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Sensitizing mothers of children with microcephaly in promoting the health of their children*

Sensibilização das mães de crianças com microcefalia na promoção da saúde de seus filhos

Sensibilización de las madres de niños con microcefalia en la promoción de la salud de sus hijos

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ABSTRACT

Objective: To report the educational experiences of mothers or caregivers of children with microcephaly, as developed by an academic team with the theme of promoting these children's health. **Method:** This is an experience report by undergraduate nursing students and Health and Environment Post-Graduation students and professors of Tiradentes University on educational interventions carried out in three reference units for the care of children with microcephaly in the state of Sergipe. The study sample was taken by convenience. **Results:** A total of 70 mothers or primary caregivers of children with a confirmed diagnosis of microcephaly during the months of September to December participated in the study. The thematic-theoretical axes selected to describe the activities were promotion of healthy eating, importance of the mother and child bond, and early stimulation of children with microcephaly. **Conclusion:** The experience reported demonstrates the importance of educational strategies in promoting the health of children with microcephaly, providing additional training to mothers/caregivers to provide holistic and humanized care to these children.

DESCRIPTORS

Microcephaly; Health Promotion; Mothers; Caregivers; Family Nursing.

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INTRODUCTION

Microcephaly is a clinical finding that results from a congenital malformation, in which a child's brain development does not occur properly and can be caused by a variety of factors from different sources, such as chemical and infectious substances, bacteria, viruses and radiation. According to the World Health Organization (WHO), standardization criteria related to microcephaly are newborns with a cephalic perimeter of less than two standard deviations below the mean for gestational age and gender[1].

Congenital anomalies are related to intrauterine congenital infection by various pathogens. "The most common pathogens by 2015 were the *Treponema pallidum* bacteria that causes syphilis (S), the *Toxoplasma gondii* protozoan which causes toxoplasmosis (TO) and rubella (R) virus, cytomegalovirus (C), herpes virus simplex (H), together composing the acronym STORCH"[2]. The high incidence of confirmed microcephaly cases in live newborns in northeastern Brazil led the Ministry of Health to enact a state of national public health emergency between the years 2015 and 2017. Scientific evidence strongly indicates that the Zika virus is associated with the increase in microcephaly cases[3-4].

A child with this anomaly has fragility in their health conditions because microcephaly is often accompanied by motor and cognitive alterations, which vary according to the degree of brain injury. Therefore, the child will present a delay in neuropsychomotor development, and in some cases there may be auditory as well as vision impairment[5].

There are several complications associated with children with microcephaly such as difficulty in speech and vision, impaired memory skills and convulsions, especially in the first days of life, which can result from brain calcifications, arthrogryposis and seizures. Therefore, these children need greater attention from the family and to receive healthcare by multiprofessional team[3,6].

Being that microcephaly not only has repercussions on the lives of children who are carriers but also on the lives of family members and health services, it is extremely important to instruct mothers and caregivers to offer these children comprehensive care that includes measures to promote child health, with emphasis on improving the quality of life of the caregiver and who is being cared for. Health education is a key tool in this process, since it helps them acquire autonomy to identify and use the ways and means to preserve and improve the overall well-being of these individuals[7].

Health education leads to recognition of individuals' weaknesses and vulnerabilities, since they offer greater visibility of risk factors, health problems, and even difficulties in caring for others and for oneself. By having knowledge of these factors, the nursing team in conjunction with other health professionals can focus on the care of individuals by developing awareness mechanisms that clarify doubts and reduce the barriers related to care[7].

Initiatives should be implemented to actively engage the mother or caregiver in the child's daily routine in order to implement child health promotion, thereby enabling autonomy and responsibility for the health determinants of the child. A child with microcephaly needs specific attention, and therefore health education can facilitate this process of improvement in healthcare[2,8].

The theoretical perspective of the present report is based on the need to develop strategies that promote the health of children with microcephaly. Health education can enable knowledge reconstruction in order to promote the autonomy of the mother or caregiver in performing care practices. Thus, the purpose of this manuscript is to report the educational experiences of mothers or caregivers of children with microcephaly, as developed by an academic team on the theme of promoting the health of these children.

METHOD

Study design

This was a descriptive qualitative study.

