ORIGINAL ARTICLE

FACILITIES AND DIFFICULTIES OF THE CHILD WITH VISUAL IMPAIRMENT FOR THE EXERCISE OF INDEPENDENCE: PERCEPTIONS OF THE FAMILY

ABSTRACT

Objective: to know the perception of family members of children with Visual Impairment about their facilities and difficulties for the exercise of independence. Method: a descriptive study, with a qualitative approach, with Thematic Analysis. Data collection was conducted through recorded semi-structured interviews, with ten family members of blind children of the Education Center for Visually Impaired, from a city in Brazilian South. The research project was approved by the Ethics Research Committee of the FURG by means of the CAAE n° 23116.002937/2011-89. Results: from the analysis of the interviews, the two categories have emerged << Perceptions about the facilities of the child with VI for the exercise of independence and >> << Perceptions about the difficulties of children with VI for the exercise of independence >>. Conclusion: it was possible to verify that the formation of a support network focused on the inclusion and accessibility of the child with VI can assist her in acquiring its independence, qualifying its living.

RESUMEN

Objetivo: conocer la percepción de familiares de niños con Deficiencia Visual acerca de sus facilidades y dificultades para el ejercicio de la independencia. Método: estudio descriptivo, de abordaje cualitativo, con Análisis Temático. La recolección de datos fue realizada por medio de entrevistas semiestructuradas grabadas, con diez familiares de niños ciegos del Centro de Educación para Discapacitados Visuales, de una ciudad del sur del Brasil. El proyecto de pesquisa foi aprobado pelo Comitê de Ética em Pesquisa da FURG e mediante CAAE nº 23116.002937/2011-89. Resultados: a partir das análises das entrevistas, emergiram as duas categorias << Percepções acerca das facilidades da criança com DV para o exercício da independência >> e << Percepções acerca das dificuldades da criança com DV para o exercício da independência >>. Conclusão: foi possível verificar que a formação de uma rede de apoio voltada para a inclusão e a acessibilidade da criança com DV pode auxiliá-la na aquisição de sua independência, qualificando o seu viver.

Study performed with support of the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior/CAPES, 2009-2011. Rio Grande (RS), Brazil.

English/Portuguese


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Nurse, Doctorate’s Student from Programa de Pós-Graduação em Enfermagem, Universidade Federal do Rio Grande/PPGENF/FURG. Scholarship Student of CAPES. Rio Grande (RS), Brazil. E-mail: agpintanel@hotmail.com; 2 Nurse, PhD Professor from the Nursing School and Programa de Pós-Graduação em Enfermagem, Universidade Federal do Rio Grande/PPGENF/FURG. Rio Grande (RS), Brazil. E-mail: acgomes@mirius.com.br; 2 Nurse and Special Student of the Master Course in Nursing from Universidade Federal do Rio Grande/FURG. Rio Grande (RS), Brazil. E-mail: daliamoder@best.com.br; 4 Nurse, PhD Professor from the Nursing School and Programa de Pós-Graduação em Enfermagem, Universidade Federal do Rio Grande/PPGENF/FURG. Rio Grande (RS), Brazil. E-mail: adriana@vetorial.net
INTRODUCTION

Visual Impairment is characterized by partial or complete loss of the ability to see. The individuals with total loss of vision or luminous perception, in a bilateral way, are considered blind. The vision plays an important role in the development of independence; So, the Visual Impairment (VI) in childhood may bring limiting consequences for acquisition of skills and performance of activities. The performance of daily tasks leads us to the importance of the independence and autonomy of people with blindness or low vision, as well as in learning of these tasks and use of technical help.

Among the harms caused by Visual Impairment are the difficulties of locomotion, comprehension and spatial orientation, limitations in communication and performance of household tasks, as well as the limitation for self-care. Daily tasks, also known as daily living activities (DLA), activities of independent and autonomous life or daily practices include hygiene activities and personal care, clothing, feeding, cleaning and home organization, leisure, among other tasks performed in daily life.

