Rajagiri Journal of Social Development
Volume 13, Number 2, December 2021

'Visible' yet 'Invisible': A Social Justice Approach to Understanding Access to Education for People with Albinism

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Abstract

The condition of albinism affects people throughout the world regardless of race, colour, gender or ethnicity. Despite its prevalence, advancements in medicine and increasing public awareness about albinism, people with albinism continue to face widespread discrimination, stigmatisation, violence and social exclusion. Their full and effective participation in society on an equal basis with others is severely hindered by attitudinal and environmental barriers. While there is a great disparity in the prevalence of albinism occurrence across the world, it occurs mostly in sub-Saharan Africa. By adopting a social justice and human rights lens, this paper explores the many complex issues that impact upon the access to education for people with albinism. The paper discusses the albinism condition and its global prevalence before going on to explain the key conceptual and theoretical contestations around the 'visibility' and 'invisibility' in the context of social justice, stigma and discrimination, disability and human rights. A key finding from the literature is that globally, children and young persons with albinism continue to experience insecurity and significant barriers to quality education, exposing them to enduring poverty and vulnerability. However, it becomes clear that in their quest for quality education, children in Africa face far greater obstacles and challenges, because the condition is

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still shrouded in secrecy, myths and a general lack of understanding and knowledge.

Keywords
albinism, disability, social justice, human rights, access to education

Introduction

Throughout the world, people with albinism (PWA), despite their 'visibility', are 'invisible' (Imafidon, 2018; Shastri, 2020). Albinism affects individuals of all races, social classes and ethnic groups, from geographical regions throughout the world. Poverty, discrimination, stigma, social exclusion and human rights abuses are some of the barriers that prevent PWA from accessing equal and quality education. This lack of access does not necessarily emanate from any 'mental or physical disability' (Mmuso, 2007, cited in Ojedokun, 2018, p.33).

The literature surrounding the condition of albinism and access to education for PWA has been largely dominated by three issues. Firstly, there are many debates in the literature that surrounds the albinism condition and specifically on how to refer or address PWA. Secondly, there are contestations by civil society, scholars and PWA themselves, on the definition of disability and whether or not albinism should be classified as a disability. Thirdly, there is the question of what challenges or obstacles are related to access to education for PWA. It is worth noting that the scholarly literature overwhelmingly tilts towards albinism in the African context, highlighting not only the complex intersections of race, colour and disability but also on the several risks that PWA in some parts of Africa, must endure (Franklin et al., 2018; Imafidon, 2018; Kromberg et al., 2020; Mswela, 2017; Mswela & Nothling-Slabbert, 2013). A possible reason for this is that international campaigns on albinism tend to reinforce the idea that 'albinism is an African issue only' (Ero et al., 2021, p.21).

The aim of this paper is to examine the challenges experienced by PWA in accessing education. The paper attempts to achieve this by understanding the contestations around albinism, disability, human rights and access to education by setting out the key conceptual and theoretical debates around albinism. Finally, the paper concludes by proposing areas for further research and recommends the need for collaboration between various stakeholders in ensuring inclusivity and dialogue with the aim of formulating an appropriate comprehensive intervention strategy designed to support learners and educators at all educational institutions.

What is Albinism?

Albinism is an inherited genetic condition that reduces melanin production, a natural substance that gives colour to the human hair, skin and eyes (Hong et al., 2006; Lund & Gaigher, 2002). An examination of the literature on albinism reveals that it was only in the 19th century that the cause of albinism was scientifically understood (Kiishweko, 2017). With regard to the conceptual definition of albinism, there is consensus that albinism is 'a group of inherited anomalies of melanin synthesis, characterised by an absence of melanin pigment' (Oetting et al., 1996, p.330). Oculocutaneous albinism is an inherited disorder characterised by low levels of skin pigment in skin, hair and eyes, visual defects and an increased risk of skin cancer (Kromberg et al., 2020). It is an inherited single-gene condition, which occurs in all ethnic groups worldwide and includes several autosomal recessive disorders affecting pigmentation. Ocular albinism is a condition where only the eyes are affected (Oetting et al., 1996). With scientific development, the medical literature reveals that there are different types of albinism and their frequency differs according to the population.

