



THE VISUAL IMPAIRMENT FOR TEENS: THE NURSE'S POINT OF VIEW
A DEFICIÊNCIA VISUAL PARA OS ADOLESCENTES: O OLHAR DA ENFERMEIRA
LA DEFICIENCIA VISUAL PARA LOS ADOLESCENTES: PUNTO DE VISTA DE UNA ENFERMERA

Marinalva Dias Quirino¹, Laura Emmanuela Lima Costa²

ABSTRACT

Objective: to analyze the meaning of the visual impairment for adolescents. **Method:** qualitative, descriptive study based on Oral History methodology. The subjects were 16 adolescents, of a specialized institution of Salvador/BA, between 12 to 18 years old, whose data were produced by semi-structured interview and analyzed by the technique of content Analysis. The research project has been approved by the Ethics Committee in Research, protocol 249798. **Results:** visual impairment adolescents face parental overprotection, discrimination, violence, difficulties in learning and locomotion, inadequate and precarious situations in healthcare, school and social inclusion. New functions in the prevention and detection of eye problems are presented to Nursing. **Conclusion:** the work with people with visual impairment includes the extension of childcare functions. It is questioned the training of nurses as a weak spot which complicates the future of these professionals in attendance to people with visual impairments. **Descriptors:** Visual Impairment; Adolescence; Nursing.

RESUMO

Objetivo: analisar o significado da deficiência visual para os adolescentes. **Método:** estudo qualitativo, descritivo com base metodológica na História Oral. Os sujeitos foram 16 adolescentes de uma instituição especializada de Salvador/BA, entre os 12 aos 18 anos, cujos dados foram produzidos pela entrevista semiestruturada e analisados pela Técnica de Análise de conteúdo. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, protocolo 249798. **Resultados:** os adolescentes com deficiência visual enfrentam a superproteção dos pais, discriminação, violência, dificuldades de aprendizado e locomoção, situações inadequadas e precárias na assistência à saúde, na inclusão escolar e social. Apresentam-se à Enfermagem novas funções na prevenção e detecção de problemas oculares. **Conclusão:** o trabalho com o corpo das pessoas com deficiência visual inclui o alargamento das funções da puericultura. Questiona-se a formação dos enfermeiros como um ponto frágil que dificulta o futuro desses profissionais no atendimento às pessoas com deficiência visual. **Descritores:** Deficiência Visual; Adolescência; Enfermagem.

RESUMEN

Objetivo: analizar el significado de la deficiencia visual para los adolescentes. **Método:** estudio cualitativo, descriptivo con base metodológica en la Historia Oral. Los sujetos fueron 16 adolescentes, de una institución especializada de Salvador/BA, entre los 12 a los 18 años, cuyos datos fueron producidos por la entrevista semiestructurada y analizados por la Técnica de Análisis de contenido. El proyecto de investigación fue aprobado por el Comité de Ética em Investigación, protocolo 249798. **Resultados:** los adolescentes con deficiencia visual enfrentan la superprotección de los padres, discriminación, violencia, dificultades de aprendizaje y locomoción, situaciones inadecuadas y precarias en la asistencia a la salud, en la inclusión escolar y social. Se presentan a la Enfermería nuevas funciones en la prevención y detección de problemas oculares. **Conclusión:** el trabajo con el cuerpo de las personas con deficiencia visual incluye el ensanchamiento de las funciones de la puericultura. Se cuestiona la formación de los enfermeros como un punto frágil que dificulta el futuro de esos profesionales en el atendimento a las personas con deficiencia visual. **Descriptor:** Deficiencia Visual; Adolescencia; Enfermería.