The way how the blind subject interacts with the world, develops its daily activities and communicates is different and occurs according to its resourcefulness, since it will fetch, dynamically, the best interpretation of what is presented to him. Blindness imposes limits and require adaptations to their carriers and if the information does not reach the blind through the sense of vision is by the other senses that he has endless possibilities to learn about the world in which is inserted.

Limitations arising from VI can interfere with functional ability of the child, committing the achievement of the childish independence. The independence can be seen as an important factor for the life and building of the childish self-esteem. Thus, the limitations arising from VI can drive the child to the exclusion or social isolation, being a major obstacle to the triad: child with VI, family and health professionals.

A child visually deprived shows a reduction in their process of cognitive development, since it has some restriction of exploration skills. Through the vision, the child builds its perceptions and representations about the things and the world. Since there is a visual impairment, it has difficulties to organize and build definitions and concepts.

The child with visual commitment may need the help from other people to the perception and formation of concepts, since it has no ability of distinguishing similarities and differences between objects through the vision, or, only, for tactile perception. Thus, individuals around it represent important elements in helping to the building of concepts and understanding on the world.

The building of concepts, mobility and environmental control may be impaired due to the absence of childhood stimulation. It is observed that the orientation of child with VI should be properly developed as a way to facilitate the acquisition of its independence. It should be understood the family as their primary social support, which is responsible for its stimulation. Thus, it is a task of the health / nursing professionals to perform a proper guidance to the child, in order to transform it into a core of childish stimulation.

It is in the relationship of the family / child that the subject will be helped in developing the necessary skills and competencies for its independence. The family environment is the first space of socialization. In fact, it suffers the changes with the birth of a handicapped child, not only in terms of reactions and feelings, but also with regard to the structure and operation.

The learning mediated by interaction with the family can assist in the development of the most varied cognitive functions, which favors the understanding that the child holds from the context in which it is inserted. The development of the child with VI may be grounded in the effectiveness of educational and instructive shares that this receives. That is why, the environment in which they are inserted must be characterized by stimulation for independence and building of the childish self-esteem.

Assist the child with VI to become itself independent, develop skills and have its previous existing skills recognized is essential to the development process itself. In this sense, the family encompass a rich core of knowledge, which can help the child to become itself independent. To act in an effective way, the handicapped child needs to be instrumentalized by health professionals.

It is hoped, with this current work, sensitize the health professionals / nurses who care for children with VI for a new gaze to the family caregivers, in order to guarantee their access to the health services and information which enable them to care for the child from the perspective of its independence. Thus, contribute to the emergence of a new family, in which children with VI are lovingly welcomed, minimizing their anguishes and fears.
It is understood that take over this role is not easy. So, the question that guided this study was: what is the perception of family caregivers of children with VI about their facilities and difficulties for the exercise of independence?

**OBJECTIVE**

- To know the perception of family members of children with Visual Impairment about their facilities and difficulties for the exercise of independence.

**METHOD**

This current study was extracted from the Cutting of the Master Thesis entitled *Strategies of the family to ensure the independence of children with Visual Impairment: subsidies for nursing action*, in force from January 2009 until the year 2011. We conducted a descriptive research, with qualitative approach. A descriptive research describes the investigated phenomenon, enabling its comprehension through lived experiences. It is qualitative because it works with a universe of meanings, reasons, aspirations, beliefs, values and attitudes, allowing greater depth of relationships, processes and the investigated phenomena.

The research was held in the second semester of 2011, in a Supplementary Education Center for the Visually Impaired People, from a city of the Brazilian South, with ten families of blind children. Data were collected through semi-structured interviews, which were single with each participant.

These interviews addressed issues relating to their perception on the facilities and difficulties for the exercise of independence of children with Visual Impairment (VI). The respondents were invited to participate in the study, being scheduled day and time for the interviews that were performed in the Supplementary Education Center for the Handicapped People, in a doctor’s office, through a questionnaire with open questions about the thematic.

