

Pedagogical resources for students with Usher Syndrome due to deafblindness in the classroom

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ABSTRACT

This paper was developed in regular school. The goal was to check the learning impact on pedagogical activities with visual adaptations for a student (12 years old) with Usher syndrome. Usher syndrome is a genetic condition: congenital hearing and eyesight loss due to Retinitis Pigmentosa, which affects the retina. The “night blindness” manifests itself, initially, because the patient struggles to see at night, followed by peripheral vision loss. The blind spots grow into “tunnel vision”. Tools such as family, teacher and patient interview; vision functional evaluation; CCTV to establish reading pattern and low-cost materials in the teacher’s presentation of content were used in the methodology. Usher syndrome generates problems and impacts the education if the teacher’s and the school’s approach to the student do not change. The organization of pedagogical resources in the classroom, respect for the student’s pace according to their conditions and visual adaptations and the distinguished and structured strategy proposal should all be directed towards an inclusive and high-quality environment to contribute to the improvement of their learning process.

Keywords: Usher syndrome. Pedagogical resources. Deaf-blindness.

INTRODUCTION

Albrecht von Graëfe (1858) was the first researcher to encounter someone who was deaf with visual impairments (Retinitis Pigmentosa), realising there were two brothers with the same symptoms. Richard Liebreich (1861) examined the Jew population in Berlin and most of them were children of blood-related parents or had ancestors with the same characteristics. Therefore, the aforementioned syndrome recessive pattern was discovered. Charles Usher (1914) described the pathology hereditary nature, identifying the association between deafness and Retinitis Pigmentosa (RP), defining it as an independent entity (Liarth et al, 2000).

RP can be diagnosed in the patient’s childhood, teen years or in their adult life and results in progressive vision loss, with different degrees. The following are crucial for its diagnosis: 1. Genetic test to identify the risk of transmission; 2. Electrophysiologic tests (ERG) to check how the rod and cone cells work and if they are deteriorating; 3. A ocular tomography (OCT), which shows if the retina is atrophied; 4. Visual field, which aims to check the peripheral vision as a RP consequence; and 5. Check the RP progress through ocular fundus exams.

There is no cure for RP, but there were significant improvements in recent years, such as vitamin A intake and docosahexaenoic acid (DHA), which have been proving to be efficient for some patients. Clinical researches are being developed using gene therapy in animals and have presented exciting results. There are also clinical trials being developed using medication that act on the cone and rod cells (Martinhago, [n. d.]). Besides these advances, Martinhago ([n. d.]) points out that “informatics technology to enhance retinal function in affected patients promise to be an interesting way of treating the problem”.

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2. USHER SYNDROME

Usher Syndrome (US) is a recessive genetic condition which causes progressive hearing loss and visual impairments due to RP, because the genetic disorder needs two genes to manifest itself, which means each parent passes on one of the syndrome genes. Therefore, only affected people can transmit the syndrome (Tamayo, 1996; Costa, 2005; Kimberlin, 2007; Cambuzzi, 2013; Cambuzzi & Costa, 2016).

RP is a degenerative disease which affects the retina photoreceptor cells (cone and rod cells), causing visual issues.

The first warning signal of retinitis pigmentosa is having difficulties to adapt to dim or bright light and vice-versa and to dark places. With RP, the rod cells are more conglomerated in the peripheral areas of the retina and therefore are the first ones to deteriorate.

The first indication to loss of peripheral vision is when the patient bumps or trips in furniture around them while trying to move. Therefore, the rod cells deterioration compromises the peripheral vision (tubular vision) and the night vision. The cone cells are centralised photoreceptor cells and when they are damaged, the ability to differentiate colours and recognise details is reduced, indicating that the central vision is affected. The loss of visual acuity manifests itself through failing to recognise shapes and small objects and struggling to read and in tasks that require detail-oriented vision.

2.1 Prevalence

Regarding the Usher Syndrome prevalence, Tamayo (1996) points out that the syndrome affects 3 to 6% of patients with congenital deafness or with partial hearing loss, and for individuals with RP, the index is 8 to 33% (Tamayo, 1996; Cambuzzi & Costa, 2016).

Liarth et al, (2000, p.458) points out that: “The syndrome occurrence is estimated by a few authors at 1.4 and, by others, at 4.4 in 100,000 individuals in the general population.” According to Kimberling et al (2010), the prevalence indicates that 1 in every 6,000 births is affected by Usher Syndrome in studies developed in the United States. Blanchet and Hamel (2009) report that Type II Usher Syndrome manifests itself more often (60% of cases) and Type III in less than 3% of the cases, but is more often found in Finland and Ashkenazi Jewish populations. Therefore, the Usher Syndrome prevalence is different in each country.