¹Nurse, Professor, Nursing School, Federal University of Bahia/UFBA. Salvador (BA), Brazil. E-mail: mdquirino@hotmail.com; ²Nurse, Master degree in Nursing, Human Science Department - Campus IV/Jacobina, State University of Bahia/UNEB. Salvador (BA), Brasil. E-mail: manuela.jacobina@gmail.com

INTRODUCTION

Adolescence is a stage of development in which the individual is dealing with a important challenge or task that is the formation of their identity versus role confusion.¹ It is a period that will define "who he is" and this identity encompasses sexual, professional and ideological identity. One of the challenges common to all adolescents, for those with visual impairment, other important aspects to their developments are increased as the difficulties of locomotion, moving and spatial orientation with security and independence, concept development, interaction with themselves, with others and with the environment, spatial placement of the body socially acceptable, development of self-esteem.²

It is necessary the knowledge of those challenges and consequently the way how adolescents experience these challenges, considering there are very few studies on the topic. It should be noted that the presence of visual impairment does not restrict the growth and development of the blind person nor preventing their insertion in school, the labor market and in other social groups.³

It is believed that they may face situations of difficulties not only for their condition, but also by the social vision built historically about people with disabilities that they are invalid, defective, disabled, exceptional, limited and incomplete human beings.⁴

It was considered that, although studies show a thematic concern, concerns still persist in order to understand how the visual impaired subjects perceive themselves in front of their differences, through an active listening means "adolescence as built in human history"^{5:92} and therefore must be "understood in their movement and their characteristics included in the historical process of the constitution".^{5:92} In this way, as a research problem, it is: how the visual impaired adolescent experience this phase of their life?

OBJETIVE

- To analyze the meaning of visual impairment for adolescents.

METHOD

This is a descriptive study with a qualitative approach, carried out in the period from July to August, 2009, using Oral History as methodological referential,⁶ where presumably a way of thinking to contemporary society, using recorded dialogues, perceptions

of social life recorded in such a way as to provide sources or documents.

The research was developed in a philanthropic institution of Salvador, Bahia, which has an agreement with the Unified Health System (SUS) and serves children and adolescents with visual impairment. Inclusion criteria were adolescents who attend the institution for at least two semesters, enrolled in regular school, without other associated disability and willingness to participate in the study; with visual impairment diagnostics with total blindness or low vision, whose family signed an informed consent form (ICF).

The semi-structured interview was the procedure used in the social research, fro data collection being analyzed by content analysis.⁷

It was sought to show the boundaries between what is an adolescent conflict and where it starts to be a characteristic of disability, considering listening to understand even the silences, the gestures, the indifference; the fears from the speeches.

The subject of this study, in its entirety, lived in neighborhoods on the outskirts of the city of Salvador/BA. They attend public school, in regular education, municipal or state. They are belonging to the lower social class whose parents are underemployed, as masons, some extra casually job, guards and mothers take care of home. Most are on a school below the level expected for their age. Only one student had not yet obtained the benefit of Providing Continuing (BPC) offered by the Federal Government.

The research was developed on the basis of Resolution 196/96. The confidentiality and privacy were assured through codes of identification of the surveyed. The research project has been approved by the Ethics Committee in Research of the Federal University of Bahia, CEP/EEUFBA on 15.06.2009, with number 08/2009, with the Cover Sheet number 249798.

The terms were transcribed to Braille for the adolescents have effective autonomy in the whole process of research.

RESULTS AND DISCUSSION

The review process resulted in four categories and six sub-categories: 1. being an adolescent with visual impairment (Behavior and Feelings expressed); The adolescent in the spaces of socialization (Family, Street, Regular School, Specialized Institution and Hospital); 3. the adolescent and the use of the cane; and 4. The adolescent and his projects for the future.

• Being an adolescent with visual impairment

There is the behavior, conduct, procedure; as a set of attitudes and reactions of the individual in the face of the social environment.

Adolescents have positioned themselves about fashion styles that are based on their preferences, such as perceptions about the hair style "Rastafarian", Jamaican model quite widespread in Bahia, in particular with young blacks and adolescents: *"my hair is rastafarian. The girl who works at the market made it [...] and at school, I'm the only one"* (Super Girl, 14 years old). They also demonstrated the social and historical context in which they live; in language with moral and socially accepted concepts; as Ultra Boy, who refers to the use of earrings in boys as something that sets a standard of behavior; the clothes the girls' identity and their hair style: *"the girls wear sandals, earrings [...] And boy who wears earring is a marginal!"* (Ultra Boy .17 years old).

