

Looking for Lost Notes: Participatory Case Study of a Family of Three Brothers with Albinism

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Abstract: *Introduction:* Albinism is an inherited genetic disorder that reduces the amount of melanin that forms in the skin, hair, and/or eyes. Albinism is one of the most common causes of visual impairment in children in the United States. The aim of this study was to (1) gain overall insight into the music learning of three brothers with albinism and (2) investigate how the teacher's proficiency and parents' perceptions of children's visual impairment contribute to their learning outcomes. *Methods:* A qualitative case study was conducted with a family of three albino brothers as the unit of analysis. The mother's and instrumental teachers' qualitative data were also used for triangulation purposes. The interview questions enabled an analysis of comparable numerical data and subjectively perceived experiences and opinions. A complete observation was also conducted for methodological triangulation. *Results:* The three brothers rated the visual approach as the most effective. The albino students preferred to use enlarged scores, positioning the music score close to the student, and additional lighting. Hong Kong has prolonged discrimination against albino families. Teacher's ignorance of albinism and visual impairment means that they fail to provide appropriate special education opportunities for students. *Discussion:* The data from this study revealed that the three albino children had no sensory compensation, as they had never received special training in how to promote their non-visual senses. Parents with albino children are afraid of stigmatization due to prolonged discrimination and labeling from outsiders. This study also shows that teacher development generally lacks the elements of teaching visually impaired students. *Implications for practitioners:* This study improves our understanding of music teaching pedagogies for visually impaired children and summarizes the challenges in terms of the physical and social settings that albino learners of music and their parents face.

Keywords: Albinism, Visual Impairment, Instrumental Learning, Stigmatization, Qualitative Case Study, Hong Kong

1. Introduction

Vision is important to the Chinese, as the eyes are regarded as windows to the soul (靈魂之窗). However, many people have congenital vision problems often caused by albinism, an inherited genetic disorder that reduces the amount of melanin in the skin, hair, and/or eyes. Albinism occurs in all racial and ethnic groups worldwide. About one in 18,000 to 20,000 people in the United States has some type of albinism [31]. According to unofficial data, China has around 90,000 people with albinism [17]. People with albinism have visual impairments that cannot be corrected with glasses, and this is one of the "most common causes of visual impairment for children in the United States"

[30]. According to National Organization for Albinism and Hypopigmentation [39], the degree of damage varies according to the type of albinism. Some are considered "legally blind" with a corrected vision of 20/200 or worse.

The topic of how effectively visually impaired people can study music has been a long-neglected research topic. Even in the field of music therapy, studies examining blind or visually impaired music learners are limited [11]. While the *Oxford Handbook of Music Therapy* [16] contains chapters on how domestic violence, learning disabilities, and even eating disorders can be treated with music learning, there are no chapters on blind or visually impaired music learners. In practice, the number of music therapists serving blind or visually impaired music learners is also very limited [10].

2. Literature Review

2.1. *A Study of the Musical Interests and Abilities of Blind and Partially Sighted Children*

According to Matawa, music is more important to visually impaired children than to sighted people [37]. Additionally, there are substantial indications that children and adolescents without vision have a greater interest in and/or musical talent for music than their vision-impaired peers. Matawa concluded that visual impairments [37], such as retinopathy of prematurity and septo-optic dysplasia, do not play a significant role in the development of musical interest and/or talent.

Sensory Compensation. In some early research, Stankov and Spillsbury revealed that non-visual senses [48], including hearing, are not automatically enhanced in visually impaired students unless they have been specially trained [29]. More recently, Pang et al. examined the superiority of blind listeners over sighted listeners in voice recognition [42]. In their comprehensive study, three subject groups, including 17 with congenital blindness, 18 with advanced blindness, and 18 with normal vision, showed no significant differences in the immediate audio recognition test. However, both the congenital and advanced blind groups performed better than sighted people on a delayed test two weeks later, with no significant difference between the two blind groups.

