

Psychological Well-Being of Adolescents Living with Albinism. A Case of One School in Bizana, Eastern Cape, South Africa

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Abstract: In many parts of Sub-Saharan countries such as Mozambique, Tanzania, and Malawi, research indicates that people with albinism face discrimination, violence, and death due to a deficit of melanin (pigmentation), which causes visual impairment, skin damage, and health problems. To investigate how South African adolescents living with albinism (ALWA) enhance their psychological well-being, a qualitative study was conducted utilising semi-structured interviews with twelve purposively sampled participants aged 14 to 18 years from one special school in Bizana, Eastern Cape. Inclusive Education (IE) policies and Carol Ryff's six-dimensional theory of psychological well-being guided this study. The school principal and the participants' legal guardians granted consent to the researchers to interview the participants. Before data collection, the researchers obtained informed consent from the participants to be audio-taped during the interviews and ensured their confidentiality and privacy. Transcribed data were coded for the identification of themes, relying on Tesch's six steps of thematic data analysis. Participants attributed their psychological well-being to the positive school environment, parental support, and the implementation of IE policies, which contributed to their self-esteem, sense of purpose, and academic performance. Furthermore, counselling, empowerment support

groups, church involvement, and emotional support from their partners indicated resilience and positive coping strategies against bullying, depression, and rejection among ALWA. These findings inform educational officials about the need to devote more resources to special schools to align with the Sustainable Development Goals of 2030, ensuring the representation of people living with albinism in tertiary institutions and beyond.

Keywords: Academic performance, albinism, bullying, inclusivity, psychological well-being.

1. Introduction

The word "albino" is derived from the Latin word "albus," meaning white (Adelakun & Ajayi, 2020). Medically, albinism is a condition characterised by a lack of pigmentation (melanin) production, which affects the melanocyte system and causes hypopigmentation of the hair, skin, and eyes (Franklin et al., 2018). Albinism was declared a disability in 2013 (Clarke & Beale, 2018), and its aetiology, particularly in Africa, has often been associated with superstitions, stigma, and discrimination, resulting in violations of the human rights of people living with the condition (Kromberg, 2018; Reimer-Kirkham et al., 2020). Some of the superstitions include the belief that sexual intercourse with people living with albinism can cure Human Immunodeficiency Virus (HIV) and that medicines made from their bodies bring luck and wealth (Mostert & Weich, 2017). Consequently, in Tanzania and South Africa, individuals with albinism have been abducted and brutally killed. Regarding romantic relationships, studies show that the majority of female individuals with albinism feel uncomfortable when approached by men, fearing rape (Mostert & Weich, 2017; Reimer-Kirkham et al., 2020). Between 2006 and 2017, the United Nations General Assembly (2019) reported 190 killings and 515 attacks in African countries. In Migori and Taita Taveta (Kenya), both young and old individuals living with albinism have been killed, with their

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body parts mutilated (Nyerere, 2022). In Ghana, individuals with albinism are treated as non-humans and subjected to emotional abuse when playing with others (Kassah, 2012). In Zimbabwe, this marginalised group is perceived to be born to mothers who engaged in infidelity with white people (Franklin et al., 2018). If such discrimination is a daily occurrence, it must be distressing for individuals with albinism and detrimental to their sense of purpose, self-acceptance, and personal growth (Tuso, 2015), thus impairing their psychological well-being. In these instances, depressive symptoms such as forgetfulness, insomnia, social withdrawal, irritability, hopelessness, deterioration of personal grooming, and suicidal ideation are likely to manifest (Aborisade, 2021). To protect individuals with albinism from abductions and brutal killings, relatives or parents should accompany them to school (Ndomondo, 2015). Due to their unusual skin colour, visual impairment (i.e., oculocutaneous albinism), teeth, and hair, adolescents living with albinism often struggle with their self-esteem and self-image (Ojedokun, 2018). Self-esteem refers to the favourable or negative perception and attitude that an individual may have towards themselves (Rosenberg et al., 1995). However, when protective factors such as parents, churches, relatives, and educators provide emotional support and demonstrate a spirit of humanity in their respective communities, the Albino Foundation (2012) found that self-esteem could be enhanced, potentially propelling them to be more assertive academically.

