BLIND PARENTS: THEIR EXPERIENCE IN CARE FOR THEIR CHILDREN[1]

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This study reflects on the difficulties and strategies of blind parents to take care of their children. The situations were related to breastfeeding, bathing, feeding, domestic accidents and administering medication. They use touch, hearing, smelling and the support network, contributing to their autonomy.

DESCRIPTORS: visually impaired persons; blindness; child

PADRES CIEGOS: EXPERIENCIAS SOBRE EL CUIDADO DE LOS HIJOS

Reflexiones sobre las dificultades y las estrategias que los padres ciegos usan cuando cuidan a sus hijos. Las situaciones se refieren a amamantar, bañar, alimentar, accidentes domésticos y dar remedios; también sobre el uso del tacto, la audición y el olfato. La importancia de la red social que contribuye para su autonomía.

DESCRIPTORES: personas con daño visual; ceguera; niño

PAIS CEGOS: EXPERIÊNCIAS SOBRE O CUIDADO DOS SEUS FILHOS

Reflexões sobre dificuldades e estratégias de pais cegos, quando cuidam de seus filhos. As situações referiam-se a amamentar, banhar, alimentar, acidentes domésticos e dar remédio, e o tato, audição e olfato e a rede social contribuindo para sua autonomia.

DESCRITORES: portadores de deficiência visual; cegueira; criança

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INTRODUCTION

In the development process of human beings, care attributes are fundamental and the best persons to talk, demonstrate and dedicate themselves to care for their children are the parents. They practice a special form of care, which often becomes their existential and essential reason for the development of their children[1]. Disabilities can interfere in this care, however, and it is important for health professionals to assess how these parents feel, which difficulties they face and what help they need[2].

To support this reflection, in-depth interviews were held, a dynamic and flexible technique that is useful to apprehend a reality, guided by the following question: *talk about your experience as a blind person in care for your children.* Subjects were parents who had children after becoming blind and who accepted to participate in the study after signing the free and informed consent term. The study was approved by the Research Ethics Committee at the Federal University of Ceará (COMEPE), registered as No 345/05.

RESULTS AND DISCUSSION

One blind father and one blind mother were selected, identified as Maria and José. Maria, 28 years old, married, housewife, basic education student, mother of four children. José, 53 years old, married, father of two daughters, public servant. After exhaustive reading of the interviews, excerpts were grouped into difficulties and strategies found to take care of their children. The tables display theme categories for the sake of a better visualization.

Table 1 – Difficulties blind parents face to take care of their children

Maria	
Feeding	*... I didn't know how to breastfeed, hold, make the baby burp...*
Hygiene	*... I didn't know how to give a bath, I was afraid the baby would fall, drink water from the bath....I didn't take care of the belly button, I was worried about the dressing...*
Health care	*... the liquid medication... there is no mark on the cup to guide me...*
Accidents	*... the two-year old boy cast paper into the fire... the girl got burnt by oil...*
José	
Father's role	*... the children should not feel responsible for us... blind people who had children with normal sight and who gave up their cane, gave up Braille and got dependent on the children...*
Accidents	*... medication care...marking in Braille... not letting things within reach...*

Help is needed for the mother to breastfeed correctly and to prevent puerperal breast problems and early weaning[3]. Latching on well is fundamental to prevent breast problem and favor affective bonding[4]. Maria mentioned difficulties to bathe the baby, insecurity about the water temperature, accident occurrence, what products to use for the baby's hygiene. Using touch and smell to take care of the child, having tools at hand and safety measures transmit self-confidence to the mother and preserve the child's well-being.

To administer liquid medication, the parents adopt a single-dose cup, which allows them to perceive when it is full by touching. Domestic accidents are prevented by storing cleaning materials, toxic and caustic products in adequate places and by keeping children away from stoves, windows and stairs. Accident prevention is part of blind persons' training for daily activities and first aid can be taught using adequate educational technology[5-6].

José highlights his responsibility as a father and manifests his rejection of blind people who delegate this role and become dependent on their children with normal sight, at a moment in life their children need them most. Nevertheless, blind parents find strategies to take care of their children.

Table 2 – Strategies blind parents find to take care of their children

	Maria
Learning	*... I took care of the baby by myself... but I had to touch everything I did... if you don't see you have to touch...*
Feeding	*... I learned to breastfeed over time... then I started to give other things, fruits, mash, I made it myself...*
Hygiene	*... I started to change a diaper... my sister... she taught me to give a bath, take care of the belly button, change, dress... I used to put in the water and knew the right temperature with my hand... I took care of the other three...*
Health care	*... I used to take them to get vaccinated, checked their body temperature... legs and arms... sign of fever, drops... I use my finger, I feel and count the drops...*
Accidents	*... there was a cloth catching fire... the six-year old girl extinguished it because she can see... if you talk with them, they remember it and won't insist...*
	José
Learning	*... we attempted to create our own resources, our own methods to be able to deal with the problem...*
Feeding	*... I manage to take care of the house, the children... giving food...*
Health care	*... medication, we mark them in Braille or with the name of the drug... the care all parents have to take, we did that, raising our children...*
Accidents	*... organize... always in the same place... grope or smell... everything is marked...*
Father's role	*... with my cane, so that I would depend on my cane and not on my daughters... someone said: "take care of your father"... I said: "she is not accompanying me, I am accompanying her, I am the responsible"*

The strategies blind parents adopt to take care of their children are based on the remaining senses, touch, smell and hearing. Using support networks is fundamental to help the blind mother to take care. She associated them with independent care strategies. Maria received support from her sister, who taught her how to feed and bathe. She also received solidarity from her neighbor, who helped her out in unexpected situations, when she took her child to the pediatrician, received instructions on how to identify fever and secretion in wounds.

To feed her son with a spoon, she holds the child's head to have an idea where the mouth is. Solid foods are offered with the spoon in small quantities and liquids in a cup. The keyword used was holding, that is, touching the child, touching the food, feeling the skin and water temperature. Organizing objects is fundamental to take care of the children. Autonomy was evidenced, although the search for support from other persons was emphasized.

When administering medication drops, they feel the drops fall with their fingers. Although legislation determines that medication should be identified in Braille, this has not been fully adopted yet. The blind are also entitled to medical prescriptions transcribed to Braille[7]. Health professionals admit that they do not master the skills needed to deliver care to these people and mention not knowing how to communicate with blind and deaf people[8].

The occurrence of domestic accidents demonstrates that the home and prevention measures are not adequate[5]. Activities of daily living the blind have to do include cooking, washing, ironing and cleaning the house, which are part of the skills they learn in special schools[9]. The blind use non-visual means to establish relationships with the persons and objects around them. They should never be deprived of real experiences, as these maximize their social adjustment[10]. José's testimony is an example of adjustment, with self-assurance and good self-esteem.

FINAL CONSIDERATIONS

This study verified the complexity of the situations blind parents experience in breastfeeding, feeding, bathing and administering medication. While

blind fathers highlight social relationships, blind mothers emphasize biological care. They develop creative strategies to take care of their children, using smelling and touching, as well as the support of families and neighbors. Health professionals, especially nurses, should get closer to these persons and produce knowledge for this group, which receives so little attention in our society.

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