There are two types of albinism that are the most common, namely type 1- OCA1 and type 2- OCA2. While the former (OCA1)is the most prevalent subtype and accounts for 50 per cent of the cases worldwide, the latter (OCA2) is responsible for 30 per cent of cases and is most commonly found in Africa. It affects an estimated 1 in 10,000 people and in certain populations such as the Tonga tribe in Zimbabwe which is a largely rural population, the prevalence is more than 1 in 1,000 (Marçon & Maia, 2019).

The literature on albinism is divided along arguments on how people with the condition should be addressed/referred to. The term 'albino' is often used in many languages including English to refer to people with albinism and although some people are comfortable with its use, others argue that the word can have a derogatory connotation. It is considered dehumanising to refer to a person in terms of a condition, hence, the terms *person with albinism* and *people with albinism* are largely accepted, as it puts the person first and the condition second (Ero et al., 2021).

Prevalence of Albinism

Globally, the prevalence of albinism varies widely between countries and within regions. The condition is present in all ethnic groups and populations in various parts of the world. For instance, the Bhatti Tribe in Pakistan has an incidence of 5 in 1,000 people, while the frequency of albinism in Europe was estimated to be between 1 person in 17,000 and 1 person in 20,000 in North America. In the Netherlands, it has been reported to be as high as 1 in 12,000 while in Northern Ireland it is 1 in 4,500–6,600. In various indigenous communities of Southern Brazil, Southern Mexico, Eastern Panama and the South Western USA, the prevalence of oculocutaneous albinism type 2 ranges from 1 in 28 to 1 in 6,500. It is estimated that the Hopi indigenous peoples of Arizona in the USA have a prevalence of 1 in 200. The Kuna indigenous peoples of Panama have an extremely high prevalence of 1 in 160 (Ero et al., 2021, p.12–13).

Similarly, there is great variance in the rates of albinism in Asia and the Pacific. In Japan, the prevalence ranges from 1 in 7,900 to 1 in 27,000. Unofficial data from India suggests that the total number of PWA is 150,000, while in China the number is 1 in 90,000. Civil society organisations in Australia estimate that the prevalence is 1 in every 17,000 people, while in New Zealand it is estimated to be 1 person in 16,000. The Pacific region, which includes Fiji, has one of the highest rates of type 2 OCA with 1 in 700 having the condition. There is little or no data about the prevalence of albinism in the Middle East and North Africa (Ero et al., 2021, p.12–13).

While there is a great disparity between the global levels of albinism, the highest incidence is in sub-Saharan Africa where 1 person in 5,000 has the condition (Bradbury-Jones et al., 2018). In South Africa, the research indicates that approximately 1 in 4,000 has the condition and it is primarily found amongst black people (Hong et al., 2006; Phatoli et al., 2015). Ero et al. (2021) caution that these global figures may be 'arbitrary and unreliable,' because no comprehensive studies have been conducted and very few countries collect official data on albinism, let alone disaggregated data. In reality, the global prevalence of albinism is much higher.

'Visible' yet 'Invisible'

People with albinism comprise a small and marginalised group in society. It has been argued that 'very little attention is paid to the protection of PWA from human rights violations, threats and violent crime' (Mswela, 2017, p.114). As a coping mechanism to avoid discrimination, labelling and alienation, PWA tend to exclude themselves from the rest of the community, essentially making themselves 'invisible', despite their 'visibility' (Lund & Gaigher, 2002; Phatoli et al., 2015; Mswela, 2017, 2018).

In Africa, Asia and South America the lack of the usual (sometimes dark) pigmentation makes PWA highly visible because of the extremely pale colour of their skin and hair. Therefore, their appearance is very different from other dark-skinned people in their communities (Bradbury-Jones et al., 2018; Franklin et al., 2018). Their 'otherness' makes them susceptible to different treatment on the grounds of their 'differentness'. Furthermore, this difference in appearance creates socialisation and adaptation problems for PWA (Lund & Gaigher, 2002). They are more likely to experience social discrimination and marginalisation because they 'do not fit neatly into either the black or white groups' (Phatoli et al., 2015, p.1). Their skin colour leads to negative social constructions. In certain instances, there is also the belief that they are evil cannibals or cursed (Ntinda, 2012 cited in Mswela & Nothling-Slabbert, 2013, p.25).

