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Original Articles

International Federation of
Library Associations and Institutions
1–11
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DOI: 10.1177/03400352221103892
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The power of information and coping with albinism: An autoethnographic study

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Abstract

This article aims to ascertain the purposes for which the author needed information when her children with albinism were born, as well as explore the mechanisms she used to find information and the challenges she experienced when searching for information. An autoethnography method is used to share her lived experience of albinism, and the data has been collected through the author's personal memory by recalling events that happened when she gave birth to her daughter in 2013 and her son in 2016. Information played a crucial role in helping the author to understand albinism better and to deal with her predicament. As a librarian and the mother of children with albinism, the author explored different mechanisms to find information. The Internet was the main source of information, as well as organisations such as Support in Namibia of Albinism Sufferers Requiring Assistance and the Namibia Albino Association Trust, which deal with the plight of people with albinism in the country.

Keywords

Information needs, albinism, autoethnography, information sources, disabilities, information seeking

Introduction

From a medical viewpoint, Schühle (2013: 7) describes albinism as 'the inability of the skin to produce the pigment melanin'. People with albinism have white skin, light-blonde hair, and light-coloured and sometimes reddish eyes. Albinism is regarded as a genetic defect, where the gene that causes albinism is passed on by parents to their children, even though, in most cases, people with albinism are born to parents without albinism (Cruz-Inigo et al., 2011). It has been found that both parents must carry the gene that causes albinism for it to be passed onto their children (Schühle, 2013).

There are different types of albinism, with the most common being oculocutaneous albinism, which affects the skin, hair and eyes (Cruz-Inigo et al., 2011; Franklin et al., 2018). This type of albinism is also the form that is most commonly found in sub-Saharan Africa, and it leaves its subjects particularly noticeable and vulnerable. This is particularly the case in a country like Tanzania, where the skin of its citizens is mainly dark (Under the Same Sun, 2014). Another form of albinism is ocular albinism, which affects only the eyes. This type of albinism is relatively uncommon and is, in most cases, recorded in males. Children with this type of albinism may have skin and hair colour that is normal, but slightly lighter than that of other family members (Under the Same Sun, 2014).

The birth of a child is supposed to be a joyous occasion for any parents. However, when a child is born with complications or disabilities, it is devastating news – and especially when it is a child with albinism, who stands out because of their skin colour. Historically, children with albinism were killed at birth in African countries such as Kenya and Tanzania (Under the Same Sun, 2012). Hence, the birth of a child with albinism is met with many misconceptions, which requires parents to equip themselves with information in order to understand and confront the myths associated with the condition. Folkman and Lazarus (1985: 152) define coping as 'cognitive

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and behavioural effects to master, reduce or tolerate the demands of stressful situations'. Moreover, Uze (2016) discusses two coping mechanisms – namely, information seeking, to reduce the uncertainty that causes stress, and information avoidance, to escape the situation by denial. When people find themselves in a stressful situation, they try to cope by seeking information from different sources in order to reduce the uncertainty they are experiencing. Alternatively, they may opt to cope without further information.

This article is extracted from my Master's dissertation, where I researched the information needs of people with albinism in the Khomas Region, Namibia. I approached the topic as the mother of an eight-year-old girl and a four-and-a-half-year-old boy, both of whom were born with albinism. Although I received information and support from doctors, I often encountered situations where I needed more information. As a librarian, I would search for such information from the available literature.

On one occasion, I was searching for information for people with albinism, particularly with regard to their information needs, but could not find any studies related to this vulnerable user group. From this experience, I started thinking about how other Namibians, especially those from disadvantaged communities such as the Himba, would manage in the same situation. Taderera and Hall's (2017) research reinforced my curiosity; they conducted a study in the Kunene Region of Namibia, where the Himba people reside, on the challenges faced by parents of children with learning disabilities. They state that accessing information is difficult for parents of children with learning disabilities because sometimes information needs to be accessed through technology such as the Internet and social media.

Accessing information can also be difficult because, in most cases, people in African society shy away from talking openly about albinism due to the stigma associated with it. Concurring with this, Rohwerder (2018) comments that misconceptions about the cause of disabilities often result from cultural or religious beliefs. Fourie (2008) emphasises that it is not always that patients do not ask for information because they are unaware of it, but because they might be shy or inhibited, or they may not ask questions due to cultural beliefs or a lower education level.