Scenario

An experience report on educational interventions was conducted in three reference units which care for children with microcephaly in the state of Sergipe between September and December 2017. The experience was related by undergraduate students in nursing, as well as Postgraduate students and professors in the Health and Environment program. The academics in this study used a field diary to record all the information they thought necessary.

Population

The study population was composed of mothers or primary caregivers of children affected by microcephaly living in the state of Sergipe. The estimated number of mothers or primary caregivers enrolled in selected health services was 129 due to the number of cases of children with microcephaly[9].

The selected sites for educational actions were reference centers for treating children with microcephaly in the state of Sergipe: The Center for Medical Specializations of Children (*CEMCA – Centro de Especialidades Médicas da Criança*), Clinical Dentistry of Tiradentes University, and the Follow-up sector of the Nossa Senhora de Lurdes Maternity. All related services are located in Aracaju, the state capital. Educational activities took place in the morning and afternoon shifts in the selected units.

The participants were mothers or primary caregivers older than 16 years of age of children with microcephaly who had a brain abnormality diagnosed by imaging and by a specific and conclusive laboratory test for Zika or other STORCH (syphilis, toxoplasmosis, rubella, cytomegalovirus or herpes simplex) and who attended the reference centers as selected on pre-scheduled days to carry out the project.

The study sample was by convenience, totaling 70 mothers or primary caregivers of children with microcephaly.

Data collection

The actions were developed and planned together with the managers of the services where the visits for the activities

were scheduled, respecting the chronological order of the superintendent's solicitation of the services.

The following techniques were used to collect the data: 1) Participant observation with field diary of the research team; and 2) an interview with the mothers through an unstructured questionnaire about their needs and desires regarding their experience in caring for a child with microcephaly.

The themes of the meetings of the educational interventions in the mentioned places of the study were then selected according to the results for the needs and the wishes of the mothers.

The meetings were carried out through a series of talks and lectures, in which the selected issues were discussed for planning the monthly activities. At the first moment, the intention of the project was explained to the mothers, main caregivers and professionals of the service. In the second moment, the mothers present in the sectors were invited to participate in the meetings where debates related to the selected themes took place. When they coincided with commemorative dates, the meetings were livened by distributing toys to stimulate the cognitive development of the children and some basic gift baskets were given to the families.

Data analysis and processing

The most important topics and their division in relevant thematic-theoretical axes were selected from the interviews with the mothers. This selection was based on the analysis of the most prevalent themes, meaning those which appeared most often in the reports of these mothers (Figure 1). A description of the educational action formulated with the themes suggested by the mothers was carried out based on the participant observation reported in the field diary.

