

VIVÊNCIA DAS FAMÍLIAS E O CUSTO NO CUIDADO DE CRIANÇAS E ADOLESCENTES COM MIELOMENINGOCELE

EXPERIENCE OF FAMILIES AND THE COST IN THE CARE OF CHILDREN AND ADOLESCENTS WITH MYELOMENINGOCELE

LA EXPERIENCIA DE LAS FAMILIAS Y EL COSTO EN EL CUIDADO DE NIÑOS Y ADOLESCENTES CON MIELOMENINGOCELE

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RESUMO

Objetivo: Compreender as vivências das famílias e o custo ao cuidado de crianças e adolescentes com mielomeningocele. **Método:** Pesquisa exploratória realizada com 16 famílias de crianças e adolescentes com mielomeningocele usuários de um Hospital de Reabilitação de Belo Horizonte/MG. Para a coleta de dados, utilizaram-se a entrevista e a observação, durante as três visitas domiciliares, realizadas em cada família participante. **Resultados:** A renda familiar média foi de dois salários mínimos. O baixo nível socioeconômico foi agravado pelas dificuldades à aquisição gratuita de materiais para a realização dos cuidados. Os custos diretos com os cuidados relacionaram-se à compra de medicamentos, fraldas, cateteres urinários e gastos com transporte, sendo menores para as famílias de adolescentes independentes. **Conclusão:** Os pais de crianças em condições crônicas vivenciam barreiras econômicas e sociais relacionadas ao custo do cuidado em domicílio e necessitam de suporte com serviços de atenção primária e de reabilitação.

Descritores: Meningomielocelose; Efeitos Psicossociais da Doença; Enfermagem em Reabilitação.

ABSTRACT

Objective: To understand the experience of families and the cost in the care of children and adolescents with myelomeningocele. **Method:** An exploratory research conducted with 16 families of children and adolescents with myelomeningocele users from a Rehabilitation Hospital in Belo Horizonte/MG. For data collection, interviews and observation were used during the three home visits to each participating family. **Results:** The average family income was about two minimum wages. The low socioeconomic level was aggravated by the difficulties in the free acquisition of materials to perform the care. The direct care costs were related to drug purchase, diapers, urinary catheters and transportation expenses, being lower for families of independent adolescents. **Conclusion:** Parents of children with chronic conditions experience economic and social barriers related to the cost of home care and need support with primary care and rehabilitation services.

Descriptors: Meningomyelocelose; Psychosocial Effects of the Illness; Rehabilitation Nursing.

RESUMEN

Objetivo: Comprender la experiencia de las familias y el costo del cuidado a niños y adolescentes con mielomeningocele. **Método:** Una investigación exploratoria realizada con 16 familias con niños y adolescentes enfermos de mielomeningocele de un Hospital de Reabilitación en Belo Horizonte/MG. Para la recolección de datos se utilizaron entrevistas y observación durante las tres visitas domiciliarias a cada familia participante. **Resultados:** El ingreso familiar promedio fue de aproximadamente 2 salarios mínimos. El bajo nivel socioeconómico se vio agravado por las dificultades en la adquisición gratuita de materiales para realizar el cuidado. Los costos directos de la atención médica se relacionaron con la compra de medicamentos, pañales, sondas urinarias y gastos con transporte, siendo menores para las familias con adolescentes independientes. **Conclusión:** Los padres de niños con afecciones crónicas experimentan barreras económicas y sociales relacionadas con el costo de la atención domiciliar y necesitan apoyo de los servicios de atención primaria y rehabilitación.

Descriptores: Meningomielocelose; Efectos Psicossociales de la Enfermedad; Enfermería en Rehabilitación.

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Como citar este artigo:

Freitas GL, Faleiros F, Silva KL. O custo do cuidado para famílias de crianças e adolescentes com mielomeningocele. Revista de Enfermagem do Centro Oeste Mineiro. 2019;9:e3282. [Access_____]; Available in:_____. DOI: <http://dx.doi.org/10.19175/recom.v9i0.3282>

INTRODUCTION

The myelomeningocele (MMC) is the most complex malformation of closing defects of the neural tube (NTDS) compatible with life and represents 75% of affected patients⁽¹⁾. The NTDS have causal multifactoriality and constitute the second largest cause of congenital malformations preceded only by heart disease⁽²⁾. The lack of folic acid is identified as the main factor responsible for the occurrence of the disease, highlighting, also, the maternal diabetes, zinc deficiency, the ingestion of alcohol, anticonvulsants and anesthetic drugs⁽³⁾.

