Objective: recognizing the profile of children and adolescents with Myelomeningocele treated at the Center for Childhood Voiding Disorders. Method: an exploratory and descriptive study with a quantitative approach. The data collection was performed with two questionnaires applied to legal guardians. The data were analyzed by statistics, presented in tables and figures. The research project was approved by the Research Ethics Committee, Protocol 204/11. Results: there was a relevance for males (63.6%), dark race (45.5%), significant presence in firstborn (54.5%), while 45.5% had no siblings of the same family, 100% used folic acid during pregnancy and 72.7% did not come into contact with that substance, according to the literature, may be causing the disease. Conclusion: this study was supported by the literature in the categories of folic acid during and before pregnancy, presence of comorbidities and associated diseases, prenatal care and use of peritoneal shunt or similar ventricle in patients with Hydrocephalus. Descriptors: Myelomeningocele; Nursing; Child.

RESUMO
Objetivo: conhecer o perfil de crianças e adolescentes com Mielomeningocele atendidos no Centro de Distúrbios Miccionais da Infância. Método: estudo exploratório e descritivo, de abordagem quantitativa. A coleta dos dados foi realizada com dois questionários aplicados aos responsáveis legais das crianças. Os dados foram analisados pela estatística, apresentados em tabelas e figuras. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, Protocolo 204/11. Resultados: houve relevância para o sexo masculino (63,6%), raça parda (45,5%), presença expressiva em primogênito (54,5%), sendo que 45,5 % não possuíam irmãos do mesmo casal, 100% usaram ácido fólico na gestação e 72,7% não entraram em contato com substância que, segundo a literatura, possa ser causadora da doença. Conclusão: o presente estudo foi corroborado pela literatura nos quesitos do uso de ácido fólico durante e antes da gestação, presença de comorbidades e doenças associadas, assistência pré-natal e uso de derivação ventrículo peritoneal ou similar, em pacientes com hidrocefalia. Descritores: Mielomeningocele; Enfermagem; Criança.

RESUMEN
Objetivo: conocer el perfil de los niños y adolescentes con Mielomeningocele tratados en el Centro de Trastornos de la Micción de la Infancia. Método: es un estudio exploratorio y descriptivo, con enfoque cuantitativo. La recolección de datos se realizó con dos cuestionarios aplicados a los tutores legales. Los datos fueron analizados por las estadísticas, que se presentan en tablas y figuras. El proyecto de investigación fue aprobado por el Comité de Ética de la Investigación, Protocolo 204/11. Resultados: hubo significancia para los hombres (63,6%), de la raza oscura (43,5%), presencia significativa en el primogénito (54,5%), mientras que el 45,5 % no tenía hermanos de la misma familia, el 100% usó ácido fólico durante el embarazo y el 72,7 % no entró en contacto con esta sustancia, de acuerdo con la literatura, pueda ser la causa de la enfermedad. Conclusión: este estudio fue apoyado por la literatura en los quesitos del uso de ácido fólico antes y durante el embarazo, la presencia de comorbididades y enfermedades asociadas, la atención prenatal y el uso de la derivación ventrículo peritoneal o similar, en pacientes con hidrocefalia. Descriptores: Mielomeningocele; Enfermería; Niño.
INTRODUCTION

The failure of closure of the neural tube elements or reopening of the tube regions, after the successful closure, can trigger defects. It stands out that the spine bifida, which can be classified as occult spine bifida or cystic spine bifida, among the forms of cystic spine bifida, Myelomeningocele (MMC) is a major form,¹ and occurs due to a failure of fusion of posterior elements of the spine, causing the externalization of meninges, nerve roots and spinal cord, which are enclosed in a pouch lined with epidermis. Running along the neural tube defects (NTDs), MMC is the most common, with a prevalence of 85% of the cases.² The failure of fusion of the posterior elements of the spine occurs between the 3rd and 5th week of intrauterine life,³ time compatible with neural formation of the fetus. The worldwide incidence is variable, averaging from 1 per 1000 live births,⁴ and it is estimated that 1 in every 800 live births in Brazil carrier of this congenital defect.⁵ A study conducted from January 2000 to August 2001 by Latin American Collaborative for Congenital Malformations (ECLAMC), the study found an average prevalence of 2,4:1.000 live births in the five Latin American countries that participated in the study, Argentina, Brazil, Chile, Uruguay and Venezuela, Brazil being the country that showed the highest.⁶

