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The continuity of care of children and adolescents with myelomeningocele: a descriptive study

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ABSTRACT

Problem: the complexity of care to children and adolescents with myelomeningocele, and the need for continuity in the home, represents a challenge for the caregiver. **Aim**: to analyze the continuity of care at home for children and adolescents with myelomeningocele. **Method**: a descriptive exploratory study using a qualitative methodology and theoretical and methodological framework of dialectics. Data were collected from 16 families, made up of children and adolescents with myelomeningocele and their mothers, through interviews and observation from May to August 2015. The observation took place during three home visits to each family. The interview was conducted during the first home visit. The data were submitted for thematic content analysis. **Preliminary results:** families have low income and face social challenges related to accessibility and to the acquisition of materials for care.

Descriptors: Rehabilitation; Myelomeningocele; Continuity of Patient Care; Caregivers.

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PROBLEM SITUATION AND ITS SIGNIFICANCE

Myelomeningocele (MMC) is the most severe form among the birth defects caused by defective closure of the neural tube. This malformation affects different body systems - neurological, renal/genitourinary, orthopedic - giving the body systems a chronic character and compromising the quality of life of children and adolescents affected and of their family(1). The rehabilitation of children and adolescents with MMC, aiming at autonomy, involves the training of parents or caregivers to perform care that goes beyond the hospital environment and need to continue at home(2). In terms of financial and emotional issues, it is possible to recognize the difficulties regarding family's suitability for the continuity of care(3).

GUIDING QUESTION

Which aspects interfering in the continuity of care of children and adolescents with myelomeningocele at home?

AIMS

Overall aim: to analyze the continuity of care at home, for children and adolescents with myelomeningocele, provided by the primary caregiver. Specific aims: to observe how the guidelines and the care provided at the hospital are followed by caregivers at home; to analyze the everyday lives of children and adolescents with myelomeningocele and their primary caregivers at home in terms of the provision of care; to identify aspects interfering in the continuity of home care of children and adolescents with myelomeningocele and the aspects interfering in their family.

METHOD

This is an exploratory descriptive study which adopts a qualitative approach. We used the dialectics as methodological framework, anchored to the theoretical of Agnes Heller. The project was approved by the Ethics Committee of the Federal University of Minas Gerais (UFMG), under number 1036625 of April 27, 2015, and by the Ethics Committee of Sarah Network of Rehabilitation Hospitals, under number 1089123, of June 1, 2015. The study included children and adolescents with MMC followed at the Rehabilitation Hospital Sarah, unit Belo Horizonte, and their primary caregivers. As inclusion criteria: to participate in the rehabilitation program in the last five years, be in the 5 to 18 year age group, resident in Belo Horizonte or cities within a radius of 60 km, and agreed to participate. Exclusion criteria were children with acute problems, change of address or hospitalization in other institutions during the collection period. In the period May 4 to June 4, 2015, were planned 54 consultations of children and adolescents with MMC with several professionals in the institution. After exploring the medical records associated with these consultations, the researcher identified 26 potential participants. Twenty-eight medical records of individuals were excluded because they did not meet the inclusion criteria. Among the potential participants, 10 refused to participate in the study. Consequently, the sample consisted of 16 families, represented by mothers, children and adolescents with MMC. The study scenario was the home of these families. Data collection occurred from May to August 2015, using as data collection techniques the interviews, guided by a semi-structured script, and observation. There were observations on home visits and all aspects considered relevant at the time were recorded in a field journal. The interview was made during the first of three home visits. Subsequent visits were aimed at the observation of the daily activities of the participants and the interaction through active listening and dialogue, seeking perceptions of everyday reality. The oldest participants signed the Terms of Consent (TCLE), and minors signed the Terms of Assent (TALE). The material from the interviews and the field journal was analyzed, based on the thematic content analysis technique proposed by Bardin, and on the relevant literature.

PRELIMINARY RESULTS

With the birth of children with MMC, mothers have become the primary caregivers. Children and adolescents in the study had an average age of 12 years and were mostly dependent on their mothers. Only three teenagers were independent. The continuity of care in the home was negatively influenced by the low income of the study participants, and exacerbated by the difficulty of acquiring medicines and materials for the patient's care. Also noteworthy were the social challenges faced by the families, represented by difficulties in accessing public places, schools and public transportation.

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