Eight mothers and two grandmothers of children with Visual Impairment who regularly attend to the aforementioned Supplementary Education Center have participated in the study. The inclusion criteria of the research were: to be familiar of child with DV, treated at Supplementary Education Center for the Handicapped People and accept to participate in the study, by signing the Free and Informed Consent Form (FICF), allow the recording of the interview and dissemination of the results.

This consent form was signed in two copies, and one copy was given to each participant.

Data were analyzed by Thematic Analysis. This technique is operationalized in three steps: Pre-analysis, in which the units of record that guided the analysis were identified; Exploration of Material, in which the initial obtained data were classified and aggregated into categories; and, finally, Treatment of obtained results, in which the interpretation of data was performed, correlating them with scholars of thematic.

The provisions of Resolution 196/96 of the National Health Council on Ethics in Health for researches with human subjects were taken into account. The project was sent to the Ethics Research Committee of the FURG and approved through the *Certificado de Apresentação para Apreciação Ética* (CAEE) nº 23116.002937/2011-89, receiving favorable opinion to its publication under the Protocol nº 36/2011. The speeches of the family members were identified by the letter F, followed by the number of the interview, as a way of guaranteeing their anonymity.

**RESULTS**

A thematic analysis of the data has generated two categories: Perceptions about the facilities of the child with DV for the exercise of independence and Perceptions about the difficulties of the child with DV for the exercise of independence.

- Perceptions about the facilities of the child with VI for the exercise of independence

Some mothers reported that even with DV, the child is able to overcome its insecurities and reach independence. They refer as facilities the child’s will for learning, its smartness, its curiosity and its sensibility in pursuit of knowing the world that surrounds it.

*I believe that the will [...]. Then, I think it will help. Then, he is going to be alright in life, without me.* (F1)

*One good thing is that she asks on everything [...] Here at school, they say it’s good, because she learns easier, she is very smart.* (F2)

*She is agile, interested. It’s like I say: it’s easy to take care of her, because she knows everything. She is very smart!* (F3)

Another listed facility by the family is the access to services and trained people for the stimulation of the child with VI. The existence of the Supplementary Education Center for Visually Impaired provides the child with VI to live with qualified professionals for its education; so, their special needs of care and education are attended.
Facilities, it's funny! She had a teacher who taught all she already knew. Later, she the teacher referrals her to someone else, who began testing her, she is really very smart and it eases up everything (F4).

They also showed as facility the coexistence of the child with other children with VI and their family members, favoring the interaction among them and the development of abilities for the exercise of daily living activities in a independent way.

Here at school, children help each other and play with her enough. She feels happy to play with someone who understands her. (F4)

Here at the school for blind people, the children help her, take her into the school and play a lot with her. She feels happy to play with someone who understands her. (F10)

He interacts more with blind people, children here from the school for blind people. He has no brother; he does not visit other schools and coexist more with adults. (F5)

Here, the ludic activities with children are slower, quieter. (F1)

For one of the grandmothers, the acquisition of knowledge about the matter arose as a positive facilitator factor for the stimulation of the child with VI, allowing it to develop itself properly.

I read a lot about it [...]. Then, it helped me for taking care of him [...] I had to actually study throughout these six years of disease. (F5)

Perceptions about the difficulties of the child with VI for the exercise of independence.

As reported by some mothers, the difficulties of the child with VI are numerous, making it a challenge to promote its autonomy and independence. Some of them, even, believe that the carrier of VI will never be totally independent.

Well, I think there are blind people that have facilities, but she has none [...] what type of facility will have? (F6)

She has all type of difficulties. She will never be independent. Would you imagine have a daughter like that? When she needs to eat, calls you, calls you for bathing her. You can spend three hours in the school and she does not realize it. That is all. She knows she has to eat, because the hunger appears. (F10)

For some interviewees there are not possibilities of autonomy in society for the child with VI. It was placed by them that, in current world, people are in a hurry to perform tasks, reach places and conquer their space. Thus, they relate the independence and autonomy to the ability of living in the world, according to an accelerated rhythm, following the changes in this society. In this sense, they reported that patients with VI always need to be monitored, not being able to become fully independent, since there are numerous obstacles to be overcome, which are hard to be overcome by the visually impaired people.

