

THE INFORMATION NEEDS OF PEOPLE WITH ALBINISM IN
KHOMAS REGION, NAMIBIA

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DECLARATION

I declare that this study, *The information needs of people with albinism in Khomas region, Namibia*, is my own work and has not been previously submitted in part or whole to any institution or publisher. All the information from other sources has been acknowledged both in the text and in the references.

Signature

Signed by candidate

15/02/2018.
Date

Anna K Ngula

DEDICATION

- This study is dedicated first and foremost to the Almighty for safeguarding me during the entire process, and for lifting me up when I felt like giving up.
- To my husband Reverend Josef Ngula and my children Josanna, Alodia and Anselmo, a special dedication to Alodia and Anselmo who were both born with albinism.
- To all brave parents of children with albinism and the lovely people with albinism in Africa.

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ABSTRACT

The dissertation is a report of an investigation of the information needs of people with albinism in Khomas region, Namibia. The investigation aims to ascertain the information needs of people with albinism (PWA), including the kind of information needs they have. It also seeks to establish the mechanisms used by PWA to seek information and to determine who initiates their information-seeking activities. Furthermore, the study identifies the challenges PWA in Khomas region face on a daily basis when seeking information and recommends information services that could be suitable for PWA in Khomas region.

For its theoretical framework, the study applies Moore (2002) and Wilson's (1996) model of information behaviour. It is situated within the interpretivism paradigm following a qualitative approach. The research design is that of a case study with aspects of auto-ethnography resulting from the researcher's personal memory of her lived experiences of albinism as a mother of two children with albinism. Face-to-face interviews were conducted with sixteen people with albinism; six parents of children with albinism (CWA); and two key informants from associations dealing with PWA in Namibia.

The findings reveal that PWA have information needs related to their condition, specifically skin and eye care, as well as other basic needs, such as shelter, employment opportunities, education prospects and the process of their acquisition of identity and travel documents. The study revealed that the internet (especially Google), the radio and television, healthcare professionals and Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA) and Namibia Albino Association Trust (NAAT) are some of the sources and mechanisms used by participants when searching for information. The organisational participants revealed that they provide a range of services to PWA, including information about skin care and protective clothing, as well as applications for disability grants.

PWA who participated in the study indicated that they encounter problems when accessing information. These include the long distances between information seekers and providers, time constraints and the cost associated with accessing information. Language was identified as a major barrier to information access because most of the content is in English. Lack of awareness of information sources coupled with poor eyesight for PWA the reading of

information in small fonts that is not provided in alternative formats a glaring challenge. The study concluded that information about albinism is critical not only for PWA, but also to an African society that often subjects PWA to grievous harm, simply because it still holds myths and stigma about albinism.

Therefore, the study recommends that it is crucial to provide information to PWA, including their family members through platforms such as open days, sensitisation meetings, and the creation of WhatsApp groups. These interventions should also be directed at society at large in order to create a sense of belonging and get rid of isolation suffered by PWA. The study also recommends that an information booklet be developed by the ministry of health and social services. This booklet should contain information on different types of disabilities that can affect unborn children, in order to prepare the parents.

Keywords: Information needs, People with albinism, Khomas Region, Namibia.

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CWA	Children with Albinism
HIV	Human Immunodeficiency Virus
FNB	First National Bank
IAAD	International Albinism Awareness Day
NAAT	Namibia Albino Association Trust
NOAH	National Organisation for Albinism and Hypopigmentation
NDC	National Disability Council
NPC	National Planning Commission
OP	Organisational Participants
OVC	Orphans and Vulnerable Children
PWA	People with Albinism
PWD	Persons with Disabilities
PWID	People with Intellectual Disabilities
PWVI	Persons with Visual Impairment
RNIB	Royal National Institute of the Blind
SINASRA	Support in Namibia of Albinism Sufferers Requiring Assistance
SPF	Sun Protection Factor
TAAM	Albino Association of Malawi
TAS	Tanzania Albinism Society
TGPSH	Tanzanian-German Programme to Support Health

UNDP

United Nations Development Population

UV

Ultra violet

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CHAPTER 1

INTRODUCTION AND CONCEPTUAL FRAMEWORK

1.1 Introduction

This study investigated the information needs of people with albinism (PWA) in Khomas region, Namibia. Although studies about 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 born with albinism as indicated in Annexure A, yet ascertaining information needs to disseminate relevant information is key to any user group (Hepworth, 2007). A study on information needs of this marginalised group is essential, particularly in Africa, as narrated in the subsequent section. This chapter provides a background to the study, articulates the research problem, objectives and research questions. In addition, the chapter covers the significance of the study, limitations and delimitations of the study, as well as ethical considerations.

From a medical viewpoint, Schühle (2013:7) describes albinism as ‘the inability of the skin to produce the pigment melanin’. People with albinism have a 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 from the parents to their children, even though, in most cases, PWA are born to parents without albinism (Cruz-Inigo, Ladizinski & Sethi, 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, the most common being oculocutaneous albinism that affects the skin, hair, and eyes (Cruz-Inigo, Ladizinski, & Sethi, 2011). This type of albinism is also the form most commonly found Sub-Saharan Africa and leaves its subject particularly noticeable and vulnerable. This is particularly the case in a country like Tanzania, where the skin of its citizens is dark (Under the Same Sun, 2014: 6). Another form of albinism is ocular albinism that 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 a skin and hair colour that is normal, but is slightly lighter than that of other family members (Under the Same Sun, 2014:6).

Albinism can occur in all genders regardless of ethnicity, and is common in all countries of the world (United Nations, General Assembly, 2013:4). It is a condition that people are born with and can, therefore, not be treated; people who are born with this condition are often referred to as albinos. Tanzanian-German Programme to Support Health (TGPSH) (2009:8) explains that the word ‘albino means a white person and is derived from the Latin word “albus” meaning white’. Although the term ‘albino’ is commonly used to refer to living creatures with albinism, it has been found inappropriate to refer to human beings as albinos. In affirmative, Thuku (2011:7) states that ‘even though the term albino is still valid today, it is very important to mention that the term is a high point of contention in the community of people with albinism’.

People with albinism prefer the recognition of their character as humans before their condition and feel that it is offensive to be referred to as albinos. They feel that such labelling effaces them as people because the emphasis is more on their condition rather than on themselves as human beings. A contrary view is that of the National Organisation for Albinism and Hypopigmentation (NOAH) (2015:1) that points out that ‘some people with albinism feel that the label ‘albino’ carries neutral or even empowering connotations’.

For ethical reasons, the researcher has established the preferred term to use for reference to the participants in this study. The researcher is a mother of children born with albinism; a baby girl who was born with albinism in 2013 and a baby boy born in 2016. As a result, she understands the connotations of ‘naming’ around albinism, particularly in the African context. She paid attention to the sensitivity of ‘naming’ or labelling and made an effort to find the preferred term when referring to the participants in the study being reported in this dissertation. The researcher focused on a term that is used both internationally and in Namibia – where the study was conducted. This is a critical issue, given that because of stigma and social rejection in many African countries, different terms are used to refer to PWA. As noted by Cruz-Inigo, Ladizinski, and Sethi (2011), most of these terms are dehumanising, with little regard to dignity of PWA.

The United Nations General Assembly’s (2013; 2015; 2016) reports about albinism often use the term ‘persons with albinism’. Furthermore, the United National, General Assembly’s report (2013:3) explains that the term ‘persons with albinism’ refers to a person before it mentions the condition and is preferred to the term ‘albino’. This is in tandem with

recognition of a person first and their condition last (Tanzanian-German Programme to Support Health, 2009).

Additionally, organisations that deal with albinism issues in Namibia, such as the Namibia Albino Association Trust (NAAT), Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA), and National Organization for Albinism and Hypopigmentation (NOAH), an international organisation based in the United States, all use the term ‘persons with albinism’ as opposed to ‘persons living with albinism’ or ‘albinos’. Most of these associations argue that albinism is not a disease that people live with but a condition they were born with. In the same vein, scholars such as Thuku (2011) use the term ‘persons with albinism’. In view of these arguments, the study adopts this widely-used term, ‘persons with albinism’, or ‘people with albinism’, unless quoting sources in which other terms are used. However, the researcher does not take for granted that every individual with albinism is satisfied with the term because ‘naming’ or ‘labelling’ can be dehumanising. Notably, Fourie (2008), in her study on cancer patients and their family, used the expression ‘patients in cancer palliative care setting’ instead of cancer patients in [a] palliative care setting. This is an example of a reference to a person first and foremost, and then their condition or situation last.

1.2 Background to the study

1.2.1 Albinism in the African context

In most cases, people in an African society shy away from talking openly about albinism because of the stigma associated with it. This is coupled with beliefs and myths around it to such an extent that sometimes it becomes a challenge for those who have information about albinism, or those who might be in need of it, to share it with PWA, or those who may need that information. It is equally a challenge for PWA 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.

Accurate and timeous information has a positive impact on PWA in the sense that they become aware of crucial health issues about their condition; they also learn about available public services. A young girl with albinism, quoted in a local newspaper, said that she wants to share information with her community to raise awareness about PWA. “I educate others

about people living with albinism and I sometimes advise other people with albinism how to take care of their skin” (“Eva Ndatipo comfortable...,” 2015:12).

In a brief overview by Thuku (2011:2) on the prevalence of albinism, results indicate that the estimated prevalence rate is 1:60 000 in Denmark, 1:110 in Nigeria and 1:3 900 in South Africa. In Tanzania, where the population of PWA is about 170 000, the estimated prevalence rate is 1:1400, while in Zimbabwe it is 1:1 000. Based on the United Nations General Assembly’s report (2015), Africa has the highest prevalence of PWA compared to other continents. The report reveals that 1:17 000 to 1:20 000 people have some form of albinism in North America and Europe, while in Sub-Saharan Africa the ratio is 1:1 000 to 1: 3 900 (United Nations, General Assembly, 2015:04). In Namibia, local newspapers reported that ‘it is believed that if our population is 2 million, then the incidence is one in 2500 people or 1:2 500’(Bause, 2008). Thus, ‘Namibia has the most albinos per capita in the world’. The country, with a population of about 2.4 million people, has between 1,800 and 2,000 people living with the condition (Kapitako, 2018).

A predominant PWA organisation in Tanzania, Under the Same Sun (2012:20-21) provides a summary of how children with albinism have been traditionally treated by some ethnic group in Africa, especially in Tanzania. The first example is the Sukuma tribe, one of the largest tribes in Tanzania that traditionally killed babies with albinism as soon as they were born. The babies’ remains were used for witchcraft rituals as advised by witchdoctors. This practice was stopped and children with albinism were spared from this practice and allowed to grow into adulthood so that they can be buried alive with the Sukuma chief when he dies. This practice was used as the supernatural escort of the chief into the afterlife. As a result, the number of PWA increased because chiefs die only occasionally (Under the Same Sun, 2012).

Among the Chagga of Tanzania, babies with albinism were left in the bushes or forests to die, while among Tanzania’s Digo people, babies with albinism were dropped into a lake that ran through the famous Amboni caves. Once dropped there, the parents and supporters waited to see if the child would emerge on the right side of the lake, in which case it is believed that the baby would emerge alive. If the child emerges on the left side of the lake, it is believed that it will emerge dead. Among the Masai in Kenya and Tanzania, children with albinism were placed on the floor of the exit gate of the cattle barn. When it was time for the cattle to graze, the barn's gate was opened, and the hungry cattle hurriedly exited the gate by trampling on

the child. If the baby survives the ordeal, it was proven to be the child of the father, so he or she was allowed to survive. Otherwise, the death of the child proved the opposite.

Ntinda (2011:244) explains that in the past, PWA were also killed in certain Namibian communities and their body parts were used for 'muti' (witchcraft practices), and each part of the body had its own use and meaning. For example, if the eyes were used for 'muti' it means your boyfriend/girlfriend or husband/wife will never cheat on you again. If the legs were used, it means that the user will be a womaniser, while if blood, hair, nails, sexual parts and breasts were used, the user will be rich.

In recent years there have been reported incidents for the killing of PWA in Africa for what is believed to be witchcraft practices. Under the Same Sun (2015) in a study titled 'history of attacks against persons with albinism' focused in Southern Africa because that where the attacks against PWA are uniquely qualified by witchcraft involving the use of human body parts as known as *juju* or *muti*. This practice started in Sukumaland, a region in the north-west of Tanzania where 'PWA are killed for their body parts to be used for witchcraft, prevention of rain, healing of HIV and AIDS, and increasing wealth and prosperity in life' (Simpson, 2015:1). In 2015, the United Nations reported six incidents of the murder of PWA in Malawi. The Association of PWA in Malawi estimates that more PWA have been targeted. It has recorded eleven attacks in Malawi since December 2014, 'six of the abducted victims were killed; while others either escaped or were rescued' (Tenthani, 2015:1).

Furthermore, the Namibia Press Agency (Nampa) and Reuters (2016:28) report that the Malawian police have recorded that 'at least 69 crimes against people with albinism have been documented in Malawi since November 2014'. 'In the past 19 months, authorities in Malawi have recorded the murder of 18 albinos and the abduction of five others, even though the number could be more than that quoted in official police statistics because of the increasing attacks in secretive ritual performances in rural areas that are probably never reported'. About 19 PWA have been killed in Burundi since 2008 (Simpson, 2015:1).

In 2010, in the Democratic Republic of the Congo, two persons were sentenced for the murder of a person with albinism. According to available information from Côte d'Ivoire and Nigeria, two cases have resulted in convictions in each country (United Nations, General Assembly, 2013:11). Nampa and Reuters (2016:28) confirm that April 2016 has been the

bloodiest month for attacks on albinos in Malawi, with four people being murdered including a child younger than two. The child’s father and four other people were arrested.

Table 1 below presents evidence of the number of PWA who have been attacked or killed, those who have been mutilated, and those who narrowly escaped the attacks, as well as missing persons. The total number is 310 recorded in 23 African countries (Under the Same Sun, 2014:11). However, from the latest sources, the killings and attacks of PWA in Malawi have increased drastically; it is also evident that Malawi could be the country with the second highest rate of cases after Tanzania.

Attacks on PWA have increased in other African countries as well. Namibia Press Agency (Nampa) and Agence France-Presse (AFP) (2016:18) report that recently, Under the Same Sun, a Canadian charity, has documented 457 attacks on PWA, including 178 murders in 26 African countries.

It can be seen from the table (below) that people in African countries have gone to the extent of committing grave robbery. This is affirmed by Thuku (2011:10) who mentions that, even in death, PWA cannot rest in peace in some parts of Tanzania because organ hunters always desecrate their graves and rob them of their body parts. This has resulted in families burying the victims inside their houses or cementing over their graves.

Information in the table below was provided by (Under the Same Sun, 2014:11).

Table 1.1: Evidence of attacks of PWA in Africa

	Killed	Survivors*	Grave Robbery & others**	TOTAL	Most recent record
Benin	2			2	2012
Botswana		3		3	1998
Burkina Faso	2	6	1	9	2012
Burundi	17	7	4	28	2013
Cameroon	2	1	4	7	2013
Democratic Republic of Congo	7	16	4	27	2013
Egypt			1	1	2011
Ghana		1		1	2009
Guinea	2	4	3	9	2013
Ivory Coast	6	9	6	21	2013
Kenya	4	8		12	2013
Malawi		2	1	3	2013
Mali	2	2	4	8	2011
Mozambique		1	1	2	2009

Namibia	1	1		2	2012
Nigeria	4		4	7	2013
Rwanda			1	1	2013
Senegal	3	3	1	7	2011
South Africa	1	1	2	4	2013
Swaziland	2	7		9	2013
Tanzania	72	49	18	1	2013
Zambia	1			1	2011
Zimbabwe	1		1	2	2012

Tenthani (2015:1) reports that PWA live in abject fear in Africa, some no longer dare to go outside, and many children with albinism have even stopped attending schools because of their fear of being attacked and killed for their body parts. These scenarios are only some of the plights that PWA or their parents go through. The killing and stigmatisation of, and discrimination against PWA in Africa by fellow Africans have prompted the United Nations General Assembly to react to the situation by proclaiming 13 June as the International Albinism Awareness Day with effect from 13 June 2015. According to the United Nations, General Assembly (2015:14), ‘this date is symbolic since it provides a platform through which stakeholders can raise public awareness on this pressing human rights issue’. The United Nations also recognises the importance of an increasing awareness and understanding of albinism in the fight against the global stigmatisation of PWA.

These examples of stigmatisation provided by Schühle (2013:8) include a popular myth in Tanzania that the white skin of an infant born with albinism is attributed to the fact that the mother had been sexually involved with a white person. On the other hand, in Malawi, the condition of albinism is thought to be contagious. The common myth is that if a pregnant woman sees a PWA, she will give birth to a child with albinism as well. It is believed that to prevent this from happening, the pregnant woman must spit on the ground to break the curse. Ntinda (2011:245) explains that in Zimbabwe it is believed that having sex with a woman who has albinism will cure a man from HIV and AIDS, and unfortunately this has resulted in many women with albinism being raped and being infected with HIV.

In addition to the myths, some people believe that it is a curse or punishment from God when one conceives or gives birth to a child with albinism. Under the Same Sun (2012:15) further narrates that PWA are generally not seen as fully human but rather as incomplete beings or animals. In Tanzania, PWA are referred to as ‘Zeru-Zeru, meaning ‘ghost’. They are also referred to as a ‘deal’, meaning the source of money. In South Africa, PWA are called ‘apes’.

Chitosi (2015:2) indicates that ‘contrary to all these beliefs, albinism is not infectious’. It is a genetically inherited condition that is very rare and worldwide. The apparent lack of knowledge about human albinism in many African societies gives an impression that African society is not aware that the condition also exists in animals such as whales, lions, bats, birds, snails and cockroaches (Chitosi, 2015).

Despite these myths, there are African ethnic groups that embrace albinism. For instance, in Mali among the Bamana and Manika, to give birth to a baby with albinism is considered tantamount to having twins. In Namibia, particularly among the Oshiwambo and Herero, babies with albinism are considered a special gift from God, given only to those who are blessed. Supporting this view, Ntinda (2011:244) purports that ‘some see children with albinism as a gift or blessing because such children are believed to have magical power or can tell the future’. It is also believed that having a spouse with albinism brings luck in one’s life.

Although there are many beliefs associated with albinism, most PWA are loved and treated kindly by their family members. In affirmation, Braathen and Ingstad (2006:607) note that PWA come from loving homes; the problem occurs mostly during their interaction with strangers. One of the interviewees in the Braathen and Ingstad study confirms that she had experienced difficulties in her childhood when interacting with strangers, but her parents treated her equally to her siblings and they loved her very much. Baker et al. (2010:170) indicate that beliefs surrounding albinism in southern Africa often arise due to a lack of knowledge about this condition.

Although many studies have been carried out and documented about albinism, most of them have not been communicated to the public, particularly to people in rural areas who are often neglected or receive information very late, yet it is them who mostly have a low level of education. This situation could be attributed to the limited dissemination of information in appropriate format and packaged for public consumption. This consequently contributes to the continued misunderstanding and lack of knowledge about albinism. This lack of knowledge is because very often, information about albinism is only disseminated through the media on the days that albinism is commemorated, yet the challenges faced by PWA exist each and every day. This notion was confirmed by Chitosi (2015:2), who states that attacks of PWA in Africa are engendered by the lack of knowledge, which surprisingly also exists even among medical professionals.

Even though there are numerous albinism-related challenges in southern Africa, the condition can be effectively managed by the availability of appropriate health information, eye-care facilities and the provision of skin protection creams (Baker et al., 2010:169–170). In their study on oculocutaneous albinism in an isolated Tonga community of Zimbabwe, Lund, et al. (1997:3) conclude that there is clearly a need for affected subjects to be alerted about available health facilities, and to have information about albinism that will enable them to manage and understand this condition. Masanja, Mvena and Kayunze (2014:24) note that for the society to change its attitude, myths and superstitions toward PWA, awareness should be created among young people, to widen their knowledge on albinism. This awareness will help young people to not grow up holding on to cultural beliefs that contribute to the killing of PWA.

1.2.2 Albinism from a Namibian perspective

Namibia has a population of about 2.1 million people. This includes 1 206 PWA, of which 619 are females and 587 are males (Namibia Statistics Agency, 2011:53). Recently, the chairperson of Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA) was quoted in a local daily newspaper that the figure of PWA in Namibia stands at 1 800 (“Eva Ndatipo comfortable”, 2015:12). These figures prove that there are people with this condition in Namibia, and this study is relevant to the Namibian community.

