Article

Marginalisation and Precarious Circumstances of People with Albinism (PWA): Information Needs and Services

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Abstract

The study that directed this article investigated the information needs of parents of children with albinism (CWA) in the Khomas region, and determined information services that are appropriate for people with albinism (PWA) in the Khomas region of Namibia, in order to inform the possible design of their information services. Considering PWA as a marginalised user group living under precarious circumstances in Africa, and in the interest of an inclusive information service, a study on information needs was conducted on PWA in the Khomas Region, Namibia. It was conducted within the interpretivism paradigm, following a qualitative research approach, and interviews were conducted with six parents of CWA. In addition, two representatives from organisations that deal with the plight of PWA in Namibia were interviewed as organisational participants (OP). The following information needs were identified in the study: eye-and-skin-related information needs; information on what albinism is; the causes of albinism; information on how to register for the disability grant; and education-related information. The study also revealed that the information needs of parents of CWA differ at each level of the child's growth. For example, parents stressed needing additional information because as children grow up new needs emerge. OP indicated that they use the following platforms to disseminate information to PWA: radio stations in local languages, community meetings, their websites, and the distribution of flyers in English.

Keywords: albinism; children with albinism (CWA); people with albinism (PWA); information needs; sustainable development goals; Namibia

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Introduction

Namibia has a population of about 2.1 million people and this includes 1 206 people with albinism (PWA), of whom 619 are females and 587 are males (Namibia Statistics Agency 2011, 54). The chairperson of Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA) was quoted in a local daily newspaper as saying that the figure of PWA in Namibia stands at 1 800 ("Eva Ndatipo Comfortable" 2015, 12). These figures prove that there are a significant number of people with this condition in Namibia, and as such this study is relevant to the Namibian community.

The Government of the Republic of Namibia (GRN) argues that PWA are vulnerable due to a combination of environmental, physiological and sociological factors. Consequently, PWA in Namibia are categorised as persons with disabilities (PWDs) and thus recognised as one of the vulnerable groups in the country. Allen (2010, 2) explains that PWA are vulnerable in the sense that they are visually impaired and are prone to skin cancer. *Under the Same Sun* (UTSS 2012, 14–15) further elaborates that due to visual impairment that accompanies nearly all forms of albinism, PWA are often classified as legally blind. Beyond the African continent, this description covers what is mostly the status quo and is a global growth trend. More so, being legally blind means that PWA are considered to have a physical disability as a result of their vulnerability and visual impairment. The GRN, through the Ministry of Gender Equality and Child Welfare, provides them with social grants as a way to meet their monthly basic needs.

Namibia Statistics Agency (2011, 53) defines a disability as "the long-term physical, psychological or mental condition that limits persons from carrying out everyday activities at home, school or work." Tilley (2009, 17) defines disability as "the condition that results from disadvantage, discrimination, or exclusion of people who have medical condition(s) that directly or indirectly limits them or is used by others to limit their participation in any aspect of the society." Meanwhile, the United Nations (2016, 10) explains that the term "person with a disability" has a broad scope, and it includes any person with a long-term physical, mental, intellectual or sensory impairment that may hinder his or her full and effective participation in society on an equal basis with others. Furthermore, Kimbassa (2013) argues that the traditional medical definition of disability does not recognise albinism as a disability. However, with the introduction of the International Convention on the Rights of Persons with Disabilities, visual impairment was among the types of disabilities recognised by the convention.

Linking disability to vulnerability, the study cites Maclachlan et al. (2012, 2) who define vulnerable people as "a social group that experiences limited resources and consequent high relative risk for morbidity and premature mortality." This may include children, the aged, ethnic minorities, displaced people, people suffering from some illnesses, and persons with disabilities. In Africa, mothers (women) are more vulnerable to attacks, stigmatisation and discrimination compared to fathers (men) because in Africa, albinism is more a woman's issue than it is a man's issue. This is because most of the myths (if not all) attached to albinism put a woman in the centre for having conceived a child with albinism. The issue of women and children with disabilities facing discrimination is acknowledged in the Convention of Rights of Persons with Disabilities of 2006. Similarly, UTSS (2015, 1) mentions that around the world, women and girls with albinism are particularly vulnerable to discrimination. Discrimination, stigma, myths and even murder are some of the cruel ordeals that they go through every day.

