

## MOTHERS OF VISUALLY IMPAIRED CHILDREN: DIFFICULT AND EASY ASPECTS FACED IN CARE

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### ABSTRACT

*This study aimed to identify the difficult and easy aspects faced by mothers of visually impaired (VI) children in their care. It is a descriptive qualitative study, developed in the second semester of 2011, with ten mothers of children with visual impairment from an Educational Center for the Visually Impaired, located in southern Brazil. Data were collected by means of semistructured interviews and submitted to thematic content analysis. The identified difficulties were the lack of knowledge regarding the disease and how to take care of the child, the lack of access to health services, overload generated by the dependence of the child and lack of support and prejudice within their own family. The easy aspects involved the desire for the child's healthy development, the chance of being in touch with qualified professionals for their education, and the contact with other VI children. Therefore, it is important to qualify the family for the care of VI children so as to ensure the development of skills and competencies enabling them to live with quality.*

**Descriptors:** Family. Child. Blindness. Nursing.

### RESUMO

*Objetivou-se conhecer as dificuldades e facilidades enfrentadas pelas mães de crianças com deficiência visual (DV) no cuidado. Trata-se de uma pesquisa qualitativa, descritiva, realizada no segundo semestre de 2011, com dez mães de crianças com deficiência visual, de um Centro de Educação para deficientes visuais, no sul do Brasil. Foram realizadas entrevistas semiestruturadas e análise de conteúdo temática das informações. Foram verificados como dificuldades o desconhecimento acerca da doença e da forma de cuidar da criança, a falta de acesso aos serviços de saúde, a sobrecarga pela dependência da criança, a falta de apoio e o preconceito na própria família. Quanto às facilidades, foram referidos a vontade do desenvolvimento saudável das crianças, a convivência com profissionais qualificados para sua educação e o contato com outras crianças com DV. Faz-se importante a instrumentalização da família para o cuidado à criança com DV como forma de garantir a aquisição de habilidades e competências, possibilitando-a um viver com qualidade.*

**Descritores:** Família. Criança. Cegueira. Enfermagem.

**Título:** Mães de crianças com deficiência visual: dificuldades e facilidades enfrentadas no cuidado.

### RESUMEN

*Se objetivó conocer las dificultades y facilidades enfrentadas por las madres de niños con discapacidad visual (DV) en el cuidado. Estudio cualitativo descriptivo, realizado en el segundo semestre de 2011, con diez madres de niños con discapacidad visual, de un Centro de Educación para discapacitados visuales en el sur de Brasil. Se realizaron entrevistas semiestructuradas y análisis del contenido temático de las informaciones. Como dificultades se tuvo el desconocimiento sobre la enfermedad y la forma de cuidar del niño, la falta de acceso a los servicios de salud, la carga por la dependencia del niño y la falta de apoyo y prejuicio familiar. Como facilidades se refieren la ganancia del desarrollo saludable del niño, la convivencia con profesionales cualificados para su educación y contacto con otros niños con el mismo problema. Es importante la instrumentalización del familiar para el cuidado de niños con DV para asegurar la adquisición de habilidades y competencias que les permitan vivir con calidad.*

**Descriptores:** Familia. Niño. Ceguera. Enfermería.

**Título:** Dificultades y facilidades enfrentadas por la familia para cuidar a niños con discapacidad visual.

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## INTRODUCTION

Visual impairment (VI) is understood as any form of organic impediment associated with visual illnesses that compromise the ideal functioning of sight. This impairment, once present, may lead to the total absence of an individual's visual capability. VI may happen either with or without the perception of light, and may be inherited or acquired due to various causes, such as: congenital glaucoma or cataract, retinopathy, syphilis, among others<sup>(1)</sup>.

Therefore, visually impaired individuals are considered to be those presenting none or reduced vision, which limits their daily activities<sup>(2)</sup>. Every year, approximately 500,000 children across the world develop VI<sup>(3)</sup>. In Brazil, 16.6 million individuals present some degree of VI, either total or partial, affecting all ages. Among these, 150 thousand are classified and self-reported as blind<sup>(4)</sup>.