2.2. *Cognitive Development*

According to Kirk et al., the greatest differences in cognitive development in visually impaired children compared with typically sighted children were influenced by their accumulated experience early in development [30]. Thus, a lack of vision is both a major impairment and a condition that may hinder overall cognitive development. Without vision, a child's ability to integrate information gained from experience is limited. These limitations are especially pronounced when early preschool intervention is not provided.

2.3. *Motor Development*

From as early as the 1950s, researchers have found a strong relationship between motor performance and opportunities for children with visual impairments to learn movement [41]. Later studies in the field of motor coordination have shown that people who are blind or partially sighted have poorer motor performance than people without impairments [9, 29]. More recently, Kirk et al. speculated that if visually impaired children have the same opportunities as sighted children in terms of participating in physical activities, such as "sailing, skiing, rowing, reading, snorkeling, camping," then they may have similar motor development to other schoolchildren [30]. Although visually impaired people have normal developmental potential, their motor development may be delayed due to overprotection or inexperience [36].

2.4. *Teachers' Perceptions of Teaching Visually Impaired Students*

While teachers' perceptions generate a contextual understanding that can be used in research to improve teaching practice [46] and help identify key challenges in music teacher education [13], it is difficult to find research dedicated to teachers' perceptions of visually impaired students [44].

Referring to some authors' descriptions of music teachers' experiences, Park showed the importance of giving students ongoing support and a full understanding of the needs caused by visual impairments [43]. Participating in specialized teacher training programs when needed [1], and developing music education materials to support learning for visually impaired students and teachers [7, 40] are also important parts of teachers' perceptions of teaching visually impaired students.

3. Aim and Research Questions

The aim of this study was to (1) gain overall insight into the music learning of three brothers with albinism and (2) investigate how the teacher's proficiency and the parents' perceptions of the children's visual impairment contribute to their learning outcomes. There were three research questions:

- 1) To what extent does sensory compensation exist for musical instrument learners with albinism?
- 2) What can parents do to improve the music learning efficiency and effectiveness of their children with albinism?
- 3) How a teacher's competence affects the effectiveness of teaching students with albinism.

4. Conceptual Framework

Beheshti and Barbe et al. recommended the *Representational System* which involves a person's visual, aural, or kinesthetic learning preference as the best learning style classification for music learning [4, 5]. We adopted this system as it "focuses on the sensory stimuli and strengths, and its three categories – visual, auditory and kinesthetic/tactile – relate directly to learning a musical instrument".

4.1. *Visual Learner*

A learner who is visual acquires and retains information only after seeing it [18]. The pictures they memorize tend to be in the form of pictures. Thus, in music classes, these students are able to master the skill when the teacher demonstrates specific techniques. Their performance or practice is based on their knowledge of where they are on the page. As a result of the visual stimulation provided by maestro performers, these students are motivated [5].

4.2. *Auditory Learner*

After hearing information, auditory learners acquire and

retain it. Poon Teng Fatt, states that oral lessons, discussions, and listening to others is the most effective way for them to learn [45]. Using tone, pitch, tempo, and other aspects of music, auditory learners understand the underlying meaning of music [18]. The tones of aural music students are usually beautiful because of their sensitivity to tone color and dynamics, even if they are not at the highest technical level. Music is a huge part of these students' lives. As a result, they memorize music quickly and enjoy performing frequently [5].

4.3. Kinesthetic Learner

Those who learn kinesthetically do, touch, or actively explore the physical world around them are kinesthetic learners [18]. Since they need activity, they tend to have difficulty sitting still and listening for long periods of time. The method they use to retain information is a "trial-and-error or hands-on approach" [45]. Repeating short exercises does not seem to bother these students. For these students, it may be helpful to keep explanations short and to try some exercises without an instrument. The kinesthetic learner gives the impression of being a natural performer because they are comfortable with the instrument in actual performing.

5. Method

This study applied the concept of a qualitative case study, which is "an in-depth description and analysis of a bounded system" [38]. Yin defined a case study as "an empirical inquiry

that investigates a contemporary phenomenon (the 'case') within its real-life context, especially when the boundaries between phenomenon and context may not be clearly evident" [50]. This participatory case study which is a specific form of a qualitative case study with a participatory approach which is "systematic enquiry, with the collaboration of those affected by the issue being studied, for the purpose of education and taking social action or effecting change." [47].