Approximately 6000 children born with MMC, in Europe, in the period between 1991 and 2011. It is estimated that the rate of worldwide incidence is 0.2 to 6,4/1000 born alive, observing with higher values in less developed countries⁽⁴⁾. In the United States, it has been 0,34/1,000 born alive⁽⁵⁾. The incidence of cases in Brazil, is estimated in the 0,83/1.000 to 1,87/1,000 born alive; however, the real dimension of the problem remains unknown, since there is no nationwide survey, and studies point to divergent rates⁽⁶⁾. It recognizes the increase of survival in this audience and the need of compression (or comprehension?) of the repercussions in the quality of life for adolescence and adult life⁽⁴⁾.

The sensory and motor impairment varies according to the location - thoracic, lumbar or sacral - and the severity of the spinal injury⁽⁷⁾. As major sequels or neurological complications, there are hydrocephalus, poor formation of Arnold Chiari, cognitive changes, the spinal cord and the syringomyelia⁽⁸⁾. The urologic and intestinal disorders also require the need of continuing care at home, of complex nature and compromise the quality of life of affected persons and their families⁽⁹⁻¹⁰⁾. Moreover, children and adolescents with MMC may present difficulty in locomotion, musculoskeletal deformities and changes of cutaneous sensibility⁽¹⁰⁾.

The sequelae and complications from MMC impose the need for follow-up of a therapeutic plan turned to the different bodily systems affected by malformation, giving a character of chronicity. The chronicity condition requires continuity of care at home and the need to purchase and handling of materials, supplies and medicines related to the care, as well as to spent with transportation, for evaluation with different professionals or care for clinical interurrences^(9,11). The adaptations in the daily routine of children and adolescents with MMC

and their family are imperative, causing employment limitations for the parents, causing a strong impact in routine activities, in the financial reality of the family and the quality of life⁽¹¹⁻¹²⁾.

The costs with the care can be categorized into direct, indirect and intangible or emotional. The direct costs relate to the purchase of materials and supplies and expenses related to transportation, food and treatment. Indirect costs relate to loss or reduction of working capacity of affected individuals or their caregivers by the high demand and need for care. Integrate the indirect costs the benefit received by the government, absenteeism and early retirement due to disability. And the intangible costs or emotional are the ones who resonate in psychological conditions and inter-relational of children and the whole family, causing pain and suffering⁽¹³⁻¹⁴⁾.

The cost with the care for children and adolescents with MMC increases the chances of social vulnerability, interfering in their socialization with their peers in age and in the routine of the whole family⁽¹¹⁾. Brazilian studies that address the family experiences and costs in the care for children and adolescents with MMC are scarce⁽¹²⁾; thus, wonders the influence of the cost of care in the everyday life of the family of children and adolescents with MMC? Given this context, this study aimed to understand the experiences of families and the cost for the care of children and adolescents with myelomeningocele.

METHODS

This is an exploratory research of a qualitative approach, which used the methodological background of dialectics⁽¹⁵⁾, supported by the theoretical referential of the daily life of Agnes Heller⁽¹⁶⁾. The adoption of the dialectic and its essence, the contradiction, allowed the analysis of the dynamism, the transitoriness and transformations implied in the daily routine of children and adolescents with MMC and their family.

The study participants were 16 families of children and adolescents with MMC (16 mothers and 16 children and adolescents with MMC, 32 participants), who had already done the rehabilitation program in a reference hospital in Belo Horizonte/MG. The inclusion criteria were families of children and adolescents aged between 5 and 18 years old who participated in the rehabilitation program between the years of 2010 and 2015. Recognizing the continuity of care

at home, as a process that is built gradually and, considering the difficulties coped by the family, there was established as inclusion criteria the period of five years of follow-up of the child or adolescent by the institution. The exclusion criteria included families of children and adolescents with acute problems, reported at the time of the invitation, change of address or allowed in other institutions during the data collection period. To seek to understand the experience of families, institutionalized children were not included.

For the definition of the participants, it was estimated the schedule of visits to the institution in the month of May 2015. At this time there were 54 cases provided for children and adolescents with MMC. After consulting these charts, we identified 26 potential participants, since 28 records of individuals who did not meet the inclusion criteria were excluded. There was established contact via telephone with the mothers of 26 potential participants and 10 chose not to participate.