Furthermore, it is equally a challenge for parents of children with albinism to trust other people as sources of information. For instance, when a woman gives birth to a child with albinism, it is often difficult for the community to approach her to share information because they do not know how she is likely to react.

In view of the above, I kept coming back to the question of whether other people really have access to this valuable information, and whether they are aware of the benefits available to people with albinism in Namibia. This curiosity motivated me to research the information needs of persons with albinism, including their parents, and also provided me with the opportunity to narrate my lived experience of albinism.

Contextualisation

When my daughter was born, the paediatrician did not tell me straight that my baby had albinism. He said: 'Here is the baby; she is fine, but she has problems with her eyes and skin'. I looked at my baby and asked him if she had albinism; he confirmed it with a 'yes'. The doctor could not say anything further regarding my child's condition, even though he promised my husband that he would provide me with counselling services and information.

This lack of counselling and support is contradictory to Baker et al.'s (2010) description of when a baby is born with albinism: the genetic nurses talk gently to the mother, recognising first and foremost the joy of the new birth, and then move on to tell her that the baby has albinism. They explain what the condition means, and why the baby's pigmentation is pale. They try to empower the mother by giving her information on the genetic cause and practical management of albinism, so that she can cope when she returns home with her baby.

I must admit that giving birth to a child with albinism was a shocking experience for me the first time round. My baby had white, blondish hair at birth, so albinism was detected and confirmed immediately. However, there was more confusion when friends and family visited us in the hospital, and they refused to acknowledge that the child had albinism. They indicated that my daughter did not look like she has albinism because she looked different from other children of her age who were born with the same condition. It created more confusion for me because I had never seen a small baby with albinism.

For the first two weeks after the birth of my daughter, I experienced endless uncertainty, since albinism is associated with many myths and beliefs. I thought about the different explanations attached to it, such as the belief that if you laugh at a person with albinism or are rude to them, you will give birth to a child with albinism. This is a common myth that even Lund (2001), who is from a non-African cultural background, confirms by stating that people who scold or laugh at someone with albinism will themselves produce a baby with the condition. I was asking myself whether I had ever laughed at somebody with albinism. I had a teacher with albinism, and I have a friend whose aunt has children with albinism, and there was no occasion on which I was rude to them or laughed at them.

All of these questions vanished one day when my aunt explained to me that only people with certain qualities give birth to children with albinism. I also thought that I was not being fair to God for asking him too many 'why' questions. I thought of a young lady who was suffering from cancer and was battling the disease with courage and hope. I also gained courage from watching videos of Nicholas James Vujicic, an Australian evangelist and motivational speaker with tetra-amelia syndrome, a rare disorder characterised by the absence of arms and legs. Nicholas believes that, with or without arms and legs, he shall fulfil his mission on earth.

With the birth of my son on 15 December 2016, I was emotionally prepared for a child with or without albinism. The paediatrician was informed that I already had another child with albinism, which he also confirmed with me. This time, I was offered counselling services, with the option to see a psychologist – which I did not find necessary. The doctor was concerned about me having another baby with albinism, thinking that it would devastate me.

The experience of my daughter's birth has changed over time because I have grown stronger with time. I became a laughing stock for many people, which was shocking because even those whom I thought were close to me were mocking my situation. The story went viral among some of my workmates; they were apparently told that I did not want to accept the child. What is hurtful is that people were busy spreading rumours about me, yet nobody approached me to ask how I was coping.

My children have also experienced name-calling, such as *shilumbu*, meaning 'white person', especially from strangers. I will always correct these people by telling them that the children have a name, and they are not *shilumbu*, because I find *shilumbu* discriminatory. Beukes' (n.d.) study confirms that schoolchildren with albinism are teased and called names such as 'whitey'.

You meet people who admire your children, and you find those who stare at them to the extent that it makes you feel uncomfortable, especially when you go to public places such as the hospital or church. My daughter narrated to me recently how other children at school tell her that she is a ghost, particularly when their teacher is not in class. As a result, she told me: 'I do not want to be white, but brown like my mother'. There was a day when she became unruly in church; it became difficult to control her and I left church with tears in my eyes. When we got home, after being quiet for some time, she came to me and we had the following conversation:

Daughter: I am sorry Mummy.
Mother: What did you do?
Daughter: I did not behave at church.
Mother: But why did you do it?
Daughter: Because I do not want to be white, but brown like my mother.

On the other hand, as a mother, I have become friends with people I did not know personally because of my children.

Nevertheless, I was not spared the myths noted in the literature. My neighbour accused me of cheating on my husband with a white male lecturer from the University of Namibia, where I am employed. Surprisingly, the possibility of such an accusation is confirmed by Thuku (2011), who found that there are still people who believe that a baby is born with albinism because the mother has slept with a white man.

Someone remarked that it was good that God had visited me by giving me a child with albinism because I think I am a Christian. A family member accused me of being cursed or punished by God because I think I am wealthy, and the relative further asked why was I the first one in the family to give birth to a child with albinism. Thuku (2011) explains that there are people who believe that a baby with albinism is a punishment or curse by the gods or ancestral spirits due to wrongdoing in the family. Recently, someone remarked that I should stop having children because I am only giving birth to albinos.

Despite the shaming and lack of emotional support from most of my friends and family members, I vowed never to be ashamed of my children. I have learned to react positively to the negativity associated with albinism and, as such, I am not worried about how people think or feel about them, because God gave them to me for a reason. The experience has made me a very strong person. Lastly, I thank God every day for my blessings, because I love them so dearly.

Problem and purpose of the study

Parenting a child with a disability may be a source of significant stress for many parents (Cauda-Laufer, 2017; Nabawy and Moawad, 2012; Taderera and Hall, 2017). In Africa, parents (specifically mothers) of children with albinism have suffered emotionally after the birth of their children because albinism is always blamed on them:

> a lack of awareness about albinism negatively impacts parents of children with albinism. The mother often gets the worst of this. She might be blamed for her child's paleness or for having contracted a curse. The father may accuse her of infidelity and even abandon her. This can lead to an increase in domestic violence against the mother. The community might also isolate, ostracize or expel the mother of a child with albinism to avoid the perceived curse. (Under the Same Sun, 2015: 2)

In addition, the following are examples of the remarks found in the literature that illustrate the suffering of mothers of children with albinism:

> Another woman with albinism described how her mother was viewed: 'Neighbours and relatives thought my mother had an affair with a white priest'. (Amnesty International, 2016: 20)
>
> Nyathi recalls the accusations faced by his own mother, commenting that she was accused of infidelity and of being cursed because of her children with albinism. The consequences of this accusation by members of her husband's family were that his mother suffered abuse throughout her marriage. (Baker et al., 2010: 172)

There are a number of studies on albinism in Africa in general (Braathen and Ingstad, 2006; Brilliant, 2015; Brocco, 2016; Kapitako, 2018). However, none of the literature was found to have concentrated on how parents of children with albinism cope with their children's condition and society at large. The scarcity of literature on albinism in Namibia – including information booklets in hospitals – the lack of emotional support from health personnel, curiosity and empathy are some of the issues that triggered this article. The main research question for this study is: How does information support coping with albinism?

Objectives

The study has three objectives: to (1) establish the purpose of information on albinism; (2) establish the mechanisms for information seeking; and (3) identify the challenges experienced during the information-seeking process.

Literature review

According to Adams et al. (2017), understanding autoethnography requires working at the intersection of autobiography and ethnography. However, autoethnography is distinguished from autobiography by its detailed and systematic examination of experiences in the researcher's own life, and it requires assembling stories from different sources such as photographs, journals and recordings (see also Allen-Collinson and Hockey, 2007).

For Richards (2015), writing auto-ethnographically for him was to demonstrate that by reflecting on some of his own life stories about his identity, he came to a deeper understanding of the research and himself. Chang (2008) concurs, stating that doing, sharing and reading autoethnography can also help transform researchers and readers (listeners) in the process.

In view of the above, the importance of information has been stressed in many studies (Kundu, 2017; Tubachi, 2018). Information gathering has been a key area of support for parents during the first year of their child's life as it provides a knowledge base for them to take charge of their infant's care (Douglas et al., 2017: 2603). Similarly, in a study titled 'Coping with a child with disabilities from the parents' perspective: The function of information', Pain (1999) identifies a number of roles that information played in the lives of parents. For example, information contributed to the acceptance process of parents after diagnosis and at a later stage. It also enabled them to manage their child's behaviour and judge what would maximise their child's potential. Finally, it enabled them to access services and benefits that eased their task of raising their child, thereby reducing stress and the physical duties of caring to more manageable levels.

People with albinism are not an exception with regard to the importance of information for the reason that they face many challenges compared to normally pigmented people. These include discrimination, a lack of awareness of albinism and disability in general, unemployment, social exclusion, visual impairment, emotional abuse and physical attacks (United Nations, 2015; United Nations, 2017).

The role played by information is noted in Lund's (2001) study, titled 'Health and education of children with albinism in Zimbabwe', which concludes that nearly all of the respondents wanted information on what causes albinism. Similarly, Lynch et al. (2014) found that the children who participated in their study expressed a willingness to find out more about their condition in terms of its genetic origins and learning how to protect their eyes and skin effectively. The participants further expressed their willingness to know more about why they became 'white and not black' (7: 229), and to learn about ways to cope with the difficulties they might face at different stages of their childhood and early adulthood. Cruz-Inigo et al. (2011) note that it is a good idea for people with albinism and their parents to understand the causes of albinism, its medical and psychological implications, and how to protect themselves appropriately against ultraviolet radiation. Lund et al. (1997) also support the view that there is a clear need for affected subjects to have information about albinism in order to enable them to manage and understand their condition better.

On the other hand, the parents of a child with albinism in Brocco's (2015) study narrated how they looked at their son's white skin and began to wonder how it could have happened. However, after consulting several family members, they became more relaxed and understood that their son was no different from other people but for his white skin. Douglas et al. (2017) conclude that parents seek information about the types of support and services that are available to assist them in meeting their infants' needs.

On this note, Kingrey (2005) describes information seeking as a process that involves information searching, retrieval, recognition and the application of meaningful content. Van der Molen (1999) explains that information-seeking behaviour is a strategy that many people use as a means of coping with and reducing stress during their cancer experiences. For Brashers et al. (2002), the term 'information seeking' means different things in different contexts. Moreover, Williamson et al. (2000) argue that everyone has a different set of strategies for finding the information they need for their daily life. Life circumstances, such as living alone or having a family, working, being unemployed or retired, and the type of visual impairment involved, as well as individual information-seeking preferences, all influence the ways in which people seek or acquire information (Williamson et al., 2000).

However, information is not always accessible and does not always meet the needs of specific groups, with one such group being the visually impaired (Beverley et al., 2004). Hence, Beverley et al. (2004) explain that patients need appropriate information – for example, relating to their condition and the likely outcomes with and without treatment – at the right time and in an accessible format. This is particularly important for people with visual impairment because the nature of their condition can act as a barrier not only to information but also to an awareness of what information is available.

Methodology

This study adopted an interpretivist paradigm, which supports qualitative data collection methods and analysis. Qualitative methods are usually supported by an interpretivist approach because it 'portrays the world in which reality is socially constructed, it is complex, and it is ever-changing' (Thanh and Thanh, 2015: 25). Interpretive researchers do not regard the social world as 'out there' but believe that it is constructed by human beings. The interpretive researcher becomes part of the study as a meaning-maker, interacting with other meaning-makers.

Additionally, a qualitative approach attempts to answer why, how and what questions, and is a situated activity that locates the observer in the world (Denzin and Lincoln, 2008). Denzin and Lincoln (2008) further explain that a qualitative approach consists of a set of interpretive material practices that make the world visible. These best practices turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings and memos to oneself.

This study applied autoethnography, a combination of autobiography (inward-looking) and ethnography (outward-looking), to narrate the researcher's story with regard to the information needs of people with albinism, which was triggered by giving birth to a child with albinism. Thus, this method is both process and product (Ellis et al., 2010). It considers researching about one's self by recalling memories of past events, reflecting on the past experiences of others, and examining other sources of information such as personal journals, recordings, photographs and so on. According to Fourie (2021), this method came about in order to overcome the challenges presented by existing research approaches. Nevertheless, Deitering (2017) cautions that, unlike other methods in qualitative enquiry, autoethnography should be approached on its own terms because it is a method that does not rely on representative samples, objective analysis or broadly generalisable conclusions. This method has been used in different written forms, including short stories, poems, plays, essays, articles, dialogue, comics and novels (Deitering, 2017).

Autoethnography is a researcher-friendly and reader-friendly method because it assists researchers to understand themselves and others, and, at the same time, researchers and readers can be transformed (Chang, 2008). It may 'radically alter an individual's perception of the past, inform their present, and reshape their future if they are aware and open to the transformative effects' (Custer, 2014: 2). Additionally, the method provides the researcher with easy access to data because they do not have to interview anyone else, but merely recall their own experience as a source for their investigations (Mendez, 2013). As a consequence, researchers are able to overcome issues related to obtaining informants' consent because they 'can choose which self-stories to write or present, control the mode of expression and tone, and place the piece appropriately with the “right” audience’ (Lapadat, 2017: 593).

In view of the above, it can be seen from the literature that an autoethnography research methodology has been adopted in studies where researchers explore their personal life stories and narrate their positive and negative experiences of events that have occurred in their lives. Researchers who use this methodology share stories of people with special needs in their families and lives, such as those with visual impairment, physical disabilities, chronic disease, or rare diseases and conditions.

Lapadat (2017: 594) indicates that ‘autoethnographies explore difficult life events, epiphanies, or turning points such as teenager pregnancy, sexual abuse, coming out, abortion, bulimia or death of a loved one’. Fourie (2021: 6) specifies that ‘personal stories as cautionary tales can assist autoethnographers to move through uncertainty, confusion, pain and anger to promote courageous persistence, self-revelation and therapeutic disclosure’. In consequence, this study was conducted out of empathy and curiosity. Applying autoethnography enriched my understanding of albinism, supported me in dealing with my children’s condition in a prudent manner, and empowered me to assist those who find themselves in the same situation – specifically, other parents of children with albinism and children with other types of disabilities – because ‘without being brave you might end up throwing away the child because of the abuse and insults’ (Amnesty International, 2016: 20).

Ellis et al. (2010) and Kiesinger (2002) acknowledge that writing personal stories can also be therapeutic for both the participants and the readers. For me, applying this methodology helped me to share the emotions of confusion, loneliness and excitement that I experienced after giving birth to a child with albinism, which I could not express through other means, and to deal with the ‘why’ question. Furthermore, it changed my outlook on life and enhanced my understanding of how society still perceives some issues, such as albinism. ‘For me, writing the thesis autoethnographically, to an extent, allowed me to break the silence of the past in the contexts of the research’ (Richards, 2015: 826). Even though it ‘opened old wounds, but also manifested the energy needed to heal them completely’ (Custer, 2014: 9).

In information science, autoethnography is relatively new (Bordonaro, 2020; Michels, 2010). However, Guzik (2013: 275) underscores the relevancy of this methodology in information science on the ‘grounds of its capacity to cut across dichotomised territories of personal stories and social scientific scholarship, but it can also inform practice’. There are several examples of the use of an autoethnographic methodology in information science studies. Collaborative autoethnography was used as a way of seeing the experience of caregiving as an information practice by Anderson and Fourie (2015). They applied this methodology for two reasons: first, as carers for family members with a chronic, life-limiting illness and life-threatening disease, and, second, as information practice researchers. Also, in his study ‘The place of a person in LIS research: An exploration in methodology and representation’, Michels (2010) applied an autoethnography methodology as a doctoral student using an academic library. Furthermore, Guzik’s (2013) study, titled ‘Representing ourselves in information science: A methodological essay on auto-ethnography’, also applied autoethnography. Meanwhile, Fourie’s book, *Autoethnography for Librarians and Information Scientists*, was published in 2021.

Autoethnography is a very complicated method since it is subjected to ethical questions owing to huge elements of bias. Consequently, autoethnographies have been criticised for being self-indulgent, narcissistic, introspective and individualised (Atkinson 1997 and Coffey 1999 as cited by Mendez, 2013). I made every effort to honestly disclose my reflections and experiences by guarding against being biased about albinism, and have narrated my story as it was experienced. By doing so, both negative and positive experiences are shared. Given that my study takes a qualitative and interpretivist approach, bias is unavoidable, and thus there is a link between the research methods used, the approach and the paradigm.

Personal memory

Researchers applying autoethnography can use different tools to gather data. These include ‘participant observation, interviews, conversational engagement, focus groups, narrative analysis, artifact analysis, archival research, journaling, field notes, thematic analysis, description, context, interpretation, and storytelling’ (Poulos, 2021: 5). Researchers such as Ramanayake (2020) have used their diaries as data.

In this study, the data for the autoethnography methodology was collected through my personal memory. Grbich (2013: 123) describes personal memory as ‘the one which may come from notes or merely memories of a powerful event, and the details of which are imprinted in the mind’. I used my memory of the lived experience of albinism as a data collection tool. Through this process, I could use my memory to recall all the events with regard to my daughter and son, who were both born with albinism in 2013 and 2016, respectively. The recalled events include the doctors informing me about my children's condition and the confusion I experienced because of the lack of information about albinism at that point in time, especially when my daughter was born. Other events include information provided by different doctors – for example, specialists and general practitioners – which also assisted me in coping with and understanding my children's condition.

Chang (2007: 5) acknowledges that memory is both a friend and a foe for autoethnographers. It is a friend in the sense that it allows the researcher to tap into a wealth of data to which no one else has access. However, memory also selects, shapes, limits and distorts, and fades as time goes by, blurring the vitality of the details. In this study, giving birth to another child with albinism in 2016 refreshed my memory and built more insights.

Wall (2008) used personal memory as a tool to collect data, and states that her supervisory committee was not satisfied with her employing this type of data collection tool. She thus had to provide a justification for choosing personal memory as a tool for gathering data. Wall (2008: 45) argues that 'it seems like, unless data about personal experiences are collected and somehow transformed by another researcher, they fail to qualify as legitimate'. She further points out that:

> It seems like personal experience data can only be considered legitimate if it has been recorded and transcribed by another researcher, even though both interview transcripts recorded by another researcher or told by the researcher themselves would be based on the same set of memories. (Wall, 2008: 45)

Neyman (2011: 27) explains that memory alone cannot be a single sufficient tool for collecting data as the researcher's objectivity is challenged. In this study, I narrated my experiences as objectively as possible, and the personal memory data was supplemented with data collected from interviews with other parents of children with albinism, because 'auto-ethnographic accounts do not consist solely of researchers' opinions, but they are also supported by other data that can confirm or triangulate those opinions' (Duncan, 2004: 31). Grbich (2013: 123) states that collecting data through autoethnography is time-consuming and an emotional and complex process that may involve researchers in years of writing and rewriting to gain distance from or be closer to the data.

Findings

Purposes for which information was required

Immediately after the birth of my daughter, I started searching for information on albinism because I wanted to absorb as much as I could in order to gain a thorough understanding of the condition. I was more interested in information on albinism in general, especially about her future, and not necessarily on what albinism is or its causes.

This search for information was triggered by my lack of knowledge about albinism, which had left me with the understanding that people with albinism are born with hard skin covered in sores. I did not know that damage to the skin only happens once the skin is exposed to the sun without any sun protection. Douglas et al. (2017) note that parents usually have little understanding of their child's condition immediately following the birth, and there is a need to acquire information that will acquaint them with their infant's specific needs and enhance their understanding of how to care for their child. Additionally, Braathen and Ingstad (2006) explain that some people simply do not know that the skin of people with albinism is sensitive to the sun, and some people with albinism do not know that it is the sun that causes their skin to be painful and burn.

I also expected my baby's eyes to start making movements right away, but I found out from the ophthalmologist that she would only start making eye movements after two to three months. The information that I searched for every day and that I could not obtain was in regard to my daughter's vision and whether she would be able to see and to live a normal life and go to a normal school. Seeking information on my daughter's vision was triggered more by the fact that she could not follow objects within the first three months. I sought information on my daughter's vision from the paediatrician, who referred me to an ophthalmologist, who assured me that my daughter would only start following objects after three months.

With my son, although the experience was the same, I sought information on his vision from the ophthalmologist, but I was not as stressed as I had been with my daughter, even though it took him about five to six months to start following objects. However, I was worried that he might have weaker vision than his sister.

As my daughter grew up, I was interested in searching for information on how to take care of her skin. I wanted to know about what body lotion and sunscreen were suitable for her skin because, initially, I had been using Vaseline petroleum jelly (for babies). I was also interested in what kinds of protective clothes I should dress her in, and, through researching, I learned that people with albinism need to wear light-coloured clothing because it attracts the sun less than dark colours. I also needed information on why she got small wounds on her lips, even when she had not been exposed to the sun. It has been emphasised that the lips are particularly vulnerable to sunburn, so it is important for people with albinism to apply lip screen with a high sun protection factor (Albinism Society of South Africa, 2014). I sought this information from the dermatologist.

When my daughter was starting school, I sought information on her vision – particularly on how weak or strong her vision was – because, at that time, I had already made the decision that I would enrol her in a mainstream private school. That information was necessary to help me decide if she would need to wear glasses or not.

I am currently interested in information on skin allergies because my children constantly have skin allergies, which I am afraid might permanently damage their skin.

Mechanisms used to seek information

I have acquired most of the information on albinism from the Internet. Through searching the Internet, I have gained knowledge about the types of clothes my children are supposed to wear. Currently, I am a board member of Support in Namibia of Albinism Sufferers Requiring Assistance, and I acquire a lot of information from this organisation. I have a good relationship with the president of the Namibia Albino Association Trust, who, when my daughter was born, invited us to his office, where he shared valuable information with us regarding her condition. I have joined various organisations that deal with people with albinism in different countries, such as the National Organization for Albinism and Hypopigmentation, the Albinism Community, Albinos Are Beautiful, the Albinism Society of South Africa and Under the Same Sun, which I joined on Facebook. These organisations provide valuable information and give hope because, in most cases, they offer positive thoughts, organise events, and share the success stories of people with albinism.

Through reading, I have come across various stories told by mothers of their children with albinism, who have been through the same experiences. I was given information about how to take care of my child's skin by the dermatologist. However, I came to realise that doctors lack specific knowledge on albinism too, so in most cases they tend to generalise. For example, I was told that my child would attend a special school – which is not the case because some people with albinism have stronger vision than others. Through reading, I came to realise that most people know nothing about albinism, yet they think they know everything. There is potential for the wide circulation of misinformation, therefore one has to be vigilant. The knowledge that people possess about albinism in most instances is based on myths that were created a long time ago.

Challenges experienced when searching for information

With my daughter, I did not experience many problems when seeking information on albinism, except for the distances that I had to travel to access information. The lack of relevant literature on albinism in the Namibian context is a challenge, as most of the information is about the situations in other African countries and other parts of the world.

With my son, I received confusing information, especially when I was enquiring about government services for persons with disabilities. Some officials would tell me that my son did not qualify for inclusion because he is not disabled, while others told me the opposite.

Conclusions and recommendations

The findings from my study respond to the study's research objectives, which were to establish the purposes for which information on albinism was required, establish the mechanisms for information seeking, and identify the challenges experienced during the information-seeking process. The findings have several significance implications for applying autoethnography and the role played by information in any situation.

Autoethnography has given me a voice to represent myself and to tell my story with respect to albinism as I have experienced it. It has provided me with the opportunity to share my emotions of confusion and loneliness, and the excitement that I experienced after giving birth to my daughter and son, who were born with albinism in 2013 and 2016, respectively. Additionally, I hope that my study will be inspirational for parents of children with albinism, especially in Africa, where albinism is misunderstood. Their experience in most cases is the same, and this is also supported by the findings from interviews with parents of children with albinism.

Through my research, I have also come to understand and appreciate the role that information plays in any situation. As a librarian and the mother of children with albinism, I have explored different mechanisms to find information, which have helped me to understand albinism better and to deal with my predicament. By absorbing so much information, I have been able to defy the myths and beliefs attached to the condition, and come to terms with the fact that albinism is a genetic condition.

It is for this reason that this study recommends that hospitals must offer counselling services, with the assistance of the Namibia Albino Association Trust and Support in Namibia of Albinism Sufferers Requiring Assistance, because they understand albinism and are in a better place to provide accurate information. The Ministry of Health and Social Services should ensure that psychologists and social workers attend to cases of albinism without delay to avoid children being rejected and abandoned by their parents. In addition, the Ministry of Health and Social Services should create a database of children born with disabilities for ease of access and the provision of information and other services. It is vital for Support in Namibia of Albinism Sufferers Requiring Assistance and the Namibia Albino Association Trust to establish support groups for parents of children with albinism in order to share information and that they may learn from each other. Moreover, their information booklets should be made available in all hospitals countrywide.

Declaration of conflicting interests

The author declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author received no financial support for the research, authorship and/or publication of this article.

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