I think what hinders him to be independent, sometimes, are the people themselves. People do not have patience. They want everything quickly. We have to have patience. People who see, sometimes, takes a long time to learn, why he, who does not see, has to do everything fast? For she does not need me, well, I think it actually has difficulties. (F4)

She has all type of difficulties. She will always have to have a shadow, i.e., a caregiver. I do not believe in her independence. They will be lost even if someone is there. I do not believe it. She will never be independent. (F6)

In the other school that she does not visit is so and so. There, the children who see do not have calm, want to run and I think that, for not hurting her, they let her out of the playing. (F10)

We found, in the speeches, the fear of the family is that - in search for autonomy - the child may suffer accidents and risk its life. Thus, the patients who are carriers of VI suffer when trying to win an independent life and always need attention and support from others to carry out the most varied activities. It is believed that because of this perception and these fears, the family fail to encourage, effectively, the child with VI, preventing it from reaching its fullness. Some mothers and grandmothers did not introduce stimuli in the environment to foster the child's independence, because of concern about its integrity. For them, the independent actions may mean risks to the health and life of the child with VI.

My son may not be hurt! So, I have to always be careful. He has a tumor in his left eye; in the right, he has prosthesis. So I'm afraid that he hits something. He is very hectic [...]. This is tricky, because if I leave him alone, he can get worse. (F5)

She never walks alone on the street! I've seen blind being run over. Shall I want she, daughter, stays under a bus? Of course, not! I do not leave her alone. I do not believe in her independence. (F6)

The family has interpreted that, currently, there is no respect for differences, which hinders the exploration of the environment by the child. Thus, it becomes necessary, in addition to the understanding on the
limitations, a better structuring of the environments, so that the carrier of VI can move with safety.

I think it’s just when exiting [...] in the transport [...] at home has nothing bad. Everything was arranged for free movement. (F7)

Independence is bad because of walking on the street. The locomotion of the blind people on the streets is hampered by lack of structure. I see that people do not give space to the independence of the blind individuals. (F1)

For people who see is hard, right? Now, with this limitation that she has, I think everything would be hard for her. I know and I realize. There are several here that are quite independent, but in her case, I, as a mother, I think I still have to do everything. I know she is capable, but I think it will be bad. (F7)

The data showed the fear of the family about the limitations that the VI will cause to the child’s future. When the family think about its schooling, or professional, fears for his safety and punctuates all the sacrifice that will be needed for that the child can study and work, and this is reason for many questionings. They made a comparison between the risk that the child suffers when leaving the home environment, to which is familiarized, and the street, the school or the workplace, which are unknown and frightening places.

The cars are a great concern. How will she cross the street? We, who see, can be run over! Thus, it is due to the movement. Lots of people are walking. Nobody respects, goes over the little blind man (laughs). (F4)

Outside the home it will be tricky, because how will she walk on the street alone? Imagine! If she works, she will come slowly down the street, grabbing the things. It is dangerous for anyone who sees. Already have risk. [...] And to make college is the same thing. [...] If she arrives late, she will lose tests and tasks. It’s very complicated. It’s really sad, do you know? [She cries] I would be proud to see her graduation. Here, they say it’s possible, but poor child. Will have to have someone just to take and bring her, both for studies and job. So, this person will always be available to her. And when this person cannot? (F8)

We found that, in spite of knowing on the need for the child to be introduced in these environments, as an important test for its independence, this fact is generator of concern and shows the limitation of the child with VI to achieve a promising future.

If she gets a job and has to steps out of the service at night! Imagine if a burglar sees a blind at night, alone, walking slowly, because she has to find each sidewalk? As for this fact, I think it will prevent her for having many opportunities. What time she has to leave home to reach the service? It saddens me. (F8)

Another difficulty to be faced by the child with VI is the lack of patience of the people. The different being can be interpreted with strangeness. They reported realizing that the world is not adapted to the carrier of VI, and this fact makes more difficult the inclusion of it.