Considering these challenges, it is important to remember that at the Salamanca conference held in Spain three decades ago, the South African government was one of the 92 countries that opted for inclusive education, which advocates for the rights of learners, including those living with albinism (UNESCO, 1994). Inclusive Education (IE) recognises and embraces diversity regardless of race, disability, level of education, gender, language of origin, and nationality. The Tanzanian government has ensured that diversity is embraced and that learners living with albinism are kept safe in special schools, enabling them to thrive and advance to tertiary institutions (Burke et al., 2014). In countries such as Canada, Japan, and the United Kingdom, studies found that learners with albinism excelled academically due to the support of progressive legislation that promotes and protects the rights of all learners (Office of the United Nations High Commissioner for Human Rights - OUNHCHR, 2013). However, in South Africa, research indicates that a lack of trained educators, inadequate teaching materials, and educators' negative attitudes towards learners with albinism contribute to the attrition rate among these students (Adelakun & Ajayi, 2020). Additionally, placing them in mainstream schools alongside learners without impairments can result in poor educational outcomes and subsequent unemployment due to bullying and discrimination (Harvogan & Chetty, 2023; Phatoli et al., 2015). Until recently, few schools accommodated learners living with albinism, as enshrined in the South African Schools Act 2006, following the advocacy of White Paper 6, which asserts that children with special needs have the right to education (Adelakun & Ajayi, 2020). Consequently, facilities such as special classes with movable blackboards and dim lights have been established to enable these learners to participate proactively during lessons (Gaigher et al., 2002).

Reflection on previous studies conducted in South Africa has highlighted the need to explore the psychological well-being of learners with albinism. In the Umlazi district, KwaZulu-Natal, Msomi (2014) found that they were often addressed with derogatory names, while in the Northern Cape, they faced violations from community members, peers, and educators (Harvogan & Chetty, 2023). Against this background, there is a need to investigate the protective factors available to learners with albinism in one special school in Bizana, Eastern Cape, and how these factors help them cope with their psychosocial challenges by using Ryff's six dimensions of psychological well-being alongside educational policies to promote inclusive education.

1.2 Research questions

The research questions of this study were formulated as follows:

- What is the role of the protective factors for ALWA's psychological well-being in Bizana, Eastern Cape, South Africa?

- Which coping strategies are employed by ALWA to enhance their psychological well-being?

2. Theoretical Framework

The study is underpinned by the Inclusive Education Policies and six dimensions of psychological well-being pioneered by Carol Ryff. The protection of the rights of people living with albinism is advocated by legislation such as the Office of the United Nations High Commission for Human Rights (2013) and the Constitution of the Republic of South Africa Act 108 of 1996. Additionally, the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 supports these rights. Inclusive education policies state that there should be an integration of mental health support services in educational settings to enable individuals with albinism (ALWA) to share their traumatic experiences in a safer space without fear of ridicule (White Paper 6, Department of Education 2001). Furthermore, programmes within schools and communities can ameliorate the conditions under which ALWA learn (Chirimbana et al., 2024).

Psychological well-being is a construct that originates from Positive Psychology and was developed by Carol Ryff (1989). The dimensions of psychological well-being are self-acceptance, autonomy, positive relations with others, purpose in life, personal growth, and environmental mastery. According to Ryff and Keyes (2015), when ALWA have a positive self-regard and a clear sense of their strengths, they can reach maturity and are more likely to flourish in life (i.e., self-acceptance). However, in Ghana, ALWA has struggled with self-acceptance due to social exclusion (Agyei et al., 2021). Another aspect of psychological well-being relates to how an individual connects with friends, family, and community members (positive relations with others). Tajfel and Turner's (1979) social identity theory in this study also suggests that ALWA can find their purpose in life (being industrious and self-efficacious) and develop autonomy (making informed decisions) when interacting with people who share similar characteristics. Another dimension concerns how ALWA manage their life situations (environmental mastery) for their personal growth. Setting personal goals and evaluating oneself against personal standards can help overcome social pressures (Ryff & Keyes, 1995).

