

Interpersonal relationships of low vision adolescents

Relações interpessoais de adolescentes com baixa visão

Las relaciones interpersonales de adolescentes con baja visión

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Abstract

Visual impairment can lead to restrictions on the adolescent's life in relation to educational, personal, social and labor aspects. The impact of visual impairment varies widely and depends on the degree of loss, parental attitude, family dynamics and school community. The group experience provides diverse learning, both in the sense of personal experience, as well as interpersonal. Thus, the present study aimed to ascertain the perception of adolescents with low vision regarding interpersonal relationships within the family and school environment. This research covered four adolescents with low vision, being 02 female and 02 male, who are in the age group between 12 and 18 years. A semi-structured interview was applied individually to each student as a tool for data collection. The testimonies addressed interpersonal relationships both in school and family environment with adolescents relating about their difficulties in experiencing such relationships. The present study presents adolescent's difficulties in identifying oneself in such environments and feeling part of a group.

Keywords: Adolescent; Low Vision; Interpersonal Relations.

Resumo

A deficiência visual pode acarretar restrições na vida do adolescente em relação aos aspectos educacionais, pessoais, sociais e laborativos. O impacto da deficiência visual varia muito e depende do grau da perda, da atitude dos pais, da dinâmica familiar e da comunidade escolar. A vivência grupal proporciona aprendizagens diversas, tanto no sentido da vivência pessoal, como na interpessoal. Assim,

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o presente estudo teve como objetivo averiguar a percepção de adolescentes com baixa visão a respeito das relações interpessoais no ambiente familiar e escolar. Participaram da pesquisa, 04 adolescentes com baixa visão, sendo eles 02 do sexo feminino e 02 do sexo masculino, que se situam na faixa etária entre 12 e 18 anos. Como instrumento para coleta de dados, foi utilizado a entrevista semiestruturada aplicada individualmente a cada escolar. Os depoimentos falaram das relações interpessoais na escola e na família e das dificuldades dos adolescentes em vivenciar tais relações, de se sentirem parte de um grupo.

Palavras-chave: Adolescente; Baixa visão; Relações interpessoais.

Resumen

La deficiencia visual puede acarrear restricciones en la vida del adolescente en relación a los aspectos educativos, personales, sociales y laborales. El impacto de la discapacidad visual varía mucho y depende del grado de pérdida, de la actitud de los padres, de la dinámica familiar y de la comunidad escolar. La vivencia grupal proporciona aprendizajes diversos, tanto en el sentido de la vivencia personal, como en la interpersonal. Así, el presente estudio tuvo como objetivo averiguar la percepción de adolescentes con baja visión respecto a las relaciones interpersonales en el ambiente familiar y escolar. La investigación se desarrolló con cuatro adolescentes con baja visión, siendo ellos 02 del sexo femenino y 02 del sexo masculino, que se sitúan en el grupo de edad entre 12 a 18 años. Como instrumento para la recolección de datos, se utilizó la entrevista semi-estructurada aplicada individualmente a cada escolar. Los testimonios abordaron las relaciones interpersonales en el ambiente de la escuela y de la familia con los adolescentes relatando sus dificultades en vivenciar tales relaciones. Así, el presente estudio discutió la dificultad que tienen los adolescentes de identificarse en estos ambientes y sentirse parte de un grupo.

Palabras claves: Adolescentes; Baja visión; Relaciones interpersonales.

Introduction

Low vision is understood as an organic impairment that restricts the individual's ability to perceive the world visually, being characterized by a residual vision that may be different in the vision for each subject, not allowing correction by common lenses, but it may be optimized by optical devices¹.

With respect to visual acuity, it is equal to or less than 6/18 (0.3), but equal to or greater than 3/60 (0.05) in the best eye with the best possible correction².

Therefore, low vision is characterized as a relevant alteration of the functional capacity of the vision, due to isolated or associated factors, such as low visual acuity, significant reduction of the visual field, changes in the color vision and/or sensitivity to contrasts impacting or restricting visual performance³.