The data collection occurred between May and August 2015. Two tools were used for research: semi-structured interviews and observation, both led by a guide. We used a field journal for the record of observations, which were carried out during the three home visits to each family participating in the study. The visits were performed with an interval of 30 days. The interview was recorded after authorization of participants and held always in the first home visit, with an average duration of 45 minutes and total time of 10 hours and 36 minutes and 123 pages.

The semi-structured interview guide was prepared by the main researcher using her professional experience in the care for the children, the pertinent literature and the theoretical reference. The feat of home visits allowed the observation of daily activities of the participants and the interaction, by means of active listening, dialog, perceptions about the everyday reality that culminated in guidance of behavior and the achievement of care. The total time of observations was 52 hours and 37 minutes, with average time of one hour and eight minutes per visit.

The material obtained from interviews and observations was explored, utilizing the technique of Thematic Content Analysis, which uses the pre-analysis phases; analysis of the

material; and treatment of the results, to contemplate the method⁽¹⁷⁾.

In pre-analysis there was performed the transcription and coding of the interviews and observations. The interviews were coded with alphanumeric characters, particularly E1 to E16, regarding the order in which they were carried out. The letter "M" was added to the coding corresponding to the interview, when it was a case of the mother, and the letter "C" corresponds to the child or adolescent with MMC. For the analysis, was made to read in depth of all the material available and the procedures of clipping, classification and aggregation of units of meaning. The thematic analysis seeks to discover the meaning cores of a communication, whose presence or frequency means something to the analytic object studied⁽¹⁸⁾.

We used this guidance for the elaboration of the units of meaning, which were selected based on their relationship with the objective of the study and the analytical categories of continuity of care and of everyday life, being built the empirical category: "Family experiences and the cost of care".

The invitation to participate in the study was, in principle, made to the mother of the child or adolescent, via telephone. In that moment, it was explained that the invitation extended to the Son, he being a participant of the study and mentioned the necessity of signing legal document for both. In the first home visit, the objectives were strengthened, considering the possibility of withdrawal and was asked to sign the Informed Consent Form (ICF), by the mother and, at the end of Free and Informed Consent (TALE), by the participant under age.

The ethical aspects were observed as specified in Resolution 466/2012 of the National Health Council⁽¹⁹⁾. The project was approved by the Research Ethics Committee of Federal University of Minas Gerais (UFMG), under the Opinion N 1,036,625 and by the Ethics Committee of the Network of Rehabilitation Hospitals, number 1,089.123, both of 2015.

RESULTS AND DISCUSSION

The mothers participating in the study were between 26 and 52 years old, with an average of 37 years old. Although they are in productive age, only two women worked outside of the home. The majority of participants, 14 mothers, had formal work, before the birth of the

child with MMC, evidencing that their physical and emotional needs require effort, dedication and time breastfeeding.

As for schooling, three women stated that they possess the incomplete secondary education; six, the complete secondary education; six mothers stated that they possess the incomplete basic education and a declared to be illiterate. Two mothers had returned to study recently and were enrolled in higher education. It has been observed that twelve women were married, among which three reported that their husbands were unemployed at the time of the survey.

The historic construction and social role of women in society is reflected in the family organization, especially after the birth of a child with MMC, determining the frequency of mothers as caregivers, who often forego their life projects and goals to exercise this new role⁽¹¹⁾.

“After she was born, I had no more conditions of work. And I prefer to take care of what to leave another person” (M.E.16)

“I had to come to Belo Horizonte because the treatments are all here... and there is no appeal, until today. Moved here for her. And I also work” (M.E.10)

The indirect costs, caused by the loss of working capacity tongue, who no longer have a source of income, entails, yet, psychological and emotional wear, for the loss of paper or social function, causing also an intangible cost⁽¹³⁻²⁰⁾. Give a job outside the home, too, was an aspect identified in a study with mothers caregivers of children with cerebral palsy, who reported difficulty in getting leave them under the responsibility of other people, providing a break

from their own personal and professional life and an obligation on care⁽²¹⁾.

Children and adolescents with myelomeningocele were between 7 and 17 years old, with an average of 12 years of age; 13 were females and three males. Only three participants, female, were totally unrelated to the care and activities of daily living; two were very dependent on care of third parties, including, for food and 11 participants had partial dependence for the care and activities of daily life.

