

The Challenges Encountered by Individuals with Albinism in Their Education*

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Abstract

In this study, the aim was to identify the challenges encountered by individuals with albinism throughout their educational journey. The case study method, a qualitative research approach, was employed for the study. Purposive sampling using criterion sampling technique was utilized to determine the study group. Accordingly, a total of 10 individuals diagnosed with albinism were included in the study. The Albinism Association was contacted to inform them about the purpose and process of the research. Through the association, participants were identified using a Google form. A semi-structured interview form was used as the data collection tool for the research. The interview form included 2 questions about the problems in their educational lives and possible solutions. The data collected in the research were analyzed using descriptive analysis method, and direct quotations from the participants' sentences were included. As a result of the research, it was observed that individuals with albinism experience peer bullying, are subjected to disturbing looks in the social environment at school, face difficulties in using educational materials, and cannot follow the lessons in terms of the learning process. Based on the findings, it is recommended that appropriate textbooks be organized for individuals with albinism, the physical conditions in educational environments be arranged, and teacher training include information about individuals with albinism.


Keywords: Albinism, Individuals with Albinism, Educational Challenges


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The human body is visually characterized by its diverse range of colors. When observing our surroundings, we notice individuals with various skin tones, some having brown, red, or yellow hues, while others have white or near-white skin tones. The coloration of the human body is facilitated through the melanin hormone (Kırcı, 2018). However, in some individuals, a genetic difference known as albinism occurs due to a reduction in pigmentation in hair, skin, and eyes (Dikmetaş, Şanal Doğan, & Gürdal, 2018). Albinism is a term describing a hereditary condition resulting from defects in melanin synthesis (Dursun, Vatansever, & Adıgüzel, 2021). Broadly, albinism is a variation arising from the absence of melanin pigment that imparts the ordinary color to the skin, hair, and eyes due to genetic mutations (Ünal & Coşkun, 2021). This condition can lead to both skin and vision-related health issues. For instance, individuals with albinism have light skin, making them more sensitive to sunlight. Insufficient pigment production in the eyes, iris, and retina results in reduced visual acuity and eye problems like nystagmus (Yavuzer & Yavuzer, 2023). The distinctive appearance and health challenges faced by individuals with albinism can lead to psychosocial issues in their social or educational lives (Samur, Polat, & Canpolat, 2022). The situation experienced by individuals in terms of appearance affects their body image and, due to labeling, can adversely impact their quality of life (Tsutsumi et al., 2007). These challenges may result in low self-esteem, anxiety, stress, social withdrawal, and even discontinuation of education for individuals.

Although special education policies have been present in the Turkish education system since the 1960s, the concept of special education has gained increased attention both in society and scientific studies in the last decade (Çakıroğlu & Melekoğlu, 2013). Special education aims to enhance the capacities of individuals based on their special abilities, enabling disabled individuals to become self-sufficient, integrated, and independent, contributing members of society (Orhan & Genç, 2015). Individuals with albinism, particularly due to vision problems and skin issues, face challenges in the school environment. For example, their sensitivity to sunlight, given their light skin and delicate skin, can cause discomfort when exposed to the sun. Sitting in a sunny classroom can exacerbate the problem for these individuals. Consequently, a decrease in motivation towards the lesson may occur, leading to a decline in academic success. Additionally, sitting at the back of the class due to vision problems may hinder their view of the board, resulting in similar consequences and potentially leading to the individual distancing themselves from the school environment. Considering the specific needs of individuals with albinism, it is crucial to take into account the educational environments and ensure that educational materials address vision problems.

Research on individuals with albinism has been conducted in various parts of the world, with many studies focusing on African countries (Ünal & Coşkun, 2021). Examining national and international scientific studies on albinism reveals research topics such as the quality of life of individuals with albinism (Maia et al., 2015), clinical findings in ocular albinism (Özcan, 2018), physiotherapy and rehabilitation program effectiveness for individuals with albinism (Demircioğlu & Uysal, 2017), depression, anxiety levels, self-esteem, and quality of life in individuals with albinism (Meterelliyoğlu & Yazar, 2020), psychological and personal aspects (Estrada Hernández & Harper, 2007), and sociological studies on individuals with albinism in schools (Gaigher, Lund, & Makuya, 2002). In Turkey, studies primarily focus on medical and scientific research related to albinism (Ünal, 2020). It has been observed that there is a limited number of studies on individuals with albinism in the fields of social sciences and education

(Kırıcı, 2018; Ünal & Çoşkun, 2020). This study aims to focus on the educational challenges of individuals with albinism, an underprivileged group, with the intention of gaining an in-depth understanding of their emotions and thoughts through interviews. The study is significant in revealing the problems faced by individuals with albinism at the primary, secondary, and higher education levels in Turkey. Within this scope, the research problem statement is as follows:

- What are the problems experienced by individuals with albinism in their educational lives?

Based on the foundational research question, the sub-problems of the study are as follows:

- What challenges do individuals with albinism encounter throughout their entire school life in terms of social environment, teaching-learning process, and the use of school tools and materials?
- What are the proposed solutions to the problems experienced by individuals with albinism in the education process?

Method

The research process has been structured in accordance with a qualitative approach. Qualitative research is a method that seeks to inquire into, interpret, and understand the natural progression of the problem in its context. Data is collected through methods such as observation, interviews, and document analysis, aiming for a subjective and interpretative approach that allows for the perception of previously known or unnoticed problems and the realistic consideration of natural phenomena related to the problem (Baltacı, 2019).

Research Model

In the research, the qualitative research method of case study has been employed. According to Dawidowicz (2011), a case study is a design that can be used in various fields, such as program evaluation, exploration of factors influencing individual behaviors, or understanding people's needs through their perspectives (Ceylan Çapar and Ceylan, 2022, p. 298). The general aim in a case study is to develop as comprehensive an understanding as possible about the particular case under investigation (Tight, 2010). Accordingly, the reasons and factors related to the studied case are identified.

In case studies, data are collected through questions, observations, oral or visual recordings, as well as written sources and documents (Paker, 2015). Within the scope of our study, the problems experienced by individuals with albinism were determined through interviews, and specific codes and themes were identified.

Study Group

The purposive sampling method was employed in determining the study group, utilizing the criterion sampling approach. Criterion sampling involves studying all cases that meet a pre-determined set of criteria (Yıldırım & Şimşek, 2011). Accordingly, individuals aged 18 and above diagnosed with albinism were included in the research in line with the study's objectives. Personal information of the participants is presented in Table 1.

Table 1

The Demographic Characteristics of Individuals With Albinism Included In The Study Group

Categories	Variables	Frequency	Total
Gender	Female	7	10
	Male	3	
Age	50 and above	1	10
	26–31 years old	2	
	20-25 years old	7	
Learning Level	Primary School	-	10
	Middle School	-	
	High School	-	
	University	10	
Place of Residence	İzmir	3	10
	Bolu	1	
	Ankara	4	
	Kocaeli	1	
	Balıkesir	1	

According to the data presented in Table 1; in terms of gender distribution among participants, there were 7 females and 3 males. Regarding age distribution, 7 individuals were in the 20-25 age range, 2 individuals were in the 26-31 age range, and 1 individual was aged 50 and above. In terms of educational background, it was observed that 10 participants were university graduates. Examining the distribution based on the cities where participants reside, 3 individuals were from Izmir, 4 individuals from Ankara, and 1 individual each from Bolu, Kocaeli, and Balıkesir, making a total of 10 participants.

Data Collection Tool

The data collection tools for the research consist of a personal information form and an interview form prepared by the researchers. In the qualitative data collection process of the study, the interview technique was employed to understand individuals' experiences. The aim was to reveal the experiences of individuals through the qualitative data collection tool, allowing for a more detailed, in-depth, and comprehensive examination of all data.

Personal Information Form: The form includes a total of 4 questions regarding the participants' gender, city of residence, age, and educational background.

Interview Form: A semi-structured interview form, which is one of the qualitative data collection tools, was utilized to determine the experiences, emotions, thoughts, and opinions of individuals with albinism regarding the problems they face. The interview form was prepared by the researchers and presented to an expert teacher working in the albinism association and a Turkish language teacher at a middle school for their opinions. Based on the feedback received, the questions were finalized. Accordingly, a 4-question form was prepared for the interview focusing on educational issues and recommendations.

1. "What social challenges do you encounter as individuals with albinism in your educational life?"
2. "What challenges do you face in the use of school tools and equipment in your educational life?"

3. "What problems do you encounter in the processes of learning and teaching in your educational life?"
4. "What are the proposed solutions to the problems experienced by individuals with albinism in the education process?"

Data Collection

During the process of determining and including participants, contact was established with the Albinism Association. Following discussions with the association, a participant request form was prepared using Google Forms to identify individuals willing to participate in the research. After a two-week period, individuals who responded to the form and expressed their willingness to participate were identified. Those who responded to the form were contacted, and a suitable date and time were determined for their participation. In the initial communication aimed at determining the meeting time, the purpose and significance of the research were explained to the participants in a few sentences. It was conveyed that the interviews would be conducted via Zoom, either through video or audio recording. Participants were assured that no questions that could make them uncomfortable would be posed, and the research would solely serve scientific purposes. They were also informed that there would be no identifiers in the research results and that all records would be kept confidential. After providing this information, verbal consent was obtained from the participants. On the designated day and time, online meetings were initiated through Zoom. Prior to the interviews, the researcher collected participants' personal information, such as gender, age, location, and educational background, using a personal information form created through Google Forms. After completing the form, interviews with each participant were conducted online through Zoom under the guidance of the researcher and the supervising teacher advisor, lasting a minimum of 90 minutes each. To collect, analyze, and reflect findings in the results, video and audio recordings were made during the interviews. After completing the interviews, the data was transferred to a Word document.

Analyzing the Data

The data obtained from interviews in the research were analyzed using the qualitative analysis method of descriptive analysis.

Trustworthiness

Validity and reliability concepts, which are crucial in research, have been introduced to the literature in qualitative research by Guba (1981, 1990; Lincoln and Guba, 1985) and expressed as trustworthiness. In the context of trustworthiness, there are criteria and techniques for researchers (Arslan, 2022). In this regard, a 7-item semi-structured interview draft has been prepared by the researchers to ensure the credibility of the research. For expert examination of the prepared questions, the opinions of a Turkish language teacher, a faculty member specializing in social studies education, and an individual working in an albinism association have been sought. As a result of the feedback received, the content of the questions has been revised, and 2 questions with similar answers and one irrelevant question have been removed from the interview form, resulting in a total of 4 questions. After the actual implementation of the prepared interview questions, the data were transcribed into written text and subjected to participant validation.

To ensure transferability in the research, a purposeful sampling technique was used, and detailed information about the participants was provided. In addition, the findings section includes expressions directly reflecting the opinions of the participants. For research consistency, another researcher assisted in the analysis of the data, and the codings were evaluated by comparing them using Cohen's Kappa statistic, resulting in a value of 0.83. According to this, a value of 0.80 and above is considered to indicate very good agreement and acceptable reliability (Arslan, 2022). For confirmability, all processes in the study were explained in detail. The data collected from the research were protected in a computer environment and archived at the end of the study.

Findings

In this section of the research, findings related to the challenges experienced by individuals with albinism are presented, organized under the sub-problems of the research. The text is structured by providing titles in accordance with the research's sub-problems.

The Challenges Encountered by Individuals With Albinism In Their Educational Lives

The first sub-problem of the research involved posing the question to the participants: "As individuals with albinism, what challenges do you encounter in the social, material, and instructional-learning aspects of your educational life?" The responses of the participants to this query are presented in Table 2.

Table 2

The Challenges Encountered by Individuals With Albinism In Their Educational Experience

Theme	Codes	f
Social	Peer Bullying	6
	Strange looks of the environment	4
	Contempt	1
Teaching-learning process	Difficulty reading the writing on the blackboard	6
	Not being able to follow the lesson	2
	Difficulty in the exam	2
Material	Not being able to read the textbook	7

When examining the data presented in Table 2, it is observed that individuals with albinism are most subjected to peer bullying from a social perspective. They encounter the greatest challenges related to vision issues in terms of the teaching and learning process. It is also understood that they face difficulties in reading textbooks as a material. Some expressions from the participants are as follows:

KE1: *"People throwing uncomfortable glances, being treated as if I am different, belittlement, pity. That's why I feel safer with dyed hair and wearing sunglasses."*

KK2: *"The biggest problem I faced in my educational life was my vision impairment. An individual with albinism has skin sensitivity and vision problems. I would always sit in the front row at school and ask my teacher or friends about things I couldn't see. My usual solution was this. I also had situations where I took private lessons. I acquired auxiliary*

resources to improve my vision quality. Telescopic glasses and magnifying glass were two of them. In elementary and middle school, it was generally a difficult period in terms of my education, but in the subsequent periods, I could solve my problems more easily."

KK7: "Due to the difference in my appearance, I usually attract people's attention in social settings. Sometimes, unfortunately, I can be subjected to disturbing glances. People usually remember me once they see me, but I might not recognize them when I see them again. It's not easy for me to exhibit 'bad' behavior because people usually recognize me, especially during childhood. Unfortunately, I experienced bullying during childhood because children can be a bit more ruthless in teasing and such. But if I believe in the good intentions of the person in front of me, I usually explain what albinism is and try to raise awareness."

KK3: "In elementary and middle school, I sometimes solved the difficulties of seeing the board by sitting close to the board or standing up to look at the board and then sitting back down. In high school and university, I used my phone for assistance."

KE7: "The biggest problem is not being able to see the board and not being able to follow the lesson simultaneously. You can feel dependent on your friend next to you. Sometimes, teachers may not believe you. When your written paper has larger fonts than others, others can make comments..."

Solutions Proposed for The Challenges Faced By Individuals With Albinism

In the context of the fourth sub-problem of the research, participants were queried with the question: "What are your proposed solutions to the challenges experienced as individuals with albinism?" The responses provided by the participants are presented in Table 3.

Table 3

Findings Regarding Solutions Proposed for The Challenges Faced By Individuals With Albinism

Theme	Codes	f
Scholl	School resources should be improved	5
	Textbooks should be organized according to visual impairment	5
	The physical conditions of the school and classroom should be improved	3
	Stair steps should be colored.	1
Teacher	Teachers should be made aware	5
Medicine	Support studies on albinism in medicine	2
Family	Families with albinism should be educated	1

When examining the data presented in Table 4, participants have provided recommendations concerning the improvement of school resources related to the challenges faced by individuals with albinism. These suggestions include enhancing school facilities, adapting textbooks to address visual impairments, colorizing staircase steps, raising awareness among teachers, supporting scientific research on albinism in the field of medicine, and providing educational programs for families with individuals affected by albinism. Some expressions from the participants are as follows:

KE1: *"Teachers can be enlightened to reduce educational challenges. Individuals with albinism can be informed and supported regarding devices such as telescopic glasses and digital magnifiers, which partially overcome problems arising from visual impairments. Educational programs can be offered to families of individuals with albinism."*

KK1: *"Due to the lack of depth perception, it is necessary to colorize staircase steps, and the black striped tapes applied on them need to be renewed."*

KK2: *"Support should be provided for doctors to conduct research on albinism. Healthcare services need to be improved."*

KK3: *"Adaptation of school resources to suit individuals with albinism, enlargement of bus writings for public transportation, highlighting stairs (applying tapes or painting stairs), increasing awareness about albinism from an early age, and providing comprehensive psychological support and information on albinism to families of individuals with albinism after childbirth."*

Conclusion and Discussion

The first sub-problem of the research revealed that individuals with albinism particularly experience discomfiting gazes from people and peer bullying in their educational lives, especially in their social interactions. According to Gaigher et al. (2002), individuals with albinism encounter various psychological challenges in society due to their white skin appearance. These challenges may lead to an asocial life and a smaller circle of friends. Gaigher et al. (2002) align with the findings of the first sub-problem of the research. Another conclusion indicates that individuals with albinism face difficulties in the classroom environment due to their visual impairment. It has been understood that they encounter problems in reading written content on chalkboards, as well as in using study materials such as notebooks and books. These findings in the research are consistent with the results of Kırıcı's (2018) study. In Kırıcı's (2018) research, individuals with albinism were reported to have difficulties in seeing the chalkboard, reading textbooks, and facing challenges related to teachers' limited knowledge on the subject.

Individuals with albinism generally have trouble reading writings on the board in terms of the teaching and learning process. Additionally, they face challenges in following the lessons and reading exam papers. In his 2019 study, Tekin examined the educational problems of disabled university students and identified difficulties in classes and exams for students with hearing and visual impairments. This result indicates that similar situations are encountered in other studies.

When we look at the recommendations brought forth by individuals with albinism regarding their challenges, they propose the improvement of school resources, the appropriate design of textbooks for visual problems, the colorization of stair steps for depth perception issues, raising awareness and providing education for teachers on this matter, and arranging the physical environments of schools and classrooms to meet the needs of individuals with albinism. In the study by Ünal and Çoşkun (2020), interviews were conducted with teachers, and as a result, teachers recommended large-font storybooks and magnifiers, notebooks with darker lines, modified lined notebooks, and large cardboard sheets for individuals with albinism.

Individuals with albinism often encounter various challenges, primarily associated with visual impairments. This circumstance particularly poses difficulties in the school environment, especially concerning educational materials. Additionally, due to their appearance, individuals with albinism are susceptible to peer bullying, particularly during the primary education process. This situation may lead to social isolation in their personal lives. Moreover, it can adversely impact academic achievements in the school setting.

Suggestions

Based on the findings obtained through research, the following recommendations have been made:

Suggestions for Teachers

Due to the visual challenges experienced by individuals with albinism, adjustments can be made in the educational environments regarding temperature, lighting, physical conditions, smart board displays, and font sizes on exam papers.

Suggestions for Decision Makers

Teachers can receive in-service training on how to manage the process when dealing with a student with albinism. Curriculum content related to individuals with albinism can be organized in education faculties to raise awareness among teachers on this issue.

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Conflict of Interest

No conflict of interest has been reported.

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Ethical Standards

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