Since low-vision can manifest broadly, each individual has its own particularities.¹ Therefore, it leads us to think on the social representations that are present in the identity and personality construction of these subjects. These visually impaired sub-

jects may be seen as blind individuals, other times as seers, by raising questions such as: "Who am I?", "Am I blind?", "But I can see – am I a seer?", "But why others are able to realize things that I can't?". Thus, there is a multidimensional impact of visual impairment in adolescence, since it depends on factors such as the degree of loss, parental positioning, family dynamics, configuration and acceptance of the school community, among others^{4,5}.

These uncertainties about themselves can lead the subject to develop a negative self-image, in addition to a dependence on their environment, with difficulties in accepting the optical resources.¹ Such issues in adolescence can mean an experience permeated by a self-perception of a fragmented self, with a sense of non-belonging, as well as prejudice on the part of classmates, as faced by many subjects in this situation^{6,7}.

Regarding the fragmentation of the self, it is possible to notice that this uncertainty is increased by the fact that these subjects do not recognize their own way of perceiving and relating themselves to the world. On the other hand, parents often overprotect them. Handling this also means a further delay in their autonomy and independence. Thus,

according to the perspective of this study, this attitude shows the difficulty of acceptance by parents, their fears and lack of confidence on the ability of their children to respond to their life projects and their projections. All this is the great journey to be traveled with extra luggage, and, more thoughtfully, perhaps in relation to other adolescents¹.

However, the difficulty of the parents comes from breaking expectations, as if there was a feeling of mourning related to the ways of being of the children⁸. The same feeling may be noticed in the family of visually impaired subjects, as they also faced a loss. Therefore, in order to cover family relationships, it is necessary to understand the family history, dynamics, and roles, as well as the relationships that the family members have among themselves and especially with the disabled person⁸.

Parents and the entire family may need support when a child is diagnosed with a visual impairment. Common feelings related to dealing with the diagnosis are: state of shock, guilt, depression, horror related to blindness and fear related to the future. These emotional reactions are often caused and/or exacerbated by the lack of knowledge of the diagnosis and its implications. This lack of knowledge may also compromise family involvement in the care of the child at home, at school and at the rehabilitation institution⁹.

The Salamanca Statement¹⁰ recommends the involvement of the family as part of the therapeutic project in meeting the educational needs of the patients and, therefore, it supports the participation of parents as active partners in decision-making, in school activities, and in the monitoring at home.

As well as family environment, the school environment is also of great importance in the development of adolescents. School is a great socializing experience, and an experience of living with differences of all kinds and at all levels. The school is where the adolescent often seeks to create his/her peer group. The school experience has a significant impact on the consolidation of self-esteem, either contributing to its strengthening or impairing it. At school, the adolescent has the opportunity to socialize with other adults, in addition to their parents, and to identify other role-models, both positive and negative¹¹.

There is a particular challenge for low vision adolescents in these relationships, because they feel inferior to others due to their difficulty to learn like

others and due to the lack of alternative techniques. Thus, the difference between these students is focused on modes of representation to be used as an aid in the explanation of different concepts, which is more promising than the discussion focused on the identification of the difficulties brought by the visual deficiency, always compared with the absence of these difficulties in the seers.¹²

There may be a feeling of shame or embarrassment related to the need for special aids, which are aid mechanisms to improve visual performance by redefining the image, such as optical aids: magnifying glass, glasses, and telescope¹².

Still regarding factors that involve the use of resources, it is thought that the acceptance of the group in adolescence is an important factor in the behavior of young people. Optical devices that are different from ordinary glasses, without a desirable aesthetic, or the use of school supplies different from the ones used by other colleagues can cause self-esteem problems and the consequent acceptance of the condition of a disabled person¹³.