Africa's Precarious Circumstances for PWA

In many African societies, PWA are often marginalised socially, and as a result, "marginalisation impedes their access to health services, restricts the delivery of education and isolates affected individuals from their families, communities and caregivers" (Clarke and Beale 2018, 259). The marginalisation of PWA is found in all spheres of life. They suffer from name calling and labelling as a result of their physical appearance and other attributes that accompany the condition. Almost every country in Africa's inhabitants have created a derogatory name associated with the condition.

Some of the popular names in some countries identified by Brocco (2016, 230) include some terms in Tanzania that include *Zeru-Zeru* (ghost), *Mzungu* (White person) and *Dili* (which literally means "deal" and refers to the trade of the body parts of PWA on the black market). According to *Under the Same Sun* (2012, 15), in South Africa, PWA are also called "apes." Meanwhile, in Namibia the popular names include *Shilumbu* (White person) or *ekishi/ethithi* (albino). In the past, parents would always tell their children stories of *ekishi/ethithi* as a scary creature that eats people, especially children who are disobedient, and as such this might have had an effect on how society perceives PWA up to today. The purpose of using the term *ethithi/ekishi* as an object that has a human figure was meant to create a frightening image so as to discipline children to abide by the values and norms of the family, community and society at large.

In Botswana, "the name used for an albino (*leswahe*) denotes something of which the colour has been cleaned off (in Setswana the prefix 'le' denotes an object rather than a person)" (Dart et al. 2010, 4). Meanwhile, in Malawi, women with albinism are called *Machilitso* (cure)—referring to the belief that having sex with a person with albinism can cure HIV, which often makes the PWA vulnerable to rape by people with HIV infections. Another term or abuse is *Napwere,* which likens people with albinism to a tomato that has been affected by leaf-spots that give it white patches. Noteworthy from the foregoing is that name-calling and invectives have a damaging psychological impact on the recipients of such (Amnesty International 2016, 18).

"Hypervisibility" is one of the root causes of the lack of acceptance and stigmatisation of PWA, and this is because the majority of the people have dark skin pigmentation (United Nations 2017, 5). Being a Black person with a white skin in a Black society has made those with albinism stand out in the African society, hence they are easily noticed. Consequently, many Africans have attached different explanations and understandings to the condition. Bradbury-Jones et al. (2018, 2) lament that "in Africa, lack of the usual dark pigmentation found in the indigenous population makes the visible appearance of those with the condition markedly different to those in their families and communities without albinism."

Africa is a continent that is characterised by sunlight all year round and yet PWA's skin lacks melanin, which makes it vulnerable to the sun's rays. As noted by Ikuomola (2015, 38), melanin is the pigment that protects the skin from ultraviolet rays from the sun that are known for posing a risk of getting skin cancer. Furthermore, lack of pigmentation does not only affect the skin, but it also affects the eyes and hair (Ikuomola 2015). The United Nations (2017, 8) concurs that due to the sensitivity of the skin of PWA to the sun, many PWA are likely to suffer from skin cancer, sunburn, rashes and premature skin ageing compared to dark-skinned people who are 60 times less likely to get skin cancer compared to the chance of those with albinism. The specific body parts that have been identified to be at risk compared to others are the head and neck.

In view of the above, Franklin and Lund (2017, 10) assert that the health needs of those with albinism differ from the general (Black) population in Africa. In this group, sun exposure results in many types of injury to the skin, ranging from sunburn and blisters to more permanent damage such as thickening and wrinkling of the skin, and potentially life threatening skin cancers. In addition to skin-related challenges, by nature, PWA also have poor vision, which in some instances limits them from reaching their full potential in life. Kimbassa (2013) explains that there is "hypopigmentation" of the iris choroid and retina, as well as mal-development of the fovea (a part of the retina that mediates central vision).