Despite the values stated in the United Nations Universal Declaration of Human Rights (1948), PWA face great discrimination and suffer from all sorts of abuse related to societal myths and witchcraft. The most serious amongst their experiences are ostracisation, intimidation, abandonment, neglect, abuse, infanticide, mutilation, deliberate exclusion and discard (Kiishweko, 2017; Mswela & Nothling-Slabbert, 2013) There is a common myth that if the body parts of PWA are used in witchcraft rituals and/or traditional medicine it will lead to greater wealth, good luck and success in the political arena. A lucrative trade in body parts in Africa and elsewhere motivates acts of violence and murders. Children are specifically targeted and the belief that the ritual defilement and rape of girls with albinism can cure HIV/AIDS is common. Inevitably, these forms of victimisation severely affect the mental health of PWA (Baker et al., 2010).

Over the past decade or so, civil society has reported more than 500 attacks against PWA in 25 African countries. Babies, children and adults with albinism have had to endure unprecedented levels of killings and mutilation. These cases are likely to represent only a small proportion of the actual number of attacks and violations because many are undocumented and unreported, mainly due to the limited capacity of most civil society organisations that monitor the situation, secrecy around ritual attacks, the complicity of family and community members and difficulty in accessing data from rural areas where most attacks occur. The United Nations Convention on the Rights of the Child (UNICEF, 1989) has also recognised that violence against children with albinism amounts to torture (Ero et al., 2021).

Disability or Not?

The second body of literature provides a discussion on the definition of albinism and whether or not albinism should be considered a disability. Firstly, on the definition of disability: Some writers (Francis & Silvers, 2016; Goering, 2015) argue that the definition is a contentious one as a common legal definition is lacking. Even though the medical model was initially used to understand disability, the traditional medical definition of disability does not recognise albinism. Subsequently, the social model was adopted and later it was recognised that, in addition to social and environmental circumstances, there are social and cultural barriers that play a part in excluding and marginalising people with disabilities.

Policy-makers in different countries have adopted an inconsistent approach to the question of whether PWA are disabled. While in some countries they are regarded as disabled, in others they are not. As a result, disability grants and other forms of social support are not uniformly accessible. For example, in Ecuador, disability laws recognise the needs of blind people but not those with low vision. Hence, PWA are unable to access disability grants. Similarly, in Colombia, they do not see themselves as living with a disability and do not know that they are able to obtain benefits through the disability registry (Ero et al., 2021). In other countries such as Brazil, PWA have to prove their disability on an individual basis in order to have access to the disability regime.

On an individual level, PWA themselves may not necessarily accept or adopt the ‘disabled’ label because their impairments may not be seen as severe enough, or that they may be coping adequately with the impairment and therefore do not require protection from discrimination. However, there is a 'growing recognition and acceptance that PWA should be recognised as disabled' (Franklin et al., 2018, p.2). While they are usually as healthy as the rest of the population with growth and development occurring normally, they can be classified as disabled because of the associated visual impairments which vary from mild to severe. In some cases, they may be considered legally blind as their vision is not correctable with eyeglasses.

By adopting a human rights model of disability, Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UN, 2007) (UNCRPD) conceptualises disability as 'an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.' The UNCRPD further elaborates that persons with disabilities include those who have 'long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' Therefore, the UNCRPD recognises that, due to their visual impairments, PWA *are* people with disabilities. The implementation of the UNCRPD is further supported by the United Nations Disability Inclusion Strategy (UN, 2021) which provides a foundation for 'sustainable and transformative progress on disability inclusion.'

In the UK, disability is covered under Chapter 2 of the Equality Act (2010) which protects people from discrimination, harassment and victimisation. This Act, in addition to discussing the concept of 'discrimination arising from disability,' also places an obligation on employers to provide for 'reasonable adjustments' to ensure that workers with any form of disability are not substantially disadvantaged at work. Even though albinism is not specifically mentioned, the Act has taken a broad, general and inclusive approach with an emphasis on discrimination against people with disabilities. Therefore, despite the fact that PWA are not specifically mentioned, they would be able to seek protection under the Act.

In March 2021, the European Commission adopted the Strategy for the Rights of Persons with Disabilities (2021–2030), which acknowledges not only the diversity of disabilities but also their 'invisibility' (EU, 2021). The strategy promotes an intersectional approach that takes into account the multiple disadvantages experienced by women, children and older persons with disabilities.

The World Health Organization's (2011, p.4) report on disability provides a more inclusive definition, where disability is seen as an 'umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).'