When understanding adolescence as a phase of life in which people seek other universes beyond those experienced at home, it is possible to reflect on the restriction that exists for adolescents with low vision. The journey is hampered by situations, environments and restrictive relationships, lacking of broad and meaningful experiences and opportunities for learning and development that lead to the construction of strengthened personal identities and recognized existences¹⁴.

Given the above, there is a need of works that may bring such feelings, and social representations built individually and collectively regarding the low vision in our society, because personality consolidation and freedom into adulthood only exist when dealing with these questions¹.

Thus, this study aimed to ascertain the perception of adolescents with low vision regarding interpersonal relationships within the family and school environment.

Method

This study was approved by the Research Ethics Committee under the no. 814/2011. The Free Prior Informed Consent (attached) was used to conduct the research and should be signed by the adolescents with low vision and their respective guardians, in order to comply with the terms of the

Resolution no. 196 (10-10-1997) of the National Health Council.

Sample

This research covered four adolescents with low vision, being 02 female and 02 male, who are in the age group between 12 and 18 years and attended the Visual Impaired Adolescents and Adults Program.

The criterion established by the Brazilian Statute of the Child and Adolescent was adopted for the selection of the age group, from 12 to 18 years.

Data Collection

A semi-structured interview was applied individually to each student as a tool for data collection; it included an interview script composed of variables, which, when not addressed by the participants, were addressed by the researcher.

Study variables refer to gender, age, use of assistive technology devices, interpersonal relationships in the family, and interpersonal relationships in school.

The interview developed through an exploratory study was applied by the researcher, and then quantitative data were grouped according to the selected categories, proceeding to the analysis of the content according to the theoretical reference¹⁵.

Results

Use of Assistive Technology Devices

Regarding the use of assistive technology devices, all the adolescents used some type of assistive technology, such as a magnifying glass, a board, a notebook with sharp lines and a stone, an enlargement in printed supplies, and they reported episodes of distress that took place in the school, as in relation to the enlargement of school supplies and the copy in the student's notebook made by the teacher, also according to their report:

"It was good to make use of the resources, but it's bad to depend on others";

"I have a good relationship with my teachers, and they all help me with my notebook"

"The teacher taught me closely, she dictated and there was always some classmate sitting next to me to help me."

Interpersonal Relationships at School

Regarding interpersonal relationships at school, there are reports of a sense of exclusion and that initially they were not supported by their classmates, the teachers and the staff of the school.

"The staff at the canteen is rude: 'Hurry up, come on'";

"Our relationship was not so good, as some of them were not so patient."

"I don't know any staff. The staff at the canteen is rude, they are always saying 'Hurry up, come on'".

Interpersonal Relationships at Family

With respect to the family environment, they reported to feel welcomed, as when asked how the relationship with the family was, some answers were:

"Good, great. It is better with my mother", "We do not fight, and they know my classmates."

Two adolescents reported having a closer relationship with their siblings, who are also seen as their best friends and companions:

"Well, it is good as well, it is better with my sister F."

Three adolescents reported that they usually stay at home, except when they go out with their families, restricting their social life and that they avoid the places that their classmates go. They justified that their parents prevent such events by claiming that there are dangers for a low-vision adolescent alone outside home:

"It is great: my mother is a little overprotective, she does not like me to do something crazy, like playing sports."

Discussion

Use of Assistive Technology

Assistive Technology is the interdisciplinary area of knowledge that encompasses products, resources, methodologies, strategies, practices and services that aim to promote the functionality related to the activity and involvement of persons with disabilities, impairments or reduced mobility, aiming at their autonomy, independence, quality of life and social inclusion.¹⁶ In this study, adolescents reported a resistance to the use of assistive technology devices, as they felt dependent, since the use was limited, as in the help of a classmate who had to sit next to them or in the help of a teacher making a copy in their notebooks.