5.1. Participants and Setting

The participants were three brothers born with albinism (see Table 1 for the demographic information and visual range), and with no other disabilities. It was their mother who urged them to take traditional piano lessons rather than music therapy at a privately run music studio. We selected them specifically for this study because they could help us to "discover, understand, and gain insight" into the matter, and their parents fully consented to having them share their stories [38]. Before participating in this study, the family was interviewed by many different media about the lives of albino children.

During the three-month intervention, the three brothers with albinism were invited each week to a studio designated by the first author of this study, where the first author taught them three piano pieces of similar difficulty levels using three perceptual modalities (kinesthetic, auditory, and visual). The first author matched one piece of music with one perceptual modality, and the same time was allocated to teaching using each perceptual modality.

Table 1. Demographic Data of Albino Participants.

| Pseudonyms | Gender | Age | Instrument Learnt / Years of Learning | Visual acuity ratio |
|------------|--------|-----|---------------------------------------|---------------------|
| York | M | 14 | Violin / 3 | 0.1 |
| Marco | M | 10 | Piano / 5 | 0.1 |
| Harold | M | 16 | Piano / 1 | 0.05 |

Note. Harold dropped out after a year of piano lessons. Visual acuity ratio is a measure of the ability of the eye to distinguish shapes and the details of objects at a given distance. Moderate visual impairment: 0.3 to better than 0.1; severe visual impairment: 0.1 to better than 0.05; blindness: 0.05 or worse (Department of Health [15]).

5.2. Procedures

After receiving formal consent from the boys' parents, we conducted semi-structured interviews using the interview guidelines developed for this study [14]. Experienced interviewers asked predetermined questions and spoke very little. We asked the participants about their experiences with the visual, auditory, and kinesthetic learning approaches, and we triangulated the data sources [12] by asking the students and their mothers to reflect on their daily life experiences with discrimination and labeling against albinism. We asked the regular teachers to describe their previous music teaching experience working with students with visual impairments. We also performed complete observations [12] of the essential resources and classroom layouts. This observation also served as a methodological triangulation to enhance the study's reliability [12].

All interviews and observations were audio/video recorded, transcribed, and de-identified. Audio/video files and interview transcripts are stored in password-protected files on the second author's computer. To avoid reidentification, we did not collect detailed information on the visual impairment of the student participants, and we omitted the dates of data collection in this article. All names appearing in this study are pseudonyms.

5.3. Data Analysis

The authors of this study reviewed audio/video recordings, read transcripts, and analyzed the data using a six-phase thematic analysis [6], which involved encoding transcripts to identify the final themes that were related to the research questions and to limit the overlap between them. All authors discussed the codes and themes and modified them as needed. Where discrepancies arose, we resolved them by consensus.

6. Results

6.1. Dominance of the Visual Approach

After the intervention, we conducted semi-structured interviews with each brother to find out how they rated each music learning approach—auditory, visual, and kinesthetic—

from 1 (worst) to 10 (best). Rating scales are more sensitive than dichotomous scales for “tapping attitudes, perceptions and opinions” [12]. Figure 1 shows the results.

Despite having different views on kinesthetic and auditory approaches, they all agreed that the visual approach was the best.

