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The social information needs of people with albinism (PWA): A case study of Khomas region, Namibia

Anna Ngula
University of Namibia Library, Namibia

Abstract

This paper focuses on the social information needs of people with albinism (PWA) in Khomas region, Namibia, and the sources of information used PWA to meet their information needs. The study applies Moore's model of social information needs and Wilson's model of information behaviour to investigate and understand the information needs and sources used by PWA to find information. The study was carried out using a qualitative case design within interpretivism paradigm and semi-structured face-to-face interviews were used to collect data from participants. Sixteen participants took part in the study, eight were males, and eight were female participants. Among these participants, two were children with albinism. The following information was identified as being crucial to PWA namely: skin- and eye-related information, information on what is albinism and its causes, disability grants, educational information, and emotional and psychological support. Additionally, the study established that PWA use formal, informal, and human sources of information to find information.

Keywords
people with albinism, information, social information needs, Namibia, albinism

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Introduction

Albinism is an inherited genetic condition that is passed directly from unaffected parents to their children. ‘In Africa, the prevalence of albinism generally ranges from 1 person in 5000 to as low as 1 person in 15,000. It has been reported that some selected populations in Southern Africa have prevalence rates as high as 1 in 1000 people (Ero et al., 2021: 12). Additionally, Namibia Statistic Agency (2011) indicates that Namibia has 1560 PWA. However, this number is disputed because the number is estimated to be close to 2 000 but due to myths and stigma attached to the condition it is believed that many children with albinism are hidden from society by their relatives (Mbathera, 2021).

Being born with albinism means that the body lacks melanin, making PWA vulnerable to sunburn and face an increased risk of developing skin cancer and visual impairment to varying degrees (Baker et al., 2021; Ero et al., 2021). There are different types of albinism and the most prominent one in Africa is oculocutaneous albinism which affects the hair, skin, and eyes. Hence it makes those with conditions visible in appearance and different compared to their dark-skinned families and communities (Franklin et al., 2018).

The suffering of PWA have been reported in some African countries such as Tanzania, Malawi, South Africa, Mozambique, etc. The stigmatisation, social isolation, and discrimination are experienced in the form of name callings, mockery, attacks, and killing of PWA (Likumbo et al., 2021; Ngula and Bitso, 2021). In Malawi for example, PWA are regarded as disabled because their condition is believed to prevent them from participating in everyday activities (Tambala-Kaliati et al., 2021). Additionally, the

Corresponding author:
Anna Kaukowe Ngula, University of Namibia Library, University of Namibia, Windhoek, Namibia.
Email: angula@unam.na

condition of albinism was ‘traditionally thought of as “a curse” or as some form of “punishment” from the gods’ (Ojedokun, 2018: 33). For a mother, birthing a child with albinism means a lifetime of suffering at the hands of her spouse and his family as most of them believe that a woman carries the gene that causes albinism. Various literature confirms that a lack of knowledge and understanding of albinism is the main cause of the suffering of PWA specifically in Southern Africa (Ero et al., 2021; Likumbo et al., 2021; Ojedokun, 2018).

PWA in Southern Africa and Africa, in general, live in abject fear due to attacks and killings by those who believe that their body parts contain a charm that can bring good luck and wealth. The number of reported crimes against people with albinism in Malawi for example is estimated at approximately 170 cases, including more than 20 murders since November 2014 (Amnesty International, 2021). In view of the above, Malawi is the epicenter of attacks and killings of PWA in Southern Africa. Namibia is known to be a peaceful country where PWA feel safe as only two incidents of attack and killing have been reported since 2012 (Under the Same Sun, 2012). However, on 23 March 2022, the Namibian police arrested ‘two men in Windhoek while negotiating the sale of human hair, among others, the hair of those with albinism’ (The Namibian, 2022).

Literature review

Ngula (2018) indicated that there is a scarcity of literature on the information needs of people with albinism in Namibia and Africa in general. Thus, the discussion in this section would be based on the information needs of people with disabilities and other vulnerable user groups.

Information needs have been defined as the ‘requirement that drives information seeking’ (Ikoja-Odongo and Mostert, 2006: 147). Belkin et al. (1982: 61) explain that an information need arises from a recognised anomaly in the user’s state of knowledge concerning some topic or situation and that, in general, the user is unable to specify precisely what is needed to resolve that anomaly. However, Case (2012: 5) sees it ‘as the recognition that your knowledge is inadequate to satisfy a goal that you have ‘because, every person whether literature or illiterate needs information and this need arises from the need to solve uncertainties, solve problems and make informed decisions (Adenekan, 2019: 1385). Case (2002: 92) adds that people tend to seek information that is congruent with their prior knowledge, beliefs, and opinions, and by avoiding exposure to information that conflicts with those internal states. This is evidence that people with disability have the same information needs as those without disabilities. For example, a disabled person can read a newspaper, listen to a CD, and download electronic resources from the internet to meet their information needs just as those without disabilities (Akolade et al., 2015).

Oketunji and Oketunji (2016) and Aliyu and Mohammed (2018) both found that physically challenged people need information that can address their difficult life circumstances, particularly information for survival, information on financial schemes, donor agencies, care support, and health services as well as educational, recreational, social and information for personal development.

In view of the above, for PWA effective access to information and communication, means people with albinism are empowered to know and defend their rights (Ero et al., 2021: 44). For the reason that information assists them to take care, and maintaining beautiful skin and know where to go from different services that can benefit them (Adenekan, 2019; Ngula, 2018). In addition to health needs people with albinism need social, educational, and psychological information (Adenekan, 2019; Ngula, 2018) a study titled marginalisation and precarious circumstances of people with albinism (PWA): information needs and services (Ngula and Bitso, 2021) found that the information needs of parents of children with albinism differ at each developmental stage of their children.

In view of the above, it is worth noting that, ‘information-seeking relates to how people believe that information is needed, pursued and used’ (Williams-Ilemobola et al., 2022: 2). However, this indicated that even though there is a recognition for information, not all information needs make an individual seek for information (Arowosaye and Bakare, 2022). The scholars further explained that the need to seek information is determined by the task at hand. For example, the information sought by the students will be different from the information required by doctors and architects, etc. (Arowosaye and Bakare, 2022). The processes involve a number of stages such as identifying, choosing, and locating the information that satisfies an information need (Appiah, 2017).

However, in Africa, people with albinism suffer from social exclusion and a lack of access to information is one of the contributing factors for PWA means justice is denied because access to information is a significant element of access to justice, especially for PWA who 'suffer from discrimination, stigmatisation, and social exclusion (Ero et al., 2021: 2).

Presenting information in various and appropriate format that is accessible is key for PWA who are visually impaired (Ero et al., 2021). A study carried out by Appiah (2017) on users with visual impairment concluded that students use both formal and informal methods when seeking information. It has been noted that users with visual impairment consult different sources to acquire information. This includes colleagues, the Internet, radio, lecturers, group discussion, textbooks, and handouts to acquire information (Appiah, 2017).

Theoretical framework

Moore's (2002) model of social information needs emanates from the literature review of the information needs of visually impaired people, a condition that is prevalent among PWA. The model comprises six dimensions, but only two of these dimensions were used to compile the research questions. These dimensions are:

- Function —why do people need information?
- Form — what kinds of information do people need?

In this model, Moore presents his view based on two concepts, namely, information for citizenship and information for consumption. The latter implies that people need information to enable them to make democratic choices and to know about current affairs (Moore, 2000: 6). In addition, the concept emphasises that if the citizens are not well informed, the democratic processes may become uninteresting and lack the representation of reality (Moore, 2002). Information for consumption is critical, as it influences the choices, such as schooling, healthcare, housing, social care, and other public services, that people make as consumers of products and social services in the hope that this element of consumer choice will lead to higher levels of efficiency and a better quality of living (Moore, 2002: 298). One can say that, without information, people may run the risk of making uninformed decisions. From the abovementioned, it appears that when people are empowered with the information they are able to make informed choices, and they can influence the way in which society is organised, such as by casting their votes through democratic elections. They might influence the provision of goods and services through social capital and mob psychology powered by information exchange (Fourie, 2008).

In view of the above, Moore (2002: 297) discusses social information as that which aids people to cope with and to live their daily lives. Social information is defined as the 'information that people use during their daily lives (Tilley, 2009: 64). Litzkendorf et al. (2016: 1) provide examples of social information needs, namely, information about respite and care, and information about patients' organisations and support groups. People with albinism need social information about their condition in order to cope with the challenges of life, information about treatment, and services that are available for them, especially if it is to aid them against their vulnerability or the sensitivity of their skin, and eyes to the sun. It is with the right information, at the right time, and in the right format that people with albinism will know about their entitlements to welfare benefits and social care services, and available facilities to overcome social exclusion. This information may include knowledge about where they can acquire special aids, such as protective clothing, sunscreen, hats, and visual aids that are crucial to the improvement of their lives.

Wilson's model was used to specifically address the sources of information used by PWA to find information. It focused on the stress and coping component, social learning theory, and intervening variables. The stress/coping mechanism helps to unpack information-seeking and information-avoidance behaviours. This theory helps to explain why some information needs to trigger information seeking and others do not. Stress is defined as 'the situation that exceeds a person's resources and endangers his wellbeing' (Folkman and Lazarus, 1985: 152). Furthermore, they define coping as 'cognitive and behavioural effects to master, reduce or tolerate the demands of stressful situations.

Chitosi (2015: 3) explains that persons with albinism are already extremely stressed as they look and feel different from people without albinism. Given that people with albinism are negatively impacted by the condition that affects their skin and eyesight, this can create a constant state of insecurity and distrust Stress may, therefore, be caused by bullying, as well as the social exclusion that they suffer from within a society that may affect their self-confidence. It is in this regard that a person may perceive information needs as unbearably stressful, while others may use the information to cope with their situation.

Wilson (1997: 3) provides examples of variables that may inhibit the process of information-seeking. These variables include the lack of knowledge or information, as well as language barriers and characteristics, such as hearing problems, cognitive characteristics that include the lack of medical knowledge, and nervousness. For people with albinism, characteristics of being visually impaired; fear for their lives, feelings of insecurity, social discrimination, and stigmatisation may be a hindrance to information seeking because they might be afraid to approach those who possess the required information. These above-mentioned emotional factors may form barriers throughout the search process. People with albinism may experience frustrations because, in most cases, information is not available in suitable formats for people with poor vision. This circumstance may appear as social exclusions that can be perceived as emotional to people with albinism. It is important to bear in mind their emotional experiences when researching people with albinism, who are already vulnerable and are likely to give up when experiencing frustration or anxiety.

Wilson (1997: 562) identifies passive attention, passive search, active search, and ongoing search for information-seeking processes. Passive attention is when information is acquired unintentionally, for example acquiring information by listening to the radio or watching television. Passive search is when one type of search results in the acquisition of information that happens to be relevant to the individual. The active search involves seeking information actively, for example, by asking pre-planned questions, while ongoing search refers to the type of search that is carried out to update or expand one's existing knowledge.

Rationalising the research problem

This study investigates the social information needs of people with albinism (PWA). For this reason, ascertaining information needs to disseminate relevant information is key to any user group (Hepworth, 2007). A study on the information needs of this marginalised group is essential, particularly in Africa, where there is an array of beliefs about albinism and Namibia is no exception. Although studies about the information needs of various user groups have been conducted in Africa with this study, there appears to be minimal literature on the information needs of people with albinism. Hence, the main purpose of the study is to ascertain the social information needs of PWA and establish the mechanisms they use to meet their information needs.

Objectives

- To ascertain the information needs of PWA, including the kind of information needs they have;
- Establish sources of information used by PWA to meet their information needs

Methodology

The study was carried out in Khomas region, Namibia. Khomas region is the region where Windhoek the capital city of Namibia is located, making it the most densely populated region. A qualitative approach was used within the interpretivism paradigm to conduct the study. A snowball sampling method was used to recruit 16 participants. Sarantakos (2013: 7) defines snowball sampling as the type of sampling in which the researcher chooses a few respondents, using accidental sampling or any other method, and asks them to recommend other people who meet the criteria of the research and are willing to participate in the study. This technique was preferred for two main reasons. First, it is an easy-to-use method, and it is an informal method to reach a target population. Snowball sampling was used to conduct qualitative studies, primarily through interviews. Secondly, snowball sampling was used because it is a more formal methodology of making inferences about a population of individuals who have been difficult to enumerate, using descending methods, such as household surveys (Atkinson and Flint, 2001: 1).

Additionally, a case study design was selected in the context of Matthews and Ross (2010: 128) who explain that a case may be a person, an organisation, a situation, or a country, but the study must relate to a particular aspect of the case as demonstrated in the research questions. It is based on these explanations that this study identified PWA, the Khomas region, and Namibia as specific cases. Khomas Region, Namibia, was selected as the case because of its familiarity with the researcher. In addition, there are individuals with albinism in the region who are acquainted with the researcher as a mother of children with albinism. The researcher is also a board member of Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA), an organisation that deals with the plight of people with albinism in the country. The study used semi-structured interviews to gather data. This is because interviews enable participants to obtain their interpretations of the world in which they live, and to express how they regard situations from their own point of view (Phothongsunan, 2010: 3). The interviews were conducted with people with albinism to get an understanding of their information needs and sources of information they consult to meet their information needs.

Data were content-analysed. The themes were drawn from research objectives, which correspond to Moore's model of social information needs, and Wilson's model of information behaviour. The following themes which relate to the research questions discussed were identified: Function (why do people need information?); Form (what kind of information do people need?) and sources of information used by PWA to meet their information needs.

Recruitment of participants

Sixteen participants took part in the study, eight males, and eight females. Among these participants, two were children with albinism. These children with albinism are siblings, and even though they preferred talking in the presence of their mother, they could not really answer the specific research questions posed; however, they stated that they are proud of whom they are and are not bothered about how society perceives them. It is for this reason that the findings presented in this section do not include much of their voices.

The participants' ages ranged from 14 to 72 years. The majority of those interviewed had not finished secondary education, and they are unemployed- a problem they attributed to poor eyesight and lack of support. However, most of them stated that they engage in informal businesses, such as selling 'kapana' (roasted meat) or fruits and vegetables to make a living, requiring them to spend prolonged periods in the sun, and as a result, they suffered skin damage.

Children with albinism (CWA) who participated in the study were attending primary school at the school for the visually impaired. Few of the participants have tertiary education qualifications in fields such as accounting, law, and theology; one is a student at the University of Namibia. Two are grade 12 certificate holders, while one participant who holds a grade 10 certificate runs a project that helps PWA, raises awareness of albinism, provides counselling services, and gives motivational speeches. Most of the participants reside in Tobias Hainyeko, Moses //Garoeb, and Windhoek East constituencies. Tobias Hainyeko and Moses //Garoeb constituencies are characterised by poverty and a high unemployment rate, so most of the people in these constituencies live in informal settlements. The Windhoek East constituency is regarded as an upper-class constituency where the most prominent people reside, whereas the Khomasdal constituency is regarded as a middle-class constituency.

Interviews were conducted in Windhoek for 12 days in August and September 2017 respectively. Interviews were conducted in places such as restaurants, libraries, homes, the researcher's office, and car, as participants found comfortable. Participation in the study was voluntary and participants were assured of their privacy and confidentiality throughout the study and were also informed about the objectives of the study.

The researcher approached two regional councilors who announced the study on the radio and invited participants who are willing to take part in the study to register themselves. Additionally, the researcher approached many people with albinism to take part in the study, but only a few agreed to be interviewed. Some PWA told the researcher that they are not interested, and some promised to come back to the researcher, which they never did. However, the number of participants obtained in the study was within the range of at least 10 participants as specified for qualitative interviews.

The researcher observed that those people who were willing to be interviewed are the uneducated and unemployed ones and, these people expected more than an interview from the researcher. Some narrated their personal problems to the researcher hoping the researcher was going to give them money or register them for employment or assist in acquiring places to stay. The researcher had to constantly take them back to the interview questions as they kept diverting from the interview questions. Some participants were very emotional during the interview and the researcher stopped the interview to give participants time to recover.

Presentation of findings

Emotions experienced when PWA realise they have albinism

The question was meant to understand the reaction of PWA when they became aware that they have albinism and share their emotions. The responses were based on their personal experiences and the results indicated that they reacted differently. Among those who were interviewed, it appears that those who are born among siblings with albinism expressed feeling normal about the condition. For example, participant 3's response was:

> It did not bother me too much because I have a brother and a sister who have albinism as well, I just took it normally, and as part of my life, maybe if I was the only one I would have had many questions.

In addition, other interviewees stressed that they felt normal and happy about their condition because God created them the way they are. They stressed that is not fair to worry too much because they are able to see, even though partially, perform any household chores and live life to the fullest, just like those without albinism. They provided an example of people with other types of disabilities such as the blind, deaf, and physically challenged who might not be able live life to the fullest due to their disabilities. Participant 5 remarked:

> Some people treat me well and some treat me badly, but I do not mind because this is how God created me, and it does not affect me in any way, I am just proud of who I am.

This was also noted in the literature by Brocco (2015: 1147), who stressed that albinism is a condition attributable to God's will, therefore, included among the multifaceted reality, so it must be accepted by human beings, even though it causes disgrace, sorrow, and regret.

On the contrary, some interviewees said that they felt bad when they found out they have albinism, and even at the time of the interview, they confessed that they have not made peace with it. As participant 6 reflected:

> I felt bad; I blamed myself, and my parents, and still questioned why I am different, especially because people say bad things to me, that is the reason why I am unable to answer some questions because I do not know how to answer you.

Daily experiences of PWA

This question was asked to gain an understanding of how the public perceives people with albinism, it was also important to understand if the maltreatment of PWA mentioned in several studies will be confirmed by the findings. Interviewees expressed different opinions when asked about their daily experiences with regard to their condition. Some indicated that their daily experience is normal, while others indicated that they experience a lot of difficulties such as name-calling. For example, participant 11 commented:

> You meet people, who have misconceptions about albinism, and you meet those who are impressed by you and admire you, it depends on where you are because the experience is different every day.

However, most of the interviewees are concerned that many people still lack knowledge on issues related to albinism, which could be interpreted as a denial of society when encountering a person with albinism, especially poor eyesight. People in society still do not understand what albinism is, not even lecturers at the university. Participant 1, who is a student claimed:

> I once approached a lecturer for class notes because I could not see them on the blackboard during class. He told me he does not give notes to students, and he is not bothered whether a student is normal or has some sort of disability. It is sad because it holds me back, other students know more than me because they have access to all the information.

It is for this reason that Cru-Inigo et al. (2011: 81) explain that the visual handicapped suffered by PWA make some major components of learning, such as reading on the blackboard difficult.

The negative attitudes of society toward PWA noted in various studies were confirmed by participants. Young participants indicated that they experience difficulties when they want to date or marry. Similarly, Baker et al. (2010: 176) stressed that the issue of marrying someone with albinism does not only have to do with the couple but also with family members who need to accept them in the family. Participant 2 expressed the following:

> Sometimes I fear approaching or proposing to a girl that I want because I just think she is not going to accept me because I have white skin, even though I want to marry and have children of my own.

Some interviewees mentioned that, due to a lack of knowledge and the stigma attached to albinism, some community members do not care about them, and do not want to come near them. Previous studies also reported that people refuse to shake hands with PWA, or sit next to PWA on a bus or taxi, or 'some people will not touch what I touch', or,' when it comes to sharing a cup, people will first wash it or use a different cup, but they cannot use the same cup that was used by someone with albinism' (Baker et al., 2010: 1740; Beukes, n.d.: 19).

Despite the above-mentioned, some individuals with albinism stated that they are not offended when they are called names. This was participant 8's view:

> My daily experience is good I have learned not to mind what people say about me. I am used to people calling me names such as "albino", I would always react positively because this is what I go through every day; hence, it is normal to me, and is true I am an albino.

Participants were further asked to indicate the information they need daily in order to deal with their daily experiences. Most of the interviewees remarked that the type of information they need on a daily basis depends on what they are busy with. For example, participant 11 claimed:

> The information I need daily will be determined by the environment in which I find myself and what I want the information for, for example, if am studying, I will need information related to my studies, or if I am working, I will need information about work, and not necessarily on albinism.

This is to a certain sense a confirmation that PWA need different types of information apart from information regarding their condition. Few interviewees indicated that they require information on how to protect themselves better, the type of clothing to wear, for example, the textiles, and the effectiveness of different sunscreen lotions. Additionally, a few interviewees indicated that they need information on what albinism is, and how to carry out educational campaigns and awareness not only on albinism but about disability in general.

Information needs expressed by PWA

The findings reveal that most of the questions identified in the literature review in terms of what albinism is and its causes were confirmed by participants. The majority of participants' responses revealed that undeniably PWA have a range of information needs that are related to their condition. The participants emphasised different information needs, first and foremost information on why they are different from other people in terms of skin colour.

Secondly, information on what albinism is, and the causes of albinism were noted, participants argued that they were provided with a lot of information on what causes albinism, which some found out later after conducting their own research that it was not true. A participant explained that after searching she found that albinism is a result of genes passed on from parents to their children. Baker et al. (2010: 172) provided the following example: a young South African woman who describes how her mother explained the cause of her albinism to her as something she had 'caught' by touching a child with albinism.

Thirdly, participants noted information on why PWA have poor eyesight and why their eyes jerk from side to side a condition referred to as 'nystagmus'. Furthermore, they wanted to know why they are unable to see far and properly and why their eyes cannot focus easily on objects.

The following comment from participant 8 illustrates how a PWA were curious to know the causes of albinism:

> I asked my mother why am I different, and not black like her. I also wanted to know what albinism is, why I am unable to see on the blackboard clearly, why my eyes move from one side to another, and why I am different, discriminated against, and called names.

Another participant 11 explained:

> The reason why I kept asking different people why am I different is because people provided me with many different and weird answers such as I am a blessing, whereas some told me I was a curse and others explained that I was a result of punishment from God.

From the comments given one can deduce that PWA often receives non-factual to fictitious (or unreliable) information from people in everyday life. Often people poorly literate find it difficult to distinguish between the different categories of information.

The critical information expressed and stressed by PWA was information on counselling. Some interviewees indicated that upon becoming aware that they have albinism, they needed to be supported emotionally and psychologically because, up to the time of the interview, some had not accepted who they are, and pointed out that they have many unanswered questions about their condition. The following statements support the responses expressed by participant 2:

> I needed information on counselling to understand why am I different and information on what I need to do so that I am not bothered too much about those who call me names and bully me, and I need someone to explain to me that I am a normal human being just like any other people the difference is only in the skin colour.

Participant 9's comment was as follows:

> I took my condition badly at the beginning. I was always alone and isolated, my father would always ask me why I like to be alone. Currently, I am starting to accept my condition slowly, but I still need information on where I can go for counselling, because I have experienced a lot of difficulties in my life such as being insulted for no reason, which has affected me badly.

Similarly, Estrada-Hernandez and Harper (2007: 270) found that persons with albinism may need counselling interventions directed towards maintaining positive self-esteem and attitude towards themselves and developing assertiveness and coping mechanisms, as well as social skills.

Some participants expressed basic information needs, entailing information as to the type of soaps and cream to use, as well as the clothing to wear and information on where to access aids such as hats, UV-protected clothes, sunglasses, and sunscreen lotions, and most information on how to apply for the disability grant. Some participants stressed the importance of the education-related information, as they wanted to know if there is a special school that can be attended by PWA since they have poor eyesight.

Several participants expressed a strong need for information on employment, housing, and accommodation. This concurs with the demographic data of the study, revealing that the majority of the participants were unemployed. These participants argued that in most cases they are not considered for employment; they admitted that they might not possess the necessary qualifications, but in most cases, they possess the skills needed to do some jobs. A few participants narrated that people think if they employ PWA, they will be arrested, which is not true. Additionally, they explained that since they were uneducated, they could not even work at construction sites because they will burn from the sun.

Additionally, PWA expressed information needs on how to acquire a place to put up a 'kambashu', meaning a shack of their own instead of being under somebody else's roof. Information on how to acquire national documents such the identification documents was noted by a participant. He stressed that currently, he is not benefiting from the disability grant due to his lack of documents.

In terms of needing information, two participants had never wanted information on albinism; because they did not find a valuable reason to do that, while others, including older participants, believe that they had acquired enough information on albinism through living and experience. They emphasised that in the past there were no sources that they could consult to acquire information. This was reflected in the following statements, the first from participant 13 and the second from participant 14:

I never looked for information on albinism, because I survive by the grace of the Lord.

> During those years my mother took care of me, she told me what to do and what not to do, where to play and not to play. In our days, we did not have a library or internet and there were only three radios in the village, through living and experience I have learned how to take care of myself.

Sources of information used by PWA

Most participants preferred using different sources, with the most popular ones being radio, television, and the internet (Google). However, some participants admitted that they only get information from the radio and television occasionally, those who stay in informal settlements emphasised that they do not have access to electricity, as a result, they do not own radio and television sets.

Additionally, participants presented a range of reasons why they prefer to use the internet, this includes being able to enlarge the screen to the advantage of their eyesight, as reflected in the following statement (participant 10):

> Internet is better because you can enlarge it to the size that I am able to see, pamphlets are not good, maybe in the village but people will still squint it to read the information, and most of the people try to fit a lot of information on a small piece of paper without considering the eyesight of PWA.

Participants also explained that they search for information on the internet to acquaint themselves with albinism and to better understand it themselves, rather than being told by someone who lacks first-hand knowledge because not even healthcare professionals understand what albinism is. For example, participant 12 commented:

> It is better to search on my own because I need to have a basic understanding of what albinism is, otherwise anyone can tell me anything, and misinform me because people have their own theories and tend to generalise things about albinism.

Very few participants mentioned newspapers, though they were of the opinion that newspapers do not provide them with new information, and are not at all informative. Newspapers were further criticised for not doing much when it comes to issues of albinism in the country, but they tend to concentrate more on stories concerning PWA in other countries. Furthermore, they argued that newspapers are usually written in small fonts making it difficult for PWA to read them.

Healthcare professionals, specifically nurses and doctors at the Dr Bernhard May Cancer Care Centre were major providers of information on skin-related issues and on services available to PWA offered by the government, for example, information on how to apply for the disability grant. Meanwhile, ophthalmologists were providers of eye-related information.

Local organisations for PWA such as SINASRA, Namibia Albino Association Trust (NAAT), as well as other people with albinism were preferred sources of information. Participants explained that printed materials they get from NAAT are always in a font appropriate for their eyesight because those who produced them understand issues related to albinism and their poor eyesight. Additionally, friends, families, neighbours, and others were perceived as valuable sources of information. For example, participant 11 commented:

> I prefer asking people around me for information such as my mother, grandparents, and teachers.