The MMC has a multifactorial etiology involving genetic and environmental factors; it considers the increased probability in women with diet low in folic acid, vitamins A and D, ingestion or contact with substance, like carbamazepine, valproic acid, zinc, insulin, salsates, foods with pesticides and alcohol, and socioeconomic factors. Whereas genetic factors, the chance of recurrence is 5 % for a second child, 10% for a third child and 25% for a fourth child from the same family.¹ ³,⁷

The diagnosis can be made in the pre-natal through morphological ultrasound, in which there is an enlargement of the spinal canal and the determination of alpha-fetoproteins and acetylcholinesterase, both enzymes that, when in high amounts in the amniotic fluid, may be indicative of NTD.⁴ For correction it must be performed intrauterine anesthetic-surgical procedure, if the lesion is between the vertebrae Thoracic 12 (T12) and Lumbar 5 (L5), or anesthetic-surgical after birth; procedures involving the internalization of protrusion saccular.³ ⁵

The vast majority of NTDs in Myelomeningocele occurs in the thoracolumbar level with commitment and impact on cervical and sacral regions, 8 may trigger changes / limitations sensory, motor and reflex, and chronic disabilities, varying the level and degree of involvement spinal. The clinical manifestations and the most common diseases are associated hydrocephalus, changes of anal continence and bladder, neurogenic bladder, overactive bladder, musculoskeletal changes related to ambulation, paralysis, especially in the lower limbs, and cognitive impairment.³,⁴,⁹

Spine bifida is the most common congenital malformations of the world and is responsible for important neurological sequelae,⁸ which eventually reflect physiologically in the body and affect activities of daily living.

Given this context, it is believed that it is feasible to provide knowledge to family and health professionals, especially nurses by the proximity and progressiveness of assistance that should be provided to patients, to single out, qualify and humanize the care provided for the prevention and health promotion. Because it is a disease not well defined causes of great social and economic impact on families, this study aims to recognizing the profile of children and adolescents with Spine Bifida treated at the Center for Voiding Disorders of Childhood.

METHOD

This is an exploratory and a descriptive study with a quantitative approach. The data collection was performed with two questionnaires to the legal guardians of the patients seen in the months of April and May of 2012 at the Center for Voiding Disorders of Childhood / CEDIM, who had a diagnosis of Myelomeningocele. Among the information gathered, we have: socioeconomic data of the patients, history of prenatal care and pregnancy, physiological changes of the disease and performing clean intermittent bladder catheterization.

All children and adolescents in CEDIM assisted with medical diagnosis of Myelomeningocele were included during the months of data collection in subsequent queries; patients were excluded from the first consultation did not meet necessary requirements related to catheterization, others for not being able to answer the questions and also those whose guardians refused to participate.

The sample was by convenience.¹⁰ There were eligible members those determined their voluntary participation. The study population corresponds to 100% of the demand of
children with Myelomeningocele assisted in CEDIMI, totaling 11 patients.

The data were collected in CEDIMI located in the Ambulatory Care Lecturer of Bahiana (ADAB), in the academic unit of Brotas of the Bahiana School of Medicine and Public Health, Salvador - Bahia. In the academic unit of Brotas of the Bahiana School of Medicine and Public Health, Salvador - Bahia. The preference for the field of study was due to voluntary participation of the authors in the service and for this to be a reference in the country is the only specialized center of Bahia.¹¹ The results were subjected to statistical analysis using Microsoft Excel 2007 software.

The project was submitted to the Research Ethics Committee of Bahiana School of Medicine and Public Health (EBMSP) complying with the standards and guidelines of human research, established by Resolution 196/96,¹² where 100% of the mothers did not use before pregnancy, there was use by 81.8%, with zinc (100%) and for the use of folic acid (72.7%) due to the lack of siblings.⁷ One of the major causes for this question is the reference in studies of increased probability of frequency of Myelomeningocele for the next child of the same family, 14 the present study contrasts to literature that scores the highest frequency in females and in Caucasians.¹³ This may have been due to the number of population in study population clipping.

| Characteristics of the study population n (value) % |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Age             |                 |                 |                 |                 |
| Minimum         | 8               | meses           |                 |                 |
| Maximum         | 11              | anos            |                 |                 |
| Median          | 4               | anos            |                 |                 |
| Average         | 4.6             | anos            |                 |                 |
| Standard Deviation | 3.1        | anos            |                 |                 |
| Gender          |                 |                 |                 |                 |
| Male            | 7               | 63.6            |                 |                 |
| Female          | 4               | 36.4            |                 |                 |
| Race/Color      |                 |                 |                 |                 |
| White           | 4               | 36.4            |                 |                 |
| Dark            | 5               | 45.5            |                 |                 |
| Black           | 2               | 18.2            |                 |                 |


Regarding the situation between siblings and number of siblings, it is observed that the more expressive presence of the firstborn is 54.5 %, and 45.5 % had no siblings of the same couple. One of the major causes for this question is the reference in studies of increased probability of frequency of Myelomeningocele for the next child of the same family, 14 the present study contrasts with the literature.