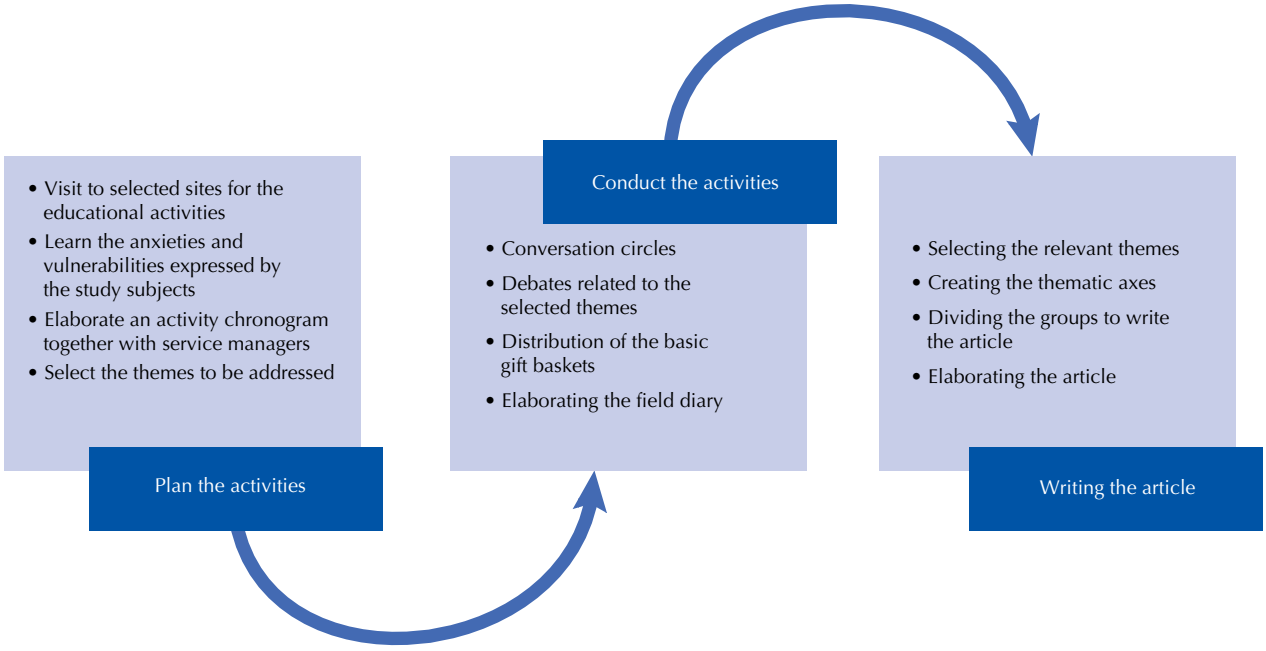

Figure 1 – Development of project planning and execution stages.

Ethical aspects

These experiences are part of the health education activities that encompass the "*Macroamor de mãe*" extension project, which was approved by the nursing coordination and extension board of the Tiradentes University in March 2017. The project was created with the aim to address the health information needs of the mothers of children with microcephaly, as identified by the students and teachers during the data collection phase of the research project.

It was approved by the Research Ethics Committee of Tiradentes University with Opinion no. 2.227.026, in accordance with the legal precepts of Resolution no. 466/12, of the National Health Council.

RESULTS

Sixty-seven (67) mothers and three primary caregivers of children with microcephaly participated in the actions during the 4 months of health education activities. These caregivers had a family bond of being the children's grandparents. The activities were distributed in the previously selected units and divided into thematic-theoretical axes as selected according to the needs identified by the participants, namely: promotion of healthy eating, importance of the mother and child bond, and early stimulation of children with microcephaly.

The "Promotion of healthy eating" theme was addressed in the first axis. The activity occurred via conversation circles in the vestibules of the offices while the mothers waited to

be called by the professionals of the unit. In this action, the importance of exclusive breastfeeding, swallowing disorder, correct positioning during feeding and care with devices such as nasoenteral and nasogastric tubes, gastrostomy and introducing the first foods were explained to them. Twenty mothers or caregivers of children with microcephaly participated in the activities.

At the beginning of the conversation activity with mothers about healthy eating, food introduction and swallowing disorders, participants reported difficulties with breastfeeding and introducing the first foods. In addition, they explained which position they used to feed their babies and which foods were introduced first. The questioning of the mothers was diverse, ranging from difficulties related to breastfeeding and introducing the first foods, comfort, and sleeping position, to psychomotor development and home care. Insufficient knowledge about the care needed in the child's diet was perceived throughout the conversation.

Therefore, the mothers were advised about the importance of exclusive breastfeeding during the first 6 months, in addition to stimulating the baby's proper latching. Mothers who were unable to exclusively maintain breastfeeding were instructed to purchase lactational formula offered by the state for free. More and more mothers or caregivers of children with microcephaly expressed doubts regarding the feeding of children during the lecture. Another important point also discussed was the correct way to prepare food and the types of food to be introduced first according to the child's age range. In addition, mothers and caregivers were instructed on essential care in food administration by nasogastric and nasoenteral tubes.

There were reports of difficulties related to infant feeding when a mother reported that her daughter acquired pneumonia associated with food bronchoaspiration due to poor positioning during the meal. The mother was instructed to provide only pasty foods in agreement with the diet prescribed by the nutritionist, and to position the child correctly with the body slightly inclined and with their legs lower in relation to the rest of the body.

There were some barriers that hindered and limited the relationship between mothers and their children during the actions conducted in the project. Thus, the theoretical thematic axis was created: the importance of the mother and child bond, in which difficulties and fears were exposed in the care process of their children through a conversation circle, being problematized as they were revealed. The activity included the presence of 25 mothers or caregivers of children with microcephaly.

The mothers reported not accepting the congenital anomaly that their child has and how it ends up being reflected in their daily habits and consequently in their bond with the child. In addition, the target subjects of the educational action unanimously explained about the difficult moment to receive the news that their child had a congenital malformation related to the Zika virus, which would cause a definite loss in its growth and development. The diagnosis that the child had a chronic illness was often only given at the time of the baby's birth, constituting an even greater shock to the mother for having to live with the news that her child might not survive.