2.1 Literature review

Coping refers to the active behavioural and cognitive efforts that ALWA may employ to manage and reduce pressure and stress (Lazarus & Folkman, 1984; Weiten, 2022). To address academic and social challenges, ALWA seek security from their families and joins groups that raise awareness about albinism (Tambala-Kaliati et al., 2020). As psychological well-being (PWB) is linked to physical health and other psychological variables such as self-esteem and optimism (Ryff & Keyes, 1995), harmony between parents and schools in providing emotional support to ALWA fosters resilience, promotes self-acceptance, and aids in the achievement of their personal goals (Bronfenbrenner, 1979). Resilience is the ability to bounce back from adversity, and it can be enhanced by proactive educators collaborating with the parents of learners facing discrimination (Weiten, 2022). Such unconditional love enables ALWA to lead productive lives and cope with adversity (Rielly, 2020). The World Health Organization (2006) posits that their wellness is reinforced in physical, psychological, social, spiritual, and economic domains, especially when supported by their parents. Conversely, a hostile environment can be detrimental for ALWA when parents contribute to the disregard and disrespect for their human rights based on their condition. For instance, Aborisade's study in Nigeria (2021) reported ALWA experiencing physical abuse, deprivation of food, and being locked outside by their maternal aunts, siblings, and biological parents. In many African countries, Owoeye et al. (2023) noted that an alarming number of ALWA live with their single mothers due to the denial of paternity by their biological fathers.

At the school level, a positive climate has been documented to produce excellent academic results for ALWA and contribute to their resilience (Magasu et al., 2020). Educators trained in inclusive education can be catalysts for ALWA's psychological well-being by writing boldly on the chalkboard, preferably with yellow chalk, providing learning materials in a large font, and encouraging them to

wear hats and occupy front seats for better visibility of the chalkboard (Vernon et al., 2021). Additionally, in Eswatini, empowerment programmes such as indoor games organised by the School Management Team (SMT), where ALWA participate in chess and table tennis, have been found to build self-esteem and resilience among ALWA (Thwala et al., 2021). Given that not all schools are equipped to provide advanced education for learners with albinism, ALWA may experience feelings of depression when faced with classroom situations that lead to social ostracism, bullying, poor cognitive functioning, and a fragmented sense of belonging. Some reports from South African schools indicate that learners with albinism have been isolated and placed at the back of the classroom to protect pregnant educators based on stereotypes suggesting that they might give birth to a stillborn if they encounter them (Baker et al., 2010).

3. Research Methodology

An interpretive paradigm was chosen for this study as it provides participants with the opportunity to share their experiences in detail, unlike the positivist paradigm (Gichuru, 2017). To gain a deeper understanding of the effects of ALWA and their coping mechanisms and to bridge the gap between practice and theory, a qualitative research approach was employed. Semi-structured interviews were used to address the research questions during data collection in a natural setting, as suggested by Creswell and Creswell (2017). The researchers followed six steps outlined by Tesch to analyse the data.

Semi-structured interviews provide researchers with the opportunity to seek clarity when participants have not adequately shared their experiences. This is achieved through prolonged discussions guided by an interview guide consisting of open-ended questions, ensuring trustworthiness, as suggested by Lincoln and Guba (1985). Purposive sampling was employed to recruit 12 participants (six males and six females) from one special school in Bizana. The participants' ages ranged from 15 to 18 years. In purposive sampling, participants do not have an equal chance of being selected; only those sharing the same culture, level of education, race, and characteristics are included (Denzin & Giardina, 2016). For uniformity, the researchers agreed to recruit four Grade 10, four Grade 11, and four Grade 12 ALWA participants. Eight of the participants indicated that they were living with both parents, whereas only four were raised in single-parent households.

