

# The Reality of Children and Adolescents with Meningomyelocele and Their Families, in the City of Belo Horizonte and Its Metropolitan Area, Brazil

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## Abstract

**Meningomyelocele is a congenital defect involving the central nervous system which is one of the most common among those compatible with life. Children affected by this condition present neurological, orthopedic, renal and urogenital complications, needing lifelong healthcare provisions. The aim of this study was to analyze the reality experienced by children and adolescents with meningomyelocele and their families in the city of Belo Horizonte and its metropolitan area, Brazil. A descriptive and exploratory study was conducted via three home visits and a scripted interview with 16 children and adolescents with meningomyelocele and their families. It was observed that mean age of children and adolescents was 12 years old, most of them did not walk (n = 10), and depended on wheel chairs and parental care. Mothers represented the main caregivers and most (n = 12) had to leave their formal work outside of the home, compromising family income. It concluded that the families had socioeconomic levels aggravated by difficulties in purchasing materials needed for their children's care. Some social challenges included barriers to education and the acquisition of medications and materials, demonstrating the need for planning public policies aimed at integrating different health services.**

## Keywords

**Meningomyelocele, Rehabilitation, Caregivers, Continuity of Patient Care, Nursing**

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### 1. Introduction

Meningomyelocele (MMC) is the most severe type of neural tube defect, characterized by the cystic protrusion of nervous tissue. This congenital defect involving the central nervous system is one of the most common among those compatible with life and occurs in the first four weeks of pregnancy [1]. According to data published by the World Health Organization (WHO), Brazil presents the fourth largest incidence rate of MMC (1.139 cases per 1000 live births) [2].

Children affected by this condition present neurological, orthopedic, renal and urogenital complications, needing lifelong healthcare provisions. Thus, MMC is characterized as a chronic condition [3]. Chronic health conditions have a biological, psychological or cognitive basis and produce function limitations, activity or social role, causing dependence medicaments, special diet, medical technology and social care support requiring health care or related services in order to be continued [4].

Initially, care is provided either by the mother or another main caregiver, due to the child's natural incapacity for self-care. As the child grows and develops, care tends to be transferred, thus promoting independence and autonomy. The socioeconomic and cultural conditions of the families caring for children and adolescents with MMC can hinder the acquisition of independence and autonomy. Thus, it is essential that trained professionals conduct neurorehabilitation in order to stimulate the process [5].

The majority of children and adolescents with MMC are able to lead an independent and autonomous lifestyle, in so far as they are encouraged to achieve a level of independence that allows them to survive and manage their lives [3]. Interventions should be initiated as early as possible. The first step is to recognize the family's socioeconomic and cultural reality and then establish a program to stimulate every day and social activities via rehabilitation processes.

The number of children participating in or dominate their care grows over time, as highlighted by the study on the transfer of parents care for teens with MMC. Do not allow children to be responsible for self-care when they are old enough and have the ability to do so may affect the development of their autonomy and encourage excessive dependence on their parents or caregivers [6].

Study explored the experiences of eleven children and young people with spina bifida, aged 6 - 18 years, about continence issues, social participation and peer relations, pointed from the minimal impact of incontinence the significant social isolation. Children and young people who were able to control his bladder had greater independence. This study shows that health professionals need to take into account the differences between these parents and their children in the attitudes and desires of incontinence management [7].

Gaining familiarity with the reality of children and adolescents with MMC and their families is essential to the successful planning of inclusive policies and to substantiate the training and professionals and family members to aid in the rehabilitation process. There are few studies on the Brazilian reality of children and adolescents affected by MMC. In this sense, the aim of the present study was to analyze the reality experienced by individuals with MMC and their family members in the city of Belo Horizonte and its metropolitan region.

### 2. Materials and Methodology

This article is an excerpt from a qualitative, descriptive and exploratory study as a doctoral thesis that portrays the reality of children and adolescents treated at a network of reference rehabilitation hospitals. As a qualitative study, conducted by three home visits and interviews the sample was well represented with 16 participants. This study based on a dialectic, theoretical and methodological framework. The research was conducted with mothers and children and adolescents with MMC receiving care at a rehabilitation hospital in the city of Belo Horizonte, Minas Gerais, Brazil.

Three home visits were made to each participating family in order to obtain a better grasp of their reality. The first visit included a semi-structured interview validated by experts in the field.

The sample comprised 16 children and adolescents between the ages of 7 and 17. They were selected based

on outpatient appointments at the referred institutions between May 4 and June 4, 2015. Inclusion criteria were: being a child or adolescent with MMC, receiving institutional treatment for at least five years and residing in Belo Horizonte or in its metropolitan region.

This study abided by the ethical standards set forth by resolution 466/2012 of the Brazilian National Health Council. Data collection took place only after the approval of the research ethics committee of the Federal University of Minas Gerais, under protocol 1,036,625, and the Sarah Network of Rehabilitation Hospitals, protocol 1,089,123. At the first home visit, we explained the objectives of the study and the possibility of refusing permission, after which willing parents or legal guardians and children each signed an informed consent form.

The data were tabulated and analyzed using descriptive statistics, simple percentages and means.

### 3. Results

All 16 participants were accompanied by their mothers during the interviews, representing the main caregivers. The results were presented according to the characteristics of the children and adolescents with MMC and that of their families.

Participating children and adolescents with MMC were between the ages of 7 and 17, with a mean age of 12 years ( $\pm 2.7$ ). In terms of gender, 3 were boys and 13 were girls. All study participants had reached school age; however, two adolescents did not attend school given the impossibility of proper transportation, and two others attended special needs schools.

In terms of the region of MMC, lesions were predominantly lumbar ( $n = 10$ ), followed by thoracic ( $n = 5$ ) and sacral ( $n = 1$ ). Regarding medication, only two adolescents did not use any medication.

Most participants did not walk ( $n = 10$ ), five were outdoor walkers and one was an indoor walker. In terms of walking aids, non-walkers moved around with the help of wheel chairs, community walkers with lower-limb orthoses and the home walker with the help of an orthosis and a walker.

Only three children did not present hydrocephalus. One 12-year-old presented hydrocephalus with spontaneous derivation, with no need for a shunt. Seven children and adolescents had hydrocephalus and needed shunts, but did not need replacements; and five participants had hydrocephalus with the need for replacements. Two children needed shunt replacements and presented severe cognitive impairment due to complications, affecting their global development.

Only three adolescents were completely independent regarding self-care and activities of daily living. Two children, both girls, presented severe cognitive deficits and were completely dependent on their mothers to carry out activities of daily living, including eating. Eleven were partially dependent and nine showed potential for independence or greater participation in activities of daily living.

Only two participants did not make use of regular medication and of the 14 who did, only two were able to obtain them free of charge. Diaper use was regular among 14 participants and 13 had to purchase this material. All of the children and adolescents in the study used clean intermittent catheterization, one adolescent used a metal catheter and nine had to purchase urinary catheters. Glove use was irregular among participants and six families acquired gloves from their reference health units. These data are presented in [Table 1](#).

The mothers were between the ages of 26 and 52, mean age was 37 years ( $\pm 6.8$ ). In terms of education levels, three women declared having incomplete secondary education; six had completed secondary education; six had incomplete elementary education and one was illiterate. Two mothers had decided to go back to school recently and were pursuing tertiary education degrees in education and social work.

Only two women had formal work outside of the home, whereas the others were homemakers. Of the 14 mothers who did not have formal work, six carried out some type of activity to increase family income: three sold beauty products, one commercialized cold porcelain clay handicrafts, one worked as a cleaner and one was a manicure, seeing customers inside and outside her home.

Most participants were married ( $n = 12$ ). One mother was single and three were divorced. Of these, only two received financial help from the father of their children and even so, irregularly. At the time of the study, three women reported that their husbands were unemployed. The mean income of most families ranged between one and three minimum monthly wages ( $n = 10$ ), followed by those who earned between three and five ( $n = 4$ ). Only two families earned up to one minimum wage, and 12 families received the Continuous Cash Benefit (BPC), granted to children or adolescents with disabilities by the Brazilian National Institute of Social Security (INSS).

The data show that 12 families were homeowners, one family paid rent and three lived in homes belonging to

**Table 1.** Distribution of children and adolescents with MMC by biosocial characteristics, Belo Horizonte and metropolitan region, Minas Gerais, Brazil, 2016.

Characteristics	Categories	n	%
<b>Gender</b>	Female	13	81.3%
	Male	3	18.8%
<b>Schooling</b>	Does not attend	2	12.5%
	Special needs program	2	12.5%
	1 <sup>st</sup> Year elementary	1	6.3%
	5 <sup>th</sup> Year elementary	3	18.8%
	6 <sup>th</sup> Year elementary	2	12.5%
	8 <sup>th</sup> Year elementary	4	25%
	1 <sup>st</sup> Year secondary	1	6.3%
<b>Use of medication</b>	3 <sup>rd</sup> Year secondary	1	6.3%
	Yes	14	87.5%
<b>Level of lesion</b>	No	2	12.5%
	Lumbar	5	31.3%
	High lumbar	2	12.5%
	Low lumbar	2	12.5%
	Lumbosacral	1	6.3%
	Sacral	1	6.3%
	Thoracic	5	31.3%
<b>Locomotion</b>	Non walker	10	62.5%
	Indoor walker	1	6.3%
	Outdoor walker	5	31.3%
<b>Hydrocephalus/derivation/ replacement</b>	No	3	18.8%
	Yes/Shunt	7	43.7%
	Yes/Shunt/Replacement	5	31.3%
	Yes/Spontaneous derivation	1	6.3%
<b>Independence</b>	Totally independent	3	18.8%
	Partially dependent	11	68.8%
	Totally dependent	2	12.5%
<b>Physical activity</b>	Yes	3	18.8%
	No	13	81.3%

other family members. Half of the participants did not own a car. These data are presented in [Table 2](#).

#### 4. Discussion

The results of this study demonstrated a greater frequency of women participants (81.3%), a finding corroborated by other authors [8]. The mean age of participants was 12 years old. Even though most were school-aged, there were two adolescents who did not attend school. They reported difficulties in acquiring transportation to take them to school and infrastructure-related problems at school. This finding emphasizes the social issue of accessibility and socialization among this population.

Schools play an important social role as mediators in the education and care for children and adolescents with

**Table 2.** Socioeconomic characteristics of the families of children and adolescents with MCC in the metropolitan region of Belo Horizonte, Minas Gerais, Brazil, 2016.

Socioeconomic characteristics	Categories	n	%
Mother's marital status	Married	12	75%
	Single	1	6.3%
	Divorced	3	18.8%
Mother's educational level	Illiterate	1	6.3%
	Incomplete elementary	6	37.5%
	Incomplete secondary	3	18.8%
Mother's profession/occupation	Complete secondary	6	37.5%
	Homemaker	14	87.5%
	Formal work	2	12.5%
Head of the household's job situation	Unemployed	5	31.3%
	Employed	11	68.8%
Continuous cash benefit	Yes	12	75%
	No	4	25%
Family income	Up to 1 minimum wage	2	12.5%
	1 to 3 minimum wages	10	62.5%
	3 to 5 minimum wages	4	25%
Owns a car	Yes	8	50%
	No	8	50%
Household	Own	12	75%
	Borrowed	3	18.8%
	Rented	1	6.3%

and without developmental alterations [9]. The school environment favors the establishment of friendships, essential for the socialization of children and adolescents. At the age of the participants of this study, missing out on this context can compromise socialization, restrict their contacts and negatively interfere with their personal development.

In terms of the region of the lesion and form of locomotion, ten (62.5%) participants presented lumbar lesion and did not walk. Similar data were found in a comparative study conducted with individuals affected by MMC in Brazil and Germany, in which 75% of the patients presented lumbar-level, 15.5% thoracic-level, 7.5% sacral-level, and 4% cervical-level lesions. Such predominance of lumbar lesions confirms the established consensus that most spinal dysraphisms occur between the fifth lumbar vertebra (L5) and first sacral vertebra (S1) [8].

Thirteen (81.2%) participants presented hydrocephalus, of which 12 needed shunts and five had to replace the drainage system. Hydrocephalus occurs in 80% - 95% of the cases and results in the compromised development of spatial abilities development. Complications related to the treatment of hydrocephalus, such as shunt malfunction or infection, can have dramatic impacts on neurocognitive outcomes. Chiari II malformation, present in most individuals, compromises motor coordination and plays a critical role in the outcomes of specific cognitive functions, such as attention, planning and learning [10]. Two participating teenage girls presented severe cognitive deficits due to complications related to shunt replacements. These adolescents were totally dependent on their mothers and attended special needs schools.

Only three (18.8%) adolescents, all girls, were totally independent in terms of self-care, activities of daily living and participating in household activities. Eleven participants depended on their mothers for bladder catheterization and bowel regulatory measures, but dressed with partial dependence and ate independently.

Two 11-year-old girls presented significant motor limitations, scoliosis and hip adduction, hindering the care

provided by their mothers. These participants were classified as partially independent.

Investigations suggest that the transition of care in adolescence to adult life must begin at 14 years of age or before, should the child be aware of their health condition and demonstrate an interest in the continuity of their treatment plan. This transition process must be conducted gradually and coordinated among health professionals, different levels of care and families [5].