In the light of this reality, VI influences the functional development of children, affecting their capability of self-care and mobility, making their social interactions difficult and compromising the development of their independence<sup>(5)</sup>. The most frequent limitations include restrictions in mobility and in the exploration of places and objects, which lead visually impaired individuals to be considered unable to participate in group activities and contribute or develop their roles or occupation<sup>(6)</sup>.

Therefore, children who have special needs, such as VI, are often isolated from contact and from establishing bonds with peers, having their interactions restricted only to relationships with adults and family members. This isolation may compromise the child's independence, since VI is understood as a limiting factor for life and for the development of strengths.

The role of the family in the care and development of the child is extremely important, since the family nucleus comprises his/her first social support network. Family interaction is seen as the basis and support for the promotion of several forms of child development<sup>(7)</sup>.

The most important care relationships take place within the family environment, by means of actions of protection, embracement, respect and strengthening of the other. Families living a situation of disability need countless strategies to cope with the situation and to encourage child independence<sup>(8)</sup>.

The family environment is considered to be the first space of child interaction and socialization. However, this environment is affected by the

birth of an impaired child, not only concerning the feelings of its members, but also due to the structural and functional changes faced by the family<sup>(5)</sup>. For this reason, these families need professional assistance so as to be prepared to take care of the VI child.

In this sense, it is the duty of health professionals to plan actions aimed at these children and their families, as well as to encourage self-care and independence<sup>(9)</sup>. With the purpose to facilitate the care provided by the family to the VI child, early intervention is found to be important, based on the orientation of the visually impaired child and on the maintenance of positive stimuli leading to the development of skills and self-care<sup>(9)</sup>.

Since family care towards the VI child is understood as fundamental, the guiding question of this study was: what are the difficult and easy aspects faced by mothers caring for a visually impaired child? Based on this question, the purpose of this study was to identify the difficult and easy aspects faced by mothers caring for a visually impaired child. The knowledge produced in this study will assist health/nursing professionals in preparing families who take care of VI children.

## METHODS

This is a qualitative descriptive study. Descriptive because it describes the phenomenon the way it is experienced<sup>(10)</sup>, whereas its qualitative approach allows to understand the feelings and values of each individual based on their perceptions<sup>(11)</sup>.

The present study was developed in the second semester of 2011, in an Educational Center for Visually Impaired Children, in Southern Brazil. This school provides primary education, from the first to the fourth grade. Besides the regular classrooms, there are also resource rooms, rooms for sensorial stimulation, a computer lab, a library, arts and crafts, pottery and physical education, with the practice of sports such as soccer, judo, dance and the development of activities of daily living (ADL), such as making the bed, cooking and others. There are also restrooms, a patio, an office and a teachers' room.

Since it is an institution for VI individuals, some symbols are easily observed, such as: handrails to facilitate moving around the school; educational projects using exclusive high-relief materials; rooms where people with visual limi-

tations are stimulated, with lights; software and different devices, such as a translator to Braille, printer and copy machine in Braille and an adapted computer lab.

The study participants were ten mothers of VI children who, after receiving information about the study purpose and methodology, signed two copies of the Free and Informed Consent Form, with each participant keeping one of the copies.

Data were obtained by means of a semistructured interview, performed with a script containing questions regarding the care provided by the family to the VI child, and analyzed as per the thematic content analysis technique proposed by Minayo<sup>(11)</sup>. This technique was developed in three phases: pre-analysis, in which the registration units that guided the analysis were identified; material exploration, in which the initial information obtained was classified and grouped into themes; and processing of the results obtained, in which data were interpreted and correlated with authors who studied the theme.

This study was performed in compliance with the guidelines of resolution 196/96 of the National Council of Ethics in Health for human research<sup>(12)</sup>. The study proposal was forwarded to the Health Research Ethics Committee of CEPAS-FURG, and later approved under the protocol number 105/2011. The reports of the study participants were identified with the letter F, and followed by the number of the interview, so as to assure their anonymity.

## RESULTS

Two themes emerged: difficult aspects faced by the family in the care of a visually impaired child and easy aspects faced by the family in the care of a visually impaired child.

### Difficult aspects faced by the family in the care of a visually impaired child

After receiving the child's VI diagnosis, it is observed that some families are not aware of the pathology that led to the visual impairment and face the lack of access to health services and information from health professionals to provide them with support in the care of the child. The unawareness regarding the situation experienced may lead to the fear of not knowing how to take care of the child, which generates difficulties.