3.1 Ethical consideration and trustworthiness

Before embarking on data collection, the chief author applied for Ethical Clearance, which was approved by the Research Committee of a university in the rural areas of the Eastern Cape Province, South Africa. Permission was sought from the School Governing Body and the school principal. A letter detailing the advantages of participation in the study was also sent to the legal guardians of the ALWA under 18 years of age from one school in Bizana. The legal guardians signed informed consent slips for their participants to be interviewed. To ensure the confidentiality of the participants during data collection, the researchers assigned pseudonyms to everyone. None of the participants withdrew from the study. Due to the sensitive nature of the topic, a debriefing session was organised by the researchers and facilitated by a qualified counselling psychologist for the participants' reflection and emotional release. To achieve the dependability of the research instrument, the researchers thoroughly documented each step of the research for transparency and involved the participants in reviewing the accuracy of the findings, as suggested by Ahmed (2024).

3.2 Data analysis

Most qualitative research employs a thematic method of data analysis. The thematic analysis offers several approaches to data interpretation, but the common goal is to classify or categorise themes that are important and relevant to the particular issue under study. This involves more than merely summarising the data; a good thematic analysis interprets and provides rich insights into the phenomenon under investigation (Denzin & Giardina, 2016). This study utilised Tesch's method of

data analysis to categorise and discuss themes, incorporating relevant quotations from the respondents, with pertinent literature cited to support the results. Tesch’s method maintains that the researcher continuously reads the information after data collection to become familiar with the content. This process allows the researcher to carefully scrutinise the data until similar information is identified, which is then coded and grouped into topics and categories (Creswell & Creswell, 2017). For data analysis, the researchers followed Tesch’s steps: familiarisation, immersion, coding, inducing, and reviewing. The data was coded into three themes: the positive role of the school, resilience, and coping strategies, with eleven subordinate themes.

4. Presentation of Results

Regarding the emergent themes from this study, the researchers avoided redundancy; therefore, they only cited those that addressed the research objectives and created new, more meaningful ones.

Table 1: Emergent Themes

Superordinate themes	Subordinate themes
The positive role of the school	<ul style="list-style-type: none"> • Self-esteem • Safe environment • Implementation of IE policies • Self-acceptance and purpose in life
Resilience	<ul style="list-style-type: none"> • Parental support • Empowerment Support Group • Educator’s support
Coping strategies	<ul style="list-style-type: none"> • Religiosity • Counseling • Intervention from the police • Emotional intimacy with sexual partners

4.1 Theme 1: The positive role of the school

Self-esteem

In line with research question one, the participants were asked, “What is the role of the protective factors for ALWA’s psychological well-being in Bizana, Eastern Cape, South Africa?” ALWA expressed that their educators and caretakers play pivotal roles in building their self-esteem, making them confident during lessons, and providing a safety net for their psychological well-being, respectively. Consequently, they feel extrinsically motivated and protected from the verbal abuse that prevails in the communities. This is how they responded:

“During winter school, when we were mixed with learners without impairments from a neighbouring school, I raised my hand with confidence and went forward to solve the Mathematics problem because of the unconditional love from our educator. That has changed how others view me and others living with albinism.”

Safe environment

Participants recommended their school as safe from violence and discrimination when asked to mention the advantages of belonging to a special school. They cited the following:

“As compared to being at home during school holidays, when we are at school, we are protected from name-calling such as izinkawu. Also, there are policies here that discourage violence or fights among one another”.

“Unlike what we see on social media where learners have been bullied by their senior learners in the dormitories, we live with the caretakers that are more like our parents who make sure that we treat each other as family members”.

Participants continued to highlight the phenomenal commitment of their educators to the implementation of inclusive education (IE) policies and their overall well-being. They emphasised that their educators have added value to their sense of purpose regarding their careers by offering remedial education on weekends in subjects such as Physical Science and Accounting. They attributed their improved academic performance to the extra time provided when writing tests and examinations. The responses below attest to their high self-esteem.

Self-acceptance and purpose in life

"At school, we are being loved by our educators, and we have accepted ourselves as we are. As a result, most of us know the careers that we will follow when we complete Grade 12. Moreover, on weekends, we get extra lessons, especially in Mathematics, English, Physical Science and Accounting."

Implementation of IE policies

"Being taught in classes that are catered for learners with special needs by educators who know that we should be given extra time during assessment, unlike in the mainstream, has improved our academic performance and intrinsic motivation."