In the context of the high prevalence of albinism in Africa and the complex and intersectional aspects of race, colour and ethnicity, it is encouraging to note that the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (2018) does take into consideration the contextual realities of the African continent. It is also no surprise that the Preamble to the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (2018, p.3) goes on to express grave concern that 'persons with disabilities continue to experience human rights violations, systemic discrimination, social exclusion and prejudice within political, social and economic spheres.'

Social justice, Stigma and Human Rights

Social justice is based on values such as inclusion, collaboration, cooperation, equal access and equal opportunity, and maybe defined as 'the fair and equitable distribution of power, resources and obligations in society to all people, regardless of race or ethnicity, age, gender, ability status, sexual orientation, religious or spiritual background.' (Van den Bos, 2003 cited in Hage et al., 2011). Closely aligned to issues of social justice/injustice is the theory of stigma.

A stigmatised person is one that possesses 'an attribute that is deeply discrediting and is rejected as a result of the attribute (Goffman, 1963, p.4). Within the albinism population, the discrediting attribute relates to their skin colour difference because of the hypopigmentation of the skin (Wan, 2003). This stigmatisation and rejection often begins the moment a baby with albinism is born and continues throughout their life. Their social rejection is connected to norms and values in society, whereby society uses a norm as a starting point for stigmatisation. As a direct consequence of their physical appearance and visual impairment, PWA worldwide experience stigma and discrimination, making them the most vulnerable and marginalised individuals in society (Mswela, 2017, 2018; Wan, 2003). The degree and severity of stigmatisation varies by region. Amongst Caucasian populations in Europe, the USA and Australia, PWA may not be as 'visible' or distinguishable from the general population. In many parts of Africa, Asia and South America, they face 'rampant aggravated discrimination,' because of their hyper visibility (Ero et al., 2021).

This is most evident in the labels used to refer to them (Brocco, 2015).For instance, in the Congo, PWA are referred to as *mbunzu gozo* (black eater of manioc) in the Sangho language, which highlights the ambiguous status of the disability within the community (Ogrizek, 1983, cited in Brocco, 2015,p.1146). In Mali, because they are susceptible to severe sunburn which makes their skin turn red, they are called *gomblè* (red man) (Imperato, 2006, cited in Brocco, 2015, p.1146). The labels *mzungu* (white man, European) and *napwere* (which refers to a pea-brownish color) are common name-calling terms for PWA in Malawi (Braathen & Ingstad, 2006, cited in Brocco, 2015). In Brazil, they are referred to as peeled cockroaches and white rats, while in Malaysia, they are called a ghost, white people or aliens. In India, they are referred to as snowman or yeti (Ero et al., 2021).

Despite being a relatively small segment of the global population, PWA are disproportionately affected by poverty, particularly in developing countries. They are subjected to complex and intersecting forms of discrimination, stigmatisation and social exclusion, to a lesser or greater degree. The discrimination against them occurs against the background of colour discrimination or what is termed 'colourism' where they are viewed as white people within a black community (Mswela & Nothling-Slabbert, 2013). They face social injustice at multiple levels of race, colour, disability and gender in many facets of their lives because of their difference/otherness. For women and girls with albinism, the discrimination is compounded on the basis of gender (Ero et al., 2021).

Goffman (1963) extrapolates that social construction comprises two main parts. Firstly, a differentiation based on certain rules. PWA, as people with other disabilities, are mainly perceived as 'different' and 'deviant' (Goffman, 1963; Reid-Cunningham, 2009). This is particularly relevant where family and community are familiar with the condition. As a result of being white in a black body, they are seen as being different and are afforded differential treatment. PWA are discriminated against because of the social constructions about their appearance and disability where the paleness of the skin colour leads to a number of negative social constructions (Mswela & Nothling-Slabbert, 2013).

Secondly, Goffman (1963) refers to 'a direct depreciation of a person,' where an attribute is needed to function as a link between the person and the stigmatisation which brings about different 'truth' about people and groups. When these differences are taken for granted, stereotypes are created which are then recreated in a way that has a negative effect on the stigmatised group (Stensson, 2008). A distinction is made between the 'we' and 'them' where the stigmatised people experience discrimination and a loss of status (Stensson, 2008). These negative attitudes and stigma affect an individual's ability to lead a full life (Brocco, 2016).

While Goffman (1963) also speaks of 'spoiled identity', the more recent disability studies on identity focus on discrimination and marginalisation created through categorisations by the 'normals' in society. According to Wan (2003), this theory identifies 'the normals' as being the 'identity spoilers' or the 'problem.' Goffman saw stigma as a process by which the reaction of others spoils normal identity where people with impairments are stigmatised by the 'normals.' Hence, we find that the majority of PWA live in marginalised social conditions and a state of economic vulnerability.