In the Brazilian Constitution, Decree no. 5296 of 2004, Article 8, paragraph V, sets as technical aid products, instruments, equipment or technology that are adapted or specially designed to improve the functionality of the disabled person or with reduced mobility, in order to favor the total or assisted personal autonomy¹⁷.

In view of the above, when the adolescents report as follows: "It was good to make use of the resources, but it's bad to depend on others" and "I have a good relationship with my teachers, and they all help me with my notebook". As pointed out, adolescents show a certain discomfort in depending on others, as if they were always relegated to the place of difference, of incapacity. Thus, the study questions the effectiveness and the way they use these devices. Do they comply with the decree? After all, if there is a series of benefits in it, why adolescents consider not using them? Under what conditions is this technical assistance being used? In what way they are being used to achieve its objectives for the autonomy of the subjects?¹⁸

In order to comply with legislation, the inclusion process should include a restructuring of the educational system and the construction of the subject with others and with the world, according to their social and historical totality and reactions and responses to challenges. This can be by means of actions in which the reality of the classroom can be connected to the theoretical aspect, in simple practices, as in the presentation of resources¹⁶.

These practices, instead of promoting the authorship of the subjects in the school process, make them dependent, since the non-use can reveal how the subject means and is signified by the social network. As well as the need to identify them with this network - a typical characteristic of adolescence - as the use of assistive technology, in the way they use it, in many cases, means to occupy another social place, which is different from theirs, and possibly is the place of disability and not just that of being an adolescent¹⁹.

Interpersonal Relationships at School

To analyze the school as a socio-cultural environment means to understand it in the perspective of culture, under a deep look, which takes into account the dimension of dynamism, of daily actions, by concrete human beings, social and historical subjects present in the history, actors in history, regardless of gender, race, color and social

status. Therefore, to discuss the school as a socio-cultural environment implies rescuing the role of the subjects in the social aspect that constitutes it as an institution²⁰.

From this idea of what the school environment means, this study aimed to analyze the adolescents' reports on interpersonal relationships with teachers, students and employees. This combination exerts a great influence on the formation of individuals.

One of the adolescents who participated in the study reported that although she enjoyed learning, the school was responsible for a great deal of pain in her life. This pain persists today, even after dropping out of school and being subjected to the recommended psychological support. In her report, she said she did not feel welcomed by her colleagues, teachers and staff. Feeling guilty, she felt that the bullying was deserved, and she allowed to be mistreated, and spent a period of time alone. When her family found out, there were so many traumatic situations that it was necessary to take her out of school and nobody was able to convince her to study in another unit. Situations like this are devastating. Considering adolescence an important period for self-knowledge, identification among peers and group formations, an adolescent who undergoes a traumatic situation like this can present many wounds in his/her subjectivity. When, if there was some sort of preparation for the school and the community, this could have been avoided or mitigated.

A research on the interpersonal relations of visually impaired students at school²¹ found that adolescents with low vision reported affectionately school experiences with their friends. With respect to teachers, the adolescents report that they are more concerned with the pace of learning than with the progress considering the pace of the student. Regarding the relationship with the employees, the adolescents reported a good interaction.

Teachers

Dealing with the teacher-student relationship demands a reflection on how the teaching-learning process takes place, which goes beyond the content for the classroom. As all the elements that make up this relationship, subjective - as the history and culture of both - and goals - as the programmatic content - impact and decisively affect school performance.

In this way, the teacher takes the role of fundamental element for the inclusion process, which has great importance for social construction. It is through this relationship that the most valuable assets of humanity are promoted, both intellectual and cultural assets, essential for the full exercise of citizenship and equity²².

So, the promotion of such aspects can be impacted when there is a disharmony in this co-existence. It could be noticed from the reports of visually impaired adolescents that the relationship with the teacher in the classroom is determined by the quality of aid provided to adolescents, which is closely connected with the use of assistive technology and also with the way that they deal with and qualify the disability. As revealed in the reports, when asked on how they evaluated their relationship with school teachers: "I have a good relationship with my (eight) teachers and they all help me with my notebook" and "Our relationship was not so good, as some of them were not so patient". It may be noted that the disabled individual demands a different kind of aid than the conventional one, so performing the task of teaching is to meet all the requirements assigned to them, based on the definition of inclusive education that includes disabled and gifted individuals, in addition to those belonging to marginalized groups or disadvantaged²². Thus, this definition suggests that the practice should be based on the inclusion, considering that the school context is characterized by heterogeneity, including these subjects.

In such a case, the teacher must be trained to be prepared for an inclusive practice²³. Therefore, to discuss inclusion is to go beyond the existence of a legislation, as although it is a necessary condition, it is not enough to ensure inclusion, since changes are still superficial and a consistent investment is required to the training of the teachers in order to result in significant pedagogical innovations. In addition, the subject must be more discussed beyond the academic environment, by experts, but rather where there is a dialogue with the society.

Employees

In the journey of the inclusion of disabled people in school, the directions of the school administration, the roles and performance of the director, coordinators, supervisors and employees should all be changed, losing the controlling, supervisory and bureaucratic character of their roles

to reacquire a pedagogical system. In addition, to leave behind the reasons why these professionals are confined to their offices, with no time to know and participate more intensely and directly on classrooms and other educational environments of schools²⁴.

But despite this ideal projected, one of the adolescents reported a distance between students and staff, failing to fulfill the pedagogical goal of inclusion: "I don't know any staff. The staff at the canteen is rude, they are always saying 'Hurry up, come on'". Such attitudes assume the controlling, supervisory and bureaucratic character, hindering the inclusion process and negatively influencing the development of this subject. On the other hand, the discourse "I talk more with the employees than with the teachers", shows that this relationship is profitable in the process of inclusion, even with flaws.

Classmates

To analyze the relationship between the students is rather to perceive the school as a socio-cultural space and to understand it from the perspective of culture, under a deeper look that takes into account the dimension of dynamism, of daily actions, by concrete human beings, social and historical subjects present in the history. Therefore, students make up a network whose main characteristic is heterogeneity. Therefore, the relationships that will be created in the institution are the result of that uniqueness and these elements will determine the quality of them, as in the personification of social groups²³.

When analyzing the school environment from this perspective it is possible to understand how are the relationships of disabled individuals with their peers, based on the particularities that compose them. Therefore, a difference was seen in the reports when asked on their relationships with classmates: "Some, yes, others, no. Many people in the class. Many people are making fun of others"; "Terrible. I was left out; they complained when asked to help me; they did not call me for homework; they mocked my vision; I was humiliated and I never fought or said anything"; "Very good, too"; "Cool"²⁹.

The most negative report was from a subject who also had difficulties with teachers and staff and had a limited use of assistive technology, revealing that the relationships in school are interdependent and the way in which he has a meaning and is

understood directly influences his inclusion in the social groups along with his independence and identity. In this way, adolescents who do not adapt to school are more likely to have unsatisfactory performances, in addition to physical and emotional impairments to their health or feelings of dissatisfaction with life. Positive interpersonal relationships and academic development are directly related, and students who perceive this support will be more likely to reach a better level of learning⁹.

The opposite, that is, negative interpersonal relationships, occurred with the same subject, who reported that she dropped out of school due to mistreatment by colleagues and to the lack of understanding of teachers and staff. The report reveals a common violence suffered by students resulting from bullying activities. By definition, “physical and/or psychological aggression performed by children and adolescents, usually in or near schools, intended to cause repeated pain or discomfort over time and with a real or perceived imbalance of power between the aggressor and the victim. This is a world phenomenon with rare tragic events, present in public and private schools involving poor or rich students”¹⁹.

Reports of adolescents with special needs have a strong connection with the relations of discriminatory experiences, influence on their education, school development and on the development of conceptions of themselves - self-esteem, self-concept, self-perception.