*One of the difficult aspects is that we don't have much access to things [...] like doctors and people who explain things. I had to learn from practice. There was no one to teach me how to use the eye drops [...] her exams. I was really scared of not knowing [...]. This is the difficulty: having people from your field (health) to explain things to us. (F1)*

It is verified that taking care of a child with special needs arises various feelings within the family<sup>(13)</sup>. Feelings of fear and inability are common until the family learns how to provide care. Projects are interrupted in face of the arrival of a new family member and the diagnosis of VI, which may also lead to feelings of grief due to the loss of the idealized perfect child. Hence, in order to provide basic care to the child and facilitate his/her adaptation to the visual limitation, the family must be assisted by health and education professionals so as to play their role properly<sup>(13)</sup>.

The unawareness regarding the pathology that led to VI, the lack of access to health services and the lack of information from health professionals to provide them with support in the care of the child may have a negative effect on the family structure, making the care of the visually impaired child burdensome and the family vulnerable. It is important to highlight the need to create programs to follow-up these families, such as groups for support and education in health, as well as the need to promote the network of social support as a means to subsidize family care<sup>(14)</sup>.

In addition, the family mentions the overload generated by the permanent need for attention in the care of the child.

*I have to leave the others at home to bring her [...]. It is difficult because if she weren't blind she would be able to learn how to walk on her own and I would be able to give more attention to my other children. My youngest son had a seizure. It was difficult to seek help for him because I have a blind girl and other children at home. The worst aspect is that she is the oldest child, she could help me take care of the others, but she can't. It is tiring, because I have the house, the other children, and I still have to take her to medical exams. (F2)*

It is evident that mothers faces overload, generated by the child's permanent need for attention and care. It is understood that the care of these children is singular, due to their frailty, and requires a care practice based on specific knowledge to support the care<sup>(14)</sup>.

This overload in the provision of care, in some situations, is a result of the lack of family support, reflected in the father figure.

*The worst aspect is that I don't have anyone at home to help me take care of her. Not even her father helps me. He thinks that because she's blind it the mother's duty to take care of her. (F2)*

In face of difficulties in the care process, a network support is necessary so as to encourage confidence and the development of skills that favor the care of the child. Therefore, nursing professionals must see the family as a unit to be cared for, which increases the child's chances of wellbeing. Visual impairment requires different care attitudes from those employed towards children who can see, evidencing the dependence of the VI child. This fact causes frustration and stress in the family due to the fear of not knowing how to take care of the child.

*My daughter has several difficulties. One of them is when she has her period. She depends on me to help her reach and change her pad. She is a girl and she needs me for everything. She cannot be alone. I fear when she has to take her medications. I never let her get and take them by herself. It is very stressful. (F3)*

*There is always a new difficulty. When she was a little girl it was the shower. She couldn't see and would scream to take a shower. After that it was the period of walking. It was horrible when she fell. In her situation, difficulties never stop coming up. It is frustrating! (F4)*

Despite the challenge and difficulties found in the care of a visually impaired child, family members are capable of playing the role of caregivers efficiently, demonstrating to be adapted and confident in the care actions, and able to perceive the child's changes and advances<sup>(15)</sup>. In order to take care of a VI child efficiently, they must be assisted, acquiring the knowledge necessary to qualify them for providing care.

The families mention the need to struggle against the tendency of overprotecting and infantilizing the child, mainly when this child presents other care demands besides the visual impairment.

*I would ask him whether he wanted to use the toilet. Whether he was thirsty, as if he couldn't speak! I was under the impression that he wouldn't have the initiative to do things. The overprotection. At first, when he was around*

*five years old, I wouldn't let him even think of doing things, because I thought that since he was blind, he was going to have difficulties doing anything. Now, he goes to the bakery alone, but I thought this would never happen. (F5)*

*I always raised her as a little girl. I think I overprotected her. She didn't develop in many aspects because I treated her like a little child. Here, at school, her teachers talk to me about the need to encourage her to be independent, but she is my only daughter. (F6)*

Another study revealed that overprotective actions may reduce the possibilities of independence of a VI child. Some concerns like the fear that the child might get hurt leads parents to protect the child at home, guiding and leading his/her each and every step. It is evident that parents fear letting the visually impaired child play with sighted children and there are cases in which the parents speak for the child, trying to solve his/her problems and even schedule the time to play with them so as to avoid the contact with other children who can see<sup>(16)</sup>. These overprotective attitudes make the interaction of the child with the surrounding world difficult, and prevent him/her from developing strengths.