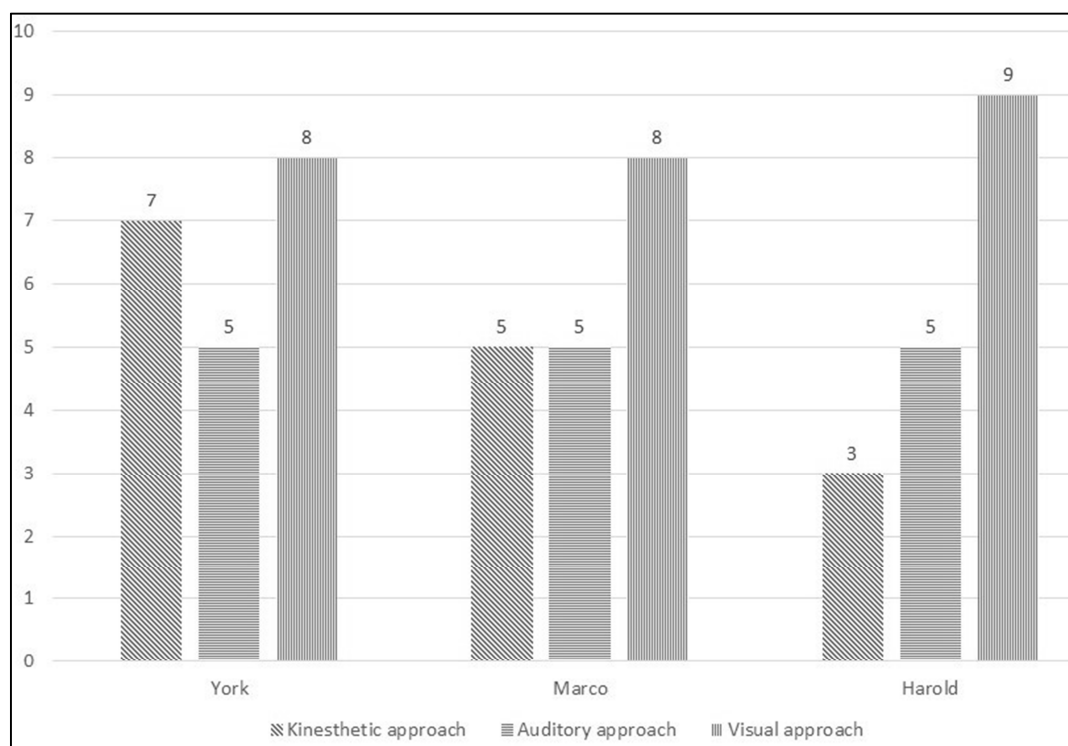


Figure 1. The Boys' Teaching Approach Preferences.

York explained that he had no difficulty reading the scores that were enlarged to A3 size, but he had trouble with reading and playing coordination. York stated, “I find that the kinesthetic approach allows me to memorize simple songs [pieces] quickly and easily, but it is difficult to memorize complex songs. I don't feel strongly about the connection between kinesthetic movement and music.” For the auditory approach, York mentioned that it was easier to identify when he made a mistake, but it was hard for him to figure out the fingering patterns without a music score.

Marco stated that the kinesthetic and auditory approaches were comparable. While both approaches could help him memorize the right-hand melodic part, the kinesthetic approach was unsuitable for memorizing the left-hand accompaniments, and the auditory method did not help match the notes heard on the keyboard. For the visual approach, Marco said, “If I had an enlarged score, I would pick up a song in a short time with confidence and security!”

Of the three brothers, Harold is the only one who thinks the auditory approach is more effective than the kinesthetic approach. He explained, “I found that both approaches made it easier to remember the melodies, but the kinesthetic approach made it difficult to recall the memory when I practiced alone!” Similar to his two older brothers, Harold

said that although he still had difficulty reading the enlarged scores, he believed that reading the music scores to play the piano was the most reliable way.

6.2. Specialty of Classroom Layout for Albino Students

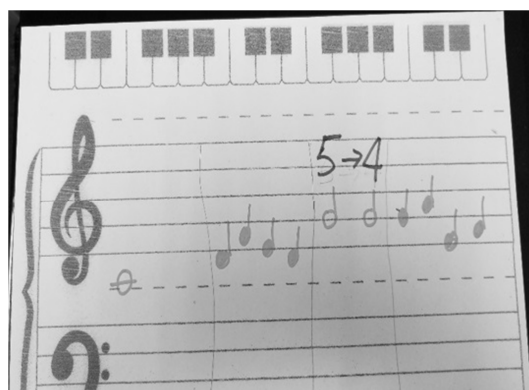


Figure 2. Enlarged Handwritten Score.