Television has great influence on adolescent's behavior, checked on Feather's speech: *"I watch the "Caminho das Indias" and I like Arrocha, pagode, rock, [...] Silvano Salles, Charlie Brown Junior [...]"* (Feather, 16 years old). It was discussed the self-image and the need for a supportive family for adolescents to their balance.¹

As for the customs adopted related to moral principles, including relationships between them, such as dating, the issue of "getting off", not having "commitment", the adolescents of the study are similar to any other adolescent, fact in both boys and girls. There were speeches like: *"Oh! Dating is not just grab the hand [...] You have to grab the hand, kiss on the lips"* (Dreamy, 13 years old).

As for the feelings expressed during the narratives there were "feel that others are pity"; "get hurt"; "think the world is cruel, violent", especially when the violence is related to their disability and, accordingly, the thematic oral history allowed the adolescents establish relationships between the subject and their social context. When an adolescent tells us about how he was humiliated, embarrassed, excluded, he reveals his relationship with these situations, as well as the emotion that accompanied his experience; i.e. tells us, then, of a story that is personal, singular, but at the same time, allows us to understand and make sense of a broader social reality.⁸ However, more than a symbolic violence, present in society, the violence felt by the subject with visual impairment, feelings denoted in their lines refer to social exclusion, powerlessness faced

with the difficulties of their disability and the social spaces that are not designed for them.

As for the **Socialization Spaces**, they were divided into 5 sub-categories: a) Family; b) Street; c) School; d) Institution; and e) Hospital.

a) Family: some speeches about the mothers of children with visual impairment denote that they feel helpless and worried about their child's daily life and their future. Speaking of violet and others they reveal this concern: *"My mother is here waiting for me. When I walk down the street, my mother doesn't like that, she hits me. There are times she hits me with her sandal, but I don't cry anymore"* (Violet, 13 years old).

The birth of a child with a disability can disrupt the dynamics, since all are involved emotionally and participate in the care of the child; feelings that might denote anxiety, fear, anger and rejection.⁹ A overprotection appears as a way of ensuring security, since families are not prepared to receive children with disabilities.

The adolescent also pointed out the need to have freedom, as a visually impaired or not, exacerbating the adolescent with visual impairment, in function of their privations imposed by family.

b) Street: Freedom and accessibility: the visual impaired, on the street, are their biggest challenges both to move, as to communicate.¹⁰ There are blind children congenital research that report specific adaptation strategies in areas such as grasping, locomotion and language development. The same still compare the acquisition of these different phases of global development of congenital blind children traveling in a country with foreign language and customs, and it is these concepts as **"heroic feats of adaptation"**.¹¹

Urban architecture is divisive and exclusionary social values, confining them in private spaces, limiting them to familiar universe or specialized institutions, which, by themselves, are not very stimulating for developing skills and varied and possible relations.¹²

On the street the greatest difficulty is the ride. Bumpy Street is terrible. I'd like to show people my difficulties, show [...] seek to improve the lives of disabled people, improving the ride, put phones already in the post, in addition to the pay phone we have to steer the posts (laughs). So we can walk better, show everybody we have difficulty. (laughter, the interviewer questioned) (Lightning, 17 years old).

The situations experienced by the respondents prove that they do not have their

rights respected by the rulers and administrators, whether mayors or other forms. The example of buildings without ramps, elevators and other mechanisms which are already mandatory, in the form of law. Decree 5,296,¹³ in its 6th article, on priority assistance comprises different treatment and immediate assistance for people with disabilities (visual, auditory, mental etc.) and chapter III (General conditions of accessibility), 8th art., about accessibility.

On the street with the people [...] when taking the bus is too complicated, some people helps, others not, I take the glasses and I pretend that I don't see anything, I'm just with the cane [...] here comes their car (the bus) and they leave and do not give satisfaction [...] (Saturnia, 17 years old).

This highlights that we have to help to a disabled person in any situation (e.g., crossing the street, blind person taking the bus, etc.), even sometimes the deficient answer wrong, interpreting this as a gesture of mercy.

c) Regular School: the school is very important, since it is in the lives of young people with great significance, providing the exercise of their identity beyond the family, in contacts with conditionings contexts and social differences, and create conditions for the production and access to new knowledge.¹⁴⁻⁵

The adolescents in this study present the school as a space where the exclusion is highlighted, the speeches relate to the school as a learning space, new opportunities, but also isolation, rejection and experiences of exclusion, prejudice and lack of preparation of the professionals that act their, in particular teachers, because they are in greater contact and for longer time:

My school is a horror! There are some students who are prejudiced, I don't even know why, it makes me angry [...] Ah! A day it was with a boy from my class [...] the teacher asked me to stay on his team and he didn't want to [...] The teachers there are idiots! They do not solve anything [...] don't talk about anything with him, nor take him for the direction, I don't have friends, I have only one friend, I don't like girl and boy, I just go out with a friend. Some people often call me blind, I want to study at Getúlio (Getúlio Vargas College, next to the institution) that there is not prejudice. Prejudiced attitudes, every time it happens [...] you're a like that, a day at school a boy wanted to ask for a snack and I was close to him and he said: ' Auntie, the blind wants more! '. He was asking for more, and not me. This is prejudiced attitude, lack of respect [...] (Dreamer, 13 years old).

It is worth mentioning the need to understand the adolescent in their living

spaces, in order to assist them in their needs, noting that, although they are very close to us, occupying common spaces, however, this occupation is completely differentiated.⁸ So, more than a exclusion as prejudice and values experienced, young people with visual impairment, present age distortion age/grades; by the many failed attempts of inclusion at school, where only themselves are hampered by the lack of preparation of the professionals and the need for more effective inclusion policies. Speaking of Saturnia reveals such a situation:

I'm in third grade, I studied before, I'm still in elementary school. Because the school I used to go wasn't prepared to welcome me, and many teachers didn't know what to do with me. It took me a lot of study. I get upset because there are some here (referring to colleagues at the institution) that are much more advanced than I (Saturnia, 17 years old).

Also experienced prejudice are presented:

My school is more or less [...] Because the boys don't like visual impaired, they put a lot of nicknames to us, at this school that I study (Feather, 16 years old).

Contradicting the legislation around the adolescent and social inclusion - Child and Adolescent Statute - ECA; Law 7,853/89, Law 9,394/96, Decree 3,298/99, law 10,172/2001, Resolution CNE 02/2001/201,^{16-7-8-9.20-1} a inclusion didn't come out of the paper. And prejudice, discrimination and the lack of preparation of professionals in education and health are notorious, handicapping the learning processes, development and training of adolescents with disabilities.

We realize that the school, as an area of construction of knowledge, is not the place where individuals with disabilities feel safe, actually, some of the speeches show having few friends not being an impediment to recognise themselves as subjects who have values, stereotypes and/or prejudices too.

d) Specialized institution: in the period of adolescence, friends and "class" are predominant role, because they are in the same age range, have the same characteristics, which allow the confrontation of bodily, emotional changes and challenges and in this space they can be themselves and demonstrated safety in interpersonal relations, since the identity that makes them equal: the visual impairment.³ As in speaking of Astro:

"[...] I already know everything here [...] I walk alone, I really like it here, I learn things [...]". Violet also puts her activities as appropriate and relevant to her needs: *"I'm always in the Institute in the morning,*

and here I do a lot of thing. I write in Braille, do text, tell story [...] (Astro, 16 years old)

Grey Wolf exemplifies his activities and mainly the autonomy that acquired from the Institution, emphasizing its importance in the lives of people with disabilities: *"I do everything, I dress up by myself, brush, tooth, get ready, I do everything alone, I make my coffee, I learned here"* (Grey Wolf, 16 years old). However, keep them in specialized environments, besides involving discrimination, it does not make a student learn more than he would learn, if he had access to a more challenging environment and common to all.²²

e) Hospitalization: generally speaking, adolescents are relatively healthy. Health problems usually occur because of the following factors: dangerous or sedentary lifestyle, poverty, violence, car accidents, depression, eating disorders, drug abuse, alcoholism and sexually transmitted diseases.²³