In the past, especially before Namibia gained independence, many babies who were born with albinism were killed by their parents who did not want them. Some parents had gone to the extent of killing more than one child if they were born with albinism. This was also practised in other African countries, as Thuku (2011:3) confirms that ‘it is this stigma that led to the killing of Esther Moraa, a Kenyan child born with albinism, by her mother in August 2010’. ‘While in court, the mother claimed that her husband convinced her to kill the baby because she was born with albinism and thus should be considered a bad omen and disgrace to the family’.

Non-governmental organisations that deal with the welfare and plight of PWA in the country include the Namibia Association Albino Trust (NAAT) that provides information and support to PWA, as well as to educate the nation about albinism. Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA) is involved, more specifically, in cancer prevention and skin treatment for PWA. Its primary concern is the survival of people with albinism and supporting their livelihood and welfare by supplying them with protective

clothing, sunscreen and relevant information aimed at preventing sun-related cancer, its complications, and early death (SINASRA, 2014:1).

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

Namibia Statistics Agency (2011:53) defines a disability as ‘the long-term physical, the psychological or mental condition that limits persons from carrying out everyday activities at home, school or work’. Tilley (2009:17) defines disability as ‘the condition that results from disadvantage, discrimination, or exclusion of people who have the medical condition(s) that directly or indirectly limits them or is used by others to limit their participation in any aspect of the society’. Meanwhile, the United Nations General Assembly (2016:10) explains that the term ‘person with disability’ has a broad scope, and it includes any person with a long-term physical, mental, intellectual or sensory impairment that may hinder his or her full and effective participation in society on an equal basis with others. Additionally, Maclachlan et al. (2012:2) define vulnerable people as ‘a social group that experiences limited resources and consequent high relative risk for morbidity and premature mortality’. This may include children, the aged, ethnic minorities, displaced people, people suffering from some illnesses, and persons with disabilities.

As mentioned earlier, as in other African countries, there have been reported incidents of killings of PWA in Namibia. The chairperson of SINASRA was quoted in a local newspaper that three babies with albinism have been killed in Namibia for purposes of ‘witchcraft’. He could not, however, divulge more information on the issue due to its sensitivity (Kapitako, 2014:4). In 2012, it was reported that one person with albinism was killed, while the other

survived the attack (Under the Same Sun, 2013:11). Although there are currently a few reports of PWA being killed for their body parts in Namibia, Namibian PWA in general still feel safe compared to those in other countries, hoping that the killings of and attacks on PWA in other African countries will not spread to Namibia. As Beukes (2015:4) laments ‘we all cannot help to wonder if the killing of PWA will not spill over to Namibia’.

1.2.3 Khomas region

The Khomas region (KR) is one of the 14 administrative regions of Namibia. The capital city of Namibia, Windhoek, is located in the Khomas region. Compared to other regions, it has a superior transportation infrastructure, and well-developed economic, finance and trade sectors. Khomas region consists of ten constituencies, namely, Tobias Hainyeko, Katutura East, Khomasdal North, Soweto, Samora Machel, Windhoek East, Windhoek Rural, Windhoek West and Moses ǀGaroëb. The Namibia Statistics Agency (2011:7) indicates that Khomas region has a population of 342 141 people of which 160 have albinism. Although Khomas region is geographically small, it is the most populated, due to immigration for employment opportunities and better living standards.

The National Planning Commission (NPC) (2007:1) indicates that Khomas region is the only region that has a dominant urban character, as six of the regions and seven constituencies lie within the urban area of Windhoek. The main urban centre of the region is Windhoek, the administrative, legislative and judicial centre of the country. Head offices of various ministries, as well as headquarters of banks, financial institutions, and other private sector companies, are found in Khomas region. Like any capital city, the region has a rich mix of cultural and ethnic groups; the predominant languages in Khomas region are English, Afrikaans, German, Oshiwambo, Nama/Damara, Otjiherero, and Portuguese (National Planning Commission, 2007).

Khomas region was chosen for this study because it is where the researcher currently resides. Khomas region is also the region where the capital city of Windhoek the capital city of Namibia is located, making it the most densely populated region. Most of the government services are found in Khomas region, which makes it easier for the study to establish if PWA in the region are aware of different services available that they can benefit from. Since the present study is the first of its kind in Namibia, it seemed more appropriate for the researcher to start in Khomas region in order to provide a baseline for future studies in other regions.

Khomas region was also chosen as the starting point because it is likely to find PWA from various ethnic and socio-economic backgrounds in the capital city.

1.3 Research problem

Although the government of Namibia and non-governmental organisations are taking care of PWA, access to relevant information to address their specific conditions and problems is limited, especially among people in rural areas who sometimes deliver babies at home. At the time of this research, there was no study found on information needs of PWA, especially in Namibia.

This conclusion was made after an intensive literature search that was conducted on various databases such as EBSCOhost, IS Web of Science, Emerald and Google Scholar, and various search engines by using keywords such as information needs, information seeking, and information behaviour in combination with albinism, and using the Boolean operator AND (Annexure A is provided as evidence).

Seemingly, respective databases cluster the information needs of PWA with other user groups' information needs, even though they have unique conditions that might often trigger distinctive information needs. The one-size-fits-all approach to user information systems and services' design does not do justice to the conditions and nature of information needs of distinct user groups such as PWA. Moreover, information services in Namibia are managed mostly by library staff who may not be qualified nor fully understand the challenges of vulnerable user groups; therefore, they may lack the capacity to serve these people with sensitivity and empathy. Studies of this vulnerable group in Namibia include Beukes's (n.d.) study on the sociological practices of discrimination against PWA in Namibia and Ntinda's (2011) study on customary practices on children with albinism in Namibia. This study investigates the information needs of PWA in Khomas region, Namibia, using Moore's (2002) model of social information needs and Wilson's (1996) model of information behaviour as its theoretical framework.

1.4 Objectives

The main objective of this study was to investigate the information needs of PWA in Khomas region, Namibia, in order to inform the design of their information services. The objectives

were adapted from Moore's (2002) model of social information needs, and Wilson's (1996) model of information behaviour; the study specifically sought to:

- Ascertain the information needs of PWA, including the kind of information needs they have;
- Establish which mechanisms PWA use to seek information that meets their information needs; and who initiates their information activity;
- Identify the challenges PWA in Khomas region face daily when seeking information; and
- Determine information services that are appropriate for PWA in Khomas region.

1.5 Research questions

Based on the objectives of the study, the research questions are as follows:

RQ1: What are the information needs of PWA and what kind of information needs do they have?

RQ2: Which mechanisms do PWA use to seek information that meet their information needs and who initiates their information activity?

RQ3: What are the challenges facing PWA in Khomas region daily when seeking information?

RQ4: Which information services are appropriate for PWA in Khomas region?

1.6 Significance of the study

As indicated earlier, in Namibia, the rate of PWA falls in the same category as people with a disability because they are usually visually impaired. Adetoro (2010:1) indicates that virtually, in all countries, it has been realised that persons with visual impairment (PVI) need information as much as sighted persons. Persons with visual impairment need information to function effectively as human beings; hence, the increasing advocacy for equal access to information for PVI in recent years.

The study is important to the PWA community in Namibia, the government of the Republic of Namibia, and the National Disability Council (NDC) because it provides an insight on the kind of information that PWA need. The study might help the government, the National Disability Council, as well as library and information services to come up with strategies on how best to meet the information needs of PWA.

It is envisaged that the study will help to improve the strategies used by the organisations dealing with albinism in Namibia to see if they are really doing enough in terms of serving PWA with information. Moreover, the study is also important to provide a Namibian perspective on the kind of challenges that PWA face daily regarding accessing the relevant and critical information timeously. Hopefully, the findings of the study will serve as an eye-opener to policy makers to formulate policies that ensure that PWA have access to information in appropriate formats. Finally, the study will benefit other disciplines and their associated institutions, such as health and education to serve PWA better.

1.7 Limitations and delimitations of the study

Research projects experience some challenges in one way or another therefore; this part of chapter one presents limitations and delimitations that impacted the study.

1.7.1 Limitations

According to Simon (2011:2), 'limitations are potential weaknesses in a study that are out of the researcher's control'. It was further explained that every study, no matter how well it is conducted and constructed, has limitations, and these limitations sometimes affect the end result and conclusions that can be drawn (Simon & Goes, 2013).

The main value for snowball sampling is to obtain respondents who are few in number or where some degree of trust is required to initiate contact (Atkinson & Flint, 2001). The study applied snowball sampling for that reason; the study only accessed PWA who were known and approached by the researcher to take part in the study. Furthermore, not all PWA and parents of CWA 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 were informed that researcher has CWA as well.

Since the study is a case restricted to Khomas region, the findings may not be generalised to PWA in the whole country. Furthermore, Simon and Goes (2013) explain that case studies may be suggestive of what may be found in similar organisations, but additional research would be needed to verify whether findings from one study could be applied elsewhere.

Another limitation is the lack of previous studies on the information needs of PWA with a focus on Namibian. Therefore, the researcher relied on 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.

1.7.2 Delimitations

Delimitations are those characteristics that define the boundary of the study (Simon, 2011:2). According to Simon and Goes (2013), delimitations can be controlled by the researcher, and they include selecting objectives of the study, research questions, theoretical framework, the population of the study and so forth. The study was only limited to Khomas region, where the researcher resides, therefore it was easy to gain access to participants due to a familiarity with the region and the organisations that deal with the plight of PWA in the country (the researcher is a member of the board of the organisations). The study was also limited to semi-structured interviews and auto-ethnography as the only methods of collecting data.

1.8 Brief definitions of concepts

Albinism: ‘is a genetic condition in which a person lacks the gene for producing melanin - the pigment that protects the skin from the sun’. People with albinism lack pigmentation in the skin, hair, and eyes (Tanzanian-German Programme to Support Health 2008:9).

Information needs: these have been defined ‘as the needs that arise when a person recognises a gap in his/her state of knowledge and wishes to resolve that anomaly’ (Nicholas, 2000:20).

Information seeking: ‘is a conscious effort to acquire information in response to a need or gap in your knowledge’ (Case, 2012:5).

Persons with albinism: ‘persons with albinism’ is the term preferred to ‘albino’, because the former puts the person before the condition rather than to equate him/her to it (Under the Same Sun, 2014:6).

Visual impairment: is a term used for people who have some degree of sight, but who have, for example, limited range of sight with spectacles, or who are squint and need special lighting to be able to see, who have cataracts or who have tunnel vision (Howell & Lazarus, 2003 cited in Seyama, 2009:8).

1.9 Outline of the research report

The following is a detailed outline of the chapters covered in the study:

- Chapter one provides the introduction, which also includes how the research paper is outlined. It provides background information on albinism in Africa and Namibia. The chapter also provides an overview of the description of Khomas region, problem statement, objectives and research questions, significance of the study, limitations, and delimitations of the study, a brief definition of concepts, and the outline of the study.
- Chapter two consists of the theoretical framework, based on Moore's (2002) model of social information needs, and Wilson's (1996) model of information behaviour. This chapter concludes with a summary of insights gained from the two models.
- Chapter three reviews related literature of the study, that was carried out according to the dimensions of the social information needs model by Moore (2002) and Wilson's (1996) model of information behaviour. The chapter also includes the summary of the insights obtained from the reviewed literature.
- Chapter four explains the research design and methodology; research paradigm, the research approach and design, the population of the study, the sampling procedure, data collection tools, and the data analysis are all described in this chapter. In addition, the issues of validity and reliability, as well as ethical considerations, are discussed in more detail in this chapter.
- Chapter five presents the data analysis and presentation of the results from interviews and personal memory of the author. Data presentation is done according to the set objectives of the study.
- Chapter six discusses the major findings of the study, draws conclusions and makes recommendations for future studies in accordance with the objectives of the study.

1.10 Summary

Chapter one presents introductory information by stating the introduction and provides an overview of albinism both in Africa and Namibia. In addition, the chapter outlines the research problem, objectives and questions guiding the study, limitations and delimitations of the study, significance of the study, and the outlines of the dissertation. The chapter further provides definitions of concepts used in the study.

CHAPTER 2

THEORETICAL FRAMEWORK

2.1 Introduction

This chapter presents the theoretical framework of the study, based on Moore's (2002) social information needs model and Wilson's (1996) model of information behaviour. The first section of the chapter describes Moore's (2002) model of social information needs, and its role in the information needs of people with albinism that was adopted to provide the main theoretical perspectives regarding the information needs of people with albinism, which is the aim of the study. In addition, the model also serves as the guiding principle to construct the research questions. The second part of the chapter describes Wilson's (1996) model of information behaviour and the role it plays in information-seeking behaviour of people with albinism, as well as the mechanisms used to meet their information needs.

Troudi (2010:2) defines a theoretical framework as the intellectual structure that guides the study and informs the view of the data. A theoretical framework 'is a specific collection of thoughts and theories that relate to the phenomenon that one chooses to investigate; it is a conceptual starting point and frame of research' (Du Plooy-Cilliers, Davis & Bezuidenhout, 2014:55).

According to Du Plooy-Cilliers, Davis and Bezuidenhout (2014:55), a theoretical framework plays the following roles in a research project:

- It outlines the theoretical scope of the study, including what is relevant or irrelevant to the study.
- It provides a guiding principle and a specific perspective through which to examine a topic.
- It highlights the focus concepts of a study.
- It identifies key variables or aspects to include in the investigation of the topic
- It guides data collection, analysis, and interpretation.
- It provides identification of new and important issues or concepts to include in the study.

- It indicates the most critical research questions that need to be answered in order to improve an understanding of a particular phenomenon.

2.2 Moore's (2002) model of social information needs

Considering the research problem, Moore's (2002) model of social information needs is relevant for this study on the information needs of visually impaired people. The model has been used successfully to analyse social information needs in different situations. The model emanates from the literature review of information needs of visually impaired people, a condition that is prevalent among PWA. It was developed to provide a framework for analysing the results of over 75 reports of research related to the information needs of visually impaired people (Beverley, Bath & Barber, 2007:12). The model was also employed by the Royal National Institute of the Blind (RNIB) as a tool for analysing information provision.

Given that several studies have used the model for theoretical framing, this attests to its credibility and reliability in information needs' studies. For instance, Henry (2012) applied the model to investigate the needs for employment information of people with intellectual disabilities (PWID), while Tilley (2009) applied Moore's model to examine the information needs of people with disabilities. Similarly, Beverley, Bath and Barber's (2007:28) study concluded that the model provides a useful basis for examining the information behaviour of visually impaired people who seek information regarding health and social care.

The model comprises of six dimensions, but only three 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?
- Agents — who initiates the information activity?

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 the 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).

Because people with albinism are also citizens and members of society, they require access to information, in order to play their role as active citizens. The inclusion of people with albinism in society was emphasised by the United Nations (UN) Secretary-General, Ban Ki-Moon, who, on the 13 June 2016, called for all countries to end the discrimination that threatens the well-being, health, and life of people with albinism. He also urged countries to provide programmes that will enable people with albinism to play a complete role in society (United Nations News Centre, 2016:1).

Information for consumption is critical, as it influences the choices, such as about 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 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). All in all, people with albinism need information to function and execute their roles and responsibilities as citizens and consumers.

However, it has been noted in the literature and elsewhere in the world, especially in Africa, that people with albinism suffer from social exclusion and a lack of access to information is one of the contributing factors. Similarly, the United Nations Development Programme representative in Namibia (UNDP), while highlighting challenges experienced by PWD in Namibia, stated that ‘the challenges people with disabilities often face include little or no access to information, transport problems and unemployment’ (Cloete, 2017:7). Additionally, as it was indicated in the background to the study, PWA live in abject fear in African societies, due to beliefs and stigma associated with the condition.

According to Mulemi and Ndolo (2014:21), the social exclusion of people with albinism is due to an inadequate access to livelihood assets, such as income-generating work and assistance, information, education, health services and employment opportunities. It is evident that social exclusion is related to a conceptualisation of stigma that explains the predicament of people with albinism.

Rispel, Molomo and Dumela (2008:20) define social exclusion as the situation of being excluded from the mainstream of societal activities due to social factors. These scholars explain that people are socially excluded when they are unable to participate in a society that displays negativity towards factors such as disability and substance abuse, as well as towards ethnic minorities-marginalised groupings.

Marcon (2013/2014:50) affirms that the social exclusion of people with albinism occurs because these people seldom receive the necessary attention, health care, or treatment that corresponds to their health needs. Marcon (2013/2014) further explains that such social exclusion may be one of the reasons why people with albinism do not have access to opportunities offered by society. It appears that it is the social context and non-supportive environment that largely structures and limits the lives of people with albinism and prevents them from reaching their full potential.

It is worth noting when taking the above discussions into consideration, that PWA need social information to cope with challenges related to their condition. 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 challenges that they face on a daily basis because it is the type of information that can assist them to meet their day-to-day needs. It is for such reasons that most of the orphans and vulnerable children (OVC) acknowledged the importance of acquiring information in order to cope with challenges they face in their lives (Mnubi-Mchombu & Ocholla, 2011:8). People with albinism need access to social 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

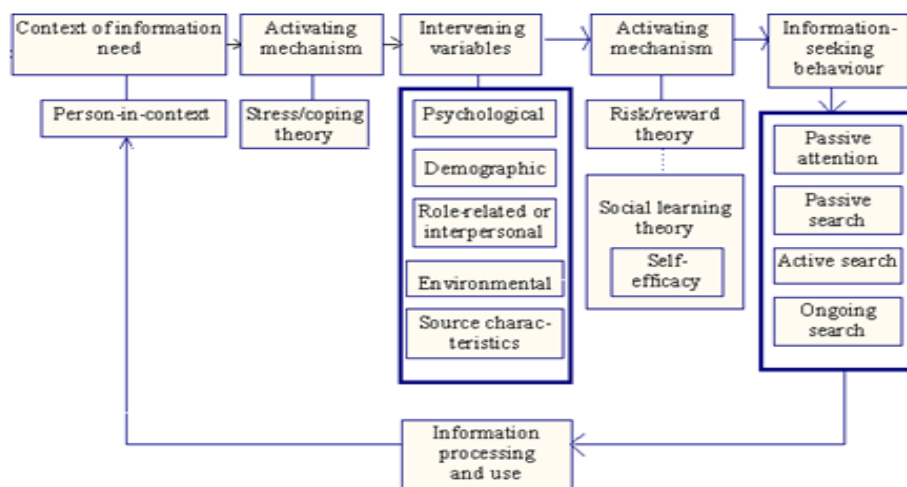
their lives. Hence, there is a need for stakeholders to take appropriate measures to promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information (Mannan, 2012:168).

2.3 Wilson’s (1996) general model of information behaviour

Wilson has developed a series of information-seeking behaviour models that attempt to integrate various information models (Wilson, 1981, 1996, 1997, 1999). Wilson’s 1996 model of information behaviour is one of macro-behaviour, but its expansion and inclusion of the theoretical framework models of information behaviour makes it a richer source of hypotheses and further research than Wilson’s earlier model (Wilson, 1999:257).

According to Beverley et al. (2007:13), Wilson’s (1996) model was not specifically developed with the information needs of visually impaired people in mind, but it was based on generic needs in general situations. Wilson (2007) remarks that the model is generic, and it is not only hospitable to a theory that might help to explain the more fundamental aspects of human behaviour, but also to various approaches to information- seeking behaviour and information searching. In this study, the model of information behaviour was used to address the research question on the mechanisms that people with albinism employ to seek information. Due to the relevance of the model, of particular interest for this study is the component of activating mechanisms. The study found the two sets of activating mechanisms illustrated in Figure 2.1 below relevant to the target group.

Figure 2.1: Wilson’s (1996) model of information behaviour



Source: Wilson (1999:257)

Uze (2016:245) explains that activating mechanisms in Wilson's (1996) model can be understood as the consideration of motivation that explains why people are motivated to seek information. Heinstrom (2003:3) further explains that motivation and interest influence the way information is used and critically evaluated. According to Robson and Robinson (2013:14), the activating mechanism in Wilson's (1996) model of information behaviour is potentially influenced by the stress/coping mechanism, or the risk/reward mechanism, social learning theory and intervening variables. In the view of the above, stress/coping and the risk/reward mechanisms motivated the target group to seek information.

