

ACCESS TO INFORMATION FOR PEOPLE WITH ALBINISM: ISSUES, CHALLENGES AND RESOLUTIONS

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ABSTRACT: Albinism is an inherited genetic condition that reduces the amount of melanin pigment formed in the skin, hair and eyes. The difference in appearance between pigmented people and those with albinism is often the object of inaccurate and harmful beliefs about the condition. These beliefs are fuelled by myths, lack of knowledge and understanding. In recent years, it has cost people with albinism (PWA) severely with the mutilation of their body parts and killings in some countries in Africa. PWA challenges include discrimination, stigmatisation, derogative naming, skin cancer, visual impairment, rejection, and social exclusion in fundamentals such as healthcare, education, and employment. Also, access to information remains a challenge to PWA due to poor eyesight and myths associated with the condition, making it difficult for society to openly discuss albinism issues and share information with those in need.

The study explored PWA's challenges, parents of children with albinism (CWA) and organisations that serve PWA in Khomas region Namibia when accessing information. The researchers adopted the interpretivism paradigm and employed a qualitative approach. Data was collected through individual face to face interviews with all the participants. Sixteen participants, both male and female, took part in the study. The findings show that PWA encounter problems when accessing information. These include lack of awareness of information sources coupled with poor eyesight for PWA and reading of information in small fonts that are not provided in alternative formats. The immediate sustainable resolution is delivering inclusive information services that avail health information in multimedia formats to accommodate people with challenges such as visual impairments and other forms of impairments. Although far-fetched, a change in mind-set and negative attitude to PWA, especially in Africa, is critical.

KEYWORDS: people with albinism, challenges, Namibia, information.

INTRODUCTION

Albinism is characterised by a lack of melanin, a pigment that gives colour to the hair, skin and eyes, and it can occur in all genders regardless of ethnicity, and it is common in all countries of the world United Nations, General Assembly (2013, 4). Every PWA inherited the condition from both parents (mother and father). It does not matter whether these parents have albinism or not; as long as they carry the genetic trait of albinism, they can potentially have a child with albinism Under the Same Sun (n.d.).

Despite the challenges caused by hypervisibility eminent with their condition, PWA have other challenges such as poor eyesight that accompanies all forms of albinism, vulnerability to skin cancer and the worst of them all is the misconception of albinism and the negative perception by African society towards albinism in general. According to Doris (2019, 61), in Sub-Saharan Africa, the condition is viewed as a curse, evil, or some form of punishment from the gods or ancestors for parents' wrongdoing.

The challenges mentioned above have contributed to PWA's social exclusion from some basic services (if not all) such as health care, education, safe employment opportunities, proper housing, and information access. Among the stated challenges, information plays a crucial role because it provides the foundation for which PWA can become aware of issues affecting their lives, make informed decisions and defy the myths associated with the conditions. However, accessing information remains a challenge due to poor eyesight. For these reasons, the National Federation of People with Disabilities of Namibia's chairperson indicated that 'People with disabilities still have limited or no access to information Namibia Press Agency (2019). The chairperson noted that information in most cases is displayed on screens for people to read for themselves. Those with visual impairment are incapable to do and therefore are automatically excluded. Besides, Albinism Umbrella (2017) indicates that poor access to information, particularly in rural areas regarding albinism, its causes and effects, preventive measures for sunburn and skin cancer is a significant concern.

THE CHALLENGES FACED BY PWA IN AFRICA

The historical use of the term 'albino' has contributed to PWA's derogatory naming throughout Africa. Although the term 'albino' is commonly used to refer to living creatures with albinism, it has been established inappropriate to refer to human beings as albinos. This was underscored by Thuku's (2011, 7) assertion that "even though the term albino is still valid today, it is essential to mention that the term is a high point of contention amongst PWA communities". This is a critical issue, given that because of stigma and social rejection in many African countries, different terms are used to refer to PWA. As noted by Cruz-Inigo, Ladizinski, and Sethi (2011), most of these terms are dehumanising, with little regard to PWA's dignity.

