Wann begann der Selbstkatheterismus mit Aufsicht:**

Alter in Jahren

27. Welche Hilfsmittel werden für den Selbstkatheterismus mit Aufsicht gebraucht:

- ☐ Keine
- ☐ Spiegel
- ☐ Sonstiges (bitte angeben)

***28. Wann begann der Selbstkatheterismus:**

Alter in Jahren

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Fragebogen Spina Bifida - Deutschland/Brasilien

29. Welche Hilfsmittel werden für den Selbstkatheterismus gebraucht:

- ☐ Keine
- ☐ Spiegel
- ☐ Sonstiges (bitte angeben)

***30. Anzahl der Harnwegsinfektionen im letzten Jahr (2010/2011) während der Durchführung von Katheterismus:**

(Definition von Harnwegsinfektionen: Vorkommen von Bakteriurie (mehr als 100.000 KBE / ml) in Kombination mit einem oder mehreren der folgenden Symptomen: Fieber (höher oder gleich 38°C), Leukozytose, Flankenschmerzen oder suprapubischen Bereich, Veränderungen in der Gewohnheit der Blasenentleerung, Übelkeit, Erbrechen, Muskelkrämpfe, Auftreten oder Intensivierung der Dysreflexiesymptome und Ausschluss anderer Ursachen für diesen Befund).

◯ unbekannt ◯ nicht einmal ◯ einmal ◯ zweimal ◯ dreimal ◯ viermal ◯ fünfmal

◯ mal (bitte angeben)

***31. Materialien zur Desinfektion/Reinigung der Genitalien:**

- ☐ Octenisept
- ☐ Protosan
- ☐ Wasser
- ☐ Steriles Wasser (z.B. Ampuwa)
- ☐ Seife
- ☐ Sonstiges (bitte angeben)

***32. Welcher Art von Katheter wird benutzt?**

- ◯ Ausschließlich Einmal-/Wegwerfmaterial
- ◯ Sonstiges (bitte angeben)

***33. Benutzt den Katheter:**

- ☐ mit Gel
- ☐ mit Hydrophiler Beschichtung
- ☐ Unbeschichtet
- ☐ Sonstiges (bitte angeben)

Fragebogen Spina Bifida - Deutschland/Brasilien

34. Wo wird die Katheterisierung vorgenommen?

- ☐ Rollstuhl
- ☐ Toilette
- ☐ Bett
- ☐ Sonstiges (bitte angeben)

∗35. Wie oft wird die Katheterisierung pro Tag durchgeführt (minimal):

◯ unbekannt ◯ kein mal ◯ 1 mal ◯ 2 mal ◯ 3 mal ◯ 4 mal ◯ 5 mal ◯ 6 mal ◯ 7 mal

◯ mal (bitte angeben)

∗36. Medikamenteneinnahme:

◯ Nein
◯ Ja

37. Welche Medikamente werden vom Patienten eingenommen:

	regelmäßig	unregelmäßig
Oxybutunin	☐	☐
Propiverin	☐	☐
Trospiumchlorid	☐	☐
Doxazosin	☐	☐
Cranbery Produkte	☐	☐
Harnansäuerung (Methionin)	☐	☐
Medikament via Blaseninstillation	☐	☐

Andere Medikamente (bitte angeben)

38. Wenn die Medikamente unregelmäßig eingenommen werden, Gründe:

- ☐ Finanzielle Schwierigkeiten
- ☐ Nebenwirkungen
- ☐ Unkenntnis der Dosis und Einnahmeintervalle
- ☐ Sonstiges (bitte angeben)

Fragebogen Spina Bifida - Deutschland/Brasilien

***39. Ziele des Hauptverantwortlichen mit der Anwendung des Katheterismus:**

- ☐ Kontinenz
- ☐ Erhaltung der Nieren
- ☐ Verhinderung von Harnwegsinfektionen
- ☐ Unbekannt
- ☐ Sonstiges (bitte angeben)

***40. Verständnis des Hauptverantwortlichen hinsichtlich der Indikation zum Katheterismus:**

- ◯ Sehr gutes / gutes Verstehen (Wissen über die Untersuchungsergebnisse, Indikation zur Katheterisierung und Risiken)
- ◯ Angemessen (versteht die wichtigsten Untersuchungsverfahren und Risiken)
- ◯ Gering ausgeprägt (nur teilweise verstanden, verwirrende Ideen)
- ◯ Keine näheren Kenntnisse

***41. Haben Sie technische Schwierigkeiten bei der Katheterisierung?**

- ☐ Nein
- ☐ Sphinktermechanismus mit Widerstand
- ☐ Probleme mit der Positionierung
- ☐ Schwierige Visualisierung der Harnröhrenöffnung
- ☐ Schlechte Rumpfkontrolle
- ☐ Schmerz / Druckempfindlichkeit
- ☐ Sonstiges (bitte angeben)

***42. Gibt es Schwierigkeiten mit der Katheterisierung zuhause?**

- ☐ Nein
- ☐ zu wenig Intimsphäre
- ☐ Kleines Bad
- ☐ Sonstiges (bitte angeben)

***43. Wird der Katheterismus auch außer Haus vorgenommen?**

- ◯ Nein
- ◯ Ja

Fragebogen Spina Bifida - Deutschland/Brasilien

***44. Trat eine Harnkontinenz nach Beginn des Katheterismus auf?**

- ◯ Nein
- ◯ Teilweise
- ◯ Ja

***45. Bekommen Sie die Materialen ohne Probleme von der Krankenkasse bezahlt?**

- ◯ Nein
- ◯ Ja

***46. Gibt es emotionale Hindernisse, die Katheterisierung (für Eltern oder Patient) erschweren?**

- ☐ Nein
- ☐ Angst
- ☐ Scham
- ☐ Unsicherheit
- ☐ Beklemmung
- ☐ Mitleid
- ☐ Sonstiges (bitte angeben)

47. Wie zufrieden sind Sie mit dem Katheterismus?

◯ gar nicht zufrieden ◯ kaum zufrieden ◯ mittelmäßig zufrieden ◯ ziemlich zufrieden ◯ sehr zufrieden

48. Schwierigkeiten bei der Katheterisierung (für den Patienten):

49. Schwierigkeiten bei der Katheterisierung (für die Eltern):

50. Haben Sie vor dem Selbstkatheterismus ein Training/Anleitung bekommen?

- ◯ Nein
- ◯ Ja

51. Wenn Sie Selbstkatheterismus bisher nicht kennen, würden Sie diesen gerne tun/erlernen?

- ◯ Nein
- ◯ Ja
- ◯ Nicht zutreffend, der Patient macht Selbstkatheterismus

Fragebogen Spina Bifida - Deutschland/Brasilien

52. Nutzen Sie Maßnahmen hinsichtlich Darm-Funktion/Stuhl-Entleerung?

- ☐ Keine
- ☐ Toilettentraining
- ☐ Anale Irrigation
- ☐ Abführmittel (Medikamente)
- ☐ Colonmassage
- ☐ Mini-Einlauf / Zäpfchen
- ☐ Anale Stimulation mit Finger
- ☐ Sonstiges (bitte angeben)

***53. Wer hat diesen Fragebogen beantwortet?**

- ◯ Patient
- ◯ Mutter
- ◯ Vater
- ◯ Andere

54. Identifikation (diese Daten sind vertraulich, werden nicht veröffentlicht und vor den Auswertungen gelöscht)

Namen des Patienten (optional)

E-mail (optional)

***55. Hiermit erkläre ich mich damit einverstanden, dass ich mich an der Studie „Deutsche und brasilianische Patienten mit der Diagnose Spina Bifida und ihre Familien - Vergleichsstudie zur Blasenkatheterisierung und psychosozialen Aspekten“ von Frau Fabiana Faleiros Santana Castro beteilige.**
In der Studie werden alle datenschutzrechtlichen Aspekte beachtet, d.h. meine persönlichen Daten werden vertraulich behandelt, anonym ausgewertet und nicht an Dritte weiter gegeben.

- ◯ Ja, ich bin einverstanden
- ◯ Nein, ich bin nicht einverstanden

56. Identifikation (diese Daten sind vertraulich, werden nicht veröffentlicht und vor den Auswertungen gelöscht)

Namen des Patienten (optional)

Name der Mutter oder des Vaters (optional)

E-mail (optional)

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Fragebogen Spina Bifida - Deutschland/Brasilien

*** 57. Hiermit erkläre ich mich damit einverstanden, dass sich mein Kind an der Studie „Deutsche und brasilianische Patienten mit der Diagnose Spina Bifida und ihre Familien - Vergleichsstudie zur Blasenkatheterisierung und psychosozialen Aspekten“ von Frau Fabiana Faleiros Santana Castro beteiligt.**
In der Studie werden alle datenschutzrechtlichen Aspekte beachtet, d.h. die persönlichen Daten des Kindes werden vertraulich behandelt, anonym ausgewertet und nicht an Dritte weiter gegeben.

◯ Ja, ich bin einverstanden

◯ Nein, ich bin nicht einverstanden

Herzlichen Dank, dass Sie an der Umfrage teilgenommen haben!

Sobald die Ergebnisse dieser Studie vorliegen, werden sie in der Zeitschrift der ASBH (Arbeitsgemeinschaft Spina Bifida und Hydrocephalus) veröffentlicht, so dass Sie hierüber oder die betreffende Internet-Seite: www.asbh.de davon erfahren können.

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APPENDIX 4 – Brazilian Questionnaire

Etapa - Brasil

*** 1. Número do questionário**

Nº

*** 2. Data da entrevista**

DD MM AAAA

Data / /

*** 3. Prontuário**

*** 4. Data de nascimento**

DD MM AAAA

exemplo: 18/08/1985 / /

*** 5. Nível da Espinha Bífida:**

◯ Sacral ◯ Lombar ◯ Torácica ◯ Cervical

*** 6. Hidrocefalia:**

◯ Não ◯ Sim

*** 7. Possui Hidrocefalia:**

◯ Compensada com válvula ◯ Compensada sem válvula ◯ Não compensada

*** 8. Locomoção**

☐ Não deambulador ☐ Deambulador comunitário

☐ Deambulador domiciliar ☐ Deambulador não funcional

*** 9. Quem é o PRINCIPAL RESPONSÁVEL pelo cateterismo?**

◯ Paciente ◯ Mãe ◯ Pai ◯ Tia ◯ Tio ◯ Avó ◯ Avô ◯ Irmã ◯ Irmão

◯ Outros

Page 1

Etapa - Brasil

***10. Escolaridade do paciente (completa):**

- ◯ Fora da idade escolar
- ◯ Nunca freqüentou escola
- ◯ Escola especial
- ◯ Educação infantil
- ◯ Iª série
- ◯ 2ª série
- ◯ 3ª série
- ◯ 4ª série
- ◯ 5ª série
- ◯ 6ª série
- ◯ 7ª série
- ◯ 8ª série
- ◯ 1ºano do 2º grau
- ◯ 2º ano do 2º grau
- ◯ 3º ano do 2º grau
- ◯ técnico
- ◯ faculdade

***11. Escolaridade completa do principal responsável pelo cateterismo:**

- ◯ Fora da idade escolar
- ◯ Não se aplica, o paciente faz autocateterismo
- ◯ Iletrado
- ◯ Iª série
- ◯ 2ª série
- ◯ 3ª série
- ◯ 4ª série
- ◯ 5ª série
- ◯ 6ª série
- ◯ 7ª série
- ◯ 8ª série
- ◯ 1ºano do 2º grau
- ◯ 2º ano do 2º grau
- ◯ 3º ano do 2º grau
- ◯ técnico
- ◯ faculdade

***12. Principal indicação do cateterismo:**

- ☐ Não se aplica, recebeu indicação de outro serviço
- ☐ Continência
- ☐ Infecção urinária de repetição
- ☐ Hidronefrose
- ☐ refluxo vesicoureteral
- ☐ elevadas pressões intravesicais

***13. Infecção urinária de repetição antes do cateterismo**

Definição: ocorrência de bacteriúria (mais de 100.000 ufc/ml), em associação a um ou mais dos seguintes achados: febre (igual ou superior à 38ºC), leucocitose, dor no flanco ou região suprapúbica, alterações no hábito de esvaziamento vesical, náuseas, vômitos, aumento do espasmo muscular, aparecimento ou intensificação de sintomas de disreflexia e exclusão de outras causas para estes achados.

◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ou +/ano ◯ não se lembra

***14. Idade do início da técnica:**

◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 ◯ 11 ◯ 12 ◯ 13

anos

Page 2

Etapa - Brasil

***15. Método inicial:**

◯ Cateterismo assistido ◯ Autocateterismo ◯ Autocateterismo com auxílio

***16. Suspendeu o cateterismo(suspendeu não é interrompeu):**

◯ Nenhuma vez ◯ uma vez ◯ mais de uma vez

***17. Principais motivos de suspensão do cateterismo (no máximo 3, preferencialmente os mais recentes):**

☐ Dificuldade financeira
☐ Dificuldade técnica para realizar o procedimento
☐ Dor
☐ Sangramento
☐ Continência sem o cateterismo
☐ Incontinência mesmo com o cateterismo
☐ Dificuldade de organizar o cotidiano
☐ Comportamento opositor da criança
☐ Infecção urinária
☐ Interrupção da medicação
☐ Falta de motivação/Preguiça
☐ Indicação para parar em outro serviço de saúde
☐ Outros

***18. Atualmente o paciente realiza:**

☐ Autocateterismo
☐ Autocateterismo com auxílio
☐ Cateterismo assistido
☐ Não realiza o cateterismo

19. Quando iniciou o autocateterismo com auxílio:

idade em anos

20. Quando iniciou o autocateterismo:

idade em anos

Page 3

Etapa - Brasil

21. Não realiza o cateterismo. Quanto tempo permaneceu fazendo o cateterismo:

Tempo (em dias) que permaneceu fazendo o cateterismo:

***22. Número de infecção urinária no último ano de realização do cateterismo:**
Definição: ocorrência de bacteriúria (mais de 100.000 ufc/ml), em associação a um ou mais dos seguintes achados: febre (igual ou superior à 38ºC), leucocitose, dor no flanco ou região suprapúbica, alterações no hábito de esvaziamento vesical, náuseas, vômitos, aumento do espasmo muscular, aparecimento ou intensificação de sintomas de disreflexia e exclusão de outras causas para estes achados.

◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9/ano ◯ não se lembra

***23. Técnica: Qual cateter é utilizado?**

◯ utiliza os dois cateteres (metálico e plástico) ◯ Sonda/Cateter metálico ◯ Cateter plástico (sonda de nelaton)

***24. Frequência do cateterismo (considerar a menor frequência)**

◯ Nenhuma ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ +5/dia

◯ Outra

25. Medicação

	Uso regular	Uso irregular (intervalo e dose inadequada)
Anticolinérgica (oxibutinina, propantelina, tolterodina)	☐	☐
Alfa bloquedor (doxazosina)	☐	☐
Imipramina	☐	☐

Outro (especifique)

26. Se o uso da medicação é irregular, ocorre por:

☐ Dificuldade financeira ☐ Não compreensão das doses e intervalos

☐ Efeitos Colaterais

☐ Outros

Etapa - Brasil

***27. Objetivos do principal responsável com o cateterismo:**

- ☐ Não sei
- ☐ Preservação renal
- ☐ Continência
- ☐ Prevenção de infecção do trato urinário
- ☐ Outros

***28. Compreensão do principal responsável em relação à indicação do cateterismo**

- ◯ Nenhuma compreensão
- ◯ Fraca (entende apenas parcialmente, confunde os dados)
- ◯ Razoável (entende os aspectos mais relevantes dos exames, procedimentos e riscos)
- ◯ Ótima/boa compreensão (conhece os resultados dos exames/ indicação do procedimento /riscos envolvidos)

***29. Enfrenta dificuldade técnica na realização do procedimento?**

- ☐ Não
- ☐ Dificuldade de visualização
- ☐ Resistência esfincteriana
- ☐ Precário controle de tronco
- ☐ Dificuldade de posicionamento
- ☐ Dor
- ☐ Outras

***30. Há dificuldade no domicílio para realizar o cateterismo?**

- ☐ Não
- ☐ Não há água encanada
- ☐ Banheiro pequeno
- ☐ Outras

***31. Faz o cateterismo também fora do domicílio?**

- ◯ Não
- ◯ Sim

32. Ultimamente tem havido sangramento?

- ◯ Não
- ◯ Sim, mas só na ponta do cateter
- ◯ Sim, importante

***33. Alcançou continência após o cateterismo?**

- ◯ Não
- ◯ Parcial (perdas eventuais, necessidade de absorventes)
- ◯ Sim

***34. Há dificuldade financeira para adquirir o material do cateterismo?**

- ◯ Não
- ◯ Sim
- ◯ Recebo doação do material

Etapa - Brasil

35. Alguma outra pessoa realiza o cateterismo em caso de necessidade?

☐ Não ☐ Paciente ☐ Mãe ☐ Pai ☐ Tia ☐ Tio ☐ Avó ☐ Avô ☐ Irmã ☐ Irmão

Outro (especifique)

*** 36. Tem algum sentimento/idéia que atrapalha o principal responsável a realizar o cateterismo?**

☐ Não
☐ Medo
☐ Vergonha
☐ Insegurança
☐ Aflição
☐ Pena
☐ Outros

*** 37. Por quem o questionário foi respondido?**

◯ Paciente
◯ Mãe
◯ Pai
◯ Outro

*** 38. Gênero do paciente:**

◯ feminino
◯ masculino

*** 39. Faz uso de medicação:**

◯ Não
◯ Sim

SHORT CURRICULUM VITAE

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Formal Education/Degree

2010 - 2012 Doctorade (PhD) in Rehabilitation Sciences
TU Dortmund University, Germany
Advisor: Prof. Dr. Christoph de Oliveira Käppler
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Major: Rehabilitation and Education in Handicapped Children
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2007 - 2009 Master in Health
Federal University of Minas Gerais (UFMG), Belo Horizonte, Brazil
Title: Intestinal Constipation in patients with Cerebral Palsy: evaluation of the results of nursing interventions
Advisor: Prof. Dr Elenice Dias Ribeiro de Paula Lima
Major: Health Sciences / Nursing

1998 - 2001 Graduation in Nursing
State University of Sao Paulo Julio de Mesquita Filho (UNESP)
Grantee of: Foundation of Research Support of the State of Sao Paulo, FAPESP, Brazil. Scientific Initiation.

Professional Experience

2002 - Present Association of Social Pioneers, *Sarah Network of Rehabilitation Hospitals* – Brazil. Nursing Team Manager
Management, administration and rehabilitation of children and teens. Specialized technical services: nursing assistance to paediatric outpatient department for bladder-intestinal re-education, training in daily activities and self-care.

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