2.3.1 Stress/coping mechanism

The stress/coping mechanism helps to unpack information-seeking and information-avoidance behaviours. This theory helps to explain why some information needs trigger information seeking and others do not. Stress is defined as 'the situation that exceeds a person's resources and endangers his wellbeing' (Folkman & 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 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.

Uze (2016:245) provides two coping mechanisms, namely, information seeking to reduce the uncertainty that causes the stress and information avoidance to escape the situation by denial. When people find themselves in this situation, they try to cope by seeking information from different sources in order to reduce the uncertainty they are experiencing. Alternatively, people may opt to cope without information.

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. In this case, people with albinism may choose to access information on the condition itself, including how to manage the condition, as well as on voluntary organisations or any available social assistance and intervention for them. On the other hand,

parents of children with albinism may also seek information on behalf of their children. Since children are often not aware that they are in need of information. What they experience is a problem - not yet identified as a need for information. It might be their parents who realise the need for information for the sake of their children. This is because, in most cases, people are motivated to acquire more information about a topic that fascinates them (Case, 2002:92).

Wan (2003:287) identifies the following coping mechanism used by people with albinism:

- The defiant — those who are quick to respond to insults and are forthright in asserting their rights.
- The activists — those who are involved in heightening public awareness about albinism in a positive light.
- The serenes — those who patiently explain their condition to others.
- The internalisers — those who resent mistreatment but internalise and assimilate the pain.
- The talkers — those who discuss their adversities with family and friends.
- The hiders — those who hide their disability to escape prejudice.
- The flamboyants — those who display themselves and publicly reveal their uniqueness.
- The positivists — those who have learned to accept albinism as part of their identity.

It is worth establishing the type of the above-mentioned coping mechanisms that the participants of the study use, because each of them presents a role or context that requires information.

An addition to the case of denial, scholars such as Case et al. (2005:2) indicate that people avoid information that is likely to cause mental discomfort or dissonance.

Moreover, a person may also avoid seeking or reading more about albinism to avoid the reality, especially when they are in the stage of denial. Chatman (1999) states that people are less likely to search for information if they do not feel that they require it. If members of the social world choose to ignore information, it is because they feel that they are coping without the particular information.

2.3.2 Risk/reward mechanism

The risk/reward theory is normally associated with issues of financial cost, for in setting out to search for information in any context; we may be risking not only financial resources but

psychological and physical resources (Wilson, 1997). This theory explains the situation whereby a person is motivated to search for information because the risk of not having the information seems high, or there is a reward or benefit if the needed information is obtained. For instance, preference given to health care professionals and the local society for the blind are the sources of information because the benefits or rewards appeared to be greater than the risks (Beverley, Bath & Barber, 2007:26).

2.3.3 Social learning theory

Bandura (1977) defines the social learning theory as a person's estimate that a given behaviour will lead to certain outcomes: 'an efficacy expectation is the conviction that one can successfully execute the behaviour required to produce the outcomes'. Bandura (1977) further explains that outcome and efficacy expectations are 'differentiated because individuals can believe that a particular course of action will produce a certain outcome'.

The social learning theory recognises that learning occurs in a social space, and that within that space, there is self-efficacy. That is the person's belief in his or her capability to perform a task or to attain a specific goal that may influence the way she or he seeks information.

Heinstrom (2003:3) states that the use of information systems does not only require technical skills but also a positive attitude and self-confidence, because information seekers can go through emotional aspects, such as frustration, impatience, information overload, resistance to new information, and computer aversion.

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 on people with albinism, who are already vulnerable and are likely to give up when experiencing frustration or anxiety.

Surrey Social and Market Research (SSMR) (2009:12) adds that, even though the information was available, it was not provided in suitable formats for people with visual impairments. So little or no choice was offered to patients, for example, information was not available in Braille or large fonts or any other suitable formats. In the context of this study, information seeking could be an unpleasant experience for PWA. Furthermore, Fourie (2008)

explains that in today's world, information is available in multimedia formats, but the challenge that faces information seekers is the ability to find such information and to utilise it meaningfully.

2.3.4 Intervening variables

Intervening variables to the information seeking process may be psychological (self-efficacy), demographic (sex, age, or level of education), role-related (being a parent of a child with albinism), environmental (social space or region that a person seeking information lives in, such as living in an area that brutalises people with albinism), and variables pertaining to the characteristics of the information source (its format, simplicity and authenticity). These variables may act as barriers to information-seeking or facilitators in some cases (Beverley, Bath & Barber, 2007: 26).

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 and feelings of insecurity, as well as the negative attitude of their society towards them may be a hindrance to information seeking because they might be afraid to approach those who possess required information

Masanja, Mvena and Kayunze (2014:24), in addition, discuss that intervening variables play a role in information seeking because their study found that awareness (knowledge) on albinism among those with the lower level of education was minimal. On the other hand, awareness increased with age categories and formal education level.

Demographic variables, such as gender, may also play a significant role in the search for information because mothers of children with albinism sometimes suffer rejection from their partners and family members, who blame them for giving birth to a child with albinism. As a result, information is guaranteed to play a crucial role in helping the mother to cope at that point in time.

Furthermore, it is evident from the model that information seeking can be an active, passive or an ongoing process. Wilson (1997:562) identifies the 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 for 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.

2.4 Insights gained from the models

The theoretical framework enabled the researcher to gain a better understanding of Moore's (2002) model of social information needs and Wilson's (1996) model of information behaviour. As a result, the following insights from the two models were carried forward. It was important to determine if the information for citizenship and information for consumption emphasised by Moore was applicable to PWA and the kind of information that they need. Additionally, it was worth determining who initiates the information activities of PWA in terms of seeking, provision and processing.

Wilson's (1996) general information behaviour was found necessary to understand the coping mechanisms applied by people with albinism when seeking information. Furthermore, Wan (2003) frames coping mechanisms for PWA that are likely to trigger different information needs and therefore it is important to establish these mechanisms in this study. Wilson's highlighted several intervening variables which serve as facilitators or inhibitors to information seeking. Therefore, the study determined how these intervening variables influence PWA when seeking information.

2.5 Summary

Chapter two explained the theoretical framework that guided the study. This was based on the two models, namely. Moore (2002) model of social information needs, as well as Wilson's (1996) model of Information behaviour. Moore's model was used as an overarching model of the study, while Wilson's model of information behaviour was used for exploring the mechanism used by PWA in order to meet their information needs.

CHAPTER 3

LITERATURE REVIEW

3.1 Introduction

This chapter reviews the literature relating to the information needs of PWA. The review of the literature is based on the research questions specified in section 1.5.

Creswell (2014:96) defines a literature review as a written summary of journal articles, books and other documents that describe the past and current state of information on the topic of a research study. Mertens (1998:34) explains that the aim of the literature review is to provide the reader with the overall framework to fit a piece in the ‘big picture’ of what is known about the topic from previous research.

Thus, a literature review explains the topic of research and builds the rationale for the problem that is studied. For this study, the literature review is conducted to ascertain studies that have been conducted by other researchers on the information needs of people with albinism (PWA), in order to address the critical questions for this study and inform the design of research instruments. In addition, a literature review is carried out to identify existing gaps that the current study attempts to fill.

3.2 Information needs

This section of the literature review examines the concept of the information needs of PWA in Khomas region, Namibia. Information needs have been defined as the ‘requirement that drives information seeking’ (Ikoja-Odongo & Mostert, 2006:147). Belkin, Oddy and Brooks (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’.

According to Taylor (2015:255), there are different types of information needs:

- Visceral need — the actual but unexpressed needs for information.
- The conscious need —the conscious, within-brain description of the need.

- The formalised need — the formal statement of the need.
- The compromised need —the question as represented by the information system.

Faibisoff and Ely (1974:3), explain that ‘information needs can be considered a generic concept then there are subsets which address information demands (or requirements) and information wants (or desires)’. These scholars further expressed that, there are individuals who can articulate demands and there are those who have a desire for information, but are unable to specify what it is that they ‘need’.

Nicholas (2000:20), however, warns that most people do not have information needs per se, but they rather experience challenges; these cognitive and emotional needs might be met by obtaining and then applying that information. Niedzwiedzka (2003:7) adds that the rise of a need is influenced by the context, which may be the person, or the role that the person plays in work and life, or the environment (social, political, economic, and technological).

In addition, Case (2002:76) acknowledges that an information need is rooted in more basic human needs, to the extent that humans have a ‘need to know’ is disputed. However, most scholars identified a secondary need that is less important than the basic needs for food, shelter, or companionship. An information need is said to be changing constantly with new and relevant sensory inputs, meaning that new questions emerge as old ones are answered, or partially satisfied (Case, 2002:76).

It seems evident that, one can simply conclude that an information need is what triggers information seeking with the purpose of solving a problem or finding an answer, filling existing gaps and dealing with ambiguity. Furthermore, it came to light that information needs are determined by the situation in which one finds himself or herself.

3.2.1 Information needs of PWA

As explained earlier, at the time of conducting this research studies on information needs of PWA had not apparently been done. Most of the literature found is on the information needs of people with visual impairment, evidence for this is provided in Annexure A. However, related literature to albinism in Africa was found primarily on their physiological condition, safety and health, particularly on attacks and killings of PWA in Africa. Thus, the discussion in this section would be based on the information needs of people with disabilities and other vulnerable groups.

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

Moore (2000:44) identifies eight clusters related to the information needs of visually impaired people. These clusters are also found to be appropriate for the information needs of PWA examined in this study. These include:

- The condition, its treatment, and likely outcome.
- Benefits and money
- Services and facilities
- Aids and equipment
- General health
- Mobility
- Housing and accommodation
- Employment, education, and training.

Rayini (2017:4) established that most of the information needs of visually impaired people were like other people's needs, with some exceptions. Similarly, Moore (2002:34) agrees that visually impaired people need all the information that fully sighted people need, to be well informed and able to participate fully as citizens. Additionally, Rayini's (2017) study found that participants sought information related to their visual disabilities and how to get around in normal life situations. Other information needs identified were health, income, and finances, recreational opportunities, government, consumer, travel and employment.

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

Tilley (2009:64) further expounds that this information may be 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. Similarly, Williamson, Schauder, and Bow (2000:14) found that participants need information about their disabilities and ways of coping with life activities.

However, information is not always accessible and does not always meet the needs of specific groups: one such group is people being visual impaired (Beverley, Bath & Booth, 2004:2). Hence, Beverley, Bath, and Barber (2011:258) explain that patients need appropriate information, for example, relating to their condition and 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 not only as a barrier to information but also to an awareness of what information is available. Similarly, Yusuf, (2012:1) found that the progress of modern societies, as well as individuals, depend a great deal upon the provision of the right kind of information, in the right form, at the right time. A study by Lund and Taylor (2008:4) found that for effective health communication, relevant information must be both accessible and usable, participants in the study indicated that they receive messages to reduce their exposure to the sun and wear a hat all the time.

3.3 Form -- of information people need

This section explains the concept of the kind of information that PWA in Khomas region, need. Regarding information choice and preferences, Wyke, Entwistle, France, Hunt, Jepson, Thompson and Ziebland (2011:5) reveal that people often need information about their health care options and the implications of decisions that are likely to affect their health. However, when faced with life-threatening illnesses, people do not only need help to interpret information but also require informed guidance to make decisions, as well as moral and emotional support (Fourie, 2008:9).

Furthermore, in a study on the health and education of children with albinism in Zimbabwe, Lund (2001:3) concludes that nearly all respondents wanted information on what causes albinism.

Similarly, Lynch, Lund and Massah (2014:7) conducted a study titled 'Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi'. This study endeavoured to collect primary data about the experiences of school children with

albinism in different education settings. The findings indicated that children who participated in the study expressed their willingness in finding 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’, and to learn about ways to cope with difficulties they may face at different stages of their childhood and early adulthood (Lynch, Lund & Massah, 2014:7).

Additionally, Lang (n.d.) compiled a list of frequently asked questions by PWA and their family members about albinism, some of those questions are listed below.

- What is albinism exactly?
- How do you stop her burning, and getting sunburnt?
- How does nystagmus affect her eyes?
- Which is the best sunscreen?
- Will she go to a special school?
- What benefits can she apply for?
- Can't she see properly and why she wears glasses indoor?

The questions posed in the studies above do not, however, harmonise with findings from a study titled ‘Labelling albinism: language and discourse surrounding people with albinism in Tanzania’, where a 19-year-old girl affirmed that even though she did not have any firm knowledge of what albinism is, she knew God created her as she was (Brocco, 2015:1147).

Cruz-Inigo, Ladizinki and Sethi (2011) noted that it is a viable idea for people with albinism and their parents to understand the causes of albinism, its medical and psychological implications, and how to appropriately protect themselves from ultraviolet radiation. Lund et al. (1997:735) 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, parents of a CWA in Brocco’s (2015:1148) study narrated how they looked at the white skin of their son and started wondering how it could have happened. However, after consulting several family members, they became relaxed and understood that their son is not different from other persons, but for his white skin.

In the light of the above a study by Research Works (2000:02) found that people with a disability need medical information that is related to their situation, treatments that they need, lifestyle factors, health services, and statutory support, because their situation raises many

psycho-social challenges that trigger information needs, such as information on how to deal with negative emotions, unanswered questions about self, low self-esteem, and dealing with strangers and 'cruel' peers (Research Works, 2000).

3.4 Agents initiating information activities

This section examines three agents who initiate information activity, namely: the information seeker, the information provider who plays a more active role in providing information, and the information processor who actively processes information on behalf of the user (Moore, 2000:12).

3.4.1 Information seeker

Pomerantz (1988:366) indicates that information seekers have options on how deep and wide their information-seeking activities should be, depending on their personality, the relevance of information and appropriateness in relation to their information needs. Case et al. (2005:6) argue that information seekers are concerned with the content of the information, not the channel through which it arrives and add that people generally have a strong preference for information that comes directly from other people that they associate with.

Henry's (2012:12) study found that participants obtained information from different sources, for example, one stated that 'I got employment needs from many different personal sources such as a friend'. The reliance on a personal information source is shown repeatedly in the results of the study and reinforces its importance. Similarly, findings drawn by Williamson, Schauder and Bow (2000), who revealed that the participants who lived with someone, usually a spouse, received a great deal of support, including information seeking, and even though they still used other sources, these are not used as extensively as those in the former group, where participants depended a great deal on friends and relatives, as well as organisations such as the Royal Victorian Institute for the Blind (RVIB) and Vision Australia, banks, and local councils.

Thus, Pomerantz (1988:366) explains that an information seeker has options as to how much or how little guidance to give a recipient with respect to what information is relevant and appropriate.

3.4.2 Information provider

Participants in Henry's (2012) study who provide information emphasised that, 'we are more information providers than anything else'. It was further argued among such information include providing information about the expectations of the service to potential employers and plenty of information around employment and training to people with intellectual disabilities and their caregivers. Tilley (2009), however, warns that providers need to be absolutely aware that persons with physical disabilities need access to information services that are designed to meet their specific needs. Physically disabled people, like the elderly, also need ready access to other information and advice services, such as those provided by the government available within the community (Tilley, 2009).

3.4.3 Information processor

Moore (2002:13) identifies many agencies that process information on behalf of users. Some of these agencies are libraries, such as public libraries, academic libraries, and special libraries that make available many resources within their collections that are already processed and easy to check. In addition to agencies that can assist people with albinism, low vision services or clinics, libraries for the blind and handicapped, closed-circuit radio reading and information for the blind, and special education services are useful, reliable agencies (National Organisation for Albinism and Hypopigmentation, 2015). Henry (2012:18-19) found that all people with intellectual disabilities who participated in the study were helped by their friends, family, caregivers and professional staff with processing employment information. Newspapers, journals, and radio stations are also important agencies for information about albinism or any genetics. These agencies obtain information from press releases and their own news-gathering activities, and then present it in user-friendly formats (Moore, 2002:13).

According to Fourie (2008:10), the need for a library includes books, videos, DVDs, and internet access, but some users find the library set up intimidating and overwhelming. This was confirmed by Preddie (2005:12), who noted that libraries did not appear to be a favoured source for information regarding genetics. It appears that people consult public libraries to acquire a better understanding of information that they had previously obtained. Public libraries can, however, play a role in terms of referring clients to appropriate sources, including medical libraries that can fulfil information needs regarding genetics (Preddie, 2005:12).

3.5 Mechanisms used by PWA to meet their information needs

This section of literature explores the mechanisms used by PWA to meet their information needs. Many theories of information behaviour have emphasised the issue of information seeking. One such theory is Wilson's (1996) model of information behaviour, which was found applicable to this study.

The model emphasises that generally, people seek and acquire information from different sources, which include formal and informal sources. However, it is very important to note that the way people engage in the information seeking process is determined by different factors. These include being employed or unemployed, and the level of education, level of impairment especially for PWA who have low vision, among other disabilities. Some PWA might seek basic information such as how to shield themselves from the sun, while others engage in advanced information seeking. These factors will also determine the use to which information is put. For PWA, these factors are crucial. For example Beverley, Bath and Barber (2007:26) have specified the degree and length of impairment and the presence of other health conditions and disabilities that may affect individuals with visual impairment information-seeking behaviour. Ikoja-Odogo and Mostert (2006:154) explain that in any information-seeking episode there are variables that positively and negatively influence information seeking.

On that note, Kingrey (2005:1) describes information seeking as the process that involves information searching, retrieval, recognition and application of meaningful content. Molen, (1999:239) explain that information-seeking behaviour is a strategy that many people use as a means of coping with and reducing stress throughout their cancer experience. For Brashers, Goldsmith and Hsieh (2002:258) the term 'information seeking' means different things in different contexts. Moreover, Williamson, Schauder and Bow (2000:15) argue that everyone has a different set of strategies for finding the information they need for their daily living. This includes life circumstances, such as being alone or having a family, working, being unemployed, or retired, the type of vision impairment involved, as well as individual information-seeking preferences, all of which influence the ways in which people seek, or incidentally acquire information (Williamson, Schauder & Bow, 2000).

According to Azadeh and Ghazemi (2016:26), several types of research have been conducted on individuals' information-seeking behaviours and patterns. They illustrate that researchers have applied different methods for gaining information under the effect of different factors.

Information needs can be individualistic; hence, the profile of the resources that participants draw upon depends on individuals (Beverley, Bath & Barber, 2007:25).

According to Niedzwiedzka (2003), however, Wilson suggests, not all information needs make a person seek information. For example, an individual does not engage in seeking activities if she or he is convinced that the knowledge possessed is sufficient to understand the situation and make an informed decision. Information avoidance may take several forms: not accepting, not using, not looking, and so forth. Underlying reasons for this behaviour have been proposed by Loo (2007:7).

Beverley, Bath and Barber's study (2007:25) found that participants prefer asking ophthalmologists more information about their visual impairment, where other participants chose to block any further information. Meanwhile, Williamson (1998:31) explains that, in most cases, information was purposely sought from family members and friends, but there were also many instances when respondents remembered acquiring information incidentally. Similarly, Mnubi-Mchombu and Ocholla (2011:10) found that most of the OVC in rural and urban areas in Namibia make use of radio and other sources, such as television, friends, relatives, teachers, and newspapers to obtain information. This view was clarified by Ikoja-Odogo and Mostert (2006:152) who suggest that information seeking does not always imply a purposeful activity, but it can also take place unintentionally. Information messages are communicated to society in every possible way, ranging from logos on every conceivable item, billboards, fliers, electronic messages, print, word of mouth, to satellite transmissions of events occurring worldwide.

Case (2012:100) mentions that information might be sought merely for stimulation or entertainment value, and sometimes it is encountered without being sought. Case (2012) further argues that some writers on information seeking assume it to be an intentional action: that is, for information to be any use, the individual must be consciously and actively looking for information. Furthermore, Williamson (1998:31) stated that, as with newspapers, most information from television and radio was acquired incidentally, rather than purposefully.

Mansour (2015:643) found that participants considered verbal over written, informal over formal, and undocumented over documented information channels and sources to solve problems relating to the everyday existence, using some helping tools and devices especially cell phones. Moreover, participants acquired information through conversations with friends, peers, colleagues in neighbouring households, either via the telephone or cell phone or

through face-to-face meetings, as well via the television (TV), and radio and newspapers and magazines (Mansour, 2015:643)

In their study, Palsbo and Kroll (2007:282) established that people, who have access to information through a variety of options such as the internet, sound or Braille, as well as exposure to information sessions such as those offered by churches and community groups perceived themselves informed.