The lack of support from the Social Security and Unified Health System (*SUS – Sistema Único de Saúde*) was also highlighted by the participants as the main cause of the mothers' hopelessness regarding their children. In addition, a lack of legal scientific support for the treatment strategies of children with microcephaly left many mothers and caregivers unsure of what should be done in relation to their child's treatment.

Rejection was observed as the main reason for abandonment, as many mothers did not feel able to care for their children because they had to give up their tasks due to the need to constantly care for the child. Social exclusion and lack of support from the health services caused many mothers to abandon their children, delivering them to the care of neighbors and grandparents.

After problematizing the themes, a dynamic was developed that stimulated the mother-child contact in order to break down barriers created by the difficulties in the care and limitation of the child. Thus, a demystification process of fragilities present in the child was initiated, with strengthening the mother-child bond as a fundamental strategy for clinically improving the children.

The last activity was a talk and workshop with 25 mothers or caregivers of children with microcephaly, including the actions of the last theoretical-thematic axis, entitled "Early stimulation of children with microcephaly", which aimed to teach simple practices of reflection stimulation of the child at home. Due to the proximity of the year-end festivities, the action that occurred in December also had a commemorative Christmas theme. Some mothers expressed their doubts about the growth and development of their children, and so problematizing the themes began at this point. The activities were very productive in clarifying several doubts that the mothers had regarding the delay in the growth and development of their children. A lack of training and poor service offered by some professionals working in the *SUS* was also exposed.

Mothers who had a better financial condition acquired a health plan for their children in order to remedy the *SUS* care deficiencies. Even so, because some specialties dealt with specific problems, they were not registered in the health care providers, leading the mothers to incur extra expenses on their child's health.

Therefore, the team of students and professors together with a physiotherapist, a speech therapist and a pediatric dentist held a conversation with the mothers and the main caregivers of the children on how to reduce the impairment caused by congenital malformation. These guidelines involved simple interventions that could be applied in the daily routine of mothers at home, such as stretching the baby's legs while changing its diapers, using gestures, colored objects and toys that emit sounds to stimulate cognition, as well as developmental cues of the first teeth and stimulation of the swallowing reflex. At the end of the action, toys were distributed to help mothers stimulate the child's reflexes at home.

In addition, because it was an event that had the purpose of celebrating the year-end festivities with the intention of providing social support, basic gift baskets were given to each family.

DISCUSSION

Mothers of children with microcephaly face daily challenges of caring for children with various changes in their development and growth. Based on this situation, the extension project enabled the opportunity for those involved to learn the reality lived by these mothers who also face economic difficulties, access to services and health information. By promoting educational health actions, it is expected that affected individuals will be transformed into multiplier agents, disseminators of information, and also strengthen relationships between mother, child and health services.

This experience report is in line with the literature on applying health education techniques to strengthen the care of children with special needs. A study carried out with children with special health needs showed that health education is a tool which enables resolving doubts, exchanging experiences, and to promote safety in care[8]. Another study which sought evidence in the literature on the use of health education in promoting the growth and neuropsychomotor development of newborns demonstrated the potential success of the results when using educational strategies to provide guidelines and clarifications related to nutrition, immunization and use of medications. In addition, the study reinforced the importance of the mothers' and their families' participation in constructing child care[10]. Thus, it is necessary to stimulate the adoption of educational practices in health services with a focus on caregivers to improve the quality of life of children with microcephaly.

The shortage of adequate health information related to healthy eating, breastfeeding and the proper position for breastfeeding the baby was noticed in the mothers' and caregivers' reports participating in this study, especially those related to feeding a child with microcephaly. A study with an educational focus in the neonatal unit found effective results in promoting the nutritional care of infants through educational interventions with their mothers or caregivers[11]. It is fundamental to adopt adequate health practices in childhood, especially foods in the first years of life, because there is a high nutritional need to ensure the growth and development of the child in these periods.