United Nations Efforts towards Disability and Marginalisation

Upon the phasing out of the millennium development goals (MDGs), and considering monitoring and evaluation reports thereof, world leaders concluded that MDGs did not really make provision for reaching out to some members of the public, especially those who are vulnerable. Consequently, the United Nations Assembly sought strategies to build on MDGs by coming up with new goals that can address the gaps from MDGs. This resulted in the crafting of United Nations Sustainable Development Goals (SDGs), comprising 17 goals with clear strategies and targets by 2030 (United Nations 2015, 6). An eminent example is Goal 1: No Poverty, the strategy of which is for people to donate what they don't use. Moreover, the SDGs focus on various aspects related to life, the environment and human interactions with the environment for their survival and advancement as encapsulated in UN Agenda 2030, as it pertains to the five Ps: "People, Planet, Prosperity, Peace and Partnerships" that are of critical importance to humanity. Four out of 17 SDGs aim to address issues related to disability, exclusion, inequality and marginalisation; elements that contribute to vulnerability in the public sphere. As an illustration, we subsequently discuss the four SDGs as sourced from the UN's sustainable development goals knowledge platform (United Nations 2015).

Goal 4: Quality Education

This is meant for working towards guaranteeing equal and accessible education by building inclusive learning environments and providing the needed support for people with disabilities.

Goal 8: Decent Work and Economic Growth

This is aimed at promoting inclusive economic growth, as well as full and productive employment allowing persons with disabilities to fully access the job market and to be economically active.

Goal 10: Reduced Inequalities

The emphasis is on the social, economic and political inclusion of persons with disabilities.

Goal 11: Sustainable Cities and Communities

The focus is on creating accessible cities and water resources; affordable, accessible and sustainable transport systems, as well as universal access to safe, inclusive, accessible and green public spaces.

During the launch of the SDGs, world leaders pledged their support to empower the most vulnerable people in our society. These vulnerable people include people within the following categories: “children, youth, and persons with disabilities (of whom more than 80% live in poverty), and people living with HIV/AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants” (United Nations 2015, 7). Considering the constraints of people with disabilities, the UN 2030 Agenda for sustainable development goals irradiate clear targets that can assist in presenting data on the success and gaps of SDGs. For instance, Agenda 2030 Target 10.2 promises to empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin or economic standing and any other status. It is for this reason that the United Nations (2017, 3) highlights that Agenda 2030 is underscored by a collective promise to “leave no one behind” with an endeavour to start with those furthest behind first. The present study therefore viewed PWA as fitting well within this endeavour and promise (United Nations 2017, 3).

Rationalising the Research Problem

Parents of CWA are bullied and discriminated against for birthing a CWA. However, the provision of information is one of the crucial factors in empowering parents of CWA to live peacefully, and understand the condition better. It is clear that many studies conducted to date in Africa on albinism have not addressed the aspects of the information needs of parents of CWA and information services that are appropriate for those with the condition. Because, with information in hand, they would know that their children are protected by the Constitution, and in the context of this study, by the

Constitution of the Republic of Namibia (amended 1998) [Namibia] of 21 March 1990, similar to any other citizen. It is against the above background and context that the researchers conducted the study to gain insights on the information needs of parents of CWA in order to suggest relevant information services.

Literature Review

PWA need information on all aspects of their lives, firstly, as citizens of Namibia and consumers of different products and services, and secondly as people with disabilities (PWD), who require specialised information related to their condition. Mansour (2015, 2) explains that no one can deny that information is important in every aspect of people's daily life. On the other hand, Beverley, Bath, and Barber (2007, 257) found that information has an important role in helping to support and improve people's health and social care, particularly in the information society of the twenty-first century.

It is for this reason that Tilley (2009, 64) emphasises that even though disabled and non-disabled people need information, people with physical disabilities need more information regarding their condition for them to be able to deal with their disabilities in addition to other general life matters. Adetoro (2010, 1) supports this view by pointing out that people with visual impairment, like any other social group, need information to reduce uncertainty, to identify, define and solve problems, and ultimately for individual growth and survival.

According to Moore (1997, 281), it is important to note that people with disabilities have needs that require the provision of special information services. First, they need information on a subject that relates to their disability. Secondly, they have a special access problem that calls for special provisions. Thirdly, for information and advice to be fully effective, it should be delivered by someone who has personal experience of disability.

Cruz-Inigo, Ladizinski, and Sethi (2011, 3) highlight the following services as essential to people with albinism:

- Dermatologic examination guidelines.
- Information on how to shield themselves from the sun.
- Information on sunglasses.
- The provision of opaque clothing that covers most of the skin, scarves, high socks, and wide-brimmed hats.