Enlarged Scores. Usually, before the class starts, Marco's regular piano teacher, Christy, goes to the studio assistant to copy some selected scores. The studio assistant uses the enlargement function of the brother MFC-J2720 copier to enlarge the scores from A4 to A3. Sometimes, in addition to

using ready-made scores, Christy handwrites the notes on an enlarged music score (see Figure 2).

Positioning and Lighting. The classroom observation indicated that the albino students cherished what little sight they had left. They all strived to use their available sight to help them play the piano, and the teacher tried to create a vision-friendly environment for them.

Vignette [an observation on July 30, 2022]

At the beginning of a piano lesson, Marco sits in front of the piano. He leans very forward, keeping his body very close to the keyboard. The teacher pulls the music stand on the piano toward the students by about 20 cm (see Figure 2). Even though the piano score had been enlarged, when Marco starts playing the piano, his head is so close to the score that his nose almost touches it. At the same time, the teacher turns on a lamp so that he could see a little more clearly.



Figure 3. *The Positioning of Music on the Piano.*

6.3. Prolonged Discrimination Against Albinism

Agnes, the mother of our three albino participants, has been working hard to share her journey as a mother of three albino children with the outside world. In an interview, she recalled:

A long time ago, I took my eldest son, Harold, for a swim. I put him on an inflatable blister and played with him. Who knew that a middle-aged couple would walk by and say, “How can you bring a dog to swim?”

Agnes shared another unpleasant story with us. On one occasion, she took Harold to get vaccinations. There was a lady next to Agnes in the Maternal and Child Health Centre who asked curiously, “Why does your child look like a white person? Is your husband white?” Agnes replied that her husband was an ordinary Chinese, and she explained in detail that her child had albinism, so he looked white. After listening to this, this lady replied, “Your husband is so stupid to believe you—you are obviously unfaithful!”

The most hostile moment Harold has experienced is when people jump back when they see him. Harold understands that other people look at albinos in a strange way. He added, “It’s okay if people say hello or even take pictures with me on the street. Just don’t be afraid!”

The above examples are just some of the many that Agnes and Harold mentioned. From these examples and the tone of Agnes’ expression, Agnes finds it difficult to cope with her sons being treated with discrimination.

6.4. Teachers’ Ignorance of Albinism

Piano teacher Victoria had a hard time teaching Harold. She recalled helplessly:

At first, I received no background information about Harold’s albinism from his parents. Of course, I had not heard of albinism, and I knew very little about how to teach visually impaired students. Although I teach my students without distinction, I really don’t know what special teaching arrangements I needed to make for Harold.

Later, when Victoria took the initiative to raise the problem of note reading with his mother Agnes, she seemed to ignore the problem and asked Victoria to treat Harold as a regular student. Finally, Victoria said helplessly, “If I had known that he was an albino student who was suffering from a severe visual impairment, I would have searched for some special methods to teach him, and now he seems to have lost interest in the piano!”

7. Discussion

7.1. The Myth of Sensory Compensation

It is widely believed that visual impairment leads to enhanced capabilities of otherwise intact systems due to sensory compensation [33, 26]. However, several studies have found no significant differences between sighted and visually impaired individuals [49, 24, 23]. However, since different studies have adopted different sampling methods and research methods, researchers have yet to reach a consensus on the existence of sensory compensation.

Kirk and Gallagher claimed that non-visual senses (e.g., hearing and smell) are not automatically strengthened unless special training is given [29]. This view was supported by the three albinos in this study, who had not received this kind of training and considered vision to be the most important sense for music learning purposes. Consistent controls for participant characteristics in terms of gender, age, level of musical achievement, degree of visual impairment, and whether visually impaired persons have superior senses to sighted persons have yet to be investigated.

7.2. Parents’ Fear of Stigmatization

Agnes chose traditional piano lessons for her sons instead of music therapy since she believed they could learn music as normal students. She may have made this decision due to a fear of stigmatization. Agnes stated in her interviews that she

receives a lot of discrimination because her sons are albino children. As Victoria, Harold's piano teacher, mentioned, Agnes never took the initiative to tell her that her son was visually impaired and needed special care. Agnes did not want to talk about the fact that her son Harold was albino. In Asia, parents are so concerned about the risk of stigma imposed by special education labeling that they rarely ask for assistance [28]. Agnes deals with stigma by withholding information from others about Harold's disability [21, 20, 32]. She was reluctant to discuss Harold's challenges with Victoria [27] or seek special education services with others [19]. Without an explicit explanation, Agnes may be skeptical about the competence of professionals to assess Harold [8], or she may object to the use of disability labels that she perceives to be stigmatizing [34]. Agnes was one of the most parents who did not participate in any parent training program [22, 30].

7.3. Lack of Teacher Development for Visually Impaired Students

There are "hits and misses" when it comes to Marco and Harold's learning experiences. Since Victoria was not aware of Harold's albinism, she did not search for special methods to teach him. Meanwhile, the first author, without formal training in special education, was more sensitive and attentive to Marco's visual impairment symptoms, and provided him with every resource she knew of from books and the internet. In general, music teachers do not receive inclusive knowledge and resources designed to help visually impaired students [44]. First author and Victoria, as general music and instrumental teachers, have to fumble in the dark when teaching Marco and Harold. Thus, pre-service teacher needs to be equipped with pedagogical skills and the resources to work with disabled students in undergraduate and graduate music education programs [25]. Victoria's experience reveals the importance of teacher training. Due to the lack of proper teacher training, Victoria was not only unaware that albinism caused visual impairment but also that special arrangements were required to teach visually impaired students. According to Baker and Green, the main considerations for visually impaired students are the use of light, a self-awareness of gestures and language, the use of specialized music software, physical guidance of students through tactile methods, the need for flexibility, knowledge of language, and different formats for music scores [23]. Victoria also admitted that there are few professional development opportunities for in-service music teachers in Hong Kong [35], specifically in relation to special education for visually impaired music learning. According to Kirk et al., special programs could be provided to support teachers' professional development, giving teachers the opportunity to observe and participate in structured interventions that help them learn how to implement effective strategies for students with special needs [30]. In simple terms, visually impaired students require teachers to have a good understanding of the needs arising from their disabilities

[43]. If the first authors and Victoria had received special education training, they would have used low vision devices or other technology to provide visual access to the students, as well as braille media and auditory media access.

In relation to the collaboration between music therapists and music educators, Yun-Springer and Silverman found that both of these professionals are concerned with the impact of music and inclusive practices on the musical and academic development of students with disabilities [51]. A collaboration between these professionals may include sharing their knowledge and publishing their findings in music education and special education journals. In Hong Kong, this practice, however, is rarely observed.

8. Conclusion

The results of this study highlight four important findings. First, all three of our albino students chose the visual approach as their most preferred approach among the three under the *Representational System*. Second, special requirements for the classroom layout for albino students included enlarged scores, positioning the music score close to the student, and additional lighting. Third, there is prolonged discrimination against albino families. Finally, due to the lack of knowledge about albinism and special education, music teachers do not know how to adjust their teaching strategies to suit visually impaired students. Based on the above findings, we also discussed the myth of sensory compensation, parent's fear of stigmatization, and the lack of teacher development for visually impaired students.

Based on a case study of three albino brothers, this study provides a better understanding of music teaching pedagogies for visually impaired children. It also offers a summary of the challenges that albino music learners and their parents face in terms of physical and social settings.

9. Limitations and Suggestions

This study has several limitations. The participants in this study were visually impaired from birth, so the results cannot be generalized to music learners with acquired visual impairments, and we have no idea regarding the similarities and differences between the two types. Also, as the data were obtained from a single Chinese family in Hong Kong, we were unable to examine regional differences at the cultural level. Future research should analyze the differences between congenital and acquired visual impairment, compare students with different degrees of visual impairment, and examine the impact of visual impairment on other senses. In addition, cultural differences in terms of the perceptions and relationships with albinos should be investigated to understand and improve communication between parents, peers, and teachers. In particular, the role of parents needs to be explored further in the future since parental involvement is paramount to learning success for children with disabilities.

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