Parents also revealed the prejudice against the VI child by members from their own family.

*I went shopping with her grandmother and she bought a teddy bear for my daughter, her twin sister. When I realized that her grandmother wasn't going to buy one for her too, I got in the line to buy it. My mother-in-law looked at me and said: - Why are you buying her a teddy bear if she can't even see it? I answered that although she couldn't see, she had the right to play just like her sister. Her hands work like her eyes. She could hold the teddy bear. That hurt me, because I wondered what would have happened if I wasn't there. (F7)*

*Her brothers are ashamed of her, so they don't help take care of her. Because of their prejudice they don't go out with her. If they can, they don't even mention they have a blind sister. I have even seen my oldest son helping other kids from the street mock her. There are many difficulties. (F3)*

Regarding the prejudice experienced within the family, it is necessary to study the feelings of other family members and sighted children, if there are any. Family members may fear that they might be asked to help take care of the child, afraid of assuming the responsibility. On the other hand, sighted siblings may feel jealous of the sibling with

VI, due to the fact that this child has the attention of other family members and the shame of his/her appearance. Therefore, there would be simultaneous feelings of anger, jealousy, abandonment and rejection, added to guilt, fear and sadness<sup>(7)</sup>.

### Easy aspects faced by the family in the care of a visually impaired child

Regarding the easy aspects found in the care of the visually impaired child, there is the desire that the child grows and develops healthily, which encourages the family member to play the caregiving role with patience and affection.

*I think the easy aspect of taking care of a child in this condition is wanting to do so. If we want to do it nothing can stop us. I am going to be really sincere, you must be patient and show affection to take care of a blind child. (F8)*

*I never give in. If I face a difficulty I always think of a way to overcome it. I do it my way, without any special education or something like that. Sometimes I see other mothers saying: - Can your son do this? Mine can't! But I when I ask how many times they tried, they answer once. This is what I am talking about. Being a mother of a blind child means being patient. You have to know that things might take a while to happen, but they do! (F10)*

In face of a situation they had never experienced and to which they are not prepared, the family of the VI child will need both emotional and technical guidance and preparation in order to facilitate the interaction of the child in society, that is, this family also needs to be rehabilitated<sup>(17)</sup>. Blindness imposes modifications in the family life, demanding re-adaptations for coping with it as to satisfy the needs and promote the autonomy of the VI child.

The family must be oriented by health professionals regarding the importance of the child stimulation, the family-child communication and their interaction with the child, acquiring new knowledge that qualifies them for the care. The stimulus produced by this family makes them approach the visual problem of the child, making them sensitive to the leads and needs of their children<sup>(17)</sup>.

The child's visual impairment mobilizes family members to form a social support network around him/her, helping each other mutually, to guarantee that he/she is cared for.

*The help from my family. If it wasn't for them, I wouldn't be as calm as I am today, in dealing with him. I thank God for having a family that embraces him with me. From the moment I was told he wouldn't see, my mother gave me all the support. She was always with me. No mother wants to learn that her son is blind, but I was really lucky for having a family that helps me. My cousin, who is almost a sister, stays with him when I need, my relatives never say no. My family got closer after this happened with my son. (F5)*

Another source of essential support, in the assistance to the family in the care of the VI child, is the Educational Center for the Visually Impaired. The possibility of relying on a place where the visually impaired child is going to be around professionals who are qualified in special education, children with the same impairment and their family members, is found to be an important source of support and stimulation.