Traditional beliefs and witchcraft have also contributed immensely to the discrimination and stigmatisation of PWA today. Among some societies in Africa, PWA are viewed as less human, and in some cases, as phantoms that do not die but disappear Uromi (2014). Ntinda (2011, 244) explains that PWA were also killed in certain Namibian communities in the past, and their body parts were used for 'muti' (witchcraft practices). The utilisation of each part of the body has a symbolic meaning. For instance, the utilisation of eyes for 'muti' means one's partner would not have an extramarital sexual relationship. The use of legs is believed to perpetuate the user of such 'muti' to promiscuity, while 'muti' with blood, hair, nails, sexual parts, and breasts would bring wealth.

In recent years, the killing of PWA started in Tanzania; it spread to some parts of Southern Africa, with Malawi topping the list, where the number of reported crimes against people with albinism in Malawi has risen to more than 163 cases, including 22 murders since November 2014, according to official figures Malekezo (2019). Namibia Press Agency (2019) article attests that Malawi judges sentenced three people to death for albinism murder.

According to Kapitako (2018), Namibia has the most albinos per capita in the world. With a population of about 2.4 million people, the country has between 1,800 and 2,000 people living with the condition. However, it is worth noting that Namibians with albinism still feel safe because they have not experienced killing in recent years. This is attributed to some of the most progressive legislation and national policies safeguarding people with albinism Kapitako (2018). But, misconceptions about the condition still exist. The following newspaper quote is presented as an example; "Besides discrimination and stigmatisation that people with albinism face in the country, Kangoute said he is fortunate to live in a peaceful society, unlike his counterparts in other parts of Africa where persons with albinism are hunted and killed for their body parts to be used in rituals and other black magic due to myths" Angula (2018).

REVIEWED LITERATURE

Generally, people with albinism have the challenge of poor eyesight, which, most of the time, prevents them from attending mainstream schools. There are very few special needs schools in Namibia, so learners with various disabilities are often grouped in one class. Most of these schools are usually under-resourced and lack information services, school libraries and assistive devices for access to information. Brilliant (2015, 224) concurs that people with albinism have a feeble correctable vision, and as a result, they are disadvantaged in schools and employment opportunities. At best, they are discriminated against, while at worst, they are hunted and often killed for their body parts for witchcraft use. In most cases, if they survive these attacks, they are very likely to develop skin cancer that is most often untreated, leading to a preventable premature death Brilliant (2015, 224).

Mawere (n.d.) expressed that this stigma about albinism exists, has always existed, and it will continue existing as if it is being passed on from generation to generation. However, this is the sickening side of society, where information about albinism is either lacking or absent, and that albinism is not a curse, a plague, or a disease. Several studies have repeatedly stated that PWA face discrimination and barriers that restrict their participation in society on an equal basis every day. Due to these challenges, PWA, especially in Africa, cannot enjoy the full range of human rights and the same standards of equality, rights and dignity as people without albinism Gaigher, Lund, & Makuya (2002); United Nations, General Assembly (2016).

The following constraints were reported by Baker et al. (2010, 170) after investigating the myths surrounding PWA in South Africa and Zimbabwe, namely, lack of finances, education, and the reduced visual understanding associated with the condition, as well as the environment of people with albinism.

Additionally, Mnubi-Mchombu and Mostert (2011, 402) identified the lack of information channels that could inform caregivers on issues such as how to apply for grants for the orphans and vulnerable children (OVC) in their care, as well as a lack of funding when traveling long distances to access information sources. Mansour (2015, 16) adds a lack of time to access information and a lack of training and skills to access it as some of the challenges noted when investigating the information needs and seeking behaviour of domestic workers in Egypt. Moreover, the psychological burden suffered from the image of being house servants and the lack of awareness about their fundamental rights, including the right to information, were other challenges disclosed by the study. According to Lund (2005, 171), a lack of knowledge among medical staff in approaching people with albinism with sensitisation or sensitivity is another challenge. It came to light that people, including healthcare professionals, often avoid physical and social contact with those who are affected; it has been proposed that this social context essentially structures and limits the lives of people with albinism, preventing them from reaching their full potential in a non-supportive environment Gaigher, Lund & Makuya (2002).