4.2 Theme 2: Resilience

The participants explained that parental support and unconditional love from their family members and educators built their resilience as they formed an association to address the challenges faced by ALWA. Most importantly, one male participant expressed that having a supportive father made him emotionally and psychologically strong because he participated in traditional ceremonies in the villages.

Parental support

"My source of strength is my father. He has demonstrated support in many ways, like going out of town with me and social gatherings in the villages."

Empowerment Support Group

"Supporting each other as ALWA during indoor games and belonging to Albino Association formed here at school help us to motivate one another and to overcome discrimination levelled against us."

One female participant expressed that at times she experiences depressive episodes following a rape ordeal. Although the incident used to disturb her cognitive functioning, she has emerged as resilient because, during Life Orientation periods, her educator equips her with effective strategies to overcome depression. The extract below is evidence of how resilient one of the ALWAs has become.

Educators' support

"Although I sometimes experience flashbacks of the rape ordeal by one of my neighbours, I am mentally strong now since, during Life- Orientation periods, our educators guide us on how to overcome stress and reclaim our dignity. Most importantly, they have taught us how to look after our skin against sun rays."

4.3 Theme 3: Coping strategies

Regarding research question two, the participants praised the school for allowing them to exercise their rights to access social workers and church services to cope with adversity. They highlighted that spending time at church, praying, and reading the Bible helped them accept themselves as they are, regardless of the lack of financial support from their biological fathers. The responses are below.

Religiosity

"The Learner Christian Movement (LCM) here at school has been my source of strength to deal with negativity and my family problems since my father is not financially supportive."

Counselling

"Attending the sessions with the social workers for our mental health has helped many of us who had suicidal thoughts because of bad treatment from some of the family members when we go back home because they don't buy skin lotion nor food."

The discussion highlighted the role of family members as protective factors. One of the female participants mentioned that she involved her two brothers in opening a case at the police station for a violation of human rights. This brave step could be attributed to the resilience and love shared among siblings.

Intervention from the police

"When two boys mocked me because I turned down their dating proposal and ended up taking my phone, I reported them at home. Thereafter, my three brothers accompanied me to the police station to open a case. I got my phone, and two culprits were warned by the police".

Finally, emotional attachment can be therapeutic and serve as a buffer against discrimination when one's sense of belonging is fulfilled by being loved unconditionally by significant others. This was expressed by a male participant, who remarked that the support he receives from his girlfriend, regardless of his self-image, is remarkable.

Emotional attachment with sexual partners

"The emotional support from my girlfriend is amazing. She is always there for me when I am feeling hopeless. Her love has made me gain respect from guys (without impairments)"

5. Discussion of Findings

Psychological well-being is pivotal for a person to live a healthy and fulfilling life. The study found that several components of well-being, namely self-acceptance, purpose in life, sense of autonomy, and personal growth, were enhanced due to the safe environment created for ALWA. For example, participants cited emotional support and a robust security system from caretakers as factors contributing to their mental health, as they live peacefully in their dormitories. This finding suggests that there is a greater likelihood of academic excellence and social cohesion among ALWA, as they are not exposed to forms of abuse and discrimination, unlike when they are at home. Moreover, their psychological well-being is protected from derogatory names such as *izinkawu* (monkeys) or *izishawa* (curses from ancestors or white pigs) (Independent News, 2019), which are often used in black communities to erode self-esteem. Another finding relates to the accommodation of diversity by educators, which has enabled ALWA students to become self-confident even when attending classes with mainstream learners. For instance, one of the Grade 12 learners solved a mathematical problem on the chalkboard. This implies that when educators are knowledgeable about inclusive education policies, there is a higher possibility of securing better opportunities for this group beyond formal schooling, especially given their underrepresentation at tertiary and corporate levels due to high illiteracy rates. Consequently, ALWA may redefine their sense of purpose and personal growth, in contrast to dropping out of school prematurely. In contrast, Harvogan and Chetty (2023) established that there is high illiteracy among people with visual impairments, as educators are not equipped with the skills to empower learners with special needs.