The Health Cross-cutting Theme²⁴ involves disparate components, which not only relate to the absence or presence of disease, but of living conditions, the use of nature, in the forms of insertion of different portions of the population in the world of work. *"It implies also, on account of the ethical aspects related to the right to life and health, rights and duties, the actions and omissions of individuals and social groups, private services and public power"*.^{24:268} There is still discussion about their rights to health, when it is said that the changes of health practices depend on the organization of the health working process. It dependd, also, of managers's knowledge, professionals and citizens regarding the social protection laws, specifically regarding disability. To meet the legal assumptions for the purposes of routing and guidance of users in the healthcare system is a preponderant factor for the exercise of citizenship and adoption competent health care.²⁵ In this case, the visual impairment can be understood as lack of health when relegated to the omission, the lack of public policies and the obfuscation on the part of who cares. And exacerbated by other complications associated with or not, motivating or not of their disabilities; will taking a format of fear, anguish and sadness.

The speeches of many of these adolescents in the study show that the hospital environment has not always been next to individual needs and the actions of doctors and nurses were confused, without a record in memory of the subjects interviewed, showing possible personal indifference in dealing with them. Saturnia demonstrates such a situation

when she says they were doctors, nurses, medical, but even their names were not remembered:

[...] after I managed to make the heart surgery, the doctor said he couldn't do the surgery at all, because he said he couldn't because then I lost the vision faster. More contact with doctors and medical [...] more doctors, and medical and nurses just when was taking the tape and give remedies [...] (Saturnia, 17 years old).

I asked another interviewee: "describe the day in the hospital that you remember". The answer was: "I don't know" (Lady Triple, 12 years old) (the interviewed made several surgeries, spent a lot of time in the hospital and can't describe the episode, she has only vague memories).

Adolescents who were hospitalized represent 11 of the 16 respondents, and to reflect about the silence and forgetfulness on the nursing professional, although staying long time hospitalized (3, 4 and 8 months) makes us think of the need for a change in the actions of the division of labor, in the process of care.

Nursing must reflect on their visibility as a profession that has as their object the care and defend the need to occupy spaces that give the recognition as a protagonist of praxis in health in society.²⁶ In nursing-patient relationship *"[...] The nurse must get to know the patient, so that there is constant dialogue between both. He must cultivate the trust of the patient through the respect and empathy undertaken on care."*^{27:2}

Lady Triple reaffirms the importance of care linked to the doctor only when he says: "the Doctor Raimundo, he medicates me, I liked him". When I asked: *"And you only remember him? What reminds you of him?"* she answers me convinced: *"He took care of me"* (Lady Triple, 12 years old).

The human warmth is good for all individuals and it has great importance in the interpersonal relationship between nurse-patient. When there is contact the professional has ability to overcome great challenge of caring with a competence and humanized way.^{27:3}

• The cane as a tool of identity of being visual impaired

The visual impaired person realizes the body through the accumulated knowledge on childhood and adolescence that becomes object of excessive concerns, and appears the shame, the pain and the sadness of not being within the pre-established standards, by feeling outside of a social context that values beauty and the exteriority is scanned, in the daily life of people.²⁸

Another factor of bodily deformity is the use of a cane, representing their fragility before the world. Their imperfection. Colossus knows the importance of the cane for his locomotion and seems not to bother with the concept of people when he says:

I have been using a cane for 4 years. It is a very essential object, it helps people to locomote, go to the places, nice [...] (Colossus, 14 years old).

Most subject of this study don't like to be seen using a cane. The feeling or the sensation that the cane exposes them in the eyes of the other, betrays the condition, unveils the inability. In their lines, they presented such feelings, such as Cosmic's:

On orientation and mobility class (OM) I use the cane [...] if it is to use I use it [...] They said I wouldn't use it [...] I found good [...] well, but I kept watching, seeing how it was. But I don't like knowing that I'm walking and people are watching me, I'm ashamed [...] shame, the people walking with a cane and the other looking [...] and I walk, I walk alone [...] even running [...]but I also think that after it was nice to use the cane (Cosmic, 16 years old).

Penumbra associates the use of cane to the disease and she does not use it when she wants to have fun, translating the feeling that it reminds her that is visually impaired:

I go out to have fun, but I do not use the cane. Because people see me differently, they will talk bad about it, so I don't go out. Since 11 years old I'm sick, I have not freedom, I can't get used to [...] (Penumbra, 14 years old).