Furthermore, Omeluzor, Oyowwe-Tinuoye, and Emeka-Ukwu (2017, 445) mention that a lack of awareness of information sources can hinder access to information. Ugah (2007, 1) further elaborates that information seekers and users may not know about the sources available because libraries' role has not been made clear to the information seekers. Beverley, Bath, and Booth (2004, 19) found the lack of knowledge on specific health topics, limited knowledge, as well as language and cultural barriers associated with ethnicity, community-level barriers, including social taboos and insufficient time, as some of the obstacles identified in their study of the health information needs of visually impaired people. Ugah (2007, 3) describes adequate infrastructure as the basic framework for any information organisation. Ugah (2007, 3) further argues that effective information access and use depends on communication facilities such as telephone, internet, telefax, computers and even postal services, as well as an adequate supply of electricity. Language limitations and illiteracy are among the identified barriers that hinder access to information. A significant number of studies on information needs have found language as a barrier to accessing information Chiware (2008); Mnubi-Mchombu & Mostert (2011); Mnubi-Mchombu (2013); Madumo (2017). Mansour (2015, 16) also notes that illiteracy was one of the challenges faced by domestic workers when accessing information. This is a

sentiment echoed by Masanja, Mvena, and Kayunze (2014, 24) who reveal that illiteracy is the main force behind the beliefs and attitudes towards albinism and PWA.

STATEMENT OF THE PROBLEM

Although the government of Namibia and non-governmental organisations are taking care of PWA, access to relevant information to address their specific conditions and problems is limited, especially among people in rural areas who sometimes deliver babies at home. At the time of this research, no study was found on PWA's information needs, especially in Namibia. This conclusion was reached after an intensive literature search that was conducted on various databases such as EBSCOhost, I.S. Web of Science, Emerald and Google Scholar, and various search engines by using keywords such as information needs, information seeking, and information behaviour in combination with albinism, and using the Boolean operator AND. Seemingly, respective databases cluster PWA's information needs with other user groups' information needs, even though they have unique conditions that might often trigger distinctive information needs. The one-size-fits-all approach to using information systems and services' design does not do justice to the conditions and nature of information needs of distinct user groups such as PWA.

RESEARCH QUESTION

What are the challenges that PWA in Khomas region face daily when seeking information?

METHODOLOGY

The study investigated the challenges experienced by people with albinism when accessing the information. It covered the parents of children with albinism, people with albinism themselves and the organisation that serves PWA in Namibia, namely: Support in Namibia for albinism sufferers requiring assistance (SINASRA) and Namibia Albino Association Trust (NAAT).

This study adopted the qualitative approach to collect and analyse data. Creswell (2013, 65) defines this approach as "the study of research problems that explore the meaning that individual groups ascribe to, either as a social or human problem". The qualitative approach involves studying the phenomena as they happen in their natural setting. Denzin and Lincoln (2008, 4) echo this sentiment by explaining that by so doing, researchers attempt to make sense of or interpret phenomena in terms of the meanings that people bring to them.

Thomas (2010, 306) points out that the qualitative approach is most appropriate when the researcher wants to become more familiar with the phenomena of interest, to achieve a deep understanding of how people think about a topic, and describe, in detail, the perspectives of research participants.

The qualitative case study design was collected through semi-structured interviews with PWA, parents of children with albinism, and the organisational representatives. Interviews are valuable sources of information, and if conducted correctly, they allow researchers to interpret and understand the meaning of participants to answer specific questions Du Plooy-Cilliers, Davis, & Bezuidenout (2014, 189).

Besides, scholars such as Henry (2012), Beverley, Bath and Barber (2007), Fourie (2008), and Litzkendorf et al. (2016), all employed semi-structured interviews to investigate the information needs of various user groups. In all these studies, it was noted that face-to-face interviews worked out well with vulnerable participants.

DATA PRESENTATION AND ANALYSIS

Among those interviewed were sixteen people with albinism; of these, eight were males, and eight were female. The study identified two organisations that deal with people's plight with albinism in the country, namely, NAAT and SINASRA. As a result, two males were interviewed as organisational participants, including the NAAT president and the chairperson of SINASRA. The NAAT president was a corporate participant and a respondent in the study as he is a person with albinism. Both interviewees are responsible for overseeing the operation of their respective organisations, including securing donations. The Namibia Albino Association Trust was established in 1999 and was officially inaugurated in 2001. SINASRA was established in 2001 by Rotarians and optometrists.