The theory of stigma, in which people who are stereotyped are seen as different and depreciated, is relevant for understanding the impact of the albinism stigma on unequal access to education and employment opportunities which are both intrinsically linked. Consequently, children with albinism who face discrimination at multiple levels may be excluded from society and from a quality education.

Worldwide, people face a number of barriers to achieving access to justice. For PWA, it occurs from the moment of birth and continues throughout their lives, mainly as a result of misconceptions, ostracism and rejection. These barriers are complex and are located within the wider structures of society, culture and economy. They include societal and cultural barriers (literacy, education, poverty and discrimination); institutional barriers (insufficient governmental resources to guarantee or facilitate access to justice, inadequate organisational structure of justice institutions, limited legal assistance and representation and the lack of enforcement of decisions); and intersectional barriers where societal and institutional barriers overlap (lack of trust in lawyers and judges and corruption) (Beqiraj & McNamara, 2014). In practice, their impact intensifies when they 'operate simultaneously and have reciprocal effects on each other' (p.6). Barriers faced by victims of human rights abuses, especially those experienced by PWA, are exacerbated by a culture of silence related to the belief in witchcraft, financial barriers and a fear of reprisals from relatives and community members when an attack has been perpetrated by a family member or a respected member of the community. They face legal illiteracy of legal processes, poor access to information, education and training, lack of political will to enforce existing legislation, inadequate resources for police to deal with cases (especially in rural areas), prejudice among police officers, prosecutors and judges against PWA and failure to conduct thorough investigations, successfully prosecute or convict. Underreporting and low levels of monitoring and follow-up by both State and non-State actors are also significant challenges. Various international human rights bodies have also raised concerns about human rights violations against PWA and place obligations on States in the form of various treaties to prevent such abuses and provide protection. These include the Universal Declaration of Human Rights, the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities, the African Charter on the Rights and Welfare of the Child and the International Convention on the Elimination of All Forms of Racial Discrimination.

Even though the international human rights regime may be beneficial in contributing to social justice, social stability and social change, some writers caution that 'human rights must always be considered as a means to an end and not an end in itself if it is to serve a meaningful purpose'(Yusuf & Woodham, 2013, p.1). Therefore, States have a duty to not only take positive action such as legal and other measures but also to provide effective protection for PWA and their family members. The implementation of human rights laws is problematic due to a number of factors which include, *inter alia*, lack of awareness and knowledge of the albinism condition, human rights advocacy excluding PWA, very few best practice examples of the human rights of persons with albinism and a lack of specific measures that cater for PWA (Ero et al., 2021).The main shortcoming is that in many countries there are no separate legislative frameworks that specifically address the human rights of PWA. Protection is usually only provided by constitutional clauses on equality and non-discrimination. For example, while PWA in Europe and North America do experience discrimination because of their visual impairment, they are still able to access services such as education and employment opportunities without any barriers (Ero et al., 2021).

Access to Education

The following international treaties acknowledge the rights of children to education, namely the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2007), the Universal Declaration of Human Rights, the UNESCO Convention against Discrimination in Education, and the International Covenant on Economic, Social and Cultural Rights(1966) (Adelakun & Ajayi, 2020). According to Article 28 of the United Nations Convention on the Rights of the Child (1989), 'Education is the basic right of every child and is essential for their cognitive, emotional, social, cultural and physical development. It provides the knowledge and skills they need to integrate into and contribute to their societies (UN, 1989).' In line with the above, the UNCRPD also guarantees the right to inclusive, quality education. States parties are urged to recognise the right of everyone to education, especially children. States are obliged to ensure inclusive and life-long educational systems at all levels, the development of full human potential, talents and creativity and full participation in society. Article 27(1) of the UNCRPD ensures that people with disabilities have the right to work and employment on an equal basis with others by encouraging an open, inclusive and accessible route to employment.

Furthermore, Goal 4 of the Sustainable Development Goal 5 emphasises inclusivity, equitable quality education and the promotion of lifelong learning opportunities for all. Of particular relevance is Target 4.5 which aims 'to eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations,' by 2030. Vulnerable groups that require particular attention and targeted strategies include persons with disabilities, indigenous peoples, ethnic minorities and the poor.