Specifically, adolescent females in this study highlighted that living with albinism requires resilience and a robust support system because they are susceptible to traumatic experiences, such as being ridiculed or pressured into romantic relationships when proposed to by men. However, a Grade 10 participant received support from her two brothers, who accompanied her to the South African Police Services (SAPS) after she was robbed of her phone. Such support from the police resonates with the African Charter on the Rights and Welfare of the Child and the UN Convention on the Rights of the Child in addressing issues of protection, discrimination, and empowerment (Taylor et al., 2019). The implications of assertiveness and resilience demonstrate that with emotional support from

home, adolescents living with albinism (ALWA) may overcome depression and anxiety associated with bullying, unlike Nigerian learners with the same condition, who were victims of social ostracism (Aborisade, 2021). Their unity in forming and belonging to an association within the school aimed at empowering them was characteristic of assertive individuals who flourish by acquiring skills to resist discrimination and advocate for their human rights. This finding aligns with the leadership skills exemplified by ALWA in Eswatini, as the support from the School Management Team extrinsically motivated them to achieve academically and resist discrimination (Thwala et al., 2021).

Research has proven that psychological support has the potential to alleviate past traumas, such as depression and abuse, when a victim seeks counselling or confides in a confidante (Weiten, 2022). This was evident when one female participant highlighted that she had acquired skills from her educator to cope with post-traumatic stress disorder after repressing her rape ordeal for a long time. Repression is a defence mechanism that offers temporary comfort when an individual pushes unpleasant experiences into the unconscious (Weiten, 2022). Other participants mentioned that their reliance on the social worker gave them the impetus to find meaning in life after receiving counselling for suicidal ideations and other mental health issues. Supporting the mental strength of ALWA in this study, Longstaff et al. (2013) established that resilience can enable individuals to recover or bounce back from adversity while making necessary adjustments, such as seeking strategies for healthy living. Religiosity was also mentioned as a coping strategy when faced with adversities, such as ill-treatment from family members and denial of paternity. Conversely, in Malawi, ALWA were segregated by church members (Tambala-Kaliati et al., 2021), leading them to experience feelings of helplessness. This finding implies that constant prayers among ALWA can buffer against mental health problems and enable them to achieve self-actualisation.

It was interesting to learn that one male participant mentioned his psychological well-being (PWB) is partly enhanced by being in love with his girlfriend, who contributed immensely to his grooming. This finding affirms classical theories, namely Freud's genital stage and Erikson's identity-versus-confusion stage, that establishing romantic relationships with people of the opposite sex during adolescence (Weiten, 2022) occurs in all individuals. Furthermore, this finding correlates with Ikuomola's (2015) study, which indicates that male adolescents living with albinism (ALWA) in African countries easily engage with women and often establish long-lasting relationships, especially when they come from affluent families. This implies that when parents, family members, and schools create a conducive environment and emotionally support ALWA, these adolescents, in turn, will cope better with living with significant others and improve their self-image and mental health, rather than distancing themselves due to a lack of self-esteem perpetuated by rejection from educators and family members. Most importantly, their confidence in maintaining romantic relationships with individuals without visual impairments refutes the myths and stereotypes that people living with albinism are different and do not survive.

6. Conclusion

The psychological well-being among ALWA needs to be reinforced, especially in black communities, as stigma is still rife. However, the findings of this study showed that a safe environment, both at school and at home, could contribute to self-acceptance, purpose in life, and leadership, particularly for ALWA when the SMT implements the IE policies. The importance of social cohesion among ALWA and emotional support from significant others cannot be overstated, as they act as a buffer against discrimination and other forms of abuse. The roles of counselling and religiosity emerged as pivotal in the PWB of ALWA, as they help learners cope with the adverse situations they find themselves in. Based on the findings, the:

- Parents should continue providing emotional and financial support to their ALWA to help them be resilient at school.
- Schools should create a conducive atmosphere for all learners.

- In the fight against discrimination related to albinism in black societies, awareness campaigns should be led by churches, the government, and communities.

7. Declarations

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