There was one day that I got on the bus with her. At that moment, an old woman looked at me and said: - Is your daughter sick? And I replied that she was not sick, but she was special. Then, the old woman said like this: - It’s because she has to give the bank for me. I said she had paid the ticket and would not let her get up to make way for a person who later goes to the dance hall. People do not realize that she is special. Sometimes, I had to get her because she had been dragged within the bus. People trample the poor little girl. So, shall I make way and have to take care of her during the entire journey? (F9)

She complains to me that children in school (conventional) are afraid to play with her; they think she has more problems than the vision. (F4)

The family is afraid that its protection inhibits the initiatives of the child to become independent and finds it difficult to change their behavior, for fear of the child cannot adapt itself.

I do not know if it’s because we do not let her feel the freedom. I overprotect, anticipate all her wishes for she does not have difficulties. Even though I do not have time only for her alone, I’m always there! I guess I do not let her reach the freedom! (F9)

I think he has created his independence, but he has to get out of his dome. He has to perceive more that it is no longer his little school, his little house. He will have to get out from under mommy’s skirt. We do everything for him and that’s not good. In the bus itself, sometimes, we meet a driver without patience. He is not positioned yet and the driver has already started the bus. So, quickly, I have to hold him. There are many barriers in this world. If for those who see the world is cruel, imagine for my son, who is blind. (F5)

**DISCUSSION**

The independence of children with VI should be encouraged so that children who are carriers of visual impairment can enjoy a normal life, using methods that make them easily cope with their limitations. The social
inclusion of the child carrier of visual impairment should be encouraged by health professionals in order to provide a labor future for it.  

As autonomy, it should be understood the ability to give itself the standards of behavior and performance, and this concept is essentially social. You could say that autonomy includes a factor which develops through the experiences lived by the child in their environment, and that is directly related to the ways of life and the kind of social interaction to which this child is subjected. Thus, every child with VI is able to develop in a satisfactory way. Nonetheless, for that this development occurs, the child in chronic situation requires time, dedication and investment of the family.  

The act of exercising its potentialities towards autonomy and independence not only motor, but cognitive and psychosocial, like feed itself and moving itself by means of its own abilities, produces positive effects on self-esteem and social interaction of the blind child. There are several obstacles that limit or, even, prevent locomotion and free movement of people with VI in the performance of their daily activities.  

The environmental adaptation becomes essential for the facilitation of activities that, subsequently, can trigger the independence of the carrier of VI in a safe way. In order to facilitate its autonomy, it should be rethought the reorganization of physical space in order to promote not only better circulation and mobility of the visually impaired individual, as well as for those who live with this subject.  

A study about the inclusion of children and adolescents with special needs showed that 17% of interviewed mothers identified the need for adequacy of the environment to the children with disabilities. The family states that the VI creates insecurity in movement of the child by the environments, in view that, because of visual impairment, the child has a narrow notion of space that surrounds it. This fact can make the child feels insecure and afraid in the face of the possibility of being alone in an environment, reinforcing their dependence on their family caregivers and the possibility of never becoming independent, being overprotected by the family members.  

In a study about the health care of people with disability, several overprotective actions arising from their caregivers were found. It is believed that these actions may reduce the possibilities of independence of the child with VI. Some fears, such as fear of children get hurt, make the parents protect the child within the house, guiding and leading every step of it.  

As reported, there is the fear of seeing the child plays with sighted children. In some situations, the child is instructed not to play and isolate itself. There are cases where the parents speak for the child, they try to solve its problems and even arrange a time to play with these to avoid the contact with other children. These attitudes of overprotection hinder the child’s interaction with the world around it and make it not develop its potentialities.  

The educational process of the child with DVI requires specific methods and systems, such as: Braille system, orientation and mobility techniques (which are to guide the individual to move around with independence in environments, such as: home, school, banks and street) daily living activities (which are to guide the student to acquire basic knowledge of hygiene, feed and clothing, among others) and learning of the Soroban techniques (apparatus adapted for the execution of mathematical calculations).  