3.6 Information services appropriate for PWA in Khomas region

This section examines the information services appropriate to meet the needs of people with albinism. Provision of information is one of the crucial factors that can help people with albinism to live peacefully without being subjected to any harmful actions, such as killing and discrimination. With access to information, people with albinism will know what is due to them. They also know that it is their right to access and use information. Additionally, with the information in hand, they will know that they are protected by the constitution, and in the context of this study, by the Constitution of the Republic of Namibia (amended 1998) [Namibia] of 21 March 1990, as any other citizens are recognised and protected.

Uganneya, Ape and Ugbagir (2012:89) define library and information services as library processes and activities with the aim of disseminating desirable information to library and information users. In other words, information services, in the most general sense, involve helping users to find information sources that meet their information needs. Seyama (2009) comments that the usefulness of services largely depends on the need one had at a given time, which was further influenced by degrees of sightedness and usability of the format of the sought information.

According to Moore (1997:281), it is very important to note that people with disabilities have needs that require the provision of special information services. First, they need information on a subject that relates to their disability. Secondly, they have a special access problem that calls for special provision. Thirdly, it is argued that information and advice to be fully effective, it should be delivered by someone who has personal experience of what it is to be disabled. Supporting this view are Lund and Taylor (2008:5) who argue that, rather than a didactic approach where information is delivered in a top-down manner by professionals, it is recommend or advocated, that a social learning approach for outreach programmes, support groups and workshops focusing on the management of albinism is introduced.

The following information services were identified by Mnubi-Mchombu and Ocholla (2011:12), namely, school/tuition fees exemption, as well as financial assistance, health services, and child care or support. Cruz-Inigo, Ladizinski and Sethi (2011:3) highlighted the following services as essential to people with albinism namely:

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

Furthermore, Tervahartiala (2015:6) reports that people with albinism in Namibia are entitled to the following services: free medical services, sunscreen, and information on how to lead a life without subjecting oneself to the harmful rays of the sun.

It is important to note that the effectiveness of information services depends greatly on the awareness raised by those responsible for serving them. This was supplemented by Nicholas (2000:97) that one can only use what they know, and what they have experienced or been trained in using. Similarly, Matingwina and Raju (2017:11) warn that successful dissemination does not entail effective dissemination, in other words, health information dissemination efforts should not be concerned with information reaching its destination, but it should focus on the effect of that information in facilitating a change in behaviour. Beverley, Bath, and Booth (2004:1) indicated in their study on the health information needs of visually impaired people that information has an important role in increasing knowledge and awareness among the public.

Lynch, Lund and Massah (2014:5) reveal that the dissemination of information about albinism is urgently needed, with more awareness among all stakeholders particularly those working in social protection, inclusive education, human rights, as well as community leaders, such as chiefs. Parents, particularly mothers, need to know where they can find much-needed support to help them protect their children and other vulnerable members of their family. It is in accordance with this explanation that Pain (1999:308) agrees that information concerning services and benefits are used predominantly, but there are instances of mixed benefits, usually because the services or benefits were not known about soon enough or not readily available, nor as comprehensive as had been hoped.

In a study about the information seeking by blind and sight-impaired citizens, Williamson, Schauder and Bow (2000) identified the following as useful channels for disseminating information, specifically, radio, audio cassettes and telephones have provided the main ways in which information was accessed by blind or visually impaired people. Similar conclusions were also made by Mnubi-Mchombu (2013:258) and Mnubi-Mchombu and Ocholla (2011:11), where respondents cited a wide range of platforms used to create awareness, such as meetings, ranging from community meetings to traditional meetings, such as church and school meetings, formal workshops and home visits by volunteers.

Furthermore, Brocco (2015) has stated that in Tanzania those channels whose primary language is in Kiswahili were used to reach out to the majority Tanzanian on issues of albinism, including national newspapers, radio and TV stations.

Lund (2001:5) found that radio talks and newspaper article were used to inform communities about albinism. The author further found that, the associations dealing with albinism issues in Zimbabwe may provide a central source of accurate and up-to-date information to PWA, their families, health care workers and teachers. Additionally, Lynch, Lund and Massah (2014:5) confirm that families in Malawi, who had access to the right clinical services, schooling (an example being a resource centres), and advice (TAAM), felt better placed to make decisions about their children's physical and emotional well-being and education. Similar conclusions are drawn by Pain (1999:307) who established that many of the parents joining a specialist voluntary organisation indicated that knowing others in a similar situation was helpful.

3.7 Challenges faced by PWA when seeking information

This part of the literature review explores the concepts of challenges faced by people with albinism. Generally, people with albinism have the challenge of poor eyesight, which, most of the time, prevents them from attending mainstream schools. There are very few special needs schools in Namibia, so learners with various disabilities are often grouped in one class. Most of these schools are usually under resourced and lacking information services, school libraries and the assistive devices for access to information. Brilliant (2015:224) concurs that people with albinism have very poor correctable vision, and as a result, they are disadvantaged in schools and in employment opportunities. At best, they are discriminated against, while at worst, they are hunted and often killed for their body parts for witchcraft

use. In most cases if they survive these attacks, they are very likely to develop skin cancer that is most often untreated, leading to a preventable premature death (Brilliant, 2015:224).

Mawere (n.d.) expressed that this stigma about albinism exists, has always existed, and it will continue existing, as if it is being passed on from generation to generation. This is, however, the sickening side of society, where information about albinism is either lacking or absent and that albinism is not a curse, a plague, or a disease.

Several studies have repeatedly stated that people with albinism face discrimination and barriers that every day restricts their participation in society on an equal basis with others. Due to these challenges, people with albinism, especially in Africa, are unable to enjoy the full range of human rights and the same standards of equality, rights and dignity as people without albinism (Gaigher, Lund, & Makuya, 2002; United Nations, General Assembly, 2016).

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

Additionally, factors that influence the challenges of accessing information, identified by Mnubi-Mchombu and Mostert (2011:402) include the lack of information channels that could inform caregivers on issues such as how to apply for grants for the OVC in their care, as well as a lack of funding when travelling long distances to access information sources. Mansour (2015:16) adds to these the lack of time to access information and lack of training and skills on how to access it as some of the challenges noted when investigating the information needs and seeking behaviour of domestic workers in Egypt. Moreover, the psychological burden suffered from the image of being house servants, and the lack of awareness about their basic rights, including the right to information, were other challenges disclosed by the study.

According to Lund (2005:171), a lack of knowledge among medical staff in approaching people with albinism with sensitisation or sensitivity is another challenge. It came to light that people, including health-care professionals, often avoid physical and social contact with those who are affected; it has been proposed that this social context largely structures and limits the lives of people with albinism, preventing them from reaching their full potential in a non-supportive environment (Gaigher, Lund & Makuya, 2002).

Furthermore, Omeluzor, Oyovwe-Tinuoye and Emeka-Ukwu (2017:445) mention that a lack of awareness of information sources can hinder access to information. Ugah (2007:1) further elaborates that information seekers and users may not know about the sources available, because the role of libraries has not been made clear to the information seekers. Beverley, Bath and Booth (2004:19) found the lack of knowledge on specific health topics, limited knowledge, as well as language and cultural barriers associated with ethnicity, community-level barriers, including social taboos and insufficient time, are some of the barriers identified in their study of health information needs of visually impaired people.

Ugah (2007:3) describes poor infrastructures as the basic framework for any information organisation. This scholar further argues that effective information access and use depends on communication facilities such as telephone, internet, telefax, computers and even postal services, as well as an adequate supply of electricity. Language limitations and illiteracy are among identified barriers that hinder access to information. A significant number of studies on information needs have found language as a barrier to accessing information (Chiwere, 2008; Mnubi-Mchombu & Mostert, 2011; Mnubi-Mchombu, 2013; Madumo, 2017). Fourie (2008) indicates that the comments of patients' and their family members' ability to understand the information and put information to use is not in a language accessible to someone who sells hamburgers for a living. A participant in the study remarked: 'I do not have [the] biology/physiology of the disease'.

Furthermore, Mansour (2015:16) also notes that illiteracy was one of the challenges faced by domestic workers when accessing information. This is a sentiment echoed by Masanja, Mvena and Kayunze (2014:24) who reveal that illiteracy is the main force behind the beliefs and attitudes toward albinism and PWA.

3.8 Insights gained from the literature review

The literature review has enabled the researcher to gain an insight into social information needs and a better understanding of Moore's 2002 model, as well as Wilson's 1996 model of information behaviour. After reviewing relevant literature, the researcher was able to address the following research questions.

- What are the information needs of PWA and what kind of information needs do they have?
- Which mechanisms do PWA use to seek information that meet their information needs and who initiates their information activity?
- What are the challenges facing PWA in Khomas region daily when seeking information? Which information services are appropriate for PWA in Khomas region?

The most important insight that emerged strongly from the literature and was carried forward is the desire that information needs are addressed. These include information for citizenship and consumption. The latter was important to inform the study about information on different products that are consumed by PWA in Khomas Region, Namibia.

This review of the literature revealed that organisations such SINASRA and NAAT need to make their services known to PWA. Therefore, the study will determine how these service providers disseminate information services to PWA. It also notes that people with albinism use different mechanisms to seek information. Some of these mechanisms were based on Wilson's (1996) model of information needs; therefore, the insight carried forward was to find out how intervening variables impact information seeking for PWA. It will also determine how PWA use information as coping strategy and what different search strategies used by PWA.

Another insight gained that was carried forward is that the agents who initiate the information activity, that is, the information seeker, and information provider as well as information processor as they have an impact on the mechanisms of information seeking. The literature presented several challenges that people with different disabilities face when accessing information. Given that people with albinism are considered as people with disabilities in Namibia, it is worth investigating whether they experience challenges like those presented in the literature, such as limited time to access information or lack of assistive devices to mention a few.

3.9 Summary

Chapter three reviews the literature related to the study. The literature review was conducted according to research questions adapted from some of Moore's (2002) dimensions and

Wilson's (1996) model. The objectives and research questions of the study were also adopted from the same dimensions. The following themes were identified, information needs of PWA, including the kind of information people with albinism need, an agent who initiates the information activity, and the mechanisms used to meet information needs. The next chapter discusses the research methodology.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 Introduction

This chapter provides a brief introduction to the research paradigm, approach and research design followed. It further explains the population, sampling method, as well as the tools used to collect and analyse data. This chapter also covers the issue of validity and reliability, as well as the ethics that the study took into consideration.

Research methodology is defined ‘as the systematic, theoretical analysis of the methods applied to a field of study, or the theoretical analysis of the body of methods and principles associated with a branch of knowledge’ (Rajasekar, Philominathan & Chinnathambi, 2006:05). In other words, the term research methodology refers ‘to the research methods, that is, the way in which data are collected and analysed, and the type of generalisations and representations derived from the data’ (Thomas, 2010:301).

4.2 Research paradigm

Willis (2007:08) views a paradigm as a set of general theoretical assumptions and laws, as well as techniques for their application that the members of a community adopt. This study has adopted the interpretivism paradigm in the context of Rowlands (2005: 81), who explains that the paradigm ‘assumes knowledge is gained, or at least filtered through social constructions, such as language, consciousness, and shared meanings’. The paradigm acknowledges the intimate relationship between the researcher and what is being explored, and the situational constraints shaping this process. The interpretivism paradigm tends to rely upon the participants’ views of the situation being studied, and it also recognises the researcher’s background and experiences (Mackenzie & Knipe, 2006:1). Thus, there are some unavoidable elements of bias in an interpretivism paradigm (Miles, Huberman & Saldana, 2014). It is deduced that the paradigm’s main idea is to understand the subjective meaning of a person, so the experiences and reflections of the researcher as a mother of two children with albinism was brought into the study.

The interpretivism paradigm supports the qualitative data collection methods and analysis. Qualitative methods are usually supported by the interpretivism approach, because it 'portrays the world in which reality is socially constructed, it is complex, and it is ever-changing' (Thahn & Thahn, 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.

Consequently, the paradigm was deemed appropriate for understanding the information needs of people with albinism in Namibia's Khomas Region. This is because the qualitative approach aims to attain rich and in-depth information, not possible to acquire by taking the quantitative approach that merely focuses on statistics.

Du Plooy-Cilliers, Davis and Bezuidenhout (2014:27) argue that within the interpretivism paradigm 'it doesn't make sense to study people in laboratory settings, as people do not live in laboratories, and as they are always influenced by the things that are happening in their environment'. This is because the goal of qualitative researchers is to attain an insider's view of the group under study. Antwi and Hamza (2015:220) echo this sentiment by indicating that, methodologically, constructivists and interpretivists do not believe in experimental or quasi-experimental research design.

Rowlands (2005:81) also argues that

Interpretivism does not pre-define dependent and independent variables, neither does it set out to test the hypothesis, but it aims to produce the understanding of the social context of the phenomenon, and the process whereby the phenomenon influences or is influenced by the social constructs.

This study was not set out to test hypothesis, neither do the research questions show variable dependency.

Following the elements of the interpretivism paradigm, this study focused on the information needs of people with albinism in Khomas region, taking the qualitative approach. The study explored the information needs of PWA in Khomas region through interviews. This is because interviews enable participants to obtain their interpretations of the world in which they live in, and to express how they regard situations from their own point of view (Phothongsunan, 2010:3).

In his study of the employment information needs of people with intellectual disabilities, Henry (2012: 10) acknowledges that many theorists of information needs and information

behaviour have advocated for the idea of context, and endorsed the principle that humans live in a socially constructed reality. A socially constructed reality is one of the major tenets of the interpretivism paradigm, which has been influential in information behaviour literature.

For instance, Henry's (2012) study on the employment information needs of people with intellectual disabilities shows that these needs are influenced by the interpretivism paradigm. Nyantakyi-Baah (2016) applied the interpretivism paradigm to investigate user perception of academic library service quality and value, the case being those of the Ghana Institute of Journalism and the Ashesi University College libraries. Garbutt (2014) in his master's thesis, views knowledge as socially constructed and understood in context. Thus, the research becomes the construction of meaning between the participants, one of whom is the researcher himself or herself (Phothongsunan, 2010:1).

Additionally, Thomas (2014: 300) argues that the purpose of the interpretive paradigm in information science is to produce an understanding of the context and the process whereby information science influences the context. In this study, the researcher, as a mother of children with albinism, and other participants of the study both constructed their own knowledge and reality by sharing the social information needs of people with albinism (PWA).

There are several limitations associated with the interpretivism paradigm. This kind of research can also be costly, since it takes place over a long period because of the need to carry out and describe an idiosyncratic observation (Shah & Al-Bargi, 2013:259). The researcher conducted face-to-face interviews herself, therefore spending some time with the participants to gain an in-depth understanding of their social information needs. By applying this paradigm, researchers 'want to see the world through the eyes of the person they are studying' (Du Plooy-Cilliers, Davis & Bezuidenhout, 2014:27).

4.3 Research approach

There are three major types of research approaches, and these include the qualitative, quantitative, and the mixed-methods approaches. Each of these approaches has its own advantages and disadvantages. Each research method is designed to explore specific research questions, and attempts to address the post-positivist approach of challenging the traditional belief of absolute truth (Williams, 2007:65).

The mixed-methods approach includes characteristics of both quantitative and qualitative approaches in a single study. The core assumption of this form of approach is that the combinations of qualitative and quantitative approaches provide a complete understanding of a research problem than either approach alone (Cresswell, 2014:4). The mixed-methods approach improves accuracy in the findings using different methods, to investigate the same subject. The approach enhances the findings of the study by providing a fuller and a complete picture of the aspects being studied (Denscombe, 2014:147).

The quantitative approach is a research approach where data is represented numerically, and in most cases, it is done through the experiment in the laboratory. The quantitative approach is concrete, with attempts to quantify social phenomena and to collect and analyse numerical data; it also focuses on the links between a smaller number of attributes across many cases (Antwi & Hamza, 2015:220).

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

The qualitative approach attempts to answer the why, how and what questions and it is a situated activity that locates the observer in the world (Denzin & Lincoln, 2008:4). Similarly, this study attempts to answer the questions outlined in chapter one. Denzin and Lincoln (2008:4) further explain that the 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 self.

4.3.1 The appropriateness of the qualitative approach

The qualitative approach was chosen because its characteristics were found to be appropriate for understanding the information needs of PWA in Khomas region. Furthermore, this approach uses various methods of gathering qualitative data, such as observations, interviews, focus group discussions, document analysis and auto-ethnography.

In addition, the rationale for choosing the qualitative approach in this study was because the researcher did not only construct what the information needs of PWA in Khomas region are, but was also interested in establishing the mechanisms used by PWA to seek information to meet their information needs.

As Madrigal and McClain (2012:2) point out, the qualitative approach provides information about users' behaviour, needs, desires, routines, uses, cases and a variety of other information that is essential in designing a product that will fit into users' lives. In addition, Creswell (2013:48) explains that the qualitative approach is used when researchers want to allow participants to share their stories, hear their voices, and minimise the power relationship that often exists between a researcher and the participants in the study.

Given that the study aims to ascertain the information needs of PWA, to inform the design of their information services, the qualitative approach was viewed appropriate. The approach enabled the researcher to hear the voices of PWA in Khomas region and allowed them to share their stories. This approach was followed so that the researcher does not overpower the participants in any way.

Furthermore, little is known about albinism, due to limited knowledge and the lack of research data, hence, a qualitative method was deemed appropriate because it enabled the researcher to attain rich data and first-hand information from PWA and those involved in their lives, such as board members of the Namibia Albino Association Trust (NAAT) and Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA). In affirmation, Braathen and Ingstad (2006:603) state that the qualitative approach is considered the most appropriate method to understand and explore the area where previous knowledge is very limited.

Patton and Cochran (2002:4) provide examples of research topics that the qualitative approach can address, such as people's experiences of health needs, health care, accessing care and keeping healthy and how experience, attitudes and life circumstances affect health needs and behaviours. The primary purpose of this study was to investigate the information needs of people with albinism, considering their social information needs, such as healthcare services, hospitals, and access to the availability of special aids, needed by PWA to protect their skin and eyes from the sun.

Thomas (2014:306) points out that the qualitative approach is most appropriate when the researcher wants to become more familiar with the phenomena of interest, to achieve a deep understanding of how people think about a topic, and describe, in detail, the perspectives of research participants.

There seems to be a common criticism levelled against the qualitative approach due to its inability to generalise the findings to a large research group, and that, most of the time, the sample of the study is not selected randomly. Defending this argument, Hancock, Ockleford and Windridge (2009:7) posit that, if the original research question sought an insight into a specific sub-group of the population instead of the general population, generalisation might not be necessary, because the sub-group is 'special' and different from a larger population. It was not necessary to generalise the findings to the entire population of people with albinism in Namibia in this study, because it dealt with issues faced by people with albinism in Khomas region, Namibia; perhaps circumstances in other regions in Africa may differ.

Ceswell (2014:105) defines a research design 'as the type of inquiry within the qualitative, quantitative and the mixed method approaches that provide specific direction for procedures in a research design'. A research design provides a plan on how data will be collected and analysed systematically to provide the answers to the specific research questions. Sarantakos (2013:121) clarifies that the type of research design used in a study is determined by different factors, such as the nature and purpose of the study, the type of population, the structure of the research, the number of researchers and research assistants, and the ideological affiliations of the researcher. This study combined the qualitative case study design and the auto-ethnography method to collect data.

4.3.2 Case study

Creswell (2013:97-98) defines a case study as 'the study of a case within a real-life, contemporary context or setting'. A case can be a programme, an event, or an activity bound in time and space (Thomas, 2014:309). Additionally, Matthews and Ross (2010:128) 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, Khomas region and Namibia as specific cases. A case itself must be pertinent to the research topic; the significance of the case is therefore in terms of its potential to produce data that will enable researchers to address their research question (Mathews & Ross, 2010:128).

As Zainal (2007:4) indicates, case studies are advantageous because they allow for data to be examined within a context of its use, meaning the situation within which the event takes place. A case study allows variations in terms of intrinsic, instrumental and collective approaches to collect and analyse both qualitative and quantitative types of data. Furthermore, a case study helps to explain the complexities of real life situations that might be difficult to capture, using methods, such as a survey and experiments. As a case study recounts a real-life situation, by rigorously describing the scenario in which the phenomenon occurs, it attempts to understand the phenomenon with its specific circumstances (Du Plooy-Cilliers, Davis & Bezuidenhout, 2014:179).