Interpersonal Relationships at Family: Parents and siblings

The family is understood as a space that provides protection and in which its members feel a sense of belonging to a group united by ties of love and affection, it has also been defined as a health system for its members. When the family feels weakened by a disease, it uses cultural knowledge and values, beliefs and practices to guide its actions in order to maintain the well-being of its components¹¹.

All participants reported that they live with their families and maintain good relationship with family members. When asked on how was the relationship with their parents: “Good, great. It is better with my mother” And the same is noticed with their siblings: “Well, it is good as well, it is better with my sister”.

But despite the apparent homogeneity of responses, there are some intriguing questions in the reports, such as when asked on relationship with their parents, an adolescent reported that “It is great: my mother is a little overprotective, she does not like me to do something crazy, like playing sports”. Another interesting story was on the relationship with their siblings, in which two sisters - both with low vision - reported “Well, it is good as well, it is better with my sister F.” and “Very Good, but it is better with B.”.

Relationship with parents

Some questions arise on parents’ relationship with the disabled child regarding the acceptance and restructuring process as to the child’s progress, as well as the concern for the future. As for the education character, “it can be liberal, that is, in which the child has total freedom; in this case, the child does not feel supported, goes through many experiences that can cause frustration and suffering. Or, it can be extremely controlling, that is, the child has no independence to do anything, the child cannot develop initiative and creativity, and has few opportunities of experiences, being unaware of his/her own ability. In both options, the child suffers and may develop behavioral disorders, such as tantrums, excessive shyness, and aggression against themselves and others”²³.

This overprotection was revealed in the speech “It is great: my mother is a little overprotective, she does not like me to do something crazy, like playing sports”, and later, when that same subject was asked to report something that was not included in the interview, he said “When I go out, it’s just to play sports.” This shows that parents put an obstacle to a social life outside the home, indicating potential dangers that they may face. If this is the phase in which the adolescent becomes increasingly independent of the family, having their own connections outside the nucleus, which are extremely important in the identity formation process, this process with other subjects can become more distant and difficult, since that relationship has not been effectively established.

Although this has been revealed by this subject, on another report related to daily activities, the adolescent reported that he always had to go out accompanied, due to his fear and also that of his family. But later, at the end of the interview, he confessed: “I drive bike and car. I have many friends

in the neighborhood, at church and at school. My vision problem did not affect my friendships'. This reveals the paradox in the report of the family when referring to the representation of danger against the autonomy of the subject.

Relationship with siblings

Siblings play a very important role in the development as the first peer-to-peer relationship, and their early influence affects all life: usually, sibling relationships are the most lasting. When one of the siblings has impairment, the relationship between them takes on a new meaning and a new sense¹².

Two sisters - both with low vision - when asked on their relationships with their siblings reported "Well, it is good as well, it is better with my sister F." and "Very Good, but it is better with B.". Revealing that despite having other siblings, they are the closest to each other. This relationship also extends to the school, where the oldest of the sisters reported "At breaks, I used to stay with F.'s friends" and another subject reported that "I spend the break with my sister and with older colleagues, her friends".

In the relationship between siblings, including one with visual impairment, siblings without disabilities help others, both in school life and in leisure activities with friends and family, and this aid can cause an overload, since they take that responsibilities due to the impairment. Therefore, as found in the reports, the fact of sharing friends with their siblings to fill this gap, suggests the importance of this relationship in social inclusion and also a responsibility that the brother takes due to the impairment.

Conclusion

Regarding the perception of the adolescents with low vision on interpersonal relations in the family and school environment who participated in the study, this study discussed a difficulty to identify themselves in such environments and to feel part of a group.

The study had limitations on the number of subjects. Therefore, there is a need for further studies that include more adolescents in order to find this difficulty and to allow potential models of intervention in this population that address not just the improvement of vision, but also emotional and identity aspects.

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