FINDINGS

Information seeking challenges of participants

This section presents the challenges experienced by participants when accessing information related to albinism. Therefore, one of the questions addressed in this section was to determine whether PWA and CWA parents experience any challenges when trying to find information. Furthermore, the section presents challenges experienced by key organisations when trying to disseminate information to PWA.

Challenges raised by PWA

Data collected revealed that some of those who possess it are not approachable when seeking information, and they are rude to PWA. Participants acknowledged being discouraged from approaching those with information after the negative experience. One interviewee (PWA2) made the following comments:

There was a time I went to the office of one of the regional councilors to inquire about information on houses because I heard people were registering themselves there, but when I got there, the regional councilor asked me what I was looking for at his office, he told me to go away; he said that I am already receiving the disability grant from the government, without giving me a chance to explain myself.

Furthermore, people with albinism commented that there are occasions when they are not provided with disabilities because people regard them as non-disabled. They explain that they experience this mostly when they are looking for information on the disability grant.

Poor eyesight was mentioned repeatedly by PWA; they maintained that even if they have access to the information, such information is always in an unsuitable format for PWA. As a participant (PWA11) claimed:

Most of the materials are in print format, and with the print, you cannot enlarge it. Books in the library are always in the form that they are sold in; being a law student, I finished law school without using a single textbook because I cannot see. I better use information that I can google because I can zoom and expand as I want, but if I have to use a newspaper article or a book, I would rather not bother.

An example given was that during conferences and meetings on disabilities, the materials distributed are usually in fonts inappropriate for PWA. The challenges of poor eyesight expressed during the interviews were like the challenges experienced at school by children with albinism who could not see on the chalkboard or print textbooks Lund (2001, 3).

Furthermore, the background colours of some print materials or PowerPoint presentations during meetings and conferences pose some of the challenges as noted by PWA. Interviewee PWA12 remarked that:

It is not only the font that is a problem but also the background color on which the information is written; for example, writing with black text on a red blood background is a problem for poor eyesight. After all, black almost blends in red, even newspaper articles, because people who write these articles do not understand issues related to disabilities.

Language is another challenge eminently hindering access to information by PWA. Participants stressed that most of the time, the information is provided in English, and most of the participants do not understand English. They claimed that information is not provided in a language accessible to PWA and their families. There is a lack of information on albinism in local and sign languages in Namibia.

Several participants highlighted a lack of awareness of where to look for information, such as the office, clinics, and so forth. They narrated that sometimes they would find themselves in a situation where they need medical attention, but when they get to the hospital, in most cases, they would not know to which room to go. Besides, sometimes they would be referred from one office to another, and, in most cases, they are likely to give up. Participant PWA8 claimed that:

My principal sent me to the hospital to get a letter stating that I have poor eyesight to be provided with extra time during the examination. Still, at Windhoek Central hospital, some offices told me to go back without being assisted; I found another person who referred me to an eye clinic that I never saw. As a result, I found a doctor who wrote a letter for me stating the following: a girl is complaining about eyes, but I am not the one who is supposed to provide her with this information or letter, and she complains that she has limited time". "As a result, I could not be assisted because the letter I got was not stating anything.

Lack of access to computers and the internet, especially after hours for those employed, is problematic. However, they explained that they could access computers and the internet at work and a public library during working hours. Financial constraint is eminently an inhibiting factor to information seeking. The majority of those interviewed mentioned the fees associated with transport due to long distances. Most of them are not driving due to poor eyesight, which is yet another disadvantage. One participant claimed that she had lost her car allowance benefit at work because she could not drive because of her poor eyesight. Only two participants have acquired a driving license and therefore able to drive themselves around. Apparently, PWA has no choice but to use public transport like taxis to access information.

The lack of communication facilities is one of the barriers identified by some participants, who revealed that they do not own television and radio sets because there is no electricity in the informal settlements where they are residing. Finally, participants' lack of time to seek information was stressed as a barrier to information seeking.