2.2 Types and characteristics

The Usher Syndrome manifests and differs itself in four types: I, II, III e IV³, described below.

Cambuzzi and Costa (2016, p.20) point out that Type I Usher Syndrome is characterized by “deep deafness since the child’s birth, night blindness during childhood with Retinitis Pigmentosa as a symptom, occurring before the age of 10.” The communication used is the Sign Language, in Brazil, the Brazilian Sign Language (Libras), which is their mother tongue. Shows poor balance and difficulties on speech development (Liarth et al., 2002).

In Type II, the hearing loss is steady. Uses hearing aid devices and is able to communicate through speech; shows night vision problems due to RP (Cambuzzi, 2013).

A patient with Type III Usher Syndrome “is born with normal hearing and, afterwards, develops a slight hearing loss, which requires the use of hearing aid devices” (Cambuzzi & Costa, 2016, p.33). Night vision symptoms manifest themselves around the age of 20, when the diagnosis of RP is usually made; shows balance problems.

Type IV manifests itself, according to Liarth et al. (2002, p.485) through: “RP, complete congenital deafness and intellectual disabilities”; this is the rarest type and affects 1% of population.

³ This is the classification created by Merin and peers, according to Liarth et al (2002).

2.3. Usher Syndrome and the classroom

Depending on the Usher Syndrome type, it is relevant that the teacher pays attention to the points mentioned in Table 1 in the classroom.

Table 1 - Points to be considered in the classroom.

Types	Relevant points in the classroom
Type I	<ul style="list-style-type: none"> * Signs should be in the visual field; * The distance between the student and the person communicating with them through sign language (teacher or interpreter); * Enough time for the student to follow the conversation.
Type II	<ul style="list-style-type: none"> * The student can communicate orally (despite the hearing loss); * Avoid noise so as to not interfere with their attention level; * Make sure that the student can read lips with the support of residual hearing. * Avoid moving around the classroom while talking, as that makes it difficult for the student to focus, because it is hard to visually follow the teacher
Type III	<ul style="list-style-type: none"> * Speech can deteriorate quickly * Speech comprehension with the support of residual hearing and lip reading * Students should be in small classrooms with: <ul style="list-style-type: none"> ** A sign language interpreter or ** A guide interpreter

Source: Rita de Cássia Silveira Cambruzzi. Created on: 2017.

2.4 Legal aspects and inclusion

Students with Usher Syndrome, as guaranteed by the Brazilian law (Brasil, 1998, 2008, 2015) should be enrolled and going to regular school. However, the school environment needs accessible and specific pedagogical resources so that the student can participate in all academic activities, that is, in the school inclusion.

Sánchez (2005, p.5) indicates that: “... The innovation in education, progressively, has been expanding in the entire educative context, as an attempt to make sure that high quality education reaches everyone.” This approach relies on the principle of equal access regardless of any conditions (including but not limited to physical, emotional, intellectual, social and linguistic conditions), as well as culture and gender, to the point of discrimination. Therefore, paradigms must be changed and schools should develop ‘a pedagogy’ to educate all children (Sanchez, 2005).

According to the National Policy for Special Education in Inclusive Education (Brasil, 2008), the inclusive context is a space in which all disable people should be and propose that prejudiced views should be broken.

The inclusive school should be understood as “an attitude, a value and belief system, not an action or a group of actions” (Arnaiz, 1996, p.27). Cambruzzi (2013, p.50), supporting that view, points out that the inclusion “should generate changes in the way we interact with others, give access to the same education codes that values and recognises the learning style...”.

Therefore, the challenge is to prioritise the sociability possibilities between students and allow for the respect to the differences through a pedagogy that results in successful learning and that benefits every student, whether able or disabled (Arnaíz, 1996; Paulon, Freitas & Pinho, 2005; Sánchez, 2005).

After considering the Usher Syndrome and the Brazilian law regarding inclusive education, we question: What can the schools propose as actions to help the student with Usher Syndrome in their education process regarding visual adaptations? To answer the previous question, this study aimed to check the learning impact by proposing pedagogical activities with visual adaptations for the student with deaf-blindness due to Type II Usher Syndrome.