Lynch, Lund, and Massah (2014, 5) reveal that the dissemination of information about albinism is urgently needed, with more awareness being called for among all stakeholders, particularly those working in social protection, inclusive education, human rights, as well as community leaders, such as chiefs. Parents, particularly mothers, also need to know where they can find the much-needed support to help them protect their children and other vulnerable members of their family. It is in accordance with this explanation that Pain (1999, 308) concurs that information concerning services and benefits is used predominantly, but there are instances of mixed benefits and this is usually because the services or benefits were not known about soon enough, they were not readily available, or they were not as comprehensive as had been hoped.

Lund (2001, 5) found that radio talks and newspaper articles were used to inform communities about albinism. Lund (2001, 5) further found that the associations dealing with albinism issues in Zimbabwe may provide a central source of accurate and up-to-date information to PWA, their families, health care workers and teachers. Parents joining a specialist voluntary organisation indicated that knowing others in a similar situation was helpful (Pain 1999, 307). For example, parents of PWA in Malawi felt well placed as they had access to the right clinical services and advice through these organisations and as such, they could make decisions about their children’s emotional well-being and education (Lynch et al. 2014, 5).

The Aim of the Study

The main aim of the study was to investigate the information needs of parents of CWA in the Khomas region, Namibia, in order to inform the possible design of their information services. More specifically, the study addressed the following objectives:

- Ascertain the information needs of parents of CWA.
- Determine information services that are appropriate for parents of CWA in the Khomas region.

Research Questions

The study addressed the following questions:

- What are the information needs of parents of CWA?
- Which information services are appropriate for parents of CWA in the Khomas region, Namibia?

Methodology

The study was conducted within an interpretivism paradigm, following the elements of the interpretivism paradigm. It focused on the information needs of parents of CWA in the Khomas region, Namibia, by specifically taking the qualitative approach. The information needs of parents of CWA in the Khomas region were explored through individual semi-structured face-to-face interviews. The Khomas region, Namibia, was selected as the case study. Therefore, the study only captured the views of some parents of CWA in the Khomas region.

A snowball sampling technique was used to locate participants and this was done according to the view of Bernard (2006, 192), who indicates that this type of sampling is appropriate for studying hard-to-find or hard-to-reach populations. People with albinism may be categorised as a hard-to-reach or hard-to-find population because in many African countries, people with albinism live in fear as they are stigmatised and socially excluded. In addition, there are very few people with albinism in Namibia, with only 1 206 people with albinism countrywide and 160 people with albinism in the Khomas region. Additionally, two males were interviewed as Organisational Participants (OP), including the president of Namibia Albino Association Trust (NAAT), and the chairperson of Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA).

Data Analysis

The parents of CWA who took part in the study were between the ages of 28 to 49 years. Among those interviewed, one was male and the rest were female. Most of the parents who were interviewed had no formal education, and in terms of their employment status, only one parent indicated that he was employed, whereas one was self-employed. One of the parents was from the Tobias Hainyeko constituency; while another one lived in the Khomasdal constituency and four were from the Moses//Garoeb constituency. Almost all the parents who took part in the study had one child with albinism; only two of the parent participants had two children (a boy and a girl) with albinism. These children ranged in age from seven months to 13 years, and all the parents indicated that their children had been born in a hospital.

Participants were recruited through different means such as through radio announcements by one of the regional councillors, the associations of PWA and referrals by individuals. Face-to-face interviews were carried out between 27 August and 8 September 2017 in Windhoek. The interviews took place in different settings such as at the regional councillor's office and the participants' houses. The interviews were conducted according to the interview guide.

The interviews were audio recorded with consent from participants (interviews were in English and Oshiwambo). Oshiwambo is a language spoken by the majority in Namibia, and many participants who took part in the study were from the Ovambo ethnic group. Lund and Roberts (2018, 89) concur by stating that the following northern regions in Namibia have the highest frequencies of albinism namely: Omusati, Oshana, Oshikoto and Ohangwena, and the majority of the people from these regions speak the Oshiwambo language. Interviews lasted between 20 and 40 minutes, depending on the willingness of the participants to talk. The majority of parents of CWA did not support the idea of interviewing their minor children, probably due to a lack of trust: only one parent allowed her two children to be interviewed in her presence.