Given that the study employed the interpretivism paradigm, the case study provided the researcher with the opportunity to gain in-depth insight into the information needs of PWA and parents of (minors) children with albinism. Khomas region, Namibia, was selected as the case because of its familiarity to 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, hence, the researcher is already associated with albinism in the region.

Familiarity with participants is important because Fourie (2008) notes that in a situation where one is studying information needs and information behaviour of 'emotionally fragile', 'sensitive' or vulnerable participants, familiarity with the setting and the participants is essential because working with a familiar group in a familiar context makes it easier for both the researcher and the participants to build trust and to open up to each other, due to an established feeling of mutual understanding and a sense of security.

The disadvantages of a case study design, as highlighted by Zainal (2007:5), is that it is often characterised by the lack of rigour, and it provides little basis for scientific generalisation, since it has a small number of respondents. Furthermore, a case study is criticised for being dependent on a single case, thus making it difficult to reach generalisation conclusions.

4.3.3 Auto-ethnography

Auto-ethnography is a type of a qualitative research that combines autobiography and ethnography research methods. According to Butler (2009:295), auto-ethnography is a qualitative research methodology that emphasises a more personal, almost intimate, level of

study. Butler (2009) further explains that this methodology gives the researcher-participant the opportunity to explore past and present experiences while gaining self-awareness of his or her interactions and their socio-cultural effects. In other words, auto-ethnography may be defined as an approach to research and writing that seeks to describe and systematically analyse (graphy) personal experience (auto), to understand cultural experiences (ethno) (Ellis, Adams & Bochner, 2010:273).

Furthermore, Patton (2015:102) explains that

Auto-ethnographers focus outward on their social and the cultural aspects of their personal experiences, and then they look inward, exposing a vulnerable self that is moved by, and may move through refract, and resist cultural interpretations.

Auto-ethnography was applied to this study to share the researcher's reflections of her social information needs as a mother of two children with albinism.

As Ngunjiri, Hernandez and Heewon (2010:11) explain, auto-ethnography allows researchers to dig deeply into their own experiences, including the attendant emotions, in ways that may not be possible if they were being interviewed by someone else. Similarly, sharing one's own story of emotions, such as loss and pain, with participants, may create more empathy, which engenders more openness.

The use of auto-ethnography in this study was advantageous because it allowed for an easy access to data since the researcher recalled her own experiences as the source from which to investigate a phenomenon. The researcher represented herself, instead of being colonised and subjected to other people's agenda; it gave her an opportunity to tell her own story. Thus, the auto-ethnography method to many people represents the right to tell their truth as experienced, without waiting for others to express what they think, or what they would want to be known or understood (Mendez, 2013: 3).

In addition, Heewon (2007:11-12) indicates that auto-ethnography is a researcher-friendly method. In the sense that it allows the researcher to access the primary data source easily from the beginning because the source is themselves. The method is also an excellent vehicle through which researchers can understand themselves and others, and it has the potential to transform self and other participants toward cross-cultural coalition building.

This method was used to narrate the researcher's story with regards to social information needs of PWA that was triggered by giving birth to a child with albinism. Her own

experience affirms the view of Custer (2014:1), who commented that the process of auto-ethnography can uncover many different feelings within the writer. The feelings may be joyful, sad, revealing, exciting and, occasionally, painful. The researcher used this method to share emotions of confusion, loneliness and the excitement that she endured after giving birth to a child with albinism. As ‘this method promotes vulnerability, nakedness, and shame, to heal psychological and emotional wounds when individuals and society are receptive to the cathartic effects of famine energies’ (Custer, 2014: 3).

Custer (2014:9) further emphasises that auto-ethnography is a transformative research method that is valuable to science because it incorporates and even celebrates individuality. The method allows a researcher a unique way of understanding their intimate and influencing relationship with the research process itself.

Literature indicates that the auto-ethnography research methodology was adopted in studies where researchers explored personal life stories, and those who narrated their good and bad experiences of events that occurred in their lives. Researchers who used this method shared familial stories of people with special needs in their families and lives, such as people with visual impairment, people with physical disability, and people with some type of chronic disease, rare diseases and conditions. Auto-ethnography was also used by many researchers to talk about their individual experiences, including the emotional and psychological effects that they endured as part of an event that occurred in their lives.

Examples of such studies include ‘Easier Said than Done: Writing Auto-ethnography’ by Wall (2008), where she shared her story as a mother of an adopted child. Laas (2012) used this method to share her story, ‘Journey through the Trials and Triumphs of Disability’. Ettore (2005) narrated her story in ‘Gender, older female bodies and auto-ethnography: finding my feminist voice by telling my illness story’, using this method. Jenks (2005) used the same research method in her study, ‘Explaining disability parents’ stories of raising children with visual impairments in a sighted world’.

In view of the above, Anderson and Fourie (2015:4) acknowledge that many auto-ethnographic and collaborative auto-ethnographic reports appear in health sciences literature, and it is much neglected in information science research. Furthermore, Guzik (2014:4) also emphasised that in information science much time and effort is spent focusing on the

information practices of the users, but literature dedicated to our own information experiences is scarce.

The following studies are presented as exemplary auto-ethnographic methodology in information studies. Collaborative auto-ethnography as a way of seeing the experience of caregiving an information practice by Anderson and Fourie (2015). In addition, Anderson and Fourie (2015:3) applied this methodology for two reasons; first, as carers for a family member with a chronic, life-limiting illness or life-threatening disease, and secondly, as information practice researchers. Also in a study, ‘the place of a person in LIS research: an exploration in methodology and representation’ Michels (2010) applied auto-ethnography methodology as a doctoral student using an academic library. Furthermore, a study by Guzik (2013 and 2014), titled ‘representing ourselves in information research: a methodological essay on auto-ethnography’ also applied auto-ethnography.

Guzik (2014) concluded that not only is auto-ethnography a relevant methodology for information science on the ground of its capacity to cut across dichotomised territories of personal stories and social scientific scholarship, but it can also inform practice. According to Michels (2010) an increased awareness of our cultural assumptions can help us to interpret and analyse such assumptions in the context of professional practice.

In view of the above, Michels (2010:166) points out that:

The lessons we learn about our cultural and social contexts from reflexive approaches can assist in developing information technologies, programs, and services that can help rather than hinder the information experiences of students, faculty and other individuals who use or have yet to use resources and services provided by information institutions such as libraries and archives.

Even though this method is regarded as an emotionally powerful qualitative methodology, it also has limitations. The method is very complicated, since it is subjected to ethical questions owing to huge elements of bias. Consequently, auto-ethnographies have been criticised for being self-indulgent, narcissistic, introspective and individualised (Mendez, 2013:3–4). The researcher made every effort to honestly disclose reflections and experiences by guarding against being biased about albinism, but narrated her story as experienced. By so doing, both negative and positive experiences were shared. Given that her study takes a qualitative and interpretivist approach, bias is unavoidable and thus there is a link between the research methods used, the approach and paradigm. The study employed auto-ethnography through

the researcher's personal memory and interviews took place with people with albinism (PWA) and parents of minor children with albinism.

4.4 Population and sampling

4.4.1 Population

Bless, Higson-Smith and Sithole (2013:177) define population as 'the entire set of objects, or people who are the focus of the research project from which the researcher wants to determine some characteristics'. Brynard, Hanekom and Brynard (2014:57) argued that 'populations' 'does not refer to the population of a country, but to objects, subjects, phenomena, cases, events and activities or cases which the researcher wishes to study in order to establish new knowledge'. Furthermore, it was explained that finding the study population involves two processes. First, specifying the characteristics of the collective units required, and then specifying those of the individuals (s) required within them (Ritchie & Lewis, 2003:87).

According to Namibia Statistics Agency (2014), the population of people with albinism in Khomas region is estimated to be 160. This figure is based on the Namibia Housing and Population Census of 2011. Therefore, the population of this study refers to all people with albinism from different constituencies of Khomas region, and parents of children with albinism. The population was chosen as it was regarded as the appropriate group to provide rich and relevant information in regard to information needs of people with albinism.

4.4.2 Sampling

Matthews and Ross (2010:153) define sampling as the selection of some cases from a larger group of potential cases. Sampling is the process of selecting a few people from the population, who will take part in the study. Sampling is important in both quantitative and qualitative approaches, including case studies. According to Punch and Oancea (2014:210), even a case study, in which the case selection itself might be straightforward, requires sampling.

Applying sampling procedure was necessary, as Mfengu (2014:19) explains, 'it is easier to work with a fraction of the group because it is more manageable, and it helps to clarify and deepen understanding of the characteristics of parent population'. It was going to be time-consuming and very expensive to interview people with albinism (PWA) from all 14 regions in Namibia.

The study adopted a snowball sampling technique. This is a non-probability type of sampling. Non-probability sampling is used when it is impossible to determine who the entire population is, or when it is difficult to gain access to the entire population (Du Plooy-Cilliers, Davis & Bezuidenhout, 2014:137). In this instance, although the population was known, it was not possible to access the entire population of people with albinism (PWA) in Khomas region as some of them did not want to be interviewed.

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. The researcher is with this type of sampling likely to involve one or only a few people, whereby each of them can be asked to nominate some other people, who would be relevant for the research (Denscombe, 2014:42). Bernard (2006:192) affirms that the snowball technique makes use of key informants or documents to locate one or more people in the population.

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 & Flint, 2001:1). Bernard (2006:192) indicates that this type of sampling is appropriate for studying hard-to-find or hard-to-reach populations. Bernard (2006) further states that a population can be hard to reach because it contains very few members who are scattered over a large area; they are stigmatised and reclusive. This includes, for example, HIV patients who do not visit the hospital for treatment, or are members of the elite group, who do not care about a researcher's need for data.

Shaghghi, Bhopal and Sheikh (2011:87) define a hard-to-reach population as the 'sub-groups of the population that is difficult to reach or involve in research or public health programs, due to the physical and geographical location or their social and economic situation'. These sub-groups are sometimes referred to as 'hidden populations', which is defined as the population that does not wish to be found or contacted.

People with albinism may be categorised as a hard-to-reach or hard-to-find population because, as mentioned earlier in the background of this study, in many African countries,

people with albinism live in fear because they are stigmatised and socially excluded. In addition, there are very few people with albinism in Namibia, with only 1206 people with albinism countrywide and 160 people with albinism in Khomas region. Supporting these sentiments, Wan (2003:279) acknowledges that albinism is a rare condition; therefore, searching for participants with albinism is a difficult task, because there are few people with albinism in the society.

In Namibia, there is no formal list of names or a database containing names of all people with albinism (PWA) in the country and Khomas region in particular, so snowball sampling was the only option deemed appropriate. Even if there were such a list, it would be unethical to share it. According to Bless, Higson-Smith and Sithole (2013:166), when the necessary population lists are not available, non-probability sampling remains the only option for the researcher.

Furthermore, Rutten et al. (2005), in their systematic literature review, found that snowball sampling was often applied in situations where the researchers were not certain that the participants would be willing to participate in the study and that this was often in the context of vulnerable people and those in precarious situations. Thus, there was no guarantee that the researchers would be able to locate sufficient research participants, as some were not willing to participate in the study; hence, the application of the snowball sampling technique to identify respondents.

Atkinson and Flint (2001:4) provide the disadvantages associated with the snowball sampling method by claiming, first, that the quality of the data and a selection bias may limit the validity of the sample that is the primary concern of recent snowball sampling. This is because elements are not randomly selected but are dependent on the first accessed subjective choices of the respondents, most snowball samples are biased and do not allow researchers to make claims to generality from a sample.

Secondly, snowball samples are biased toward the inclusion of individuals with inter-relationships, and therefore will over-emphasise cohesiveness in social networks and will miss 'isolates' who are not connected to any network that the researcher is tapped into. The researcher consulted different organisations for the purpose of this study. These include NAAT, SINASRA, different regional councillors who made announcements on the radio for participants to come forth. The researcher also sent text messages to all contacts via her cellphones, asking them if they know anybody with albinism or any parents of children with

albinism. Furthermore, people were requested to identify possible participants through different WhatsApp groups, but only few responded positively, this included a WhatsApp group for PWA. All these were an attempt to obtain a larger sample.

4.4.3 Sample size

Connaway and Powell (2010:129) state that the number of sampling units selected from the population is called the size of the sample. It is not easy to determine the sample size in snowballing from the onset because the sample size is determined by the willingness of the participants. Data collection ended when there were no longer people willing to participate in the study and when the researcher was satisfied that she has accumulated enough data to help address the research questions: that is, reached saturation.

Sarantakos (2013:183) emphasises that saturation emerges out of data and not out of logical thinking and other calculations. Saturation is reached when the gathering of fresh data no longer sparks new insight or reveals new properties (Creswell, 2014:189). Edwards and Holland (2013:65) indicate that when research employs the interpretive or grounded approach, saturation is always mooted as the ideal guide for the number of interviews to be conducted.

An interview is regarded as one of the methods by which one's results can reach saturation (Fusch & Ness, 2015:1409), because in qualitative studies, as Edwards and Holland (2013:65) argue, the range of meaning should determine the number of interviewees in the study, and not the number in the sample representing types of people, as in quantitative studies. Patton and Cochran (2002:9) support this idea by indicating that sample sizes are typically small in qualitative work. In the interest of collecting rich data, the effort was made to solicit PWA of different age groups, education background, and tribes, which, however, determined by the willingness of participants. In addition, two people with albinism, serving as board members of two organisations dealing with albinism in Namibia, were interviewed as organisational participants. A total of 26 interviews were carried out, plus the researcher who narrated her lived experience of albinism.

Table 4.1: below presents detailed information on the sample size.

Female participants with albinism	8
Male participants with albinism	8
Female parent participants	5

Male parent participant	1
Researcher	1
Organisational participants	2

4.5 Data collection methods

According to Kajornboon (2005:1), data collection is an essential component of conducting research, and even though it is regarded as a complicated task, data can be gathered from several sources, including written documents, records, workplaces, the internet, surveys or interviews. It is, therefore, important to choose appropriate research tools for the study at hand to enhance the validity of the findings. Mathews and Ross (2010:181) define data collection as the practical activity — one that must be carried out within time, spatial and resource constraints.

Several factors guide researchers on the use of appropriate data collection methods. These factors include the nature of the research problem investigated and the characteristics of the research participants. The study used reflections and personal experiences through auto-ethnography and a qualitative case study design, whose data were collected through semi-structured interviews with PWA, parents of children with albinism, and the memory of the researcher.

4.5.1 Interviews

Mathews and Ross (2010:219) define an interview as a data collection method that facilitates direct communication between two people, either face to face or at a distance via telephone or via the internet. An interview is a type of conversation between two or more people. Du Plooy-Cilliers, Davis and Bezuidenhout (2014:189) elaborate that interviews are a form of conversation with the primary aim of obtaining information, based on open-ended questions. Generally, interviews allow the researcher to gain in-depth information to capture the deep understanding of participants' experiences, and to make room for further probing. Interviews are valuable sources of information, and if conducted correctly, they allow researchers to interpret and understand the meaning of participants to answer to specific questions (Du Plooy-Cilliers, Davis & Bezuidenhout, 2014:189).

Sarantakos (2013:298) comments that interviews produce a high response rate and they allow the researcher to observe non-verbal behaviour. In addition, interviews are easy to administer,

since they do not require a certain level of literacy from respondents because interview questions can be translated into the language spoken and understood by the respondents.

The limitations of interviews are that they can be expensive, time-consuming and are affected by the 'interviewer' factor and the possible bias associated with it. Interviews are less useful when discussing sensitive issues, and they can take place through various forms, such as structured, semi-structured and unstructured interviews.

4.5.2 Semi-structured interviews

A semi-structured interview is when the researcher has a list of questions or series of topics that they want to cover in the interview, but there is flexibility in how and when the questions are put, and how the interviewee can respond (Edwards & Holland, 2013:291). These types of interviews are mostly used to collect data in a wide variety of research designs, and it is mostly associated with collection of qualitative data when the researcher is interested in people's experiences, behaviour, and understandings, and how and why they experience and understand the social world in this way (Mathews & Ross, 2010:222).

Similarly, Bless, Higson-Smith and Sithole (2013:340) expound that qualitative interviews and focus groups discussions are nearly always semi-structured or unstructured because these formats encourage respondents to describe their experience with the least interference and influence from others. Semi-structured or unstructured interviews are flexible methods that, as indicated by Edwards and Holland (2013:30), allow the interviewee to talk from their own perspective, using their own frame of reference and ideas and meanings that are familiar to them. This type of interview does not only adhere to the interview schedule, but it allows for the researcher to prompt responses and probe deeper into the experiences of the interviewees. In this sense, issues that the interviewer did not think of might be brought up by the respondents.

Owing to the explanations above, the study made use of face-to-face semi-structured interviews, and the researcher collected data herself as she is familiar with the Khomas region and is already associated with albinism in the region. Semi-structured interviews were used because the study adopted an interpretative paradigm that is qualitative in nature.

Scholars such as Henry (2012), Beverley, Bath and Barber (2007), Fourie (2008) and Litzkendorf et al. (2016), all employed semi-structured interviews to investigate the

information needs of various user groups. In all these studies, it was noted that face-to-face interviews worked out well with vulnerable participants.

Interviews were carried out between 27 August and 8 September 2017 in Windhoek. They took place in different settings such as at a restaurant, library, the researcher's office, home or car, at the regional councillor's office and the participants' offices and houses. The interviews were conducted according to the interview guide presented in Annexures C to G. 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, 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 interviews were tape recorded with consent from participants (interviews were in English and Oshiwambo). Oshiwambo is a language spoken by the majority in Namibia, and many participants who took part in the study were from the Ovambo ethnic group. Interviews lasted between 20 and 40 minutes, depending on the willingness of the participants to talk. The majority of parents of children with albinism did not support the idea of interviewing their minor children, probably due to a lack of trust: only one parent allowed her two children to be interviewed. The same applies to the parents themselves, as the majority of those approached were not willing to participate in the study, some told the researcher to go interview herself since she has children with albinism and the experience is the same. Some preferred to be interviewed over the telephone as they did not want the researcher to visit their houses. Such visits never took place because they did not answer their cellphones. Some problems encountered in this study during the data collection were similar to those identified by Mnumbi-Mchombu (2013:103) during the data collection in the study titled 'Information needs and seeking behaviour of orphans and vulnerable children and their caregivers, and the role of service providers in Namibia'.

The researcher also observed that some parent participants only opened up after hearing that the researcher is also a mother of children with albinism. In the view of the above, Jenks (2005:149) explained that:

All the parents who have told their stories to me knew they were telling their stories to a parent who was also raising a visually impaired child in a sighted

world. While we have had different experiences, especially if our children are blind versus visually impaired, we are more similar to one another than we are to parents of fully sighted children. I believe that knowing I'm part of the culture of parents who are raising blind and visually impaired children affects the stories I'm told.

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 for them. 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.

4.5.3 Personal memory

According to Wall (2008:45) several researchers, such as Sparkes (1996), Ettore (2005) and Holt (2001), applied the auto-ethnography methodology, but they used different tools to collect data. Their tools include medical reports, diary extracts, newspaper articles, letters, articles, medical laboratory reports, journals, emails and memos.

In this study, data collection in auto-ethnography methodology was obtained through the personal memory of the researcher. Grbich (2013:123) describe 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'.

The researcher used her memory of the lived experience of albinism as a data collection tool. Through this process the researcher could use her memory to recall all the events with regards to her daughter and son who were both born with albinism in 2013 and 2016 respectively. The recalled events include events such as doctors informing her about her children's condition and the confusion she experienced because of lack of information about albinism at that point in time especially when her daughter was born. Other events include information provided by different doctors, for example, specialists and general practitioners that also assisted her in coping with and understanding her child's condition.

Heewon (2007:5) acknowledges that memory is both a friend and foe of auto-ethnographers. It is a friend in the sense that it allows the researcher to tap into the wealth of data to which no one else has access to, because the memory selects, shapes, limits and distorts, but the

memory also fades as time goes, blurring the vitality of 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 the tool to collect data, and states that the supervisory committee was not satisfied with her employing this type of data collection tool. She had thus to provide a justification for choosing the 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’. Wall (2008: 45) 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.