The process of social exclusion of people with disabilities, such as the case of the blind child, is as old as the socialization of the human being and - in the face of this situation - the families may encounter difficulties for its social integration. Probably, this is one of the reasons for the visually impaired individuals and, also, people with other disabilities, still suffer prejudice and discrimination.  

The prejudice is in assuming that the blind is a less capable subject. Some may hesitate to touch or guide the blind, while others generalize the vision impairment under the form of a complete inability, so that the individual shouts at the blind as if it were deaf or tries to lift it as if it were cripple. The individuals who have any disability bring with themselves a history of exclusion and prejudice before the society, constituting a serious social problem. Blind individuals, for a long time, were forgotten of the society because of their peculiar characteristic: not see.  

Some people think that the blind individuals live in eternal darkness, are sick, unable and, due to their handicap, cannot make or build anything. On this view, it is not difficult to understand why the disabled people are stigmatized and stereotyped as sick. The society, by little knowing, understanding and accepting the different designs attributes, negative designations, and, thereby, exclude them from participating in it.
Thus, the disabled people start to absorb, internalize and transmit the image that they are sick. Therefore, this view limits the possibilities for a broader experience in leisure and social coexistence, limiting them only to environments of their larger domain, such as home and school.

The independence of child carrier of VI can be compromised by feelings of pity and sympathy, often developed by those who live with it. These feelings trigger attitudes of overprotection, as to protect it, excessively, at home; guide it or lead her to places without guidance to certain places; avoid that it plays with sighted children; not allow playing to take greater power and seek to solve its problems judging the child's disability in their resolution.21

It is understood the need to prepare families to cope with the limitations of the VI in children, so that they believe in the need of it to become as independent as possible to build its identity as someone capable of making his own decisions.

CONCLUSION

The study aimed to understand the perception of family caregivers of children with VI about their facilities and difficulties for the exercise of independence. Mothers have indicated as facilities for the development of independence of children with VI the child's will to learn and overcome its difficulties; its smartness, curiosity and sensitivity.

Another feature highlighted in this study was the existence of the Supplementary Education Center for the Visually Impaired José Alvarez de Azevedo. In this space, the child carrier of VI can live with qualified professionals for its education, and its special needs of care and education can be attended. They (carriers of VI) may also have contact with other children with VI and their families, favoring the interaction among them. For some mothers and grandmothers, the acquisition of knowledge about the topic emerges as a positive facilitator factor of family care for the child.

As difficulties for the development of independence, were highlighted: the lack of respect in society by the blind people, prejudice, demands of the fulfillment of tasks at an accelerated rhythm, the lack of security for transiting in public places and the need for adaptation of the child with VI to unknown environments.

For some respondents, there are not possibilities of independence in society for the child with VI. They believe that they will always require an escort and fight against overprotective attitudes that hinder the acquisition of independence by the child with VI.

We found that despite the difficulties faced by children with VI for the acquisition of independence these can be overcome. The coexistence between the family and the child with a disability and the experiences gained over time can make that the family has minimized its fear of caring.

Due to the difficulties experienced by the child with VI for the acquisition of its independence became evident the need of preparation for the inclusion of visually impaired subjects in school, at work and in society in general. It is necessary to teach the family on the forms of stimulation of the child which enables it to move around by environments, minimizing the risks to its integrity.

The struggle for social inclusion of the visually impaired individual transcends the existence of specific legislation. Media campaigns to denounce the discrimination suffered by these patients and ways to ensure their autonomous insertion and movement become necessary. It is hoped, with this current work, sensitize the health / nursing workers who care for children carriers of VI and their families, guaranteeing them the access to health services and information to enable them to care for the child in terms of its independence.

We conclude that, even with the difficulties, the formation of a support network focused on the inclusion and accessibility of the child with VI can assist it in acquiring its independence, qualifying its living.

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