Challenges raised by parents

The same question was posed to parents of children with albinism about their challenges when seeking information. Lack of finances to access information was one of the main difficulties noted by parents. The parent's participants indicated that even though information related to application forms for disability grants are available at different centres and offices throughout Windhoek, parents must travel to different health facilities. State doctors usually complete these forms. Meanwhile, parent participants narrated how sometimes they are turned away by some officers when they try to access information on how to register their children for the disability grants; these officers apparently inform them that their children do not qualify for the disability grant because they are not disabled. A parent participant (Parent1) narrated that:

When I try to acquire information to register her for a disability grant, they always tell me that the child is not disabled; until now, she is not recorded as such; therefore, she is not getting any assistance from the government.

Parent participants shared similar sentiments to PWA that a lack of awareness of where to look for information is a challenge for them, such as the office, clinics, and so forth. An example provided by a parent was when her child had sores on her legs, she would go to the hospital, but at the hospital, she would not know exactly where to start or whom to approach to get treatment.

The language barrier was mentioned almost by all participants because information on albinism is always provided in English, the official language, making it impossible for them to access such information. Participants indicated that even newspapers and pamphlets are written in English, and television programmes are broadcast in English. Sometimes in hospitals, clinics and offices, people communicate in English. A participant claimed that sometimes she would take her daughter with her so that she can translate for her, while Parent 4 remarked that:

I do not understand English very well, and most of the information on albinism is provided in English, and I have never come across information on albinism in Oshiwambo.

Challenges raised by organisational participants

Organisational Participant 1 mentioned that the biggest challenge for disseminating information is reaching out to people who still believe that albinism is a curse. Lund (2005, 171) explains that raising community awareness to improve social integration and acceptance is a significant challenge in a region where albinism is steeped in myths and superstitions and misconceptions that albinism is contagious affected families have been cursed, resulting in fear and misunderstanding. Besides, OP2 linked the lack of a budget to cover the organisation's activities such as raising awareness throughout the country, lack of understanding of what albinism is, and long distances to travel to disseminate information.

DISCUSSION

Challenges experienced by participants when searching for information

Some of the significant obstacles to prevent access to information can be attributed to issues unrelated to albinism. These include long distances, Lack of funds, language barriers, lack of time, Lack of electricity, etc. Most of these barriers were confirmed by previous studies Mansour (2015); Mnubi-Mchombu & Mostert (2011); Baker et al. (2010); Beverley, Bath & Booth (2004). Lack of relevant literature or materials on albinism, especially from a Namibian perspective, lacks equipment, such as computers with an internet connection. Participants mentioned a lack of ownership of radio and television sets due to the none availability of electricity.

The organisational participants also mentioned that the challenges they face when disseminating information are reaching out to people who still believe that albinism is a curse, budget constraints, and a lack of understanding of what albinism is. Some of the challenges are presented below.

Lack of finance, long distances and lack of time

This study indicates that a lack of finance when seeking information is an impediment; this is mainly due to long distances between information seekers and information providers. The interviewees admitted having no taxi money. This is so, despite the majority of them acknowledging that they receive the disability grant from the government and being able to generate extra income from their informal businesses. Organisation participants mentioned that lack of adequate funds makes it difficult for them to reach out to PWA countrywide to implement their activities because they depend on donations. Financial constraints, limited infrastructure, and public transport inefficiencies, as well as long distances that one needs to travel from one area to the next to access information resources, were noted by Mnubi-Mchombu & Mostert (2011, 402); Mnubi-Mchombu & Ocholla (2011, 39); Nakuta & Mnubi-Mchombu (2013, 343) specified distance to government departments to access information as a barrier.

Lack of time to seek information was stressed by participants, especially those whose livelihoods are sustained through informal businesses, who complained that they do not have time to seek information that will require them to leave their businesses unattended. This constraint has been discussed in several previous studies such as Mansour (2015); Beverley, Bath & Booth (2004); Madumo (2017).

Language

The findings show that most of the information on albinism in Namibia is written in English, making it difficult for some PWA to absorb it. The study results confirm that the majority of those interviewed did not have secondary education, hence making it difficult for them to understand English. A participant confirmed that she has never come across information on albinism in the Oshiwambo language, one of the vernacular languages spoken in the country. Even the flyers used by SINASRA to disseminate information about albinism were available in English only.

Chiware (2008, 34) explained that though very small, the Namibian population is highly diversified in terms of languages and makes it difficult for service providers to satisfy all the language groups, especially when they cannot read English Afrikaans. Mnubi-Mchombu and Mostert's study (2011, 402) found language to be a barrier to accessing information. They explained that a caregiver would sometimes go to an office only to be told that the person who can understand and communicate in their language was not available and returned later when the official was available.

Lack of awareness on where to look for information

The findings showed that most of the participants were not familiar with information-seeking techniques and, in most cases, they are referred from one office to another until they give up. This process also cost money and time. Madumo (2017, 28) explained that lack of awareness "simply means not knowing where to find information when in need of information and faced with a complex task or a problem". These findings were substantiated by reviewed literature by Beverley, Bath, and Barber (2011) that visual impairment can be a barrier to information and be aware of what information is available. Also, Crudden and Sansing (2011, 175) highlighted that visually impaired people's failure to seek services is because they are unaware of the help available to them. Nakuta and Mnubi-Mchombu's (2013, 343) study singled out too much bureaucracy as the highest impediment to government information.

Poor eyesight

Information needs to be provided in as many formats as possible and large print because PWA participants mentioned that their poor eyesight makes it very difficult for them to access information that is in general provided in inappropriate fonts and formats. They claimed that information is in print formats; therefore, it cannot be zoomed or enlarged to cater to them. The researcher observed that even flyers used by SINASRA were in an inappropriate font for PWA. This agrees with reviewed literature that even though people with visual impairments (PWVI) have information needs related to their condition, this information is not always accessible and does not always meet specific groups' needs, and one such being people with visual impairment Beverley, Bath & Booth (2004, 2).

Beverley, Bath, and Barber (2007, 2) also explain that when dealing with people with visual impairments, a more comprehensive range of formats should be available, for example, large print, audio cassettes, internet (with internet so that one can send emails, floppy disks, Braille (but a more comprehensive range, so that people have got more choices) instead of having a standard print letter that visually impaired users cannot read.

RESOLUTIONS ON HOW TO IMPROVE ACCESS TO INFORMATION

This section presents suggestions made by participants with albinism on how access to information can be improved. Therefore, participants were asked to make suggestions as to how the community, the nation, or the government could assist in meeting people's information needs with albinism. The aim was to ascertain the modes and platforms through which PWA prefer to receive information.

Almost all respondents identified regional councillors as platforms that can be used to disseminate information on albinism to the community. They stressed that regional councilors understand their people's needs better and have a special programme on local radio stations that airs every morning. As such, they can include information and services directed to PWA in their announcements.

Other suggestions were to organise community meetings and bring PWA together to share experiences. They also indicate that PWA should be provided with information through the platforms that are easily accessible to them, such as radio and newspapers in appropriate fonts and information in vernacular languages to make sure that those less educated and in the villages are not left out. Participants further emphasised that PWA needs information, but it is equally essential to sensitise PWA's society. For example, they need to explain that PWA are normal human beings who deserve to be treated humanely.

Several participants argued that the government should provide finances for sensitisation campaigns because the information is vital. With data, information, and knowledge, PWA know what services they are entitled to and where to go to access them. They will be able to share this information with others because albinism is a condition that will not go away; it is not like a disease that you can cure once and for all.

Furthermore, participants appealed to the Ministry of Information and Communication Technology to ensure that information is accessible to everyone, not only to those who can read print materials. They should implement an easy-to-read mechanism, explained as a mechanism used by the United Nations (U.N.) to provide information to people with intellectual disabilities. Participant PWA 11 articulated this:

The ministry should ensure that books and pamphlets and other printed materials such as newspapers are written in larger fonts; at least they can use Arial 14 up; otherwise, font 11 will not work for us.

Another suggestion was that the government recognise sign language as an official language and have official documents in sign language, such as the Namibian Constitution, where people learn their rights.

CONCLUSION

The study identified many challenges experienced by participants when accessing information. All participants identified long distances that they have to travel to access information and lack of funds. People with albinism raised a concern that information is never presented in appropriate fonts and formats for their eyesight. Other challenges include rude staff members, people who refuse to classify PWA as disabled and lack of awareness of where to look for information when the need arises. Language barriers, a lack of facilities such as access to computers and the internet, radio and television, and a lack of literature about albinism specifically in Namibia, are some barriers identified by participants.

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