Social media and public libraries were the least popular mechanism used by PWA.

Discussion

Information needs expressed by PWA

The findings reveal that PWA have information needs related to their condition, which is supported Tilley (2009) and Rayini (2017), both of whom found that participants sought information related to their visual and physical disabilities to be able to deal with their disabilities over and above, or in addition to other general life matters pertaining to their roles.

The study identified the following information needs: eye-and-skin-related information needs, information on what albinism is and the causes of albinism, information on how to register for the disability grant, education-related information, and emotional and psychological support information. The findings of the study agree with reviewed literature that people with disability (PWD) might need information about their condition, available facilities, self-help groups, rights, and privileges as well as information on how they can apply for a social welfare benefit (Tilley, 2009: 64). Additionally, the study revealed that PWA had other information needs related to housing, accommodation, employment, and national documentation. Most of the information needs revealed by participants were similar to the information needs of people with visual impairments as identified in the reviewed literature (Moore, 2000). The findings showed that questions asked by participants as part of their information needs were also confirmed by previous findings (Lang, n.d.; Lund, 2001; Lynch et al., 2014). The information needs identified by the participants of this study are presented below.

The study found that there is a desire for knowledge about albinism among those interviewed. This is displayed in the kind of questions asked about visual impairment. Participants demonstrated their need for information on why they have poor eyesight, a university student who took part in the interview explained that she could not see on the blackboard during lectures and lecturers refused to assist Some PWA were also interested to know why their eyes move from one side to the other and why they cannot easily focus on objects. Hong et al. (2006: 4) explain that due to a lack of retinal pigment required for the normal development of the visual system, PWA experience photophobia, myopia, and other visual problems including nystagmus and strabismus. Notably, Lund (2001: 5) pointed out that some eye problems, such as nystagmus, cannot be cured and it will always restrict their visual ability

Participants exhibited a clear picture of outstanding information needs, which was reflected in the answers they sought. This includes a curiosity to know why they are white and not black and information on what causes albinism.

During the interviews, participants indicated that they desire information on counselling as some of them have not accepted who they are. This was apparent even during the interviewing process: some participants were very emotional and kept shaking their heads (a sign of denial). Information on how to access these services, however, remains unknown. Hong et al. (2006: 4) state that PWA must deal with psychological and social challenges – in addition to their health concerns. According to these scholars, a study conducted in Nigeria found that PWA tend to be more withdrawn from social situations to avoid being noticed, they are emotionally unstable, and are less assertive.

The findings showed that these types of information needs were mostly expressed by participants who are unemployed, less educated, and reside in informal settlements. They expressed the need for employment to support themselves and their children, as the disability grant they receive from the government is inadequate to cater to all their needs. They were, however, dissatisfied that most of the time they are not considered for employment, because people have their own beliefs and understanding. Baker et al. (2010: 175) explain that a lack of understanding of albinism plays a significant role in the problems faced by PWA seeking employment: their physical appearance and visual impairment influence the ways in which potential employers regard PWA. There is also a concern that PWA cannot, for example, work, as construction workers because they would be required to spend prolonged periods of time in the sun, and with no or little education it is difficult to get an indoor job.

Another participant mentioned that he needs information on how to obtain national documents. He explained that he does not benefit from the disability grant, as he cannot be registered without proper documentation. This is endorsed by Mnubi-Mchombu (2013: 38) who noted that a lack of relevant documents, such as birth and death certificates, prevents orphans and vulnerable children (OVC) and their caregivers from accessing important information on grants. According to Niilenge (2017: 6), the NAAT president confirmed that a number of PWA have no access to disability grants because they have no identity documents

Sources used to meet the information needs

The study applied the Wilson theory of information behaviour that emphasised that information can be acquired purposively or incidentally. Therefore, the purpose of applying this objective to the study was to establish sources used by PWA and the parents of CWA to find information in order to meet their information needs. The findings showed that formal, informal, and human sources of information were used. This includes the internet (Google), radio, television, newspapers, healthcare personnel, such as dermatologists and ophthalmologists, and SINASRA and NAAT, as well as family members, friends, neighbours, teachers, and so forth. Previous studies confirmed that people use incidentally or purposively sources to acquire information (Mnubi-Mchombu and Ocholla, 2011: 10; Williamson, 1998).

It is worth revealing that the internet was the most useful source for meeting the information needs of all participants. The fact that PWA were able to use the internet to access information despite their poor eyesight was advantageous because they could find a wide range of information via the internet. Internet was the preferred source because participants were dissatisfied with other services such as information provided by others, such as healthcare professionals, whom the participants accused of lacking first-hand knowledge of albinism. Thus, participants who consulted the internet could make independent decisions regarding albinism. A similar trend was observed in a study by Williamson et al. (2000), who mentioned that participants were happy because with the internet they had access to a wide range of information and they could access information that was previously inaccessible.

The findings showed that the radio was another preferred source mentioned by most participants. They (participants) argued that in most cases radio programms are broadcast in vernacular languages. Mnubi-Mchombu (2013: 256) found the radio to be an accessible and relatively cheap medium because it does not cost a lot of money to buy a radio, and the fact that radio broadcasts were mainly done in local languages made it ideal for information sharing and acquisition.

Several interpersonal sources were also found useful by participants in accessing information, namely, healthcare professional at Dr Bernard May Cancer Care Centre at Windhoek Hospital, family members, friends, neighbours, spouses, and other individuals with albinism. Healthcare professionals mainly advise PWA on how to take care of their skin and eyes and inform them about different services available and doctors specifically assist with the completion of the disability grant forms.

Very few participants mentioned newspapers. Those that did, however, criticised newspapers for not being useful for the following reasons: they do not provide participants with new information which they are longing for and were accused of focusing on albinism issues outside the borders of Namibia. This is so, despite previous studies establishing that information from newspapers in most cases is acquired incidentally (Williamson, 998). Furthermore, newspaper articles were criticised for being written on small fronts, which makes it difficult for PWA to read them. Similarly, Williamson et al. (2000) confirm that traditionally access to printed materials for someone who is blind or sight-impaired has been mediated through others such as a family member, a helper, or an organisation.

Organisations such as SINASRA and NAAT were among those consulted by participants. These two organisations were responsible for providing a wide range of information and support, such as information on albinism, and acquiring and benefitting from services such as hats, sunscreen lotions, eyeglasses, and ultraviolet (UV) protective clothes. They offer advice on the use of sunscreen lotions and assist with information on how PWA can apply for the disability grant.

It is surprising and interesting to note that despite the role being played by social media nowadays, only one participant mentioned using Facebook to find information. However, it was clear that family members, friends, neighbours, spouses, NAAT, and SINASRA were the most valuable sources of support for PWA as they assisted them to cope and manage the condition.

Limitations and future research

Considering that the study applied the snowball sampling method only PWA who were known and approached by the researcher took part in the study. Furthermore, not all PWA whom the researcher approached were willing to take part in the study- an issue the researcher attributed to the lack of trust because some only opened up when they learned that the researcher has children with albinism.

Since the study is a case restricted to the Khomas region, the findings may not be generalised to PWA in the whole country. Another limitation is the lack of previous studies on the information needs of PWA with a focus on Namibians. Therefore, the researcher relied on the literature on the information needs of people with visual impairment, one of the characteristics that describe PWA. In addition, the literature on studies of other vulnerable groups was considered.

In view of the above, this study serves as a reference point to provide a baseline for future studies on the same topic in other parts of Namibia, especially in Ohangwena and Kavango East and West regions. Moreover, evidence from literature searches also indicates that there is no known study on the information needs of PWA in Namibia, Africa, and the world at large; hence this study can fill the gap.

The age of participants ranges from 14 to 72 years old. However, it is anticipated that there is a need to conduct further studies on the information needs of PWA considering how the age variable influences the response of participants.

Conclusion

The aim of the study was to investigate the information needs of PWA using Moore's model of social information needs and Wilson's model of information behaviour as the theoretical framework guiding the study. The study pointed out the following information needs, namely: skin- and eye-related information, information on what is albinism and its causes, disability grants, educational information, and emotional and psychological support.

The study also concluded that participants made use of both purposively and incidentally modes of acquiring information. The main sources of information preferred by participants were the internet, radio, television, healthcare professionals, family members, friends, and neighbours. Newspapers and radio though preferred by some PWA were criticised for not being informative enough, as they do not communicate the needed information to the participants, and most especially the newspapers are written in small fonts.

ORCID iD

Anna Kaukowe Ngula https://orcid.org/0000-0001-8439-0664

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Author Biography

Anna Ngula is head of the Technical Services Department at the University of Namibia Library. She holds a Master of Philosophy degree in Library and Information Science (University of Cape Town, South Africa) and an Honours degree in Information Science (cum laude, University of South Africa). Additionally, she is a part-time lecturer in the School of Humanities and Development, Department of Social Sciences at the University of Namibia. Her areas of interest include information needs and information-seeking behavior with a special focus on disability issues, cataloging and classification, metadata, indexing and abstracting, and new media technologies.