*One of the easy aspects was coming to school. Here I had the support I needed to take care of her. It gets easier because the mothers can talk and teach each other. Our fear is calmed down. I think seeing my daughter being well treated by her teachers also facilitates. At school everyone strives, because it is a place dedicated to it, prepared to teach how to coexist. I think this is an easy aspect. I have been here for almost 10 years. I work as a volunteer while my daughter studies. She is around other blind children here and professionals who are prepared to teach blind children. This doesn't happen in other schools. (F1)*

Another easy aspect evidenced in the study is the existence and access of the child to the Educational Center for Visually Impaired Children, where these children are going to be around other children with VI and professionals who are specialized in the education of visually impaired children. It is known that the co-existence of visually impaired individuals in society is important, since this will provide them with greater possibilities of learning and adapting to daily limitations.

It is verified that the acquisition of knowledge regarding VI is a facilitator for the family care towards the child.

*I read a lot about his cancer. That is what helped me take care of him. I went for it. I had to really study it, during these six years of disease. (F9)*

The exchange of knowledge and experiences leads the groups to discuss and share their diffi-

culties and limitations, which originates ideas and opinions that help overcome the situation experienced. Mind structures are going to be built by the children, through their possibilities of interaction and action over the environment and its quality<sup>(18)</sup>. Therefore, through meaningful, social, emotional, cognitive and adaptive experiences, the child is able to explore possibilities by interacting with people outside the family circle and with the surrounding world, favoring his/her development<sup>(18)</sup>.

The construction of language and the overall development take place in the socioemotional relationship, thus, children with VI need to relate with other children at their age, sighted or not, in order to be able to identify themselves, build their bodily image and test their perceptive, symbolic and pre-logic hypotheses. Hence, living with other children at their age range will contribute to the acquisition of concepts and the construction of language<sup>(7)</sup>.

These experiences are not only stimulating, but also a means for the child to participate in discussions and debates regarding his/her problems and limitations, as well as to learn the strategies used by the others. In these experiences, the children have the opportunity to establish new relationships, to get to know themselves better, to discover their skills in the others and the contribution that each one of them may offer to the group in a process of learning and constructing knowledge<sup>(7)</sup>.

Therefore, it is relevant that parents, caregivers and health professionals interact, stimulating the child early, introducing him/her to the social context, creating a favorable environment so that he/she achieves a compatible development to the current stage of life, until he/she may have the ability to become independent and socially active<sup>(17)</sup>.

## FINAL CONSIDERATIONS

The data found in this study evidenced that mothers face unawareness as for the cause of the child's visual impairment and the lack of access to health services. They receive poor information from health professionals regarding VI and the best way to take care of the child. There is also overload in the family, generated by the permanent dependence of the VI child. This overload results from the lack of support of other family members who live with the child. In addition, there is poor participation of the father in the direct care of the children.

Overprotective actions, which are performed as a result of feeling sorry for the VI child, lead to difficulties in care. Caregivers perceive they are infantilizing VI children, minimizing their strengths, thus they eventually require more care than what would be really necessary. Another difficulty faced by the family in the care of a visually impaired child was the presence of prejudice among members of their own family. On the other hand, it is verified that these difficulties may be overcome, since the experience between the family and the impaired child and those acquired over time may minimize the mothers' fear of caring.

As a result of the several difficulties experienced by the mothers in the daily care of the VI child, many of them discredit the existence of easy aspects in the care process. However, the desire of seeing their children develop healthily leads to the obtainment of strengths in the execution of their role as caregivers of a VI child. Another easy aspect was the existence of the Educational Center for the Visually Impaired. In this place, the VI children are assisted by professionals who are qualified for their education, having their special care and education needs satisfied. In addition, they have contact with other visually impaired children and their families, favoring the interaction between them.

For some mothers, the acquisition of knowledge regarding the subject appears as a positive facilitating factor in the family care towards the child. Despite the difficulties, it is verified that the VI of the child may orientate family members towards the formation of a network of social support, aimed at assuring the ideal care of the child.

It is concluded that the work with the family of a visually impaired child becomes an important facilitator in the adaptation to the situation of this child so that he/she may fully assume and live with the impairment safely. The family must be guided by health/nursing professionals as for the importance of child stimulation, communication and family-child interaction.

Among the limitations of this study, there is the lack of studies developed by nurses with visually impaired children and the questions involving their care. It is believed that either few nurses work together with visually impaired children and their families, or they do not publish their experiences and knowledge, choosing not to contribute. Child VI is a work field for nurses who establish health education as one of the pillars of their practice.

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