Inadequate nutrient intake can lead to childhood vulnerability, which may compromise nutritional status and lead to the development of nutritional deficiencies or excesses. These conditions may make the child more susceptible to diarrhea and infections, as well as impair development of their motor, visual, mental and intellectual systems[12]. According to the Brazilian Ministry of Health, a child with microcephaly is more susceptible to illness due to the inefficient supply of nutrients, resulting from their low swallowing capacity and absorption of food[8]. Therefore, it is necessary that mothers and caregivers of these children receive adequate nutritional guidance which focuses on exclusive breastfeeding.

Exclusive breastfeeding offered in the first 6 months of life is the best food choice because it represents a positive health gain, in addition to the initial development of the emotional relationship between mother and child[12]. Studies have already shown the direct relationship of breastfeeding with benefits in growth, nutrition, intellectual, motor and psychoemotional development, that it collaborates in forming the child's immune system and provides protection against gastrointestinal, respiratory and allergic infections[11,13-14]. Exclusive breastfeeding should be encouraged through the use of appropriate technique that stimulates proper latching and demystifying the fear of breastfeeding a child with swallowing disorder, and increasing the confidence and commitment of these mothers in caring for their child[15].

A child with microcephaly may have great difficulty in feeding, which may be related to swallowing disorders, irritability, craniofacial disproportion, delayed eruption of the first teeth, among other factors[16]. In view of the need for information related to the swallowing disorder of these children, this study addressed the essential care at the moment of feeding and in administrating food by tubes through an educational intervention in order to avoid bronchoaspiration of the food. Another study which reported an educational experience in promoting infant care stated that it is important to pay special attention to the nutritional health of a child to avoid complications in their development and growth[17]. Therefore, guidance and training caregivers in relation to the feeding care of a child using tubes is extremely important, since this procedure requires the necessary minimum knowledge involving administration of diets, cleaning tubes and stomas to be done at home[18].

In the educational interventions in health carried out in the present study, it was possible to perceive a weakening in the bond between the mother and the child. This finding is in agreement with a study with mothers of children with malformations, in which it was demonstrated that chronic congenital anomalies represent an enormous obstacle to the child's development and to their family relationship, especially with their mother, who is the person almost exclusively responsible for all care during this process. The arrival of a child with some type of disability can generate difficult situations in a family, mainly due to the lack of information about the clinical conditions of the disease[19]. A study that evaluated the mother-infant interaction at the moment of hospital discharge showed that establishing bonding and attachment can be hindered by a lack of opportunities for the mother to interact with her child, causing a disruption in the future relationship of both[20]. Therefore, it is necessary that the health team host the family, providing support for child care and psychological support for mothers and caregivers. In addition, guidance should be given on the clinical situation of a child with microcephaly, promoting its care and bonding the mother with her child.

The creation of a mother-child bond is a facilitating factor for care of the child, and it is incumbent upon health professionals to be responsible for stimulating and disseminating important information so that the mothers or

caregivers feel capable of performing it correctly[21]. Given this, it is extremely important to formulate strategies that inform, emphasize and value the presence of the mother in the caring process of her child.

Questions by the mothers or caregivers of children with microcephaly on their children's growth and development was resolved by giving them educational information about their growth and development, as well as their early stimulation. This report was also evidenced in another study carried out in a public educational center in Santa Catarina, which used educational strategies to disseminate basic concepts of early stimulation of babies, resulting in an improvement in their motor and intellectual development. Actions which instruct parents of children with abnormalities in their development should be elaborated with the purpose of reinforcing the family's participation in the child's treatment, improving their interaction and facilitating understanding of the individual needs of each baby[22]. Early intervention is defined as adequate and continuous stimulation that takes into account the sensory areas, enabling the child to develop to the maximum of their neuropsychomotor potential[2,14].

Early stimulation of the child is to make their brain, even when immature and developing, capable of receiving normal sensations and responding to them properly. Family members play a very important role in the treatment of a child with microcephaly, mainly because their need for this support will be constant[14]. The home environment needs to be stimulating, such as when changing clothes, bathing, offering toys and food, making the child's daily care routine promote their development[3]. In this way, technical capacities for early stimulation should be disseminated, and health professionals are essential actors in disseminating and instructing this information to these mothers and caregivers.