Furthermore, studies have recognized that children aged six years and over, who have functional manual abilities and are not cognitively compromised, can be considered fit to learn the self-catheterization process. The transition to self-catheterization may be problematic and negatively influenced by factors related to the complexity of their condition, additional functional complications, to the disability itself, and also the family's economic, social and cultural characteristics [8].

The low socioeconomic level of the participating families is noteworthy; whose mean family income was BRL 1947. Furthermore, 75% or twelve families received the Continued Cash Benefit ensured by the National Institute of Social Security. Most mothers (10%, or 62.6%) had not finished secondary education, and only two (12.5%) had formal work outside of the home. At the time of the study, three fathers were unemployed and two families were living off one BPC alone. Of the families whose father was unemployed, one had a mother who complemented the household income by selling beauty products.

The BPC is a monthly minimum wage, which at the time of the study was BRL 788,00, paid to older adults and people living with disabilities, cared for by specialized institutions, and who have disabilities that compromise independent living and work [11]. This resource includes expenses with food, medication, transportation or any other item needed for care.

The low socioeconomic level of the participating families was aggravated by the challenges faced to acquire materials for care provision. As observed, only two participants did not use medication. Of those who took medication, only two had free access to them, whereas 12 had to buy at least part of their continuous-use medications.

The results also showed difficulties in acquiring materials such as disposable diapers, bladder catheters and disposable gloves, essential to the care required for these children and adolescents. Of all the participants, 14 made regular use of disposable diapers and 13 families had to purchase this material. All participants used catheters for bladder catheterization and six families could not acquire this material free of charge, thus having to purchase it. One adolescent used a metal catheter. The use of disposable gloves was irregular among the participants, and four families purchased such gloves and six acquired them free of charge from reference health units.

A comparative study conducted between Brazil and Germany investigated the right to health and access to bladder catheterization materials. The results showed that the German participants received more financial assistance and had an easier time acquiring bladder catheterization material when compared to the Brazilian participants. Participants also mentioned financial difficulties as one of the reasons for interrupting intermittent catheterization [12].

In all of the cases studied in the present investigation, mothers were the main caregivers, representing a reality already described in the literature, in which the care for children with chronic health conditions is strongly associated with mothers [13]. The mother's role in the family setting tends to be that of providing comprehensive care and sparing no efforts to ensure the best for their children, especially when they present some disability [14].

Only two mothers had formal work outside of the home. In their new function as caregivers, mothers tend to adapt their routines to dedicate themselves to their child's care. Studies show that the reason for this situation is related to the high level of care related to demands, with procedures that are repeated several times a day and the need for constant trips to health institutions, thus making it impossible for the caregivers in this study to have formal work [15].

The low socioeconomic conditions of the families in this study were affected by paternal unemployment, maternal subemployment and the need to purchase care materials that should be provided by health services. Even so, 75% [12] of the families were homeowners. Three families lived in a residence provided by other family members and one lived in a rented house. Even though most were homeowners, all of the families reported having to adapt the residence, for which they lacked financial means.

Most of the families needed to conduct structural changes to the residence's physical space to adapt the environment. Some of the architectural modifications that would generate additional expenses included widening doorways, adapting bathrooms, and building ramps. The interviews with the families showed that they recog-



nized the need for such modifications and the financial difficulty that delays their realization.

Data analysis demonstrated that the care provided to the children and adolescents with MMC at home carries with it not only emotional costs for the family, but also financial. Such financial costs are aggravated by chronicity, which requires ongoing and increasing expenses. As the child grows and develops, different needs emerge, such as changes to their support devices and care materials.

Despite the small sample of this study, which can present a limitation, we found that direct onsite observation allowed for a better identification of the reality of children and adolescents with MMC and families residing in the metropolitan region of Belo Horizonte. This population was characterized by low family income levels and social difficulties, such as the acquisition of materials needed for care.

## 5. Final Considerations

This study describes the social reality involving individuals with MMC and their family members. Some social challenges included barriers to education and the acquisition of medications and materials, demonstrating the need for planning public policies aimed at integrating different health services. We urge that comprehensiveness of care and monitoring of this population is sought through actions that congregate different health, education and social work services, with the goal of empowering, lending autonomy and inclusion to individuals with physical disabilities and their families.

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## Conflict of Interest

The authors confirm that this article content has no conflict of interest.

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### List of Abbreviations

MMC—Meningomyelocele

BPC—Continued Cash Benefit

INSS—National Institute of Social Security