According to Ngunjiri, Hernandez and Heewon (2010:3), researchers, such as Anderson (2006), Holt (2003), Salzman (2002), and Sparkes (2002), acknowledge that there is a distinction between the researcher-participant relationships, which has become the source of criticism, challenging the scientific credibility of the methodology.

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, the researcher narrated her experience as objectively as possible, and the personal memory data were supplemented with data collected from interviews with other parents of children with albinism, because ‘auto-ethnographic accounts do not consist solely of researcher’s opinions, but they are also supported by other data that can confirm or triangulate those opinions’ (Duncan, 2004:31).

Grbich (2013:123) explains that collecting data through auto-ethnography is time-consuming, and it is an emotional and complex process that may involve researchers in the years of writing and rewrite, to gain distance from or to be closer to the data.

4.7 Data analysis

According to Hancock, Ockleford, and Windridge (2009:24), analysing data in a research project involves summarising the mass of data collected, and presenting the results in a way that communicates the most important feature. In qualitative analysis, data are also seen as ‘representations of human acts and utterances’, and documents are also seen as data (Sarantakos, 2013:365).

4.7.1 Content analysis

Data were analysed using content analysis. Hsieh and Shannon (2005:1277) explain that content analysis is one of the numerous techniques used to analyse textual data, and the content may be words —meaning, pictures, symbols, ideas, themes or any other communicated message. A text was defined as

Anything written, visual or spoken that serves as a medium for communication, which includes books, newspaper or magazine articles, advertisements, speeches, official documents, films or videotapes, musical lyrics, photographs, articles of clothing, websites, or works of art (Neyman, 2011:361).

Du Plooy-Cilliers, Davis and Bezuidenhout (2014:191) argue that ‘in doing a qualitative content analysis, the researcher is working in an interpretive paradigm with the goal of providing a thick description of the social reality mirrored in the text’.

Du Plooy-Cilliers, Davis and Bezuidenhout (2014:191) state that the strengths of content analysis are that it is an effective method, mostly when looking at narratives (stories) in texts such as journals, diaries, books, brochures, written documents, transcription, news reports and visual media. Du Plooy-Cilliers, Davis and Bezuidenhout (2014) further elaborated that the focus is on textual content, such as stories, written and spoken words, as well as visualised narratives. Transcription of interviews with open-ended questions and focus groups may be analysed insightfully through this inductive method. Content analysis was deemed a suitable method of analysing data in this study, as the method is regarded as an appropriate and effective method to analyse qualitative data.

The following tools, namely, themes and codes or categories were used to analyse data. Ziebland and McPherson (2006:408) explain that the ‘aim of coding or categorising is to make sure that all interview sections that are related under the same heading can be retrieved with ease’. The codes and themes were drawn from Moore’s (2002) model of social information needs, and Wilson’s (1996) model of information behaviour. Wilson’s model (1996) was employed to specifically look at the mechanisms used by PWA to meet their information needs. The themes were drawn from the research questions and 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 in Chapter 1 were identified: Function (why do people need information?); Form (what kind of information do people need?); Agents (who initiates the information activity?);

and Mechanisms (which mechanisms can be used to meet information needs?). Data were analysed manually.

4.8 Piloting study

According to Walliman (2006:90), a pilot study is a pre-test of an instrument or other types of surveys on a small number of cases before it is used on the entire population. The aim of pilot studies in qualitative research is to establish whether respondents are accessible, and the site convenient, and to determine whether the data collection tools or techniques would generate enough information. Pilot studies are done with the purpose of determining if the plan is well constructed and whether any changes or adjustment are needed (Sarantakos, 2013:266).

A pre-test was conducted using a person with albinism and parents of children with albinism to pre-test the semi-structured interviews guide. The pre-test was conducted at the beginning of August 2017, before the main study started on 27 August 2017. The consent form was signed by participants. Before the pilot study was carried out, the participants were informed that the interviews were carried out as part of piloting the research instruments, hence they should focus on how easy the questions were or whether rephrasing them was necessary. The participants asked for clarification with few questions, but according to the researcher, this does not mean that participants did not understand the questions, or the questions were ambiguous. They just needed some explanations since the concept of information needs is not easily understood by a lay-person.

4.9 Validity and reliability

According to Creswell (2014:201), validity refers to the situation where ‘the researcher checks for accuracy of the findings of the study by employing certain procedures’. It is one of the strengths of research, and it is based on determining whether the findings are accurate from various viewpoints that include research itself, the participants of the study, or the reader of an account of the research process. Engaging multiple methods, such as observation, interviews, and recording, led to a more valid, reliable and diverse construction of realities.

The study used auto-ethnography and case study designs so that personal reflections of the researcher as a mother of a child with albinism were used together with semi-structured

interviews with PWA, parents or guardians and key informants, and these are considered as multiple methods of searching and gathering data.

For auto-ethnographers, validity evokes in readers a feeling that the experience described is life-like, believable and possible and that what has been represented could be true (Ellis, Adams & Bochner, 2010). As mentioned earlier, the bias associated with qualitative research and auto-ethnography was acknowledged and an honest self-disclosure of the researcher's experience was carried out throughout the whole process.

However, Plummer (2001), cited by Ellis, Adams and Bochner (2010:10) clarifies that

What matters is the way in which the story enables the reader [listener] to enter the subjective world of the teller to see the world from his or her point of view, even if this world does not “match reality.

Truthfulness plays a very important part in auto-ethnographic studies. ‘Being truthful entails getting down to both participants and researcher’s emotional truth, and this would involve a fair amount of introspection in the field notes, journal entries and ultimately in the writing up of the stories’ (Raab, 2013:11).

Mendez (2013:3) cautions that this method requires honesty and willingness to self-disclosure. As the researcher is a mother of two children with albinism, and a respondent in the study she is thus aware that she might be accused of narrating her experience subjectively and selectively, even though she intended to honestly self-disclose her experiences.

Du Plooy-Cilliers, Davis and Bezuidenhout (2014:29) indicate that interpretivism does not believe in an objective external reality that is experienced by everyone, but it is rather a paradigm whereby reality depends on a person’s circumstances, culture, and experience, which might not be the same. Qualitative studies that are situated in interpretivism, therefore, are subjective and unique, so the reliability of the instrument producing the same results repeatedly is not a crucial issue.

Golafshanu (2003:601) argues that there can be no validity without reliability, so the study could not ignore incorporating the reliability aspect. Sarantakos (1998:83) refers to reliability as the stability of an instrument, in order to produce consistent results. A method is reliable if it produces the same results whenever it is repeated. The researcher is deemed, in this study, to be the instrument that was used to collect data, and she requires pre-testing through a pilot study to determine if she were to conduct the interviews consistently and to psychologically

prepare herself to collect data in a sensitive area. Fourie (2008) alludes to the importance of the psychological preparation of the researcher, where she/he feels emotionally connected to the setting.

4.10 Ethical considerations

The proposed study was designed and carried out in accordance with ethical standards. David and Resnik (2011:2) define ethics as ‘the method, procedure, or perspective for deciding how to act’. Ethics serve as the guidelines on how researchers should act and conduct themselves during the research process. Since human subjects were involved, it was necessary to obtain ethical clearance and permission to access the participants.

The researcher applied for ethical clearance for the research instruments to the Faculty of Humanities at the University of Cape Town, where she is registered for her master’s. Thereafter, the researcher sought permission from the Khomas Regional Council through the chief regional officer to conduct research in the region. The evidence that the researcher sought permission from both institutions is presented in annexures H and I.

The researcher sought permission to interview participants, parents, and guardians, and the parents were informed about the nature and purpose of the study. The researcher also requested permission to tape record the interviews. The participants were requested to sign an informed consent form after they ascertained that they were fully informed and that they understood the nature and purpose of the study. Moreover, the participants were informed that they have the right not to participate in the study, the right not to answer all the questions, the right to talk alone or in the presence of anyone they trust, and the right to withdraw any time from the interview without anything being held against them.

Namibian law regards children under 18 years as minors, so the researcher sought permission from parents or guardians of minors who took part in the study. The researcher indicated that the parents and guardians should consider being present when their child was being interviewed. This process was done through a substitute consent or third-party consent form.

Drew (2007:57) explains that substitute consent or third-party consent is the consent given by someone other than the person to be involved in the study, and it is usually done when the study involves participants who are dependent on others for their welfare, for example, minor children or people with cognitive or emotional disabilities, or when participants do not have the capacity to make decisions.

Morrow and Richards (1996:94) explain that the reason for requiring parental permission and assent relates to parents' rights to have a say in what is happening to their children. The interviews were conducted in the presence of the parents and guardians of minor children, or any other person that the participant feels comfortable with.

Findings in chapter five has been presented anonymously, and will be communicated in the dissertation and in any journal articles in which the study will be published. This was communicated to all the participants before the interviews began. Although the instrument was presented to the research ethics committee in English, it was also translated into vernacular languages because some people did not have good command of the English language. However, all the translated instruments were submitted to the Khomas Region Council. The translated instruments are presented in annexure F and G.

4.11 Summary

Chapter four presents the rationale of why the researcher opted for the methods that were adopted in the study. The study uses the interpretive paradigm and makes use of the qualitative research approach that applies case study design and auto-ethnography methodology. The chapter outlines the sampling method used in the study, this being a non-probability sampling technique. The chapter also discusses the different tools used to collect data, such as semi-structured interviews and personal memory. The methods and techniques used to analyse data have been described. This chapter also discusses how the research methods would ensure that the instrument produces valid and reliable findings, and highlights the ethics that the researcher took into considerations.

CHAPTER FIVE

PRESENTATION OF FINDINGS

5.1 Introduction

The previous chapter outlined the research methodology that was followed to conduct this study. This chapter presents the results and interpretations of the data that were collected by conducting semi-structured interviews with people with albinism, parents of children with albinism, as well as Organisations dealing with albinism in Namibia. Furthermore, the researcher narrated her lived experience of albinism through the recall of personal memory. Thematic content analysis was used to analyse data collected from participants. The focal aim of the study was to investigate the information needs of people with albinism (PWA) in Khomas region. The study was guided by the following four critical questions. What are the information needs of PWA and what kind of information needs do they have? Which mechanisms do PWA use to seek information that meet their information needs and who initiates their information activity? What are the challenges facing PWA in Khomas region daily when seeking information? Which information services are appropriate for PWA in Khomas region?

For the sake of anonymity when presenting data, participants were allocated codes. For example, PWA are referred to as PWA 1, 2, 3, parents of children with albinism will be referred to as Parent 1, 2, 3, and Organisational Participants (OP) as OP 1,2.

5.2 Description of research participants

This part of chapter five presents a description of participants who took part in the study, and focuses on three main categories, namely, a description of PWA, parents of CWA and Organisational Participants (OP). Participants were described in terms of age, gender, level of education and the constituency in which they live; additionally, parent participants were asked to indicate the number of children with albinism they have and whether these children were born at home or in a hospital.

5.2.1 People with albinism

Among those interviewed, were sixteen people with albinism; of these, eight were males, and eight were female participants. 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 chapter do not include much of their voices.

The participants' ages ranged from 14 to 72 years. The majority of those who were 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.

CWA who participated in the study were attending primary school at the school of 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 certificates holders, while one participant who holds a grade 10 certificate runs a project that helps PWA, raises awareness of albinism, provides counselling services and give motivational speeches.

Most of the participants reside in Tobias Hainyeko, Moses //Garob and Windhoek East constituencies. Tobias Hainyeko and Moses //Garob 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 most prominent people reside, whereas the Khomasdal constituency is regarded as a middle-class constituency.

5.2.2 Parents of children with albinism

Six parents of children with albinism were interviewed; of which one was male and the rest were female. The parents of children with albinism who took part in the study were between the ages of 28 to 49 years. Most of the parents who were interviewed have no formal education, and in terms of their employment status, only one parent indicated that he is employed, whereas one was self-employed.

One of the parents is from the Tobias Hainyeko constituency; while another one lives in Khomasdal constituency and four are from the Moses //Garob constituency. Almost all the

parents who took part in the study have one child with albinism; only two of the parent participants have two children (a boy and a girl) with albinism. These children range in age from seven months to thirteen years, and all the parents indicated that their children were born in a hospital.

5.2.3 Organisational participants

The study identified two organisations that deal with the plight of people with albinism in the country, namely, the Namibia Albino Association Trust (NAAT) and Support in Namibia of Albinism Sufferers Requiring Assistance (SINASRA). As a result, two males were interviewed as organisational participants, including the president of NAAT, and the chairperson of SINASRA. The president of NAAT was not only an organisational participant, but also a respondent in the study as he is a person with albinism. Both interviewees are responsible for overseeing the operation of their respective organisations, including securing donations. The Namibia Albino Association Trust was established in 1999 and was officially inaugurated in 2001. SINASRA was established in 2001 by Rotarians and optometrists.

The respondents were asked to briefly explain the objectives of their respective organisations. It was deduced that SINASRA's objectives are:

- To provide free medical and health care to people with albinism, including free eye and skin examinations.
- To supply PWA with protective clothing, sun block, sunglasses, and visual aid.

Meanwhile, the objective of NAAT is to take care of PWA in Namibia by making sure they are treated as equally as people without albinism.

When asked about the major activities of their organisations, both NAAT and SINASRA indicated that their major activities are to raise awareness countrywide and make the community understand that a PWA is a normal human being.

Table 5.1: Demographic data of participants

Profile of respondents	PWA	Parents of CWA	Organisational participants
Gender			
Male	8	1	2
Female	8	5	
Age	14-72 years	28-49 CWA 7 months-13 years	
Level of education			
No formal education		4	
Primary school	6		
Secondary school	4	1	
Diploma	2	1	
Bachelor degree	2		
Master's degree	1		
Constituency in which they reside			
Windhoek rural	0	0	
Windhoek east	4	0	
Katutura east	1	0	
Katutura central	1	0	
Tobias Hainyeko	4	1	
Moses //Garob	4	4	
Samora Machel	0	0	
Windhoek West	0	0	
Khomasdal	2	1	
Khomasdal North	0	0	
Number of children with albinism			
Parent 1		1	
Parent 2		1	
Parent 3		1	
Parent 4		1	
Parent 5		2	
Parent 6		2	

1

¹ The reason why there is no formal education category for PWA is because none of the participants indicated that they have formal education. The interview guide for organisational participants omitted provision for the age of participants hence that information could not be provided

5.3 Presentation of findings

This section presents an analysis of data according to the research questions provided in annexure C to G. Data was obtained through face-to-face interviews with PWA, parents of children with albinism and organisational participants. This chapter will be presented according to the following themes:

- Description of research participants
- Awareness of organisations for PWA
- Information needs of PWA
- Mechanisms for seeking information
- Information services of PWA
- Challenges experienced by PWA
- The concept information needs also deals with PWA's concerns, uncertainties and aspirations

5.3.1 Awareness of organisations for PWA

The aim of this section was to establish awareness among PWA regarding organisations in Namibia dealing with the plight of albinism. The main point was to establish if PWA in Namibia are aware of these organisations and to determine if PWA benefit from services offered by them.

When asked if they have any knowledge of organisations that deal with PWA in the country, most participants acknowledged that they are not aware of any such organisations and that is reason why they could not join them.

Few participants were familiar with SINASRA and NAAT. One participant specified awareness of First National Bank (FNB); however, FNB only sponsors hats for PWA. Another participant was aware of Epupa Investment, a company responsible for the distribution of pension money to pensioners and other beneficiaries including PWA on behalf of the government.

The participants who are aware of SINASRA and NAAT indicated that they are not members of any of the above-mentioned organisations, and this issue that was clarified by the organisational participants that PWA do not need a membership with these organisations, but if they have albinism, they become members automatically.

When asked about how they gained awareness about the existence of these organisations, participants revealed that it was through nurses and doctors at the Dr Bernhard May Cancer Care Centre at Windhoek Central Hospital, they indicated that they collect their aids there and through board members of SINASRA and NAAT, especially when they visit the school of the visually impaired or through research.

When asked about the services and support they get from these organisations, they indicated that they acquire more information on albinism and are able to help other PWA. The first PWA participant in the study reported: ‘Just recently a board member of SINASRA informed me that I should stop relaxing my hair because my skull will absorb the chemicals which can cause brain cancer’. They also acquire and benefit from items such as hats, sun lotions and sunglasses, and ultra violet (UV) protective clothes.

5.3.2 Awareness among parents of children with albinism

On the same note, when parent participants were asked if they were aware of organisations for people with albinism in the country, few participants mentioned the names of NAAT members, but they could not identify the organisation to which they belonged. A few acknowledged that they had heard about these organisations on the radio, even though they could not reveal the names of the organisations, and further stated that they have never met those who are in charge.

On the other hand, participants indicated that their children do not benefit from services offered by these organisations. As Parent3 reflected:

He does not receive any assistance from the organisations. Is just me fighting on my own to acquire the necessary aids such as the protective clothing and sunscreen. I have been buying the hats from Pep store.

Another participant (parent1) explained:

My daughter use to be supported by an organisation from America by the name of ...Swiss I am not sure of the name, at the school where she started attending pre-primary school. I use to sell ‘kapana’ roasted meat in order to help her, but I have realised that selling is not for me. I am currently running a day care, and the small that I get from there I buy her the sunscreen and protective clothing because she does not get assistance from the organisations.

It is, however, clear those parents do not seem to have any idea that materials they collect from Dr Bernard May Cancer Care Centre come from these organisations, especially SINASRA.

5.3.3 General experience of dealing with organisations for PWA

Furthermore, participants were asked to share their experiences in dealing with these organisations; the aim here being to determine whether their attitudes were positive or negative.

Participants who claimed to know about SINASRA and NAAT expressed a positive attitude and also their experience with them was positive. Participant PWA4 claimed:

I have learned so much from SINASRA; it is also through them that I came to understand my condition better and accept myself the way I am.... SINASRA inspired and helped me to move out of my comfort zone, and now I am becoming a better person every day.

5.3.4 Awareness campaigns by PWA organisations

When organisational participants were asked how they raise awareness of PWA, both organisations mentioned that they make use of different platforms such as radio, and television programmes, such as *Good Morning Namibia* and print media such as newspapers. OP1 indicated that they allocate multilingual volunteers from the University of Namibia to various radio stations. Currently, the organisation has a project run by two Dutch volunteers who are raising awareness about albinism countrywide in schools, hospitals and villages.

Meanwhile, OP2 conveyed that they raise awareness by organising community meetings with PWA and community members countrywide.

5.3.5 Emotions experienced when people realised their PWA status

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, PWA3'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 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 the 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. PWA5 remarked:

Some people treat me good and some treat me bad, but I do not mind because this is how God created me, and I does not affect me in anyway, 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 PWA6 reflected:

I felt bad; I blamed myself, parents, and still question 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.

5.3.6 Parents' emotional experiences after birth of a CWA

Similarly, parent participants were asked how they felt when they became aware that their children have albinism. The aim was to establish their reactions, because generally, people react differently to different situations.

All parent participants in the study expressed happiness when their children were born. They articulated that their CWA are just the same as those without albinism, the difference is only in the skin colour. Parent1 shared her joy by stating:

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

However, two parent participants shared their experience that albinism was not detected right after the birth of their children, which caused them confusion because their babies' skins were not changing to black. This was reflected in the following statement by Parent4.

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

A similar thought to that of PWA was shared by parents of CWA, who have people with albinism in their families. They articulated that they were not surprised when their children were born because albinism is normal to them. These findings were substantiated by those of Brocco (2015:1148), who recounted that in cases where there is a record of PWA in the past generations, the mother is not blamed for a CWA, and albinism is classified as normal. Parent participant6 explained:

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

Even though parents expressed joy and love for their children, one interviewee indicated that the father of her child abandoned her and their son upon birth. Parent participant5 reflected this in the following statement:

The problem I have is that when he was born his father left us, he told me he does not give birth to albinos, now our son is growing, and he is asking me that he wants to meet his father, a question I do not know how to answer. Even at the beginning of this year (2017), I met his father after all these years, but he did not want to talk about our son.

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

5.3.7 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 experience with regards 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, PWA11 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 denial of society when encountering a person with albinism especially poor eyesight. People in the society still do not understand what albinism is, not even lecturers at the university. PWA1, a student participant claimed:

I once approached a lecturer for class notes because I could not see 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 disabilities. 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 Cru-Zingo, Ladizinki, and Sethi (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 the 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. PWA2 expressed the following:

Sometimes I fear approaching or proposing a girl that I want because I just think she is not going to accept me because I have a 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 PWA8's view:

My daily experience is good I have learned not to mind about what people say about me. I am used to people calling 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, PWA11 participant 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, 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.