In addition to microcephaly, there are numerous other disorders caused by congenital infection related to STORCH + Zika such as important alterations in vision, hearing and motor development which demand comprehensive care with a differentiated look[6,14]. Microcephaly has become a major public health problem because of its complex nature and its repercussions on the family and health services. A study with children with neuromotor delay in the state of Minas Gerais emphasized that the healthcare of children with special needs should be considered in an interdisciplinary way for rehabilitating and improving the quality of life of these children[23]. It is the responsibility of this team to host, guide and encourage parents during the rehabilitation process of the child, to encourage family members to interact with the child through actions which aim at their development and promote their functionality, autonomy and independence[7-8,14].

CONCLUSION

The reported experience demonstrated the importance of educational strategies in promoting the health of children with microcephaly, providing additional training to offer holistic and humanized care focusing on improving the quality of life of their children. The care of these children requires the present and constant performance of the mother or caregivers, since this morbidity will be present for their whole life.

Conducting this experience gave greater visibility to the needs of the mothers or main caregivers of their children, in addition to allowing immersion in the lived reality in the project, acquiring new knowledge, and deepening in the theme and understanding of the healthcare network of these children.

The activities provided personal and academic growth to the nursing undergraduates involved in the actions, because it was possible to put the planned educational strategies into practice and to develop the academic's role as an educator; a skill widely used in the daily practice of nursing. It was possible to visualize the importance of health education in diffusing knowledge through extension to the population. The importance of team performance with an interdisciplinary focus in promotion and attention to the health of children with microcephaly is well known. Implementing methodologies which favor health education becomes essential to improve the quality of life of these children and their caregivers.

Mothers and caregivers of children with microcephaly benefited from the actions, especially given the emerging microcephaly situation, as health services in Sergipe and Brazil are still in the adaptation and structuring process and many gaps are still open. Therefore, the project's actions were important as a support to assist mothers and caregivers in their challenges related to the care of their child.

RESUMO

Objetivo: Relatar as experiências educativas das mães ou cuidadoras de crianças com microcefalia, desenvolvidas por equipe acadêmica na temática da promoção da saúde dessas crianças. **Método:** Trata-se de relato de experiência vivenciado por alunos do curso de graduação em enfermagem, discentes e docentes do programa de Pós-Graduação em Saúde e Ambiente da Universidade Tiradentes sobre intervenções educativas realizadas em três unidades de referência no atendimento à criança com microcefalia no estado de Sergipe. A amostra do estudo foi de conveniência. **Resultados:** Participaram da pesquisa 70 mães ou cuidadoras principais de crianças com diagnóstico confirmado de microcefalia, durante os meses de setembro a dezembro. Os eixos temáticos-teóricos selecionados para descrever as atividades foram promoção da alimentação saudável, importância do vínculo mãe e filho e estimulação precoce de crianças com microcefalia. **Conclusão:** A experiência relatada demostrou a importância das estratégias educativas na promoção da saúde de crianças com microcefalia, proporcionando capacitação adicional às mães/cuidadoras para que estas ofereçam um cuidado holístico e humanizado a essas crianças.

DESCRITORES

Microcefalia; Promoção da Saúde; Mães; Cuidadores; Enfermagem Familiar.

RESUMEN

Objetivo: Relatar las experiencias educativas de las madres o cuidadoras de niños con microcefalia, desarrolladas por equipo académico en la temática de la promoción de la salud de esos niños. **Método:** Se trata de relato de experiencia vivida por alumnos de la carrera universitaria de enfermería, discentes y docentes del programa de Posgrado en Salud y Ambiente de la Universidad Tiradentes acerca de intervenciones educativas realizadas en tres unidades de referencia en la atención al niño con microcefalia en el Estado de Sergipe. La muestra del estudio fue de conveniencia. **Resultados:** Participaron en la investigación 70 madres o cuidadoras principales de niños con diagnóstico de microcefalia, durante los meses de septiembre a diciembre. Los ejes temáticos-teóricos seleccionados para describir las actividades fueron promoción de la alimentación sana, importancia del vínculo madre e hijo y estimulación precoz de niños con microcefalia. **Conclusión:** La experiencia relatada demostró la importancia de las estrategias educativas en la promoción de la salud de niños con microcefalia, proporcionando capacitación adicional a las madres/cuidadoras a fin de que estas proporcionen un cuidado holístico y humanizado a esos niños.

DESCRIPTORES

Microcefalia; Promoción de la Salud; Madres; Cuidadores; Enfermería de la Familia.

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