Regarding the use of medication, 14 made regular use of at least one medicine, among which two purchase charge, while 12 buy, at least, part of the medication used regularly. In virtue of the bladder and intestinal incontinence, the use of diapers is necessary and regular for 14 children and adolescents being that 13 need to buy them.

All participants make use of urinary catheter, for the emptying of the bladder, just a teenager used metal probe. Regarding the acquisition of disposable urinary catheter, six families reported cannot acquire this material free of charge.

For the realization of measures of intestinal reeducation, families need disposable gloves, being its irregular use among the participants. It was identified that four families buy this material and six acquire disposable gloves, free of charge, in the health units of reference.

Table 1 illustrates the regular use or not of materials and medicines needed to care for children and adolescents with MMC, as well as its form of access, whether by purchase or acquisition, next to the public network of health services.

Board 1 - Use and access to materials and medicines related to the care of children and adolescents with myelomeningocele. Belo Horizonte, MG, Brazil, 2015.

MATERIAL	REGULAR USE		IRREGULAR USE OR NON USE
	PURCHASE	ADQUIRED	
Medicines	12	2	2
Diapers	13	1	2
Disposable Urinary Catheter	6	9	1*
Gloves	4	6	6

Prepared by the authors *A teenager makes use of metal probe.

The care to child and adolescent with MMC in the household has a cost not only emotional, for the family, but also financial. This direct

financial cost is aggravated by chronicity, which requires continuous and increasing spending, since, with the growth and development of the

child, if your needs change with changing their support apparatuses, medicines and materials for the implementation of care. The demands of priority care for children and adolescents with MMC, require the frequent use of medications, diapers, urinary catheter and disposable gloves. The families have expressed difficulty in the acquisition of materials and medications with the basic network of healthcare services, which occurred in an irregular manner, showing a discontinuity of the primary care services in care for this demand.

The network of services of Basic Care or Primary Health Care represents the user's input to the health system, provides for the supply of inputs and basic medicines to the care and care must be based on the essential attributes of access, longitudinality, comprehensiveness and focused attention on the family, respecting the principles of doctrine of the Single Health System (SUS) of the integrality, universality and equity⁽²²⁾. However, the mothers highlighted difficulties concerning the acquisition of material and difficulties of attention to the child with chronic condition.

"The diaper also I was earning. In addition, I don't know what happened they stopped to donate the diaper. Since the last month. They were donating a package of diapers per month with 10 diapers. The rest was all purchased. A package with 10 does not give nor for a week" (M.E.8)

"I receive probes, but always is missing. When it does not come, we buy" (M.E.13)

The acquisition of materials free of charge represented a difficulty mentioned by all the families who see forced to buy inputs that should be provided. The low income and the need for materials purchase commit the budget of families, limiting, including their leisure and social activities.

Financial expenses with children and adolescents in chronic condition reach families of different socioeconomic levels and in different ways, and the financial difficulties, resulting from the treatment associated with high load of care may be related to greater likelihood of depressive symptoms in parents⁽²³⁾.

The literature review about the need of support to parents of children with cancer, the psychological impact, highlights the need for ongoing evaluation and monitoring of their mental health at risk of parental maladjustment, related to factors such as low socioeconomic level

and family income, lower level of education, unemployment and the risk and severity of illness of the child⁽²⁴⁾.

The average family income declared approximately two minimum wages (minimum wage at the time, R\$ 788.00), the low level of maternal schooling and parental unemployment expose the families participating in the study, the risk of emotional and psychological disorders. It should be emphasized that 12 families received the benefit of the Continued Benefit Payments (BPC), the value of a minimum wage, guaranteed by the federal government to elderly people with chronic conditions and low-income proven and only two had the benefit as a source of income.

The literature review, which examined the production of knowledge about the chronic conditions or chronic diseases in children and adolescents, also identified the low socioeconomic level compounded by difficulties of acquisition of materials and inputs, in health services, as a major challenge for the families⁽²⁵⁾.

The clinical weakness inherent to participants demands the need for regular monitoring by services and specialized health teams. The displacement until the reference services represents a direct cost mentioned by half of the families who participated in this study. Transport costs represent a difficulty reported by family resident, also, in the city of Belo Horizonte, not being an expense exclusive for families in other cities and who need greater displacements, evidencing the social challenge related to mobility and accessibility for children with disabilities.