3. METHOD

The research is characterized by a case study as an investigation ‘strategy’ in a phenomenon real situation (Yin, 1989). The study case as a research strategy is very important in the real situation and due to its scope (Yin, 2001).

Oliveira (2011), on the other hand, emphasises that, since it is a broad phenomenon, it is not possible to reproduce it outside of its context. Rodrigues (2012, p.2), regarding evidence based intervention (EBI), also considers the “educative process, school complexity and diversity”. Besides those aspects, learning happens in its own context, with someone else allowing the student to be independent.

To develop this research, ethical principles were observed and respected according to the statement issued by the Ethical Committee, as well as actions for the research development and execution.

3.1 Participants

The participants in this research were: i) a 12 years old student, who we will call here Lucas to comply to ethical principles, diagnosed with Usher Syndrome, enrolled in the 5th grade, in a regular school and a bilingual class; ii) his mother; and iii) his bilingual class teacher, who communicated with Lucas through Sign Language. It should be clarified that the bilingual class is taught in Sign Language, as a first language, and Portuguese as a second language, according to the Education Policy for Deaf Individuals in the State of Santa Catarina (2004).

3.2 Place

The investigation was developed in a regular school where there was also a bilingual class, in São José, Santa Catarina, Brazil. The school bases its education process in the Santa Catarina Curriculum Proposal (1998), the Education Policy for Deaf Individuals in the State of Santa Catarina (2004) and the National Policy for Inclusive Education (2008), “legitimizing equal learning opportunities for everyone” (Cambuzzi, 2013, p.87).

3.3 Instruments

Main instruments used were: i) Semi-structured interview with the student’s mother, with open and close-ended questions, aiming to collect information regarding the family aspects about blood-relation between her and the student’s father; ii) Interview Protocol with Lucas, aiming to get his opinion about situations he experienced in the school environment and mediated with help from the bilingual class teacher to interpret the questions; iii) Questionnaire with the teacher to see her opinion about Lucas regarding different aspects (including but not limited to classroom behaviour, visual postures, relationship with his class mates); iv) Observation protocol aiming to assess Lucas’ behaviour in the classroom; v) Evaluations such as the Functional Evaluation Guide for 10/17 years old and the Vision Functional Evaluation Checklist (Ladeira & Queirós, 2002) were carried out at the beginning and at the end of the research, aiming to check Lucas’ visual conditions; e, vi) A Field Journal was kept throughout the investigative process to support the report of systematisation of the situations experienced in different times, which are susceptible to interpretation throughout the research.

The instruments (interviews, questionnaires, and observation protocols) were previously elaborated. Afterwards, they were reviewed by three judges aiming to check consistency, coherence and semantic validation of questions to avoid bias in the analysis and application of the collected data.

3.4 Materials

Visual materials (images) from the Internet and from software were used in the pedagogical interventions after a previous consult about the subject was presented in class by Lucas’ teacher. Besides that, distorted images were avoided due to Lucas’ vision problems. The material had a low cost and was printed with the best possible resolution, to keep the images clear and organised in the same order the content was presented.

Classroom observations were registered continually and descriptively. The observation protocol elaboration was based on the teacher’s questionnaire, allowing the identification of categories when registering the observation and allowing it to be analysed more quickly.

Documentary researches (with the family’s and institution consent) was another source of information collected in Lucas’ chart, from the institution where he studied before, as a baby, in an Essential Stimulation Program.

4. PROCEDURES FOR DATA COLLECTION AND ANALYSIS

The data was collected through information gathering using the instruments mentioned before: Interviews, questionnaire, documentary research, evaluation regarding Lucas' vision to check his visual competency throughout the investigation process.

Through documentary research, we collected information regarding Lucas' diagnosis process. At four months old, Lucas was diagnosed with sensorineural hearing loss through the BERA test. We collected information regarding his participation in the Essential Stimulation Service, which started when Lucas was 15 months old and only stopped when he was 3 years and 11 months old and his goals were deemed as achieved, so his participation on the program was terminated.

The interview with his mother resulted in information regarding the Usher Syndrome cause, consanguinity, since his parent's parents (his grandparents, from both sides of the family) were cousins. Therefore, Lucas' parents were cousins. His mother informed us that the diagnosis was made early on because she had an older brother with the same syndrome. She described his visual and hearing behaviours based on the symptoms indicators: struggling with abrupt luminosity changes in sunny days or when going from a bright space to a dimly lit space or vice-versa; struggling to see people and objects by his side; and decreased vision quality due to RP, as well as his sensorineural hearing loss.

In the questionnaire, his bilingual teacher informed us that Lucas is a curious kid and uses sign language when he is interested and becomes irritated when he does not understand a certain activity. He is organised when taking notes about his classes. He needs someone to point out parts of the activities so he can comprehend it as a whole. In daily activities, he uses only his right eye to see.

Information provided by his teacher confirmed the observations regarding light perception and its direction and that Lucas turned his face or placed his hand on his face, preventing the light to shine on his eyes when it was too bright. However, Lucas experienced other difficulties, such as going up the stairs in dark places; going into a movie theatre leaning into someone's shoulders to help him move around and, after getting used to the situation, he tried to walk on his own. However, Lucas, due to his progressive eyesight loss, frequently bumped into people and into the walls and posts. He asked for support by placing his hand on someone's shoulders and waist when walking to his chair in the classroom.

Lucas was starting to notice his struggles regarding abrupt changes in luminosity and did not accept them, saying his vision was okay, but his behaviours showed the exact opposite. He did not accept the situation, stating that he could see, even though his class mates gave him friendly reminders regarding his visual 'limitations'. Initially, when asked about the font type (Verdana, Arial, and Tahoma) and size, he said he was not able to see it (started with 20/22 and went to 24, 28), going all the way up to 36 at the end of the research, due to improper lighting. This was a natural reaction, because he was gradually experiencing his second loss, the visual one.

The pedagogical intervention was directed after collecting information about Lucas' needs with the help of his bilingual teacher and knowing what was being presented in the classroom. It was organised in a certain way to meet Lucas' needs in the activities established by the class subjects. Particularities observed in different real learning situations were considered while preparing the material for Lucas' learning activities, as well as in the results indicated in the vision function evaluation and the Checklist.

CCTV was the only technology based equipment used to establish Lucas' reading pattern based on font type and size to be used in his activities (see Image 1).



Image 1. CCTV using zoom 3.5x, 2.5x and 1.5 (top and bottom of the image), respectively.

Source: Fundação Catarinense de Educação Especial. São José, Santa Catarina, Brazil.

Low technology pedagogical resources were used, such as the images exemplifying the indicated materials, below:

i. high quality printed materials appropriated to the activities, according to the content (Image 2);

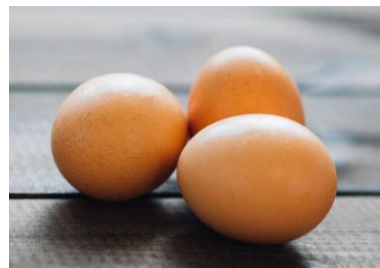


Image 2. Content for Portuguese class: Singular and plural.

Source: Cambuzzi, 2013.

ii. reading stand (image 3);



Image 3. Printed material stands for reading.

Source: Cambuzzi (2013). Materials provided by: Fundação Catarinense de Educação Especial. São José, Santa Catarina, Brazil

iii. notebook in which the lines were thickened with a 6B pencil.

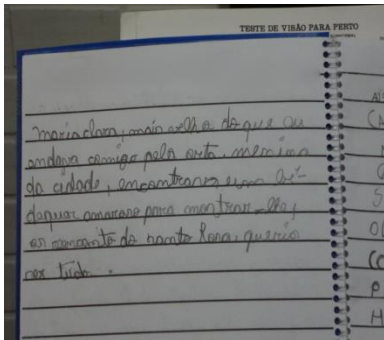


Image 4. Notebook in which the lines were thickened with a 6B pencil.

Source: Cambruzzi, 2013.

iv. Typescope as a reading guide (Image 5);

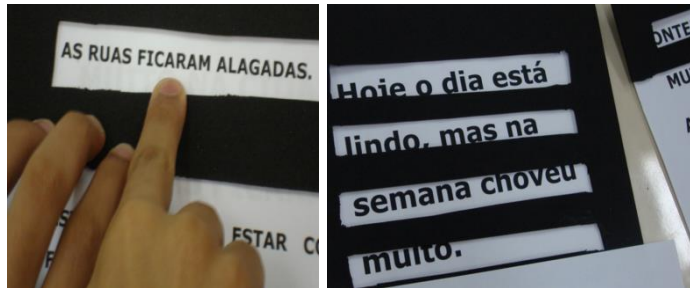


Image 5. Typescope used as a reading aid.

Source: Cambruzzi, 2013.

v. adapted maps (Image 6).



Image 6. Geography class: texturized and adapted maps.