Similarly, the majority of parents of CWA who were approached to take part in the study were not willing to participate in the study, with some telling the researcher to go interview herself since she has CWA and the experience is the same. Some preferred to be interviewed by telephone as they did not want the researcher to visit their houses. However, such telephone interviews never took place because the prospective interviewees did not answer their cellphones. Some problems encountered in this study during the data collection were similar to those identified by Mnubi-Mchombu (2013, 103).

Findings

This section presents the findings of the study according to the objectives of the study.

Parents' Emotional Experiences after the Birth of a Child with Albinism (CWA)

Parent participants were asked to explain how they felt when they became aware that their child had albinism. The aim was to establish their reactions, because generally, people react differently to different situations.

All parent participants in the study expressed happiness when their children were born. They articulated that their CWA are just the same as those without albinism, as the difference is only in the skin colour. Parent 1 shared her joy by stating that:

> I was excited when my child was born because she is just a normal child like my other children; the difference is only in skin colour. For example, you will find people who are dark in complexion, and those who are light in complexion, the same applies to her.

However, two parent participants shared their experience that albinism was not detected right after the birth of their children, which caused them confusion because their babies' skins were not changing to black. This was reflected in the following statement by Parent 4.

> I did not know how I felt because at first doctors could not confirm that the child has albinism. I also did not pick it up because normally children are born with a white skin. After six months I went back to the hospital, because I was worried that his skin colour was not changing, I was referred to a doctor who examined the child and confirmed that he has albinism. Now, I love him so much, even though I did not expect him, I wish God can give me a baby girl with albinism because I have a boy.

A similar thought to that of PWA was shared by parents of CWA who had people with albinism in their families. They articulated that they were not surprised when their children were born because albinism is normal to them. These findings corroborate those of Brocco (2015, 1148), who recounted that in cases where there is a record of PWA in the past generations, the mother is not blamed for a child with albinism, and albinism is classified as normal. Parent 6 explained that:

> Immediately after delivering my child nurses covered me so that I do not see him, I asked them if the baby had died or why are they covering me? They told me he has albinism, I told them to bring my baby, my reactions surprised them. Nonetheless, I was happy, it never bothered me because I have three siblings with albinism, who also have CWA, so it is a normal condition to me.

Even though parents expressed joy and love for their children, one interviewee indicated that the father of her child abandoned her and their son upon birth. Parent 5 reflected this in the following statement:

> The problem I have is that when he was born his father left us, he told me he does not give birth to albinos, now our son is growing, and he is asking about his father and would like to meet him. I do not know what to say to him and how to solve this issue. At the beginning of this year [2017], I met his father after all these years, but he did not want to talk about our son.

These results confirm the findings of Braathen and Ingstad (2006), and Estrada-Hernandez and Harper (2007), who report that it has been feared that due to the appearance of a child with albinism, fathers of some of these children might deny paternity, even though all mothers talk of a great love for their children. The incidents of children being rejected and abandoned because they have albinism are common in Namibia. The following quotes were taken from a local newspaper: "He was very shocked when he found out the baby looks like this. … He has since not been the same man I know, as he believes we have been bewitched. … According to him, the baby looks like this, because I have been sleeping around … so, he says this is not his baby, because there are no albinos in his family" (Haingura 2013).

Daily Experiences of Parents of CWA

Parents of CWA articulated that their experience is both good and bad; and some indicated that they were laughed at and mocked for giving birth to a child with albinism, as articulated by Parent 4.

> When I gave birth to my child people started to talk and laugh at me behind my back. They accused me of being impregnated by a Chinese man. A man once ran away from me, apparently because I have a child with albinism; he asked if I have given birth to an albino, I asked him if albinos are not people, he just laughed and ran away.

It is for such reasons that Braathen and Ingstad (2006, 600) explain that the superstition surrounding albinism places mothers of CWA in a vulnerable position and subject to stigmatisation and harassment from society, which results in severe psychological distress.

One participant indicated that some children without albinism did not like to play with her daughter, something the child blamed on herself for having a white skin. A mother of a CWA stressed that her own father did not like his granddaughter because she had albinism and he called her names. Instead of calling her by her real name, he referred to her as an "albino child" or he would just call her a derogatory name, such as *kathithi*, the *Oshiwambo* word that is used to refer to a PWA. This situation has psychological consequences for the child.

The scenario is completely different from what is mentioned in the literature, where it is seen that most PWA experience difficulties upon their interaction with strangers, but at home, they are loved and treated as normal (Baker et al. 2010, 173; Braathen and Ingstad 2006).

Information Needs

Information Needs Expressed by Parents

Parent participants were asked to indicate their information needs with regards to their children's condition. This section is divided into three categories: firstly, the information they required right after finding out that their children had albinism; secondly, the information they required as their children were growing up, and thirdly, the information they currently need.

Information Needs Expressed by Parents at the Time they Discovered that their Children had Albinism

The majority of parents of CWA reported that they were not provided with information by health professionals on the birth of their children. However, one mother revealed that she was offered counselling services, but she turned down the offer. Furthermore, when asked about the type of information they needed after giving birth, almost all participants expressed a strong need for information regarding their children's skincare as a cancer-prevention method. Most of the parent participants knew that the skin of PWA is sensitive to the sun, therefore, they were aware that their children needed extra care and protection. Parent 1 commented thus:

> As God has given me this child, I thought about what I needed to do to take care of her and protect her so that she does not get sores which could lead to skin cancer. Protection from the sun is all I did for the first five months.

Another participant, Parent 6, reflected thus:

> When my baby was one month old, I went to the doctor at the hospital and I told him that I do not want my baby to have sores like other CWA, I asked him for information on what I can do. The doctor told me he is not a doctor for albinism, but referred me to a dermatologist and wrote a referral letter that I took with; the dermatologist provided me with information on how to take care of his skin.

For that reason, the parents that participated in the study were interested to know the kind of clothes their children would need to put on and the type of body lotions they could use. For example, a parent participant mentioned that Vaseline was not suitable for her baby's skin as every time she applied it on him, the child developed some small pimples. As such, she wanted information on the type of lotion she could use. Furthermore, parent participants expressed information on how to register their children for the disability grant for them to be able to buy the necessary clothing and aids. Moreover, they narrated that having a child with albinism was expensive compared to children without albinism because the CWA have extra needs because of their condition. Moreover, parents expressed the need to know where and how to acquire glasses, especially for children who were going to school.

A parent participant expressed the need to know why and how they got a child with albinism. Furthermore, Parent 3 expressed that:

> Even though I asked myself these questions, it did not bother me too much because I know I am not the first one to get a baby with albinism. Therefore, I started researching on what albinism is, and as a result, I got information that albinism is caused by a lack of melanin. The reason why I sought information is that I was provided with a lot of inauthentic information.

Information Needs as Children Grew up

It appears that the information needs of the parents of CWA differ at each stage of their child's growth. When asked about the information they needed as their children were growing up, most of the parent participants expressed a need for information on the vision or eyesight of their babies as well as the type of eye glasses that they could wear. One of the comments (from Parent 2) was:

> As the months went by, I was worried as I expected her eyes to start moving right after birth, but it did not happen, and at five months, she could not see. That is how I started searching for information. I wanted to know if she was completely blind or if the eyesight was still coming. I took her to an ophthalmologist who took her to the theatre and that's how they discovered she has a very weak vision (she can only see 20%), nonetheless they assured me that the baby's sight is still coming.

Current Information Needs of the Parents

Even though some of the information needs expressed by parents right after the birth of their children remained the same as current information needs, parents stressed needing additional information because as children grow up new needs emerge. This includes information related to the type of sunscreen to use in terms of sun protection factor (SPF). They wanted to know if they could continue to use the sunscreen with the same SPF or if they needed to change. For example, a parent participant wanted to know if SPF 50 would be good enough for her son who liked playing soccer.

Another parent participant (Parent 3) remarked that:

> As he is becoming big his needs are also becoming many; for example, I need information on where to get his aids and what type of soap, lotions, and clothes to wear. Currently, I am just giving him any soaps and lotions that I have because I do not have information on the type of products that are suitable for his skin. I also need information on what kind of lotion to apply during each season. For example, I heard that during winter he could use Vaseline and in other seasons I do not know what he can use.

Some parents were curious to know the type of food that their CWA should eat. Parent 6 expressed that:

> I need to know if there is any food that they should eat or not, because sometimes I see their skin changing, but when I consult a doctor for information, the doctor would recommend a cream or sun lotion but I do not see any changes after they have applied it; that is the reason why I am worried if there is any food that is harmful to their skin.

Furthermore, information expressed by parents as being critical includes information on education. Parents were interested to know which school they should send their children to, for example, government or private, and whether they should send them to a normal school or to a school for the visually impaired.

On the other hand, one parent indicated that her daughter refused to attend the school for the visually impaired for reasons only known to herself, therefore, the mother opted for a private school. Her mother (Parent 2) made the following comments during the interviews:

> As a mother, to me it makes sense because taking her to [a] visually impaired school won't make any difference, there they are treated special, but, she will grow up one-day finish matric and eventually go to University but there are no Universities for visually impaired and [the] community out [there] will not treat her special.

Surrey Social and Marketing Research (2009) reports that this type of education could be very isolating, and it is recommended that some mainstream schooling be undertaken so as to provide CWA wider social contacts and to learn how to function in the "real world." These results match with the findings of Gaigher, Lund and Makuya (2002), whose respondents mostly preferred to attend a mainstream school, while others preferred to be at a special school.

Interestingly, most parent participants opted for a school for the visually impaired because the teachers there are supportive and understand issues related to learners with special needs. According to Cruz-Inigo et al. (2011, 82), this is because "albinos are often discriminated against, and the system in place does not have the educational provisions to address their poor eyesight, as well as to allow them to succeed and compete with the non-albino population."

Information Services

Information Services of PWA Organisations in the Khomas Region

This section addresses the information services that are appropriate to parents of CWA. The following questions were asked during the interviewing process: what are the current information services that organisations such as SINASRA and NAAT offer to parents of CWA, and what are the strategies used by these organisations to disseminate information to them in order to meet their information needs?

Current Information Services

Organisational participants (OP) were asked about the information services offered by these organisations to people with albinism. OP 2 offered the following information services, namely: information on how to apply sunscreen lotion, information on the type of protective clothing to wear, hats, and sunscreen lotion to use. Moreover, they provide information on how to apply for the disability grant and facilitate the whole process, and also assist with information on how and where to acquire different aids. OP 1 also disseminates relevant information aimed at preventing sun-related cancer, its complications, and early death.

Dissemination of Information by PWA Organisations

When asked about how they disseminate information about albinism in the country, OP 1 explained that they distributed flyers but admitted that they contained outdated information in English; and they also used local radio stations in vernacular languages and shared information through their websites that had not been updated for a long time. The participant, however, also admitted that they did not share information through face-to-face meetings, even though the chairperson acknowledged that it might be an effective way of reaching out to PWA. Moreover, they had a Facebook page (albino care SINASRA) that was not active. Furthermore, they issued press releases, especially on days prior to 13 June— the International Albinism Awareness Day (IAAD). OP 1 also did presentations in Namibia and South Africa on albinism.

OP 2 emphasised organising a community meeting with PWA, and the organisation used media, including print media, and different radio stations in vernacular languages. It was also acknowledged that their organisation did not have a website, a Facebook page, or a WhatsApp page. Moreover, they were asked whether they disseminated information in other languages or just in English, a question they answered by indicating that information was disseminated in other vernacular languages as well.

Conclusion

The study concluded that the parents of CWA had information needs related to their children’s condition and this included skin and eye-related information, information on how to register their children for disability grants, education-related information and information on how they conceived CWA and what albinism is. It is important to note that the information needs of parents of CWA change from time to time and are triggered by their children’s growth and developmental stages. The study also concluded that it is important for service providers to have an idea of the people they are serving in terms of social, economic and educational status in order to serve them better. This is in terms of the platforms and languages that are used to disseminate information to parents of CWA.

The study concluded with a suggestion that, since in most cases expectant mothers are caught off guard as some types of disabilities such as albinism cannot be detected by the sonar during the pregnancy, it is thus of utmost importance for health facilities in Namibia and elsewhere in the world to have support mechanisms in place for the mothers that are giving birth, especially to children who are born with any kind of disabilities.

Moreover, the Ministry of Health and Social Services and relevant stakeholders should come up with a booklet that provides mothers of unborn children with information on different types of disabilities that might affect unborn babies. Such information will prepare mothers mentally and prepare them to expect the negative and positive results of childbearing.

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