In Africa, the African Charter on the Rights and Welfare of the Child (1990) is the main instrument of the African human rights system for promoting and protecting the rights of the child (African Union, 1990).While numerous policy and legislative advancements have been effected to enhance access to education for all children, in reality children with albinism experience a range of negative educational experiences. Attitudinal and structural barriers can compound the challenges faced by these children. For example, it is reported that in Japan, in order to enrol in school, children with albinism have to dye their hair. In India, children have difficulty gaining admission to schools due to objections from other students' parents who believe that albinism is contagious. In Europe, the Pacific and the Middle East, there are reports that children with albinism experience name-calling, physical violence and verbal abuse bullying and stigma (Ero et al., 2021, p.55–56).

Educational institutions serve to perpetuate and institutonalise systems of injustice for PWA. Sometimes they are educated in specialist schools for visually impaired children, although there is an increasing move to adopt inclusive education in mainstream educational settings. It has been reported that, globally, children with albinism face many obstacles in the school environment; including bullying and name-calling, perpetrated by both fellow students and teachers. There is 'little to no reasonable accommodation' made for them (Ero et al., 2021, p.56). This is especially the case in parts of Africa, South America and Asia where there is heightened discrimination and stigma associated with the condition. The lack of accommodation for low vision is considered the most significant barrier to education. Access to reading material with large print remains a challenge, which leads to low self-esteem and negative attitudes around their capacity to learn and achieve. Another exacerbating factor is that because teachers lack knowledge and/or understanding of the condition, they are unable to support them adequately by accommodating their vision challenges and the risks of exposure to the sun. Even though 'reasonable accommodations and supports are guaranteed in law' in many European countries, in practice, students do not always receive these supports. Similarly, in Asian countries, accommodations and adaptive devices are only available upon request and in the United Kingdom and Ireland, parents have to navigate the educational tribunal system to access the relevant support for their children (Ero et al.,2021). Hence, these children perform poorly academically; severely impacting upon their ability to enter tertiary institutions and obtain suitable employment, which exposes them to enduring poverty and vulnerability.

Apart from their low vision, children with albinism display no other cognitive or academic learning disabilities and can perform as well as any other student in the classroom (Baker, 2018). However, some parents believe they are not 'worth educating' (Lynch et al., 2014) because they will not be able to contribute to society in the same way as other children can. The myth that these children will die young means that many are prevented from attending school (Baker, 2018).

A study on albinism in children in Malawi (Franklin et al., 2018) revealed that parents feared sending their children to school out of concern for their safety while walking to school and the lack of confidence in teachers' abilities to keep them safe. Those that do make it to school suffer incessant teasing, bullying by peers, low self-esteem and lack of assertiveness. The high drop-out rate among children with disabilities, including those with albinism, is also a cause for concern (UNESCO, 2009) as it results in them often not having adequate social or economic tools to live productive lives (Baker et al., 2010). Social discrimination, superstition and prejudice including murder threats due to myths and beliefs, coupled with the physical challenges are factors that interact with educational opportunities (Kiishweko, 2017).

Access to tertiary education is another sector where PWA experience enormous challenges. While it is widely accepted that tertiary education is essential for economic and social development and to meet the needs of the knowledge economy, a very small percentage of PWA are able to access higher education (Phago & Thwala, 2015 cited in Harry et al., 2018, p.1). Tertiary education can offer an opportunity to those individuals excluded in the past to compete in the labour market (Chinyamurindi, 2012, 2016 cited in Harry et al., 2018, p.1). Furthermore, access to tertiary education is an important way in which PWA may transform their identity by challenging deeply ingrained social prejudices, which often label people with albinism as having limited cognitive capacity. Hence, promoting educational inclusivity is crucial to the lives of PWA (Kiishweko, 2017).

The Covid-19 pandemic has posed further challenges for PWA, children and youth. The shift to remote instruction and learning at educational institutions has exacerbated the situation, especially for students with disabilities (Meleo-Erwin et al., 2020). PWA, who are generally isolated, find themselves further isolated due to the sudden change in social behavioural patterns. Preliminary data reveals that university students with learning disabilities experienced difficulties adjusting to the new course delivery format, as well as the new expectations that they had to meet (Meleo-Erwin et al., 2020).

