

Rehabilitation of children and adolescents with myelomeningocele: the daily life of mothers-caregivers



Reabilitação de crianças e adolescentes com mielomeningocele: o cotidiano de mães cuidadoras

Rehabilitación de los niños y adolescentes con mielomeningocele: el día a día de las madres

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ABSTRACT

Objective: To analyze the daily routine of mothers-caregivers of children and adolescents with myelomeningocele at home.

Method: Descriptive, exploratory, qualitative research. Data were collected with 16 mothers of children and adolescents with myelomeningocele by means of interviews and observation from May to August 2015, in municipalities of Minas Gerais, Brazil. The data were submitted to qualitative analysis.

Results: The daily care routine of the mothers at home revealed two empirical categories: a) the impact of the birth on naturalization of care, and (b) changes in the routine of the mothers and women. The daily lives of these mothers is marked by caring that restricts their possibilities and activities to within the walls of their homes, although the mothers desire the independence of their children.

Conclusion: The emotional, economic, and social transformations, and the difficulties of these mothers to ensure the continuity of care highlight the importance of inclusive public policies, and the importance of health workers in the rehabilitation of children and adolescents with myelomeningocele and their families.

Keywords: Meningomyelocele. Caregivers. Continuity of patient care. Rehabilitation.

RESUMO

Objetivo: Analisar o cotidiano de cuidados praticados por mães de crianças e de adolescentes com mielomeningocele no domicílio.

Métodos: Estudo descritivo-exploratório, abordagem qualitativa. Os dados foram coletados com 16 mães de crianças e de adolescentes com mielomeningocele, por meio de entrevista e observação, de maio a agosto de 2015, em municípios de Minas Gerais, e submetidos à Análise de Conteúdo Temática.

Resultados: As categorias: "Do impacto do nascimento à naturalização dos cuidados" e "A mudança no cotidiano da mulher mãe" evidenciam um cotidiano materno marcado pelo cuidado, limitando suas possibilidades e atividades aos muros das próprias casas, sendo a independência dos filhos um desejo expresso pelas mães.

Conclusões: As transformações nos âmbitos emocional, econômico e social e as dificuldades enfrentadas pelas mães para garantir a continuidade do cuidado apontam a relevância de políticas públicas inclusivas e a importância dos profissionais de saúde na reabilitação de crianças e adolescentes com mielomeningocele e para suas famílias.

Palavras-chave: Meningomielocele. Cuidadores. Continuidade da assistência ao paciente. Reabilitação.

RESUMEN

Objetivo: Analizar la vida diaria de madres de niños y adolescentes con mielomeningocele en casa.

Método: Estudio descriptivo-exploratorio, abordaje cualitativo. Datos recolectados con 16 madres de niños y adolescentes con mielomeningocele, a través de entrevistas y observación, de mayo a agosto de 2015, en municipios de Minas Gerais. Los datos fueron sometidos a Análisis de Contenido Temático.

Resultados: Las categorías: "Del impacto del nacimiento a la naturalización de los cuidados" y "El cambio en el día a día de la mujer madre", evidencian un cotidiano materno marcado por el cuidado, limitando sus posibilidades y actividades a los muros de las propias casas, siendo la independencia de los hijos un deseo expresado por las madres.

Conclusiones: Las transformaciones en los ámbitos emocional, económico y social y las dificultades enfrentadas por las madres para garantizar la continuidad del cuidado, apuntan la relevancia de políticas públicas inclusivas y la importancia de los profesionales de salud en la rehabilitación de niños y adolescentes con mielomeningocele y sus familias

Palabras clave: Meningomielocele. Cuidadores. Continuidad de la atención al paciente. Reabilitación.

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INTRODUCTION

The birth of a child with a chronic health condition modifies the dynamics of the family and the daily lives of its members, especially the mother, due to the new demands of the child. This new arrangement leads to the emergence of the primary caregiver⁽¹⁾.

The main caregiver is directly responsible for tending to the child and may or may not be someone in the family. This caregiver generally renounces a social and economic role to fully tend to and meet all the needs of the child⁽²⁾. A study on the social support to families of children with chronic health conditions identified that most of the responsibilities are assumed by the mothers⁽³⁾.

Myelomeningocele (MMC) is a congenital malformation caused by neural tube closure defects (NTCs), in which the embryonic spinal cord is displaced dorsally due to the absence of supporting structures⁽⁴⁾. The care of children with MMC consists of the correct management of the main complications of this malformation, namely neurological, orthopaedic and kidney disorders. The neurological disorders are chiefly impaired neuropsychomotor development, hydrocephalus, Arnold Chiari malformation, and neurogenic bladder and bowel dysfunction. Orthopaedic manifestations occur in the form of lower limb paralysis, congenital club foot, congenital dislocation of the hip, scoliosis, motor impairment and generalized muscle contractures. Renal complications due to neurogenic bladder dysfunction is characterised by urinary incontinence, changes in sexuality, vesicoureteral reflux and hydronephrosis⁽⁵⁾.

Fifty years ago, the survival rate of babies born with MMC was approximately 10%. Currently, with advancements of health treatments, survival until adulthood is more than 50%. Consequently, one of the focal points of rehabilitating this population is the transition of care throughout adolescence to adulthood, which includes issues that can compromise quality of life, autonomy and participation⁽⁶⁾.

The involved alterations affect the quality of life of children and adolescents with MMC and their caregivers, which are usually the mothers, due to the chronic nature of this condition and the need for a continued treatment plan that mostly focuses on neurogenic bladder and bowel, and skin care⁽⁷⁾.

Children and adolescents with chronic health conditions require special attention and rehabilitation. The parents or guardian must supervise, observe and care for the child according to its needs, which are mostly deter-

mined by the health condition and the fact that they are still developing⁽⁸⁾.

The daily lives of these families represents the location where life occurs, considering that man is transformed by the environment in which he is inserted⁽⁹⁾. In view of these considerations, the guiding question of this study was: what is the reality of mothers-caregivers of children and adolescents with MMC? Investigating the daily lives of the mothers and caregivers of children and adolescents with MMC can provide greater insight into the phenomenon to help health workers create a viable therapeutic plan, and support the creation of better health policies for people with chronic health conditions and their families. Therefore, the aim of this paper is to analyse the daily care routines of the mothers of children and adolescents with myelomeningocele, at home.

METHODS

This is a descriptive-exploratory study with a qualitative approach and the theoretical framework of the dialectic, which is based on the theoretical framework of Agnes Heller, and excerpted from thesis entitled: *A continuidade do cuidado de crianças e adolescentes com mielomeningocele no domicílio*⁽¹⁰⁾.

The participants of the study were 16 mothers of children and adolescents with MMC that attended the outpatient rehabilitation programme of a rehabilitation hospital network in the city of Belo Horizonte. The criteria for inclusion were mothers of children and adolescents between the ages of 5 and 18 who had participated in the rehabilitation programme in the last five years, and residents of Belo Horizonte and the metropolitan region. The exclusion criteria were mothers of children with acute problems, change of address, and mothers of children admitted to other institutions during the data collection period.

The data collection techniques were observation and interviews. The support resources were a semi-structured interview script, an observation script, and the researcher's field journal. For the observation stage, the researchers visited each participating family three times with a 30-day interval between each visit.

Data collection occurred from May to August 2015. The first contact with the mothers was made by the researcher, by phone, for an average of 7 minutes. During this short conversation, the researcher scheduled the first home visit. The visits were always scheduled at a time and day chosen by the families, and lasted 60 minutes on average.

During the first home visit, the researcher explained the objectives of the research and asked the mothers to sign an informed consent statement, after which the semi-structured interview was conducted with the script and recognition of the place of residence. All the interviews lasted around 45 minutes and were taped with the consent of the participants.

During the second visit, the researcher observed the care provided by the mothers and provided self-care guidelines for the children and adolescents with potential for independence or even potential for greater participation in the activities of daily life. During the last visit to each family, the researcher provided answers to the initial questions and allowed the mothers to talk freely about the three visitations.

The material obtained from the interviews and the observations recorded in the journal were explored using the thematic content analysis technique proposed by Bardin⁽¹¹⁾.

The interviews were transcribed, and any silence, doubts and exclamations were maintained. In order to protect the identity of the participants, the interviews were coded with alphanumeric characters, namely E1 to E16. The material obtained from the observations was recorded in the field journal on numbered pages and coded with the letter "O" followed by the number corresponding to the interview, and the letters a, b or c, which referred to the first, the second or third visit, respectively.

All the material was skim read until the content was impregnated and saturated. The material was then read in depth, followed by outlining, classification and aggregation of the units of meaning, which resulted in two empirical categories: a) the impact of birth on the naturalization of care, and (b) changes in the routine of the mothers and women.

Ethical aspects were observed as specified in Resolution 466/2012 of the Conselho Nacional de Saúde⁽¹²⁾. The project was approved by the research ethics committee of the Universidade Federal de Minas Gerais (UFMG), number 1.036.625, and by the ethics committee of the Rede Sarah de Hospitais de Reabilitação, a network of rehabilitation hospitals, in Brasília, number 1.089.123, both of 2015.

■ RESULTS AND DISCUSSION

Characterisation of the participants

Data analysis revealed that the 16 mothers were between the ages of 26 and 52, with an average age of 37

years. Although they were in productive age, only two women worked outside their homes at the time of the survey; one as a general service assistant at a state school (E.3), and another as a security guard at a night event (E.2). Most of the participants, 14 mothers, had formal jobs, but stated that they had to stop working to care for their children.

The need for child care and the financial condition of the family demanded the adaptation of these women to a new reality, which caused some mothers to get informal jobs. Of these women, three mothers worked as consultants for beauty products (E.1, E.4, and E.8) and had more time to stay at home; one mother did handcrafted items with cold porcelain at home (E.5); one did sporadic house cleaning for customers (E.7); and another mother worked as a manicurist (E.9) and attended people in and out of her home.

As for education, three women claimed they had not finished secondary school (E.1, E.5, E.13); six said they had finished secondary school (E. 2, E.4, E.10, E.11, E.12, and E.16); six said they had not finished primary school (E.3, E.6, E.7, E.9, E.14, and E.15); and one claimed to be illiterate (E.8). Two mothers, E.2 and E.11, had recently returned to school and were pursuing a higher education in social services and education, respectively.

At the time of the study, nine women stated they were married and that their husbands were employed (E.4, E.5, E.7, E.9, E.10, E.11, E.12, E.13, E.16); three women said they were married and their husbands were unemployed (E.1, E.14, E.15); and four women were not married or in a stable relationship (E. 2, E.3, E.6, E.8). It was also found that three women (E.9, E.10, and E.12) were married to men who are not the biological fathers of their children with a chronic health condition.

The impact of the birth on the naturalization of care

The statements of the mothers showed that their daily lives were affected by the transformation since the moment of birth, when they knew they would be the mothers of children with a chronic health condition, as shown below:

Her birth came as a surprise. It changed everything. It was [...] I had never heard of it. I've never heard of it. Spine, a malformation of the spinal cord. What is that, dear God? So, as I was saying, I have matured a lot (E.1.8).

After she was born, it all changed a lot, a lot in my life. I knew at birth and that scared me. I already lived here with

her father and then we separated. I was always at the hospital, at the doctor's, I think that triggered the separation [...] (E.2.8).

The birth caused surprise and shock. The new, the unknown had to be incorporated into the daily lives of the mothers. The modifications were imperative. The experience of caring for a child with a chronic health condition mostly includes trips to the health services and the need for care at home. The statement of one of the mothers, E.2, shows that their absence in the marital relationship may have contributed to the breakup of the marriage, and suggests that the prioritization and high demand for child care causes strain and compromises their emotional relationships.

The everyday care routine of children and adolescents with a chronic health condition and their families constitutes a major challenge and becomes a daily struggle given the experiences that are inherent to treatment, successive hospital stays, and special care that prevent or limit desirable life experiences and impair their own development⁽⁷⁾.

The dynamics of the marital relationship shifts due to the greater involvement of the mothers to meet the needs of their child, the elements of tension and conversations about the situation of the child, the care and responsibility, and the "lesser time" spent with the spouse in order to monitor and accompany the child during hospital stays, and at consultations and examinations⁽¹³⁾.

The child with MMC requires care beyond the care that is considered normal for children without growth or development problems, which triggered fear, insecurity and anxiety among the mothers-caregivers. Moreover, they recognised that the birth of a child with a chronic condition was a difficult time for them, and the cause of great suffering.

It changed my whole routine. Everything. I was on the verge of depression because I had to insert the probe and she cried, and I cried. Lots of crying. I was always crying, I just cried all the time (E.1.10).

At the beginning it was more difficult. I didn't have any experience taking care of a disabled children. I had never even seen it. I just heard others talk about it. I had never seen it. Taking care. Touching. It takes a lot of care. Especially with her spine, I was afraid to put her on my lap, of hurting her, of it getting out of place, breaking [...] Me and her father [...] With time I got used to it [...] (E.8.24).

In a study on the family organization of care for children with a chronic condition, the statements of the mothers also suggest fear and insecurity due to the lack of experience, the possibility of complications at home and, consequently, of the child not receiving the necessary care⁽¹⁴⁾. The feelings of struggle, sacrifice and guilt are all present in the statements, and thus characterise how they perceive the moment they are experiencing⁽¹⁵⁻¹⁶⁾.

The coming of a child generates dreams and hopes for their future. However, these dreams are shattered or interrupted with the condition of chronicity, which causes feelings of frustration and suffering⁽¹⁵⁾.

Before the birth of a child with a chronic condition, the family recognizes and becomes sure of its role. In the case of a diagnosed disability or chronic condition, however, the behaviour of the family changes, and it must now deal with feelings of guilt, rejection, denial or despair, which also changes their family relationships and the family structure⁽¹⁷⁾.

The data showed that the confrontation of a chronic condition in childhood is traumatic and difficult for the mothers. Mothers reported that the birth of a child with MMC affected their daily life, created fear and insecurity for the new reality, and led them to transform their lives in order to incorporate a previously unknown condition and critical care to maintain the lives of their children.

Everyday life is the "lifeworld" that it dialectically produced and reproduced in an eternal movement; it is the world of objectification. The concept of everyday life (or daily life) is defined as that which is lived, and the social life of individuals and their interrelations. This concept differs from that of the daily routine, which consists of repeated acts without perceiving their meaning or importance⁽⁹⁾.

It is in the daily life that life occurs. It is where men and women experience and exteriorise their passions, senses, intellectual capabilities, manual and manipulative skills, feelings, ideas, ideologies, beliefs, and tastes⁽¹⁸⁾.

Daily life is marked by common events related to the everyday life of any human being, such as eating, working, leisure, and reproduction. However, daily life can be marked by profound transformations, disasters, environmental changes, and the birth of a child with a chronic health condition, according to the concept elaborated by Agnes Heller.

For the organisation of care in a new daily life, mothers must overcome the initial feelings of fear, guilt or insecurity, and use their vital force to discover new ways to produce life and adapt to the new routine. The feelings of fear and insecurity mentioned by the mothers

were overcome over time as the child and their needs became a true part of the everyday life of the mother, and as they became familiar with the unknown, and incorporated and adapted the needs of their child to the daily life.

In the past, as we didn't know how it was, especially when she started with the catheter, because before she did Credê, we started with Credê. When she started with the catheter I was afraid of hurting her, they still used that metal probe, which doesn't exist today. So, we were afraid to hurt her, I thought I would puncture her, I didn't know the length of the catheter we could push in, but today I don't have that problem. Nothing that's too tough (E.4.10).

In the beginning it was all different, as soon as I found out she had mielo. When I found out I needed to use the catheter, I had never heard of it in my life. She was six years old when started with the catheter, six years old. She was really small. At first it was all different. Her father [...] we still lived together [...] He cried all the time [...] I did it, he cried all the time. He was always worried. After a time, we got used to it, normal (M.E. 8.16).

Children with chronic health conditions and their parents accumulate knowledge of the care system through their daily experiences⁽⁹⁾. The first contact with technological devices to provide care causes fear and doubt regarding proper use, and these feelings fade over time as the family adapts and learns from the experience of providing the care at home⁽¹³⁾.

A comparative study in Brazil and Germany with people with MMC and their caregivers on feelings related to intermittent catheterisation also detected the fear of hurting the child when introducing the urinary catheter⁽¹⁹⁾.

In time, the family also learns to live with and accept the chronic condition of the child, which enables them to go on with their lives and triggers feelings that seemed dormant, such as the joy and encouragement. The family needs to maintain hope and freedom of choice by promoting a new family organization and a less traumatic adaptation⁽¹⁵⁾.

The initial feelings of guilt, fear or insecurity give space to a force that allows these mothers-caregivers to unveil the new and adapt to a new established reality⁽²⁰⁾.

Naturalisation with the daily life of care represents what Agnes Heller calls life force or vital capacity, that is, the ability of humans to adapt to diversity and to change through learning new ways, means, and methods that permit survival⁽⁹⁾.

It was found that the mothers-caregivers used their vital capacity to learn to care for their children with a chronic condition, incorporated and adapted their technical skills to their daily lives, used their creativity, and abdicated their own dreams to ensure quality life for their children. Confronting a chronic condition in childhood is traumatic and difficult for the mothers. This situation can be aggravated by the lack of support of a family, social or healthcare network that provides comprehensive support for the mothers, which suggests the need to coordinate different services.

Changes in the routine of the mothers and women

As mentioned previously, only two women had formal jobs. Most of the participants stated they had left their formal jobs outside their homes to take care of their children.

The wife/mother, in this new role of caregiver, modifies her life to devote attention to her child. Leaving the formal job and embracing this care becomes a necessity. For some mothers, this reality required adjustments due to the unfavourable financial condition of the family. Some of the women used their creativity to perform activities that would both provide a better family income and allow them to spend time at home to care for their children. The average income of the families in the study was around two minimum wages.

The need to quit a formal job due to the arrival of a child with a chronic health condition was also observed in a study with mothers-caregivers of children with cerebral palsy. This study found that these women rarely manage to leave their children in the care of other people, which causes a rupture of their personal life and creates the obligation to provide care⁽³⁾. The study stresses that the mothers are mostly responsible for all the care activities, and suggests that the daily care of a child with a chronic health condition makes it difficult for the wife/mother/caregiver to continue with her activities.

I worked, yes. I worked in a family home, as a house cleaner. I stopped when she was born. I had to stop everything in fact [...] (E.10.3).

Before I had her I worked, after she was born, I stopped working. I worked in other people's houses. House cleaner (E.15.1).

After she was born I had to stop working. And I'd rather take care of her than leave it to someone else (E.16.1).

I do cold porcelain crafts. Not long ago I was working outside the house, but it's tough because my sister took care of him for me, but then I had to pay her and it was easier if I just stayed at home (M.E. 5.1).

The role of the mother in the family setting is that of provider of comprehensive care who spares no efforts to ensure the best for her child, especially when she has a child with a disability⁽¹⁷⁾.

Quitting or reducing work was also observed in other studies. The high demands of care with procedures that must be repeated several times a day and the need for constant visits to healthcare facilities made it impossible for the caregivers of this study to maintain a formal job⁽¹³⁾.

All the participating mothers performed clean, assisted intermittent catheterisation (CIC) on their children at least four times a day since neurogenic bladder is a sequel of MMC.

CIC is the preferred method of treatment used worldwide to prevent mortality from kidney complications and acquired urinary continence, and to improve the quality of life of individuals with congenital or acquired spinal cord injury. This method consists of inserting a catheter via the urethra at specific time intervals, and requires discipline, regularity and availability in order to be effective. Continued practice reduces the risk of infection, which is the main complication⁽²¹⁾.

Data analysis revealed that the need to perform catheterisation at regular intervals deeply affects the daily lives of these mothers. Most of the mothers-caregivers stated their distress at having to continuously and regularly perform CIC, and the desire that their children perform the procedure themselves. Regularly performing CIC affects the lives of these women because they must plan their own activities according to the strict schedule they have to follow.

I try to go out at that time so I can come back and do everything [...] My day is a clock. You end up having to follow this schedule, there is no other way (E.10.22).

When I go to college, I don't do the catheterisation. I do it beforehand and when I get back (E.11.8).

I always go out after I've taken care of everything. She's already gone to school [...] (E.14.18).

But usually at home, weekends and holidays, it's every 4 hours sharp. It's 5 catheterisations a day (E.16.7).

Her father and I [...] hope she learns to do it (M.E. 11.24).

I want her to be more independent, especially for the catheterisation (M.E. 12.28).

The reorganisation of the mother's own routine and the construction of everyday care strategies to perform CIC, ensure correct intestinal functions, provide skin care, and administer medication configure a care plan that the mothers-caregivers prepare and perform without the continuous supervision of healthcare professionals.

Some of the mothers found it hard to incorporate intestinal re-education measures and skin care in their daily lives, and often neglected this care. CIC, however, was performed with more regularity.

I don't usually do the belly and buttocks massage. I don't have a schedule. When it's time to go, she goes. There are times when she feels something and goes to the bathroom. Or she doesn't feel anything and does it [poop] in diaper (E.8.12).

They provided the toilet training, but she doesn't stay. If she stays there, like five minutes, she gets stressed out. She hasn't the patience to stay. So we just leave her (E.13.11).

The rashes are minimal. I don't fuss over it that much [...] I just use some cream to prevent rashes (E.7.12).

The statements suggest that the mothers consider catheterisation a more complex form of care that causes serious complications if neglected. It was noted that the mere recognition of the benefits of intestinal re-education and skin care, such as ensuring regular bowel habits and preventing skin rashes, which can impair health and the socialisation of their children, does not guarantee that the mothers will complete these tasks in their daily lives, which, in turn, jeopardises the continuity of this care.

During the visitations, it was observed that the main priority of these mothers is the care of their children. For some mothers, everyday activities are reduced to such care, housework, and visits to the health services. Opportunities for fun and recreation, when they exist, are limited to going to church, and visiting family members and accessible public places, such as shopping centres.

Mine and hers, she is always the priority. First thing, get up in the morning, take care of her first. Then comes the house, my things, whatever. But she was always the priority (E.10.12).

We spend a lot of time at home. We go out to the doctor and that's it [...] (E.6.27).

We hardly every go out. Hardly ever. They go out a lot. They go to their father's house, out for a ride. From there the father takes them out. I hardly ever go out. I just stay at home, really. I actually like to stay home (E.8.25).

The difficulty in enjoying leisure time due to the difficulty and strain of leaving the house with all the necessary artefacts restricts any activities and causes the social isolation of the entire family. Furthermore, the primary caregiver can have concerns regarding the interruption of care and the quality of care provided by a designated person⁽¹³⁾.

The daily lives of these mothers is limited to domestic chores and taking care of their children, with the added difficulty of maintaining a formal job outside the home. The requirements of direct and scheduled care, as in the case of CIC, jeopardises the social lives of the mothers-caretakers. The low socioeconomic level and the locomotive difficulties of the children and adolescents hinders the possibility of family leisure activities, and the daily lives of these families is restricted to the home.

■ FINAL CONSIDERATIONS

Analysing the everyday lives of the mothers of children with MMC revealed that the continuity of care goes beyond executing the techniques at home. The continuous everyday care activities profoundly transform the lives of these women in several family-related, emotional, economic, and social aspects. Moreover, the mothers face difficulties inside and outside their homes to ensure the continuity of care.

Understanding this problem can support the creation of inclusive public policies and stresses the importance of health professionals in the rehabilitation of children and adolescents with MMC and their families to ensure the continuity of care and maximize autonomy, quality of life, and participation in society.

Rehabilitation has been considered a fertile field in nursing since medical and scientific advancements have increased the life expectancy of people with chronic health conditions. It is therefore essential for nurses and nursing students to learn more about this field in order to improve the quality of life of this population.

A limitation of this study is the fact that the research did not include the support of social welfare services. This study reveals important aspects of the organisation

of the daily lives of mothers-caregivers that should be considered during the creation of therapeutic plans, with the participation of health professionals and the mothers. We recommend further studies that focus on the continuity of home care for children with chronic health conditions.

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