5.3.8 Daily experiences of parents of children with albinism

Parents of children with albinism articulated that their experience is both good and bad; and some indicated they were laughed at and mocked for giving birth to a child with albinism, as articulated by Parent4.

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

It is for such reasons that Braathen and Ingstad (2006:600) explained that the superstitious surrounding albinism places mothers of children with albinism in a vulnerable position,

subject to stigmatisation and harassment from the society which results in severe psychological distress.

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

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

5.4 Information needs of PWA

This section presents data on the information needs of PWA, including the kind of information needs they have. The question was aimed at ascertaining the information needs of PWA and to know the kind of information needs that they require in their lives.

5.4.1 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 as 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 PWA8 illustrates how a participant was 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, why I am different, discriminated against, and called names.

Another participant (PWA11) 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 I am a blessing, whereas some told me I was a curse and others explained that I was as a result of punishment from God.

From the comments given one can deduce that PWA often receive 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 PWA2:

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 PWA9'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 a 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 the clothing to wear and information on where to access aids such as hats, UV protected clothes, sunglasses and sunscreen lotions, and the mostly 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 employee 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 were 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 PWA13 and the second from PWA14:

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.

5.4.2 Information needs expressed by parents

Similarly, parent participants were asked to indicate the information with regard to their children condition that they need. This section was divided into three categories: firstly information they required right after finding out that their children have albinism, secondly, information they required as their children were growing up, and thirdly, information they currently need.

a. Information needs expressed by parents at the time they discovered that their children have albinism

The majority of parents of children with albinism reported that they were not provided with information by health professionals on the birth of their children. However, one mother revealed that she was offered counselling, but she refused.

Asked about the type of information they needed after giving birth, almost all participants expressed a strong need for information regarding their children's skincare as a cancer prevention method. Most of the parent participants knew that the skin of PWA is sensitive to the sun; therefore, their children need extra care and protection. Parent1 commented:

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

Another participant, Parent6, reflected:

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

For that reason, parents participants were interested to know the kind of clothes their children need to put on and the type of body lotions they can use. For example, a parent participant mentioned that Vaseline was not suitable for her baby's skin; every time she applies it he gets small pimples. As a result, she wanted information on the type of lotion she can use. Furthermore, parent participants expressed information on how to register their children for the disability grant, to be able to buy the necessary clothing and aids. They narrated that, having a child with albinism is expensive compared to children without albinism because

they have extra needs because of their condition. Moreover, parents expressed the need to know where and how to acquire glasses, especially for children who are school going.

A parent participant expressed the need to know why and how they got a child with albinism. Furthermore, Parent3 explained:

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

b. Information needs as children grew up

It appears that the information needs of the parents of children with albinism differ at each stage of their child's growth. When asked about the information they needed as their children were growing up, most of the parent participants expressed a need for information on the vision or eyesight of their babies as well as the type of eye glasses that they can wear. One of the comments (from Parent2) was:

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

c. Current information needs of the parents

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

Another parent participant (Parent3) remarked:

As he is becoming big his needs are also becoming many, for example, I need information on where to get his aids and what type of soap, lotions, and clothes to wear. Currently, I am just giving him any soaps, and lotions that I have because I do not have information on the type products that are suitable for his skin. I also need

Information on what kind of lotion to apply during each season, for example, I heard that during winter he can use Vaseline and other seasons I do not know what he can use.

Some parents were curious to know the type of food that their children with albinism should eat. Parent participant6 explained:

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

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

On the other hand, one parent indicated that her daughter refused to attend the school for the visually impaired for reasons only known to herself; therefore, the mother opted for a private school. Her mother (Parent2) made the following comments during the interviews:

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

Surrey Social and Marketing Research (2009) reported that this type of education could be very isolating, and it is recommended that some mainstream schooling be undertaken to provide CWA wider social contacts and to learn how to function in the 'real world'.

These results match with findings of Gaigher, Lund and Makuya (2002), whose respondents mostly preferred to attend a mainstream school, while others preferred to be at a special school.

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

5.4.3 Information needs expressed by key organisations

Organisational participants were required to indicate the kind of information needed by PWA. This question was intended to determine the information needs that are, in their view, important to PWA.

Both organisational participants mentioned the need for information on what albinism is to get rid of the stigma. With the relevant information, society will have a better understanding of what albinism is, and thus change the way they perceive PWA. These include people such as the parents and society in general. As stated above, information includes how to take care of their skin so that they do not get skin cancer and on what services are available to them. Meanwhile, information on human rights issues, in particular, was noted, because PWA need to understand what is due to them and that they are protected by the Constitution of the Republic of Namibia, just like any other citizens.

The organisational participants were asked to indicate the type of information that PWA look for when they come to their organisations. OP2 mentioned that the most required information was on how to register for the disability grant. He explained that parents bring their children with them to complete the disability form and refer them to the right persons for further assistance; sometimes those in charge take these forms to the medical doctors for completion. Meanwhile, OP1 noted the need for information on skin cancer, especially by those already affected. People with albinism to seek assistance and advice on what do, in most cases we would refer them to the Dr Bernard May Cancer Care Centre for further assistance and treatment.

5.4.4 Concerns, uncertainties, and worries of PWA

People with albinism were asked whether they had any concerns, uncertainties, and worries, in order to determine their information needs. Participants expressed several concerns about people who still do not embrace albinism, the lack of knowledge about albinism among society, the lack of understanding that PWA are normal human beings, and skin cancer

Furthermore, some interviewees are concerned about whether the killing of PWA in other African countries such as Tanzania and Malawi will not spread over to Namibia. Concern about being killed was expressed several times. PWA8 claims:

I wanted to go and study further outside Namibia, but I was told that PWA in other countries in Africa is [sic] being killed. As a result, I changed my mind because I am scared of being surrounded by people that I do not know who might hurt me.

All those who took part in the study expressed the need to provide the society with information on what albinism is and to raise awareness of the fact that PWA are normal human beings. Brocco (2016:123) highlighted a number of international organisations such as Under the Same Sun (UTSS) and Tanzania Albinism Society (TAS) that deal with the plight of PWA in some countries in Africa, with the aim of informing community that PWA are as 'normal' as other human beings.

On the other side, the study also found that it is crucial for PWA to be given information on how to protect their skin and on what clothes to wear as a skin cancer prevention method.

5.4.5 Aspirations and information required for their achievement

The participants aspire to achieve different things in life, such as studying further. Some want to be ambassadors for their country to raise awareness about albinism, and to give motivational speeches and counselling to PWA and their parents. One interviewee (PWA11) articulated:

I want to help others to realise that PWA are not different and are capable of achieving anything and also want to help those with albinism who are less fortunate and are unable to take care of their skin, thus, I want to be a star in my country.

Those unemployed aspire to be employed and acquire a piece of land where they can build their houses, while few aspire to get married and start a family. PWA2 mentioned that she aspires to be a politician and PWA1 stated that:

I needed information from the municipality on how to acquire a piece of land and employment information from different ministries; as well as information on career.

With regards to their aspirations, interviewees expressed that they need different information to achieve what they desired, such as information about how many PWA are in Namibia so that they could be properly attended to. Some need different types of information about the government system and information on how to make speeches to the public.

5.5 Mechanisms for seeking information

This section was meant to establish the mechanisms used by PWA to seek information that meet their information needs; and to determine who initiates their information activity. The aim was to tackle the following questions, the mechanisms used by PWA and parents of children with albinism to find information, and to determine who supports, encourages and helps them cope when looking for information.

5.5.1 Mechanisms used by PWA

As identified in the literature review, people in general use different types of mechanisms to acquire information that can help them to care for their condition and meet their information needs. This question was asked in relation to Wilson's model of information behaviour. Most participants prefer to use different mechanisms, 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 (PWA10):

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 taking into account 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, PWA12 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 it.

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, 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 PWA11 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.

5.5.2 Mechanisms used by parents

Parents of children with albinism were asked the same question as PWA regarding the mechanism they use to find information. The preferred and most popular were radio, television, internet (Google), healthcare professionals including dermatologists and ophthalmologists, and newspapers. Dermatologists and ophthalmologists were popular and preferred sources among parent participants because they consult them for information related to their children's eyesight and skin.

Parent1 revealed during the interviews that she once came across a story on albinism in old newspapers (for 2010), however, a parent participant criticised newspapers and the radio for not being informative and not telling them what they want to hear. As parent5 explained

Newspapers and radio only tell us where to get sunscreen lotions and emphasise that we must register the children for the disability grant, but they do not provide other information that we want to hear, such as information on what is albinism.

SINASRA has a pamphlet which provide valuable channel for this types of information every day, however the pamphlet is only available in English.

In terms of information pursued, some parent participants indicated that they never bothered to search for information because they did not know where to go to acquire such information.

Parent 3 remarked:

I am currently not looking for any information because, in the beginning, there was no one who could help me to acquire this information.

5.5.3 Organisations providing information and support

When asked who supports the PWA to cope with the condition, most of the interviewees indicated that they were supported by their family members, both immediate and extended, neighbours, friends, other siblings with albinism, SINASRA, and NAAT. In terms of coping and managing the condition some participants gave their opinions again that information played a very crucial role. PWA14 mentioned that:

My family is very supportive and understands albinism very well; they are very proud of me, and in most cases, they even forget that I have albinism; they love me for who I am.

However, few interviewees indicated that nobody helps them to cope or manage their condition. For example, PWA4 narrated the following:

I just survive on my own, and I search for information myself because I have accepted who I am, this is because I grew up in a normal school system when you either drown or survive, therefore, I have learned to do things on my own.

5.5.4 Provision of information for parents of CWA

For parents of children with albinism, most of them mentioned their partners as people who support them to cope and manage their children's condition. Some parents indicated that their family is supportive and helps them to cope with albinism, especially those who come from families where there are many people with albinism and understand the condition very well.

Parent2's experience was as follows:

She is the first and only one in the family with albinism, therefore my family is very supportive, for example, everybody contributes to her aids; she is that flower that everybody wants to have a piece of, they just love her so much.

Parent5 remarked: He is everybody's love in the family, he does not struggle with anything, if he asks me for anything and I do not have, he will always call one of my cousins who would provide him with whatever he needs, all the people in the family are there for him.

The contrary view of another participating parent indicated that she survives through praying and attending church services, as her family is not supportive.

5.6 Information services of PWA organisations in the Khomas region

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

5.6.1 Current information services

Participants were asked about the information services offered by these organisations to people with albinism. OP2 offered the following information services namely: information on how to apply sunscreen lotion, information on the type of protective clothing to wear, hats, and sunscreen lotion to use. Moreover, they provide information on how to apply for the disability grant and facilitate the whole process, and also assist with information on how and where to acquire different aids. OP1 also disseminates relevant information aimed at preventing sun-related cancer, its complications, and early death.

5.6.2 Dissemination of information by PWA organisations

When asked about how they disseminate information about albinism in the country, OP1 explained that they distribute flyers but admitted that they contained outdated information in English; they use local radio stations in vernacular languages and share information through their websites that have not been updated for a long time. The participant, however, also admitted that they do not share information through face-to-face meetings, even though the chairperson acknowledged that it might be an effective way of reaching out to PWA. Moreover, they have a Facebook page (albino care SINASRA) which is not active. They issue press releases, especially on days prior to 13 June – the International Albinism Awareness Day (IAAD). OP1 also does presentations in Namibia and South Africa on albinism.

OP2 emphasised organising a community meeting with PWA, and the organisation used media, including print media; and different radio stations in vernacular languages. It was also acknowledged that their organisation does not have a website, a Facebook page, or a WhatsApp page.

They were asked whether they disseminate information in other languages or just in English, a question they answered by indicating that information is disseminated in other vernacular languages as well.

5.7 Information seeking challenges of participants

This section presents the challenges experienced by participants when accessing information related to albinism. One of the models applied in the study was the Wilson model of information behaviour that acknowledges that there are different intervening variables that can serve as an inhibitor or facilitator to accessing information. Therefore, one of the

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

5.7.1 Challenges raised by PWA

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

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

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

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

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

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

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

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

Language is a problem. Participants stressed that most of the time the information is provided in English, and most of the participants do not understand English. They claimed that information is not provided in a language that is accessible to PWA and their families, and there is lack of information on albinism in local and sign languages in Namibia. `

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

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

Lack of access to computers and the internet, especially after hours for those employed, is a problem, although they explained that they could access computers and the internet at work and a public library during working hours. Lack of finances was recognised as inhibiting factors to information seeking. The majority of those interviewed mentioned fees associated with transport due to long distances. That most of them are not driving due to poor eyesight is a disadvantage. One participant claimed that she had lost her car allowance benefit at work because she cannot drive because of her poor eyesight. Only two participants have acquired a driving licence and are driving, this means that PWA are required to use public transport like taxis to access information.

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

5.7.2 Challenges raised by parents

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

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

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

The language barrier was mentioned almost by all participants because information on albinism is always provided in English, the official language, thus making it impossible for them to access such information. Participants indicated that even newspapers and, pamphlets are written in English and television programmes are broadcast in English. Sometimes in hospitals, clinics and offices people communicate in English. A participant claimed that sometimes she would take her daughter with so that she can translate for her, while Parent4 remarked:

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

5.7.3 Challenges raised by organisational participants

Organisational participant1 mentioned that the biggest challenge for disseminating information is reaching out to people who still believe that albinism is a curse. Lund (2005:171) explains that raising community awareness to improve social integration and

acceptance is a major challenge in a region where albinism is steeped in myths and superstition and misconceptions that albinism is contagious, or that affected families have been cursed, resulting in fear and misunderstanding. In addition, OP2 linked the lack of a budget to cover the activities for the organisation, such as raising awareness through the country, lack of understanding of what albinism is, and long distances that they have to travel in order to disseminate information.

5.8 Suggestions on how to improve access to information

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

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

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

Several participants argued that the government should provide a lot of finances for sensitisation campaigns because information is key. With information, PWA knows what services they are entitled to, as well as where to go to access them. As such they will be able to share this information with others because albinism is a condition that will not go away, is not like a disease that you can cure once and for all.

Furthermore, participants appealed for the Ministry of Information and Communication Technology to make sure that information is accessible to everyone, not only to those that are able to read print materials. They should implement an easy to read mechanism, explained as a mechanism used by the United Nations (UN) to provide information to people with intellectual disabilities. Participant PWA 11 articulated this thus:

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

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

5.9 Data analysis based on the personal memory of the researcher

This section of the study presents the researcher's narrative about her lived experience with albinism through personal memory. As stated in the previous chapters, the researcher is a mother of a four-year-old girl and a year-old baby boy with albinism. The researcher narrates her experience applying the research questions used to interview parents of children with albinism, but with a few exceptions. The following questions are addressed: how the researcher reacted when she found out that her children have albinism, including her daily experience with regard to her children's condition. Furthermore, the researcher expresses her information needs, and the mechanism she uses to find information regarding albinism and to determine who supports and encourages her when searching for information. She concludes by stating the challenges she experienced when accessing information on albinism.

5.9.1 Context to the decision to explore auto-ethnography

For my master's degree dissertation, I decided to investigate the information needs of people with albinism in Khomas region, given that people need information of various kinds from time to time. I approached this topic as a mother of a four-year-old girl and a one-year-old baby boy both of whom were born with albinism. Although I received information and support from the doctors, I often encountered situations that needed information then and there. As a librarian, I would search for such information from the literature.

At some stage I was searching for information services for PWA, particularly their information needs, but I could not find any studies related to this vulnerable user group. From this experience, I started thinking about how any Namibian can manage in the same situation.

It kept coming back to me as to whether other people really have access to this valuable information, and if they are aware of the benefits for PWA in their country. This curiosity then motivated me to study the information needs of persons with albinism, including their parents, and that is why the parents of the children with albinism were also participants in the study.

5.9.2 My reaction upon giving birth to a child with albinism

When my daughter was born, the paediatrician did not tell me straight that the baby has albinism; he said: 'Here is the baby; she is fine, but she has problems with the eyes and skin'. I looked at the baby and asked him if she has albinism, and he confirmed with a 'yes'. The doctor did 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 (2010:171) explanation that when a baby is born with albinism, the genetic nurses talk gently to the mother of the baby, recognising first and foremost the joy of the new birth, and move on to tell the mother 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 to me the first time. The baby had white, blondish hair at birth, so albinism was detected and confirmed immediately at birth. However, there was more confusion when friends and family visited us in the hospital, and they refused to acknowledge that the child has albinism. Some claimed that a child who has albinism would have some features that would tell that she has albinism, and so forth. 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 had endless 'why' questions since albinism is associated with many myths and beliefs. I thought about different explanations attached to it, such as the belief that if one laughs at a person with albinism, or is rude to them, they will give birth to the child with albinism. This is a common myth that even Lund (2001:3) confirms, stating that people who scold or laugh at someone with albinism will themselves produce a baby with the condition. I was asking myself if I have 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 not a day where I was rude to them or I laughed at them.

All 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 this disease with courage and hope. I also gained the courage from watching videos of Nicholas James Vujicic, who is an Australian Evangelist and motivational speaker with an innate 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 have 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 my having another baby with albinism, thinking it would devastate me.

5.9.3 My experiences regarding my children’s condition

My experience from my daughter’s birth has changed over time because I grew stronger with time. Despite the fact, that I became a laughing stock to 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 people were busy spreading rumours about me, yet nobody approached me to ask how I was coping.

My children also experience name callings such as ‘shilumbu’, meaning ‘white person’, especially from strangers. I would always correct these people by telling them that she has a name, and she is not ‘shilumbu’, because I find ‘shilumbu’ discriminatory. This concurs with results from Beukes’ (n.d.) study which confirmed that school children with albinism are teased and called names such as ‘whitey’.

You meet people who would admire your children, and you find those who would strangely stare at them to the extent that it makes one uncomfortable, especially when we 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'. On the other hand, I have made friends with people I do not know personally because of my children.

Nevertheless, I was not spared from 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 these accusations was confirmed by Thuku (2011:3), 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 is good that, God 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 stated why am I the first one in the family to give birth to a child with albinism. Thuku (2011:4) explains that there are people who believe that a baby with albinism is a punishment or curse from the gods or ancestral spirits due to wrong doings in the family.

Despite the shaming and lack of emotional support from most friends and family members, I vowed to never be ashamed of my children. I have learned to react positively to the negativity associated with albinism, and as such, I am not bothered 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, I love them so dearly.

5.9.4 Information I needed

Right after the birth of my daughter, I started searching for information on albinism, because I wanted to absorb as much as I could to gain a profound 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. Searching for information was triggered by the lack of knowledge about albinism, which left me with an understanding that PWA are born with a hard skin with sores all over. I did not know that damage to the skin only happens once the skin is exposed to the sun without any sun protection. Some people simply do not know that the skin of PWA is sensitive to the sun, and some people with albinism do not know that it is the sun that causes the skin to hurt and burn (Braathen & Ingstad, 2006:609).

I also expected my baby's eyes to start making movements right away, but I found out from the ophthalmologist, that it can only start making movements after two to three months. The information that I searched for every day and that I could not get a satisfactory answer for

was information on my daughter's vision and whether she would be able to see and to live a normal life and whether she would be able to go to a normal school. Seeking for 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 for information on my daughter's vision from the paediatrician, who referred me to an ophthalmologist, assuring me that the child would only start following objects after three months.

With my son, even though the experience was the same, I searched for information on his vision from the ophthalmologist, but I was not as stressed as I was with my daughter, even though it took him about five to six months to start following objects. However, I am worried that he might have a vision weaker than that of 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 the suitable body lotion and sunscreen for her skin because initially I had been using Vaseline petroleum jelly (for babies). I was also interested in the kind of protective clothes I should dress her, so through researching, I learned that PWA needs to wear light-coloured clothes because they attract minimal sun compared to dark colours. I also needed information on why she gets small wounds on the lips, even if she was not exposed to the sun. Meanwhile, it has been emphasised that lips are particularly vulnerable to sunburn, so it is important for people with albinism to apply a high sun protection factor lip screen (Albinism Society of South Africa, 2014). I sought this information from the dermatologist.

When my daughter was starting school, I sought for information on her vision particularly how weak or strong her vision is, because at that time I had already made a decision that I will enrol her in a mainstream private school. The information was necessary to help me decide if she will 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 damage their skin permanently.

5.9.6 Mechanisms I used to seek information

I acquired most of the information on albinism from the internet. Through searching the internet, I have gained knowledge about the type of clothes my baby is supposed to wear. Currently, I am a board member of SINASRA, and I acquire a lot of information from the organisation. I have a good relationship with the president of NAAT, whom when my

daughter was born, invited us to his office to share valuable information with us regarding her condition. I have joined various organisations that deal with PWA in different countries, such as the National Organisation for Albinism and Hypopigmentation (NOAH), the Albinism Community, Albinos are beautiful, The Albinism Society of South Africa (ASSA), and Under the Same Sun, which I joined on Facebook. These organisations provide valuable information and give hope because in most cases, they share a lot of positive thoughts, organise events, and share success stories of PWA.

Through reading, I came across various stories told by mothers of children with albinism who went through the same experience. I was given information about how to take care of the 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 what they know. For example, I was told that my child will attend a special school, something that is not true, because some PWA 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 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.

5.9.7 Support when searching for information

Fortunately, I started receiving support from other doctors who came to the maternity ward to see other children; some doctors would come to me and offer me words of comfort. For example, one said: ‘You have given birth to a child with albinism, so you need to understand she is just a normal human being; she just has a certain condition.’ Furthermore, my doctor told me that ‘God only gives special things to special people; God gave you a child with albinism, who requires special care because you are special’.

My husband is my pillar of strength: he helps me to cope and manage our children's condition. I do not necessarily receive support from extended family members or friends, as they do not probably understand the challenge that comes with the condition.

5.9.8 Challenges I experience when searching for information

With my daughter, I did not experience a lot of problems when seeking information on albinism, except for the distances that I had to travel to access information. Lack of relevant literature on albinism in the Namibian context is a challenge, as most of the information found is about the situation in other African countries.

With my son, I receive confusing information, especially when I am enquiring about the disability grant. Some officials would tell me that the child does not qualify for the disability grant because he is not disabled, while other tells me the opposite.

5.10 Summary

Chapter five presents the findings of the study. The findings are based on analysis of data obtained from semi-structured face-to-face interviews with PWA, parents of children with albinism, key informants, and the researcher narrative of her lived experience with albinism. In general, the information needs expressed by PWA, parents of CWA, organisational participants, and the researcher are similar.

CHAPTER SIX

DISCUSSION OF THE FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

6.1 Introduction

The chapter discusses the finding of the study in the context of research questions and theories supporting the study and based on the discussion conclusions are drawn and recommendations are made.

6.2 Summary of findings

This section discusses the findings of the study according to the research questions and based on data obtained from the interviews with PWA, parents of CWA, organisational participants and the researcher's personal memory. Furthermore, the findings are discussed in accordance with the models guiding the study.

6.2.1 Information needs

The findings reveal that PWA have information needs related to their condition. The literature reviewed 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 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 by (Moore, 2000). The findings showed that questions asked by participants as part of their information needs were

also confirmed by previous findings (Lynch, Lund & Massah, 2014; Lund, 2001; Lang, n.d.). The information needs identified by the participants of this study are presented below.

a. Eye-related information

The study found that there is the 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 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 refuse 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, Zeeb, and Repacholi (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.

Lack of knowledge about albinism also caused confusion among parents of CWA who were concerned about the eyesight of their children. For example, parent participants wanted to know if their children were completely blind or whether eyesight was still coming, while some expected their children eyes to start moving immediately after birth. Furthermore, parents needed information on how to acquire sunglasses and glasses for their children.

b. Skin-related information

Information on how to take care of their skin was mostly preferred by participants, especially the type of soap and cream to use and clothes to wear. Parent participants were concerned about how to protect their children so that they do not burn from the sun which can cause skin cancer. This is because most of them knew from the onset that CWA are sensitive to the sun, hence, they require extra care and protection. Lund (2001:5) explains that sun-protection information should stress low cost-prevention strategies and emphasise sun avoidance: wearing wide-brimmed hats and thick-weave, dark coloured cotton clothes as well as staying out the sun in the middle of the day and seeking shade whenever possible. A school learner with albinism made the following remarks 'My skin burst when I walk in the sun'. 'I want some help to make it stop' (Niilenge, 2017a:3).

Information on the type of soap to use, especially seasonally was critical for parent participants. For example, a mother of CWA mentioned that Vaseline was not good for her child's skin hence; she needed to know what lotion to use. Meanwhile, few participants were curious to know if the type of food their children eat can have a bad effect on their skin, information on why CWA get wounds on their lips and information on what causes skin allergy and how to prevent it were noted by participants.

c. Information on what albinism entails

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. A thought echoed by parent participants who wanted information on how they conceived a child with albinism. The researcher shared her story of how she questioned herself as to why she conceived a child with albinism.

Similar experience of uncertainty was reported by (Braathen & Ingstad, 2006; Hong, Zeeb & Repacholi, 2006; Brocco, 2016). A participant from one the studies remarked ‘I was worried, I even blamed God: “Why did you give me this child, what have I done to have this child? Sometimes I am confused; I don’t know what causes it’. Sometimes I am thinking that I have been bewitched by people, or maybe it’s God’... explained that many PWA did not fully understand their condition. Another participant comments ‘neither did someone explain to me what albinism is, nor did the teacher ever say something about my condition in the classroom’.

The reason why participants wanted answers to these questions is that they were provided with a lot of information or answers which were not true; therefore, they had a desire to distinguish between facts and fiction to make an informed decision. The answers and information provided were often contradictory and even caused them more confusion; some information provided was positive, while some was negative. For example, some PWA were informed that they were a curse, while others were told that they are a blessing.

d. Disability grant

Information on how to register for disability grant was in high demand by all respondents. Organisational participants also confirmed that people who visit the organisation seek information on how to register their children for the disability grant. Study confirmed that PWD need information on how to apply for social benefits (Tilley, 2009). According to

Mnumbi-Mchombu (2013:252), the need for information on where to get financial assistance and grants remains one of the priorities of orphans and vulnerable children, as well as caregivers.

In Namibia, CWA are given 250 Namibia dollars, while unemployed adults with albinism get 1300.00 Namibian dollars as a disability grant monthly. According to the Department of Poverty Eradication and Social Welfare (2017:35), the Namibian government provides social grants to persons with disabilities to enhance their income and social welfare. This is because PWA have additional needs related to their condition. Some of these needs include security, health education on how to prevent skin cancer, protective clothing and optician services (International Federation of Red Cross and Red Crescent Societies, 2009:17).

e. Educational-related information

The need for education-related information is identified mostly by parent participants who have to decide what kind of school to send their children to. This included choosing between a private, a government school or a school for the visually impaired that is owned by a government- a question also confirmed by (Lang, n.d.). This information is necessary because PWA have poor vision, hence placing them in any available school can be challenging, especially when teachers are not aware of their disabilities. According to Lidman (2016), one of the characteristics of albinism is low vision, however, if no one knows that is an effect of albinism, the child struggles in school and is unable to see the blackboard or follow along with the class. They often end up failing tests, forcing them to repeat grades and eventually dropping out.

A parent participant disclosed that her daughter would lie on the table when others are writing during lessons because she could not see on the blackboard. This is in line with a newspaper article written by Niilenge's (2017a) where children experienced difficulty reading print on white paper and as a result performing poorly in class. 'I need some glasses so that I can read well, and my eyes need protection' (Niilenge, 2017a:3). Furthermore, the learner's teacher explains that 'the boys have been performing poorly as they have difficulties reading, especially on white paper'. 'We tried to move them to the front of the class, in order to focus better, but [it] is not helping much' (Niilenge, 2017a:3).

f. Emotional and psychological support

Another challenge identified was a lack of information on where and how PWA can access counselling services. 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 head (a sign of denial). Information on how to access these services, however, remains unknown. Hong, Zeeb and Rapocholi (2006:4) and state that PWA must deal with the 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.

g. Information related to employment, housing, and national documents

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 government is inadequate to cater for 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.

In addition, the findings revealed that PWA need information on how to acquire a piece of land to put up shacks of their own because being unemployed means that they cannot afford to buy a decent house, and the price of houses in Namibia is very high.

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 OVC and their caregivers from accessing important information on grants.

According to Niilenge (2017b:6), the NAAT president confirmed that a number of PWA have no access to disability grants because they have no identity documents.

6.2.2 Mechanisms used to meet information needs

The study applied the Wilson theory of information behaviour that emphasised that information can be acquired purposively or incidentally. Therefore, the objective of this study was to establish the mechanisms 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 & Ocholla, 2011:10; Williamson, 1998).

It is worth revealing that internet was the most useful mechanism for meeting the information needs of all participants, including the researcher. 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 preferred 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 on albinism. Thus participants who consulted the internet could make independent decisions regarding albinism. A similar trend was observed in a study by Williamson, Schauder and Bow (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 radios programmes 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 was 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 professionals 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 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, 1998). Furthermore, newspaper articles were criticised for being written in small fonts, which makes it difficult for PWA to read it. Similarly, Williamson, Schauder and Bow (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 acquire and benefit from services such as hats, sunscreen lotions, eye glasses, and ultra violet (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 surprisingly interesting to note that despite the role being played by social media nowadays, only one participant mentioned using Facebook to find information. The researcher used Facebook to connect with organisations that deal with PWA in different countries such as NOAH, Albinism Community; Albinos are beautiful and Under the Same Sun.

However, it was clear that to family members, friends, neighbours, spouses, NAAT and SINSRA were most the valuable sources of support for PWA, and parents of CWA, as they assisted them to cope and manage the condition.

6.2.3 Information services

The findings from the interviews with organisational participants indicated that organisations offer the following information services to PWA: information on how PWA can be protected from the sun; advice PWA including family members of PWA, on how to use sunscreen lotions and information on the type of protective clothing to wear and where to acquire these aids. Moreover, they disseminate relevant information aimed at preventing sun-related cancer, its complications, and early death. The findings agreed with previous studies even though with few exceptions (Cruz-Inigo, Ladiziski & Sethi, 2011).

Furthermore, the organisational participants reveal that the two organisations mainly use the following platforms to disseminate information to PWA: radio stations in local languages, community meetings, their websites, and the distribution of flyers in English, press releases, and presentations. However, not all the platforms might be evenly suitable for most participants, who are uneducated, unemployed and poverty-stricken, and this created a gap in the following up of information and use of available services.

It also came to light that one of the organisations does not hold face-to-face meetings with people with albinism even, though it could be the most effective and powerful method for providing information to PWA. Organising face-to-face meetings with PWA might be an effective method, as it was demonstrated in the findings of the study that some participants did not have a good command of the English language, and with this method information can be translated into local languages.

It is also worth noting that previous studies that addressed the information needs of OVC and caregivers (Mnubi-Mchombu, 2013; Mnubi-Mchombu and Ocholla, 2011) cited a wide range of meetings, ranging from community meetings to traditional meetings such as church and school meetings, formal workshops and home visits by volunteers. Lund and Taylor (2008) also concluded that outreach programmes and workshops are some of the most appropriate methods for disseminating information to PWA.

In addition, the findings reveal that some participants do not have access to infrastructures such as the internet and computers which could hinder accessing information which was disseminated through channels such as websites and other platforms. This is in contrast to Henry (2012:25), whose participants cited being happy because they could access the internet at home and they can use it to find information. Other problems identified by participants

were the lack of ownership of radio and television sets where participants indicated that they do not own these items because where they reside there is no electricity.

In the light of the above, the following newspaper article title serves as a proof of a lack of awareness of information sources which can hinder access to information emphasised previously by Omeluzor, Oyovwe-Tinuoye and Emeka-Ukwu (2017), namely, ‘Albino pupils looking for help’. Three albino boys in Namibia were appealing to good Samaritans for assistance to cope with their condition. Their teacher stated that: ‘We do not have much knowledge on how to search for help, but, we hope some people will come forward and offer necessary help’ (Niilenge, 2017a:3).

Furthermore, lack of awareness can be attributed to parent participants mentioning that their children do not benefit from services offered by these organisations and to why a majority of those interviewed have no knowledge of the existence of these organisations, and the people in charge. Previous studies emphasised the importance of these organisations. Parents of PWA in Malawi felt well placed as they had access to the right clinical services and advice through these organisations and could make decisions about their children's emotional well-being and education (Lynch, Lund & Massah, 2014:5). In addition, Pain (1999:307) concluded that most of the parents joining a specialist voluntary organisation indicated that knowing others in a similar situation was helpful.

The study established that information on where to get assistance and what services are available to PWA remains a priority among the participants. This shows that a gap exists between the services offered by organisations and the information required by participants that could be attributed to a lack of awareness as well. For example, the findings show that almost all participants specified needing information on how to apply for a disability grant, even though it was one of the critical services offered by NAAT.

6.2.4 Challenges experienced by participants when searching for information

Some of the major challenges to prevent access to information can be attributed to issues unrelated to albinism. These include long distances, lack of funds, language barriers, lack of time, lack of electricity etc. Most of these barriers were confirmed by previous studies such as (Mansour, 2015; Mnubi-Mchombu & Mostert, 2011; Baker et al., 2010; Beverley, Bath & Booth, 2004). Lack of relevant literature or materials on albinism, especially from a Namibian perspective, a lack of equipment, such as computers with internet connection, a

lack of ownership of radio and televisions sets due to the none availability of electricity were mentioned by participants.

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

a. Lack of finance, long distances and lack of time

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

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

b. Language

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

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

c. Lack of awareness on where to look for information

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

d. Poor eyesight

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

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

6.3 Discussion of findings based on theoretical frameworks

6.3.1 Wilson theory of information behaviour

Wilson's (1996) model of information behaviour was used to address the research question on the mechanisms that people with albinism employ to seek information. The stress/coping mechanism, or the risk/reward mechanism and intervening variables formed the basis of the analysis of the interview data.

a. Activating mechanisms

The activating mechanism is one of the components of information behaviour in Wilson's (1996) model. This component was necessary for the study to determine the coping mechanisms applied by PWA when searching for information. Discussed under this component is stress and coping theories, including coping strategies as proposed by Wan (2003), who looks at how those affected by albinism cope with the condition. Additionally, the risk and reward theory component was also discussed.

i. Stress/ coping theory

Participants exhibited different coping mechanisms such as searching for information while others opted to do without information. For example, most of the interviewees searched for information in order to find out why they were white and not black or wanted to know what albinism is, and why their eyes move from side to side. Furthermore, parents' participants acknowledged seeking information on eye-related issues from ophthalmologists. For example, 'I expected my daughter's eyes to start making movements right away, but I found out from the ophthalmologists that this occurs from two to three months'. The previous study by Beverley, Bath and Barber (2007:25) found that some participants chose to ask their ophthalmologists for more information about their visual impairment while others 'blocked' any further information.

The findings also confirm that some participants showed no interest in information because they did not see the need for seeking information and they argued that they survived by the grace of the Lord. Additionally, some participants never sought information because in the past there were no sources that they could consult. Seemingly they accepted their faith and believe that they, they believe that they have acquired enough information through living with the condition and experience.

Wan (2003:287), on the other hand, describes eight coping mechanisms. Three of these mechanisms were confirmed by the findings of this study namely: The activists: ‘those who are involved in heightening public awareness about albinism in a positive light’. The study found that some participants with albinism aspire to become ambassadors of their country and to raise more awareness about albinism, to become motivational speakers and provide counselling to the PWA. PWA 10 is one such person:

I want to help others realise that[a] PWA is normal human being and help those with albinism who are unable to help themselves I want to be a star in my country.

Serene: ‘those who patiently explain their condition to others’. The researcher explains that she would always correct strangers who refer to her children as ‘Shilumbu’. This is to make society aware that PWA are human beings, the difference being only in the skin colour.

The positivists: ‘those who have learned to accept albinism as part of their identity’. This coping mechanism was confirmed by the researcher who mentioned that:

I have learned to react positively to the negativity associated with albinism as such I am not bothered about how people think or feel about my children because God gave them to me for a reason.

Some participants with albinism argued that they are not bothered by those who call them names because they experience it every day hence, it is normal to them. Additionally, the findings reveal that participants are content with who they are and attributed their condition to God’s will. Most of the parent participants interviewed mentioned being happy when their children were born and were never bothered by the fact that they have albinism. Positivists spoke of the importance of accepting and loving themselves as they are (Wan, 2003).

ii. Risks and rewards

Participants admitted consulting different sources for information, such as SINASRA and NAAT as well as the internet, the radio and healthcare professionals because the benefits of acquiring information were greater than the risks. The parents of children with albinism indicated searching for information on how to take care of their children's skins, including what soaps and lotions to use and food to eat to avoid the risk of skin cancer and of making uninformed decisions.

b. Intervening variables

The study identified many intervening variables, which can act as barriers or facilitators of information seeking for people with albinism. Most of the identified intervening variables were like those identified by Wilson's model of information behaviour such as:

i. Demographic background variable

This included age, gender, level of education and the constituency in which participants reside. Intervening variables that could affect parents of children with albinisms included demographic information was included for parents of children with albinism: the number of children with albinism they have, the age of the children, and whether these children were born in the hospital or at home.

It was interesting to note that age did not play a significant role in inhibiting information seeking, because a participant who is 72 years pointed out that he uses the internet to find information.

The level of education serves as both enabler and inhibitor of information seeking. The findings reveal that PWA who are educated could find information by actively searching for information on the internet. Through searching, some participants obtained knowledge of SINSARA and NAAT and thus they could consult these two organisations and those in charge of relevant information and support. Orange, Seitz and Kor (2012:5) note that the level of education co-determines the chances of gaining` information and the ability to enhance personal knowledge because one can apply technological devices to access information. Meanwhile, participants with lower levels of education relied on other people for information, such as healthcare professionals at the Dr Bernard May Cancer Care Centre at Windhoek Central Hospital.

Furthermore, PWA who were educated understood albinism better and were not concerned about how other people perceive them compared to those less educated. Participant PWA 14 commented that:

PWA with less levels of education tend to concentrate more on themselves and on what people are saying about them, unlike educated ones who are busy with their career and life.

In affirmation, Braathern and Ingstad (2006:606) have stated that people with albinism who came from families with more resources, where the parents have an education, have more faith and hopes for the future and have less worries related to other people's reactions toward them.

ii. Environmental variable

The findings reveal that the environmental variable can serve as both a facilitator and a barrier to information seeking.

An environmental variable serves as a facilitator to information in the sense that since organisations such as NAAT and SINASRA, all government ministries, and referral hospitals are found in Khomas region, are convenient for participants to easily access the available information and services.

Most PWA who took part in the study viewed the lack of finances as a barrier to access information, as does the distance that one has to travel in order to access information. They admitted that accessing information in Khomas region comes with cost due to the long distances between information providers and information seekers.

Another intervening variable identified from the findings was language. Participants argued that most information on albinism is provided in English, making it difficult for PWA who is less educated to access it. Chiware (2008:34) explains that the official language in Namibia is English, official publications are, therefore, in English and Afrikaans, and most participants in his study could not understand or were unable to read any of these languages.

Culture as a barrier to information by one of the key informants, is a challenge to the dissemination of information to people who believe that albinism is a curse. As Orange, Seitz and Kor (2012:6) explain, cultural values and norms can influence the way in which information is disseminated and the level of importance is assigned to information and knowledge in general, thus the cultural mind-set might impose barriers to knowledge flow.

According to the findings, lack of communication facilities is one of the major challenges faced by some participants – especially those who reside in informal settlements. The lack of electricity and the resultant access to television and radio sets. They argued that the reasons why they did not bother to own these important information sources are because they do not have access to electricity, a utility that is classified nowadays as one of the basic needs. Furthermore, lack of access to important infrastructures such as the internet and computers, lack of time are some of the barriers reported by participants.

iii. Characteristics of source variable

According to Wilson (1997:561), a fundamental requirement for information seeking is that some sources of information should be accessible, because the lack of an easily accessible source may inhibit information seeking altogether. The study reveals that there is a lack of relevant literature on albinism in Namibia as indicated in chapter 1 Section 1.3 and Chapter 3, Section 3.1. Participants expressed their frustrations that information on albinism is never provided in fonts appropriate for PWA or in alternative formats, making it difficult for them to access such information. This is supported by Beverley, Bