

# WHITE CHILDREN'S BLACK PROBLEMS: PROBLEMS EXPERIENCED BY CHILDREN WITH ALBINISM IN THEIR EDUCATIONAL LIFE

## PROBLEMAS NEGROS DE CRIANÇAS BRANCAS: PROBLEMAS EXPERIMENTADOS POR CRIANÇAS COM ALBINISMO EM SUA VIDA EDUCACIONAL\*

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**Abstract:** Albinism, which occurs due to insufficient or no secretion of the melanin pigment secreted by the body, is defined among rare diseases. Albinism disease affects all hairs in the skin, eyes and body. The occurrence of the mentioned problem in the production of melanin pigment causes problems such as low vision of individuals with albinism and tremors in the eyes, etc. This situation affects all areas of the life of individuals with albinism as well as their educational life. Although albinism has many known or unknown types, it causes the body to be sensitive to light, have poor vision and experience strabismus etc. In this study, the subject of education of individuals with albinism is discussed. The purpose of the research is to address the problems experienced by individuals with albinism in their educational lives. The data of the study were obtained through in-depth interviews with seven people, five students with albinism and two parents of students with albinism, through a semi-structured questionnaire. Analyzes were made as a result of the interviews. As a result, it was determined that individuals with albinism experienced problems related to vision, appearance, teachers, peers and families while continuing their education.

**Keywords:** Children's Albinism. Educational Life.

**Resumo:** O albinismo, que ocorre devido à secreção insuficiente ou inexistente do pigmento melanina secretado pelo organismo, é definido entre as doenças raras. A doença do albinismo afeta todos os pelos da pele, olhos e corpo. A ocorrência do problema mencionado na produção do pigmento melanina causa problemas como baixa visão de indivíduos com albinismo e tremores nos olhos, etc. Esta situação afeta todas as áreas da vida dos indivíduos com albinismo, bem como sua vida educacional. Embora o albinismo tenha muitos tipos conhecidos ou desconhecidos, ele faz com que o corpo seja sensível à luz, tenha visão deficiente e experimente estrabismo etc. Neste estudo, o assunto da educação de indivíduos com albinismo é discutido. O objetivo da pesquisa é abordar os problemas vivenciados por indivíduos com albinismo em suas vidas educacionais. Os dados do estudo foram obtidos por meio de entrevistas em profundidade com sete pessoas, cinco alunos com albinismo e dois pais de alunos com albinismo, por meio de um questionário semiestruturado. As análises foram feitas a partir das entrevistas. Como resultado, foi determinado

\* Artigo recebido em 27/05/2022 e aprovado para publicação pelo Conselho Editorial em 05/07/2022.

\*\* This study was presented as an oral presentation at the "International Symposium on Social and Educational Sciences" held in Istanbul between 22-23 February 2020.

I would like to thank ŞEYMA YAZAR for her contributions to this study

que os indivíduos com albinismo experimentaram problemas relacionados à visão, aparência, professores, colegas e familiares enquanto continuavam sua educação.

Palavras-chave: Crianças. Albinismo. Vida Educacional.

## INTRODUCTION

Albinism is one of the rare diseases known as hereditary and global prevalence 1:17,000 caused by the inability to secrete melanin pigment secreted by the body, which can be seen in all countries of the world and in individuals of all social classes (Kruijt et al. 2018; Marçon and Maia 2019). This affects all hairs in the skin, eyes and body. Experiencing this problem in the production of melanin pigment leads to problems such as photophobia, nystagmus (tremor in the eye) and low vision. Although albinism has many known or unknown types, it causes the body to be sensitive to light, have poor vision and experience strabismus etc. (Şafak, 2012). Therefore, this situation affects all areas of the life of individuals with albinism as well as their educational lives. However, it should be noted that when the researches conducted in the sample of Turkey are examined, it is seen that, contrary to the literature, individuals with albinism participate in the educational processes although they have difficulty in their educational lives (Meterelliyoç and Yazar: 2020). Although the number of students with albinism in Turkey is not clearly known, considering the total number of albinism about 4000-6000 in the country, it can be said that there are between 1500-2000 individuals with albinism continuing education (Kırıcı, 2018).

Individuals with albinism, whose presence is easily noticed due to their remarkable appearance, constantly twitching eyes and behavior such as looking closely at objects, often face situations such as being mocked by their peers, especially at a young age. Situations such as not making arrangements according to individual characteristics in the classroom environment, having difficulty in seeing the board, not adjusting the light appropriately in the environment, and some difficulties in peer acceptance can negatively affect the behavior of individuals with albinism (Ünal and Coşkun, 2021).

Individuals with albinism are born with vision problems such as astigmatism, strabismus, and nystagmus. This situation also leads to visual loss that varies from person to person. These individuals, who are mostly classified as less sighted, are directed either to inclusive education or to the school for the visually impaired. Despite all the interventions, individuals with visual acuity between 20/70 and 20/200 in the well-seeing eye are called less-seeing. Individuals with low vision albinism need large-point materials, magnifiers or assistive technologies (Özyürek, 1995; Ocak, et al., 2018; Şafak, 2012; Ünal ve Arslan, 2021).

The fact that albinism causes visual disorders affects the educational life of individuals very much. Education is the process of transferring knowledge that will help the individual to adapt to social life and ensure social development. Although this process is divided into two parts as informal and formal, it refers to a whole. Therefore, in this process, it is not possible to provide an equal and fair education in informal education, which can be defined as teaching something to the individual, unplanned education of the circles such as family, friends, etc. However, in formal education areas, which express a planned and programmed education process, it is necessary to carry out studies that will prevent the problems arising from health problems of individuals with albinism from becoming more complex in the social environment and ensure justice in education (Kırıcı).2018).

One of the problems that students with albinism experience at school is being ostracized by their friends. In her study, Doris (2019) suggested that teachers and parents should encourage their students and schools with albinism to stay at school, and that sensitivity programs related to albinism should be introduced in schools to raise awareness for students at school, so that students can accept students with albinism.

One of the most fundamental problems in education is that both education systems and other social systems focus on uniform education, which covers only the common characteristics of students and neglects individual differences, sometimes due to structural inadequacies and sometimes intellectual reasons. However, although teachers have adopted the standard characteristics of students, they can approach students differently by combining the features that make students unique. In such an approach, it is desirable to use this distinction in the organization of teaching services based on individual differences in the learning environment. Although individualized and adapted education is a concept that is generally used in the education of children with disabilities, it has been demonstrated that it is a viable concept for all students, whether they are disabled or not (Ünal & Coşkun, 2021).

There are only two studies on the education of children with albinism in Turkey, the first of which is; In Kırıcı's (2018) study, when the school process was examined, it was revealed that individuals with albinism generally have vision-related problems. Visually impaired students have difficulties in some lessons due to their disabilities. Students who are assumed to be equal in the classroom environment have different ways of acquiring knowledge. This difference varies according to the past experiences of visually impaired children as well as their visual disabilities. Teachers should take this into account while

teaching the lessons. Because in Turkey, many students study together in classrooms. As a result of the measurements and evaluations made in the lessons, it is revealed that each student has a different level of knowledge. Many researchers attribute the main reason for this situation to individual differences among students. Each student has different learning styles depending on their individual characteristics. After the learning styles of the students are determined, the quality of the education will change positively (Demir and Şen, 2009). And the second is; This is a study by Ünal and Coşkun (2021), in which the problems faced by individuals with albinism in participation in education and social life in Turkey and their coping methods are discussed

When a literature study is conducted on the education of individuals with albinism in Turkey, it is seen that the studies are quite limited. For this reason, it was deemed appropriate to conduct such a study in the field of social sciences in Turkey. The aim of this study; The aim is to address the problems faced by individuals with albinism living in Turkey during their education. For this purpose, an answer to the following question is sought; What are the problems experienced by individuals with albinism in their education life?

## METHODOLOGY

Being with albinism affects all areas of the life of individuals with albinism as well as their educational life. For this reason, this study deals with the education of individuals with albinism. Therefore, the aim of the research is to address the problems experienced by individuals with albinism in their educational lives. The main problem of the research is the question “What are the problems that individuals with albinism experience in their educational life?”. The sub-problems are;

- What problems do they have with their friends?
- What problems do they have with vision?
- What are the problems they have with their teachers?

The data of the study were obtained by interviewing seven people in total, five students with albinism and two parents of students with albinism. Participants with albinism are all students. The age of the student participants varies between 10 and 20. Parents are 45 and 50 years old. Two of the participants with albinism are female and three are male students. Both parents are women. The interviews were conducted in depth through a semi-structured questionnaire. Therefore, qualitative data analysis method was

used in the research. Parent interviews are generally supportive and the opinions of individuals with albinism are generally included in this study.

## RESULTS

In the analysis made as a result of the interviews, it was determined that individuals with albinism experienced problems related to vision, appearance, teachers, peers and families while continuing their education. Therefore, five categories were formed as a result of the interviews. The first of these categories is the problems they experience in terms of vision in educational processes. Most of the interviewees stated that they felt different from the individuals around them and their friends, and they experienced this in primary school. They stated that they understood this when they were falling behind in the context of lessons or social activities from their friends due to not being able to see the gesture of the teacher and the board. Participant 1 (19), who was interviewed, stated that although he/she was sitting at the front when he/she started primary school, he/she could not see the board and at first he/she thought that his/her friends could not see the board like him/her. Participant2 (20), another participant, stated that although he/she used glasses, he/she could not see the board and that he/she was exposed to accusations by other friends such as “you are wearing glasses but you cannot see the board, and you are lying”.

The methods used by each student to benefit from the board differ from each other. Participant3 (13) said that he/she could take his/her tablet to the school with the approval of his/her principal and take a photo of the board and read what was written on the board, and also that his/her teacher held it close to him/her while showing something. Participant2 (20) and Participant1 (19) stated that they could see the board better if they sat in the front. Participant 4 (10) asked his/her teacher to sit in the front in order to see the board, but this request was rejected by the teacher on the grounds that it would be reflected as "discrimination" to other students. Likewise, he/she said that the teacher sent a photocopy to the house as his/her homework and that the teacher did not insist on doing this even though his/her parents talked to the teacher about printing these photocopies in large fonts. Participant4 stated that although the delegation report and the report taken from RAM and the family met with the school administration, the exams were not printed in large points.

The second category is the problems they experience related to their appearance in education process. Participant4 (10) stated that his/her friends made fun of him/her as a

joke, made statements such as "Nineee, ninee" and sometimes exaggerated and he/she took offence, and once he/she physically fought with a friend for this reason.

The third category is the problems they experience with their teachers during the education process. The answers received from the interviewees on this subject differed. Participant3 (13) stated that his teacher took appropriate care of him in primary school because his teacher had a friend with albinism. Similarly, Participant1 (19) stated that his/her friends and teachers treated him/her very understandingly and that he/she was an exception in this regard and that he/she was lucky thanks to this. However, Participant4 (10) stated that his/her teacher did not take care of him/her and even the teacher refused his/her wish to sit in front. Likewise, Participant5 (17) was accused of lying by his/her teacher and participant5 (17)'s requests were answered negatively. The teacher of the participant2 (20) did not accept the inability to see as a reason for not keeping the notebook organized and blamed the participant2 (20) in this regard.

The fourth category is the problems they experience with their peers during the education process. Participant2 (20) stated that he/she went to private school until high school and was excluded by his/her friends, and that he/she had about one or two good friends in primary school. Participant3 (13)'s mother said that her son came home crying many times and said, "*Mom, they do not let me in their games because I do not see as well as they do, because I get a ball on my head*". Participant1 (19) stated that he/she was generally on good terms with his/her friends, but that his/her lessons being good might be one of the reasons contributing to this.

In the fifth and last category is the problems they have with their families during the education process. Accordingly, Participant2 (20) stated that although his/her parents were doctors, they still had difficulty in understanding him/her, but they did not have any problems at that moment. Participant1 (19) similarly stated that he/she had a sister with albinism, that his/her parents were experienced in this regard and that they were trying to understand at least. The families of Participant3 (13) and Participant4 (10) support and try to understand their children as much as they can, as we observed in the interviews. Participant4 (10)'s mother told him/her that he/she was a little "different" from other people and tried to teach him/her that he/she should be at peace with this difference. In addition to these positive examples, Participant5 (17) stated that his/her family did not understand him/her at all and attributed this to the low level of education of his/her family, but Participant2 (20) stated that although his/her parents were doctors, they did not understand him/her at first. During the interview, the mother of the participant3 answered

the question *"How many children do you have?"* as she had 5 children, 4 of them were 'normal' and one of them was the Participant4. Participant5 (17) added that when he/she couldn't see something, his/her father said something like; *"Don't exaggerate, can't you see at all?"*.

## DISCUSSION AND CONCLUSION

As a result of this study, it was seen that individuals with albinism faced many problems in their educational lives. These problems were addressed in five categories in this study. These are problems related to vision, appearance, teachers, peers and families. The problems experienced by individuals with albinism in these five categories are explained in detail in the findings section.

As a result of the problems experienced by individuals with albinism in their educational lives, various suggestions have been developed to minimize these problems. First of all, as a result of this study, it was seen that the families of children born with albinism were not given enough information about albinism. Therefore, the family itself does not have enough information about albinism, cannot understand its own child at first, and some problems arise. As a result, families should be informed about albinism by the doctor when the child is born.

Secondly, it is very important for families to explain albinism to their children in a language that they can understand after they have learned enough about it because all of the interviewees stated in different ways that their parents did not give them any explanation about albinism and why they could not see well until a certain age or why their hair, eyebrows, eyelashes and skin colors were different from other people. Instead of being overprotective and keeping their children away from everything as their children see less than their peers, families should spend time together by making various activities suitable for them. In addition, when individuals reach adolescence, they mostly want to hide their differences and do not want to attract attention. For example, an individual with albinism needs a large-point printed paper to read the exam paper better, but does not tell his/her teacher because he/she does not want his/her friends to know that he/she is different. Or although he/she can't see the board, he/she doesn't let anybody notice that he/she doesn't see. In such cases, the family and the teacher should behave very carefully in cooperation and psychological support should be provided if necessary.

Thirdly, when the child with albinism reaches primary school age, the parent should definitely contact the classroom teacher and school administration, and the most

appropriate learning environment should be provided to the child according to the needs of the child. The family should consult with the school psychological counselor, the school psychological counselor should direct the family and the child to the RAM (Guidance Research Center), where certain tests should be applied to the child and a report should be prepared according to the needs of the child. This report is different from the Disability Report, but a disability report must have already been issued in order for this report to be issued. The Disability Report is a report that should be taken from public hospitals and states proportionally how much the disability restricts the daily life of the person. In albinism, the sections to be applied for obtaining a disability report are eyes and skin. The reputation of the disability report is not very good among the people, but it has many benefits for the recipient, contrary to what is thought (Such as additional time in high school and university entrance exams, large font size, marker or reader, additional score, free urban transportation, free entrance to museums and public theaters, right to enter EKPSS and become a civil servant.). Disability report and this report obtained from RAM are official documents and are necessary to provide the best learning environment in line with the needs of the child (Within the scope of the support training room, the individual with albinism takes one-to-one lessons from certain teachers, such as printing written papers with large font size.). If the school administration or the teacher still does not do what needs to be done for the child, the parent has the right to complain if he/she has this report. Finally, the whole society should be informed about albinism, not just schools. When people say 'albino', the first thing that comes to mind is people with white hair and white skin. Rather, we should tell the society that individuals with albinism see less and are disturbed by too much sunlight. Some of the frequently encountered sentences of individuals with albinism:

*Why don't you wear glasses? Answer: Because when we wear glasses, our vision does not completely heal.*

*Isn't there a cure? Answer: Yes, not yet.*

*Don't look so closely, your eyes will be distorted. Answer: I look closely as my eyesight has already deteriorated.*

One of the biggest problems that come to the agenda in the interviews is the problem of not seeing the board. There is a system that is applied in some countries in Europe: a tablet is placed in the row of the child with low vision, and this tablet is reflected on the wooden tablet by establishing a system, and the student with low vision can follow the lesson without any problems like his/her other friends. The Ministry of National



Education should also implement such a system in Turkey. In addition, textbooks are sent to schools by the Ministry of National Education at the beginning of the year. Especially with the data-based education system, the special needs of the students will be better known, so special printed large point textbooks should be printed for students with albinism. MEB and ÖSYM print personalized booklets for high school and university entrance exams, give additional time, give readers and markers if needed and requested, but since the entrance guide is renewed every year, parents and students should follow the up-to-date information. In conclusion;

- Teachers and students who have an individual with albinism in their class should be informed about this,
- Doctors should inform parents of children with albinism about this after birth,
- Families should be trained on this subject,
- The technological tools that should be used to benefit from the board should be released by the school administration,
- School guidance services should be more knowledgeable and informative on technical issues such as reports etc.

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