The use of the cane to the adolescents in this study shown sometimes as a necessity or as an object that shows them as a handicapped, differentiating it negatively to the other.

The loss of independent mobility can be considered the largest obstacle for the individual brought to the interactive visual impairment: a fact that seems substantial and significantly change their own lifestyle.^{29: s/p}

• The adolescent and their future projects

It was observed in this study that in addition to the disability, which already puts them in the category of "special" to develop any kind of occupation, the issue also appears to belong to a social class or class fraction of children of employees or with underemployed, which, for the most part, produce life precariously, on their own and that remain with the benefit of Providing Continuing (BPC). Another issue is education, which is a considerable a gap if related to chronological

age and career, i.e. an distortion age/grades that translates into psychosocial and educational losses.³⁰ Likewise, disabled people with good qualifications, however, socially underprivileged, will only work in companies through incentive law 8,213/91.³¹

The adolescents of this study make plans for the future, but the fragility of their dreams reflects insecurity in terms of conditions for a real date in the world of the labour market, although some recognize their difficulties, such as the case of Colossus:

When I grow up [...] when I be man [...] I want to be a teacher of Portuguese language and English, Spanish, German, French and that's it [...] I just don't know yet where to learn so many different languages [...] (laughs) (Colossus, 14 years old).

Shadow dreams a hard world to reach, mainly because it is governed by their own laws and perverse, based on capitalism and neo-liberal principles, that dictate the esthetics in the path imposed by media and the values underlying it: "My future [...] and my profession [...] I want to be a model, I want to be a model!". (Penumbra, 14 years old) The work is seen as the border between what is and what is civilizing barbaric, marginal, and that historically, socioeconomic differences over establishing relations between violence and poverty, vagrancy and delinquency, severely individuals who are poor or excluded from social standards accepted and held by the upper classes.⁸

CONCLUSION

In the course of this research, one of the challenges was that this text could contribute to an approximation or the establishment of a dialogue between health and education; understanding that the education and its process to include people with disabilities is the result of actions and interfaces between these two areas, realizing however, that alone it will not solve the problems that conceptually involves the difference between sickness/health and disabilities.

The invisibility of the nursing professional, who deals with the visual impaired directly, was reciprocal to emptying their needs and understanding of their potential. Without doubt, the need for a new thinking emerge by the experience of nursing, as a condition of caregiver. On the other hand, with this study, it can also become aware of actions that are already developed in the citizenship and the search for solutions to a more dignified experience and establishing opportunities for considered socially excluded, such as the place researched allowing to realize that even

with the denial of rights exist something innovative, incipient but people with disabilities are beginning to be seen.

The role of nursing, in this way, it is evidenced, which leads us to emphasize in hopes of possibilities in their everyday life interventionist workspaces in dealing directly with adolescents, children, youth, adults or seniors, by proximity to the profession and allows the sense of social justice, equity and citizen awareness, since it specifically can act in schools, in the prevention and detection of eye problems including trachomain neonatology also detecting and screening and ocular changes in various forms of care (recognition of disabilities in the communities by entering the community agent and units of the family health program, already in the school health program, working with the body of persons with visual impairments and their social interactions during dating, in marriage, in the guidance of genetic counseling) for people with visual impairments require.

Another factor is the training of nurses, the curriculum is a weak spot that tightens the future of these new professionals in the expansion of these challenging roles, as well as the creation of research groups at the universities of nursing, enabling research and extension to develop new perspectives on this issue.

Transforming the concept of social inclusion in the concept of an inclusive society, everyone has the right to health, being visual impaired adolescents or black women and poor, whether black men and poor, building their citizenships, rejecting the idea of negation and denial of rights deficiencies.

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Corresponding Address

Laura Emmanuela Lima Costa
Universidade do Estado da Bahia
Departamento de Ciências Humanas - Campus
IV/Jacobina
Rua Mário Luiz Vieira, 129
Bairro Estação
CEP 44700-000 – Jacobina (BA), Brazil