Regarding the pregnancy group treated at the Center for Voiding Disorders of Childhood (CEDIMI), it was identified that 100 % of the mothers had prenatal care with minimum of 7 consultations. The type of cesarean parturition was the most frequent (81.8%) and the weight of the newborn, the least encountered was 2750 grams minimum and 3990 grams maximum, as shown in Table 3. Studies have referenced that there is an increased likelihood in Newborn with low weight.⁷ It is noteworthy that the value considered for the weight of a newborn is less than 2.500 grams.¹⁵ The items analyzed emphasize the importance of early detection of disease study, which will influence the programming of cesarean section in the preparation of the family and multidisciplinary team to receive and welcome the newborn.

It is observed, in the study group, that 100% of caregivers had no prior knowledge of Myelomeningocele, there was no report of involvement of 1st degree relatives of people with the disease (100%), in relation to the existence of MMC in children of the same bed, in which the occurrence was 12.2%, and 9.1% non-occurrence; this question did not apply to 72.7% due to the lack of siblings.

Regarding the characteristics of the occurrence of events during pregnancy, it is envisioned that 90.9% did not use alcohol, cigarettes and / or illicit drugs, in contrast with the literature that punctuates the abusive use of alcohol as a predisposing factor for environmental Myelomeningocele;³ 72.7 % did not use or come into contact with any type of substance before or during pregnancy, there was no report of ingestion or contact with zinc (100%) and for the use of folic acid during pregnancy, there was use by 81.8%, where 100% of the mothers did not use before pregnancy due to the fact of pregnancy was being approved under protocol number 204/11. The term informed consent was signed by the legal representative of the study patients, as recommended in the above-mentioned resolution.

**RESULTS AND DISCUSSION**

The profile of patients analyzed was drawn from three items, age, gender and race / color. Table 1 highlights the minimum age of the population of 8 months old and maximum of 11 years old, with an average of 4.6 years old. The predominance was observed with 63.6% male and 45.5% dark race; both in contrast to literature that scores the highest frequency in females and in Caucasians.¹³ This may have been due to the number of population in study population clipping.

English/Portuguese

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not planned; studies have shown that periconceptional supplementation with folic acid for at least three months before conception until the twelfth week intrauterine is considered effective in preventing Myelomeningocele.⁴,¹⁴

Children with Myelomeningocele may show disabilities and chronic comorbidities in high frequency, such as hydrocephalus, neurogenic bladder, overactive bladder, bowel dysfunction, orthopedic problems and paralysis of the lower limbs. Besides these physical disabilities, may also have social emotional and psychosocial disorders, and cognitive impairment.¹ Regarding comorbidities and resources used for treatment, 100 % had comorbidities arising from or associated with MMC; 81,8 % used valve or ventriculoperitoneal shunt function in hydrocephalus, highlighting the prevalence of valve (77,8%), a fact which is opposed to theoretical frameworks that link the valve increases the frequency of mechanical complications, especially in malfunction and infections, notably the ventriculitis;16 72,7 % did not use a prosthesis or orthosis on lower limb and 72,7% performed clean intermittent catheterization to minimize urinary changes.

### Table 2. Characterization of Myelomeningocele in the studied population in the Centre of Childhood Voiding Disorders (CEDIMI), Salvador Bahia - April/May, 2012.

<table>
<thead>
<tr>
<th>The questionnaire responses of Myelomeningocele</th>
<th>YES</th>
<th>NO</th>
<th>NSA</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The caregiver already had some kind of knowledge of the disease before the discovery of this child as a carrier?</td>
<td>-</td>
<td>-</td>
<td>11</td>
</tr>
<tr>
<td>2. Any first relative of the parents already had MCC?</td>
<td>-</td>
<td>-</td>
<td>11</td>
</tr>
<tr>
<td>3. Among the sons of the same couple there is another that is the bearer of MCC?*</td>
<td>2</td>
<td>18,2</td>
<td>9</td>
</tr>
<tr>
<td>4. Made or makes use of: alcoholic beverages, cigarettes and/or illegal drugs?**</td>
<td>1</td>
<td>9,1</td>
<td>9</td>
</tr>
<tr>
<td>5. Made use of any medication before or during pregnancy?²</td>
<td>3</td>
<td>27,3</td>
<td>8</td>
</tr>
<tr>
<td>6. Made use of folic acid in pregnancy?</td>
<td>9</td>
<td>81,8</td>
<td>2</td>
</tr>
<tr>
<td>7. Presence of Comorbidities?</td>
<td>11</td>
<td>100,0</td>
<td>-</td>
</tr>
<tr>
<td>8. Made use or came into contact with zinc in pregnancy?</td>
<td>-</td>
<td>-</td>
<td>11</td>
</tr>
<tr>
<td>11. Makes use of ventricle-peritoneal shunt or similar?***</td>
<td>9</td>
<td>81,8</td>
<td>2</td>
</tr>
<tr>
<td>12. Makes use of prosthesis or orthosis in LL:</td>
<td>3</td>
<td>27,3</td>
<td>8</td>
</tr>
<tr>
<td>13. Makes use of intermittent vesical catheterization?</td>
<td>8</td>
<td>72,7</td>
<td>3</td>
</tr>
</tbody>
</table>

Source: information collected from children of the Centre of Voiding Disorders of childhood (CEDIMI), Teaching Ambulatory-Care of Escola Bahiana de Medicina e Saúde Pública, unit of Brotas. Own authorship, Salvador - BA, 2012. * YES Car 1.2; ** Yes – liquor; Of those who responded YES 22.2% - Derivation; 77.8% valve; 2 who responded YES 66.7% Antiemetic; 33.3% formaldehyde.

On amendments and guidelines for procedures in patients with Spine Bifida, we found that 81,8% was not reported / identified the presence of speech difficulties, slurring of speech or swallowing, opposition to the studies that punctuate the cognitive impairment as one of the main clinical manifestations and trigger the need for more effective care;3 54,5% have indication of completion of the catheterization 4 times / day.

In the percentage distribution of the changes resulting from Myelomeningocele, punctuated in Chart 1, we highlight high rates for urinary changes (100%), with 72,7% patients with neurogenic bladder, urinary incontinence 63,3% , 36,4% of retention, 27,3% of residual urine and overactive bladder, 63,6% have uncontrolled anal sphincter muscles and skeletal changes, 36,4% have impaired sensibility in the lower limbs , 81,8% had hydrocephalus and 9,1% had cognitive impairments.
Santos SA dos, Souza MIAW de, Calasans MTA. Profile of children and teens with myelomeningocele.

The analysis of Figure 2 allows us to identifying the cumulative percentage distribution of MCC changes, showing that 27.3% of the population studied had 3 changes and 18.2% have 10 of the 13 verified amendments.

The percentage distribution, considering the degree of difficulty in relation to clean intermittent bladder catheterization of the study population, displayed in Figure 3, shows that 36.4% have no difficulty in performing the procedure, 18.2% have difficulties in grade from 3 to 4 and 5 to 6, 9.8% from 7 to 8 and 18.2%. Such question does not apply due to the performance of the technique.
Given the different levels of difficulties reported, we attempted to identify the possible causes for the existing complications or not performing catheterization. It was found that 45.5% reported no difficulty, in 18.2% the procedure is compromised by the acquisition of material and technical and 9.1 by rejection of the child, lack of time and uncertainty.

CONCLUSION

This study showed the profiles of patients at the Center for Voiding Disorders of Childhood (CEDIMI), located in ADAB Bahia School of Medicine and Public Health, who introduced itself as a clipping of the people from Bahia with Myelomeningocele.

This study was supported by the literature in the categories of folic acid use during and before pregnancy, cesarean parturition, presence of comorbidities and associated diseases, prenatal care and use of ventricle peritoneal shunt, or similar, in patients with hydrocephalus. In contrast, differences exist - identified most affected gender and race, use or contact with substances which, according to the literature, are possible causes of Myelomeningocele and taking genetics as a triggering factor.

Myelomeningocele is a disease of great physiological impact on the body. Although the physiological changes are inevitable, they can and should be shaped in order to minimize the changes in daily life. Nurses must be prepared to watch these patients and, thus, is responsible for establishing goals, such as promoting adaptive responses using information on the level of adaptation of the focal person and contextual stimuli. Thus, the process of care, either by family members or by health professionals, requires the establishment of a supportive relationship with the care, understanding it as a singular being, respecting its limitations and encouraging its potential and independence.

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Profile of children and teens with myelomeningocele.

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