Source: Cambruzzi (2013). Material provided by: Fundação Catarinense de Educação Especial. São José, Santa Catarina, Brazil.

Observations were carried out in different spaces: lunch time at school, a visit to the supermarket (aiming to establish the lowest price to use in a mathematics problem to be solved); Portuguese, Physical Education, and Science classes. In learning situations, the teacher needed to explain several times the problems statements to reinforce the mediation for Lucas to comprehend the concepts regarding the problem solution and, once he had established the relations, to solve it.

In mobility situations, he was comfortable indoors, not showing any issues, since he already knew the space. But outdoors he was more cautious, because he needed to adapt to lighting changes.

Visual competency was registered through a vision functional evaluation (Ladeira & Queirós, 2002) and the Checklist, which require near and far sight evaluations.

Regarding his vision, his struggles to adapt to abrupt changes in lighting were getting worse and his visual field was reducing, as Lucas could only identify objects right in front of him. He would get closer to the chalkboard to identify and see written details several times. On dictionary reading, he could not participate due to the font size, which was too small. He struggled to read signs due to font size and type and because they were not clear enough due to contrast.

On the map for river, mountain chains, population and geographical division identification, for example, Lucas struggled and showed some discomfort due to different symbols. In the classroom activities, he could comprehend images with contrast, indicated with the help of visual sweep. Regarding his daily life and mobility, Lucas seemed to be relatively in control.

5. RESULTS AND DISCUSSION

The collected and analysed data indicate that the results were satisfactory, since the classroom activities were accessible when presenting the content and to mediate Lucas' understanding of the concepts. When the task was significant and accessible, Lucas was able to offer proper responses.

Transformation through low-cost pedagogical resources made sure Lucas could visually access the classes content to stimulate his residual vision, because due to RP, he showed a progressive visual loss, which is common in Usher Syndrome patients.

Regarding the aforementioned difficulties such as his big shock to adapt to his new reality with the progressive loss, since he was experiencing a process leading to an imminent complete visual loss. Barczinski (1985), Samaniego (2004) and Medeiros (2009) point out a reaction regarding progressive visual loss and the psychological trauma caused by that loss. That psychological reaction is due to the "experience of grief, depression, pain, family reorganization after the diagnosis" (Galhordas & Lima, 2004, p.40). This is a long process with several defence mechanisms involved, leading the patient to build a whole new identity, as Oliveira, R. A. (2000), Oliveira (2004) and Fecho et al (2009) point out.

Samaniego and Muñoz (2004, p.367) also mention that the new condition "triggers emotions, distress, depression and negative thoughts in the family and these feelings reflect on the patient, since they see themselves face to face with a second loss".

Intervention with the proper pedagogical resources offered significant changes in the student's visual behaviour, that is, texts were presented in Verdana, after comparing with other font types (Arial Black, Times New Roman). Lucas presented proper behaviours with the content reproduced in his notebook, using his finger to mark the line and reading with the typescope.

His far-sightedness did not allow him to see small or medium fonts in street signs and billboard ads.

FINAL REMARKS

Usher syndrome generates problems and impacts the education if the teacher's and the school's approach to the student do not change. The teacher's role is vital regarding the educational advances, because using certain strategies (contrast, bigger fonts, thickened lines, typescope, images, and so on) to support the activities helps the student to progress regarding their learning process through significant and structured activities.

Given the research results, it is vital to establish an integrated support program that maximizes the visual efficiency to reduce, correct or eliminate the difficulties experienced by the student with Usher Syndrome in their learning environment.

Pedagogical resources organization in the classroom, respect towards the student's pace regarding his conditions and visual adaptations and proposing distinguished strategies are actions that should be taken in order to develop a high quality inclusive environment.

The school, as an institution, should support the student through distinguished strategies, initiate communication in different ways to keep in touch with people with Usher Syndrome. Through intervention and the development of beneficial emotional and social actions, it is possible to significantly reduce possible academic failures.

Due to progressive vision loss, it is essential to schedule medical follow up appointments, since the student presented evident losses compatible with Usher Syndrome, such as progressively increasing the font size.

Therefore, it is necessary:

- * that the teacher and pedagogical staff organizes the materials in a contextualized manner;
- * to respect the student's pace regarding visual conditions, that is, knowing how their visual loss progresses;
- * to propose distinguished strategies due to their educational implications towards a high-quality education; and,

* to observe the teachers and managers training and the elaboration of materials and books available.

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