Closely related to access to education is the right of access to employment and an adequate standard of living. Due to their high drop-out rates and low levels of education, PWA face exclusion from jobs that involve working indoors (such as in an office) and end up suffering from sun exposure that increases their risk of skin cancer. They may also encounter discrimination in the workplace where they are stereotyped and stigmatised as being inferior or incompetent; and whose physical presence may scare off potential customers. Unemployment, low-paying jobs, difficulties in accessing loans and disinheritance by family members because of their condition, result in many PWA living in poverty. Furthermore, knowledge on how to access social security benefits based on disability is lacking.

Conclusion

This paper sought to understand the many complex and intersecting issues that impact upon the access to education for PWA. By adopting a social justice and human rights lens, the paper explores the key conceptual and theoretical debates around the albinism condition, disability and human rights. Finally, the paper concludes by proposing areas for further research that may drive policy analysis and development, rights awareness-raising and educational programmes on albinism. Furthermore, it is only through inclusivity and dialogue that countries will be able to formulate culturally appropriate, comprehensive intervention strategies within a human rights framework, that are designed to support and empower learners and educators at all educational institutions.

An overview of the scholarly literature on albinism reveals a greater emphasis on albinism in Africa with a great deal of attention being paid to stigma, discrimination and human rights abuses perpetrated against PWA.

This is mainly because the intersections of race, colour and ethnicity are more 'visible' in Africa. Despite the paucity of data on the prevalence of albinism globally, estimates suggest that there are hundreds of thousands of people with the condition. The absence of accurate data results in governments not including PWA in their policy-making, reform strategies and initiatives (Kiishweko, 2017), thereby perpetuating their 'invisibility'. There is a need for governments to include albinism in official databases and conduct population-based studies to provide a reliable estimate of these figures (Marçon & Maia, 2019). Further research is required on the global, regional and country-specific incidence and distribution of the condition.

The literature also reveals that the issue of 'disability or not?' is fraught with contestations and controversy, without a straight forward answer. There is no consensus that albinism is a disability, neither among the public nor among those with the condition, or even in each country's legislative and/ or policy framework.

Worldwide, children with albinism face insecurity and significant barriers to quality education, to a lesser or greater degree. There is a dearth of literature on the psychosocial issues and challenges faced by these children. The experiences and perspectives of children as narrated by children with albinism themselves is an unexplored area of research. This means that there is a limited understanding of their needs. Hence, interventions to better support, empower and protect them are lacking.

Although violence against PWA is widely reported by the media globally, albinism remains under-researched and under-theorised. This reiterates the need for increased awareness of the albinism condition to better address the misconceptions associated with it.

Policy makers should ensure that awareness-raising and education on the condition are mandatory for all teachers in the public education system, in order to adequately cater for the special needs of children with albinism. The absence of academic interest and research on access to education has resulted in insufficient strategies and interventions to create better educational and economic opportunities for children and youth with albinism. Identified areas include specific governmental and societal strategies and interventions that cover access to healthcare, academic education, safety and security, economic empowerment and social awareness. Among the stakeholders who could help PWA to access justice are the State, the judiciary, the legal profession, paralegals and community-based advice centres, law clinics, the law and education faculties at universities and non-governmental organisations.

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Rajagiri Journal of Social Development
Volume 13, Number 2, December 2021

Ungendered Social Support for Cancer Patients in the Patriarchal Hegemony in Kerala

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Abstract

Although the hallmark set for the Kerala development model is an egalitarian ideology, the increasing incidence of dowry deaths and gender discrimination calls for comprehensive and intensive investigations into the prevailing social reality on gender equality in Kerala. This study explored one of the worst scenarios in life to find out whether people discriminate against women there. The study's objective was to compare the perceived social support and hope among women and men who have cancer in the Ernakulam district of Kerala. This study adopted a quantitative survey method and collected data from 240 cancer patients in 15 randomly selected panchayats in the Ernakulam district. It elicited their sociodemographic data, perceived social support and hope, using a self-structured questionnaire, the multidimensional scale of perceived social support, and the Herth Hope Index. The use of inferential statistics compared the values obtained for the perceived social support and hope for both male and female respondents. The result showed no significant difference between the dependent variables measured for men and women, which confirmed the ungendered care for cancer patients in Kerala.

Keywords

empathy, family, cancer care, awareness, social conscience

Introduction

The egalitarian ideology embraced by the Indian State of Kerala in achieving a unique social development has drawn wide attention within the country and globally (Altbach, 2013; Bowles, 2020). Although on one

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