"In fact, what I spend with him is a matter of petrol, too. Because I have to take diaper, to go to the hospital, sometimes I have to go to school. So, petrol everyone spends much" (M.E.5)

"You have to put petrol in the car to go. Sometimes when there is not my husband who takes me, I have to pay someone, paying the petrol of the person who is going to take me" (M.E.9).

In a study that assessed the financial experience of families in caring for children and adolescents with cancer, held in the municipality of the state of São Paulo, Brazil, showed that the increase in spending occurred, mostly with food, transportation, purchase of materials not granted by primary care services and the need for structural reforms in the home⁽²⁶⁾.

The families of the three teenagers (E.1, E.4 and E.7) presented independent monthly direct costs lower when compared to the other

participants of the study. The family E.1 reported direct cost with the purchase of urinary catheter for intermittent bladder catheterization clean. The family E.4 stated direct cost with medicines and napkins approximately R\$ 230.00 per month. The family of E.7 reported direct cost with the purchase of gel lubricant, for the urinary catheter and with transport, since the adolescent makes use of metal probe, and the medication is gained in the basic network of healthcare services. The families of two children, totally dependent (E10 and E16), who had severe cognitive impairment and made use of a greater number of medications, reported average monthly direct cost of R\$550.00. The remaining participants reported having average monthly cost of R\$ 290.00.

The intangible costs or emotional are immeasurable and relate to pain and suffering they cause emotional and psychological repercussions, compromising the quality of life of individuals affected by disease or chronic conditions and their caregivers⁽¹³⁻¹⁴⁾. It is subjective elements and difficult to assess, perhaps for this reason, little explored in the national literature.

"It makes you want to cry when you don't have... to buy things... it is not easy..." (M.E.3)

Children and adolescents with MMC require unusual care continuously throughout life, may cope clinical complications that require long periods of hospitalization and need monitoring by health services in a systematic way. Such aspects interfere in the socialization of children and adolescents, by the need of school absenteeism, preventing their coexistence with pairs of age, which can cause difficulty of interaction and social isolation. The quality of life of children and adolescents with MMC and their families can be compromised significantly, reflecting an intangible cost of great magnitude.

The weakness of children with disabilities is not related to their inability. On the opposite, it concerns their ability to adapt, to overcome risk factors, be they physical or social. In a society little inclusive, this adaptation is limited, and the vulnerability is related to the difficulties of social inclusion, to the clinical instability, to the restricted social life, to the difficulty of access to services by disarticulation of the system and the lonely family care⁽²⁷⁾. It is, therefore the nurse's role not only in providing care to children with MMC, but also in establishing the link with the family, to the transition of care for adolescence

and adulthood, to cope with situations of vulnerability in different cycles of life and to the pursuit of social inclusion and a better quality of life⁽²⁸⁾.

CONCLUSION

The biopsychosocial experiences that involve the care for children and adolescents with MMC in homes have a cost not only emotional for the family, but also financial, which is aggravated by the chronicity. The direct cost of care involves the need for purchase materials, as well as spending on transport, by the need of displacements. The direct costs for independent persons are smaller, when compared to the direct costs of children and adolescents totally dependent.

The indirect costs of care relate to the need of the mother to abdicate her own employment and accept the role of a caregiver, a fact which undermines the family budget and creates emotional distress. The emotional distress experienced by families has been exacerbated by the financial demand generated by care, evidencing an intangible cost. Professionals should consider the social and economic aspects of families, in drawing up the plan of care, seeking to ensure the adequate supply of essential inputs and develop strategies that minimize avoidable costs.

It was identified that families need the support from health services and show difficulty of acquisition of materials along the Network of Primary Health Care; however, the study sought not the social support network or social assistance, may be considered a limitation. It recognizes the need of research that deepen regarding the relationship of the network services, as well as the elaboration of studies those involve the cost for the care for children with chronic conditions. It suggests the effective integration, in the areas of education, health and social assistance, for the construction of directed public policies.

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Note:

Article extracted from the Doctoral Thesis: “The (dis) continuity of care of children and adolescents with myelomeningocele at home”, linked to the Nursing Graduate Program of the Federal University of Minas Gerais.

Acknowledgment:

To Dr. Roseni Rosângela de Sena (in memoriam), Emeritus Professor at the Nursing School of the Federal University of Minas Gerais, for her guidance, dedication and support for the realization of this project.

Received in: 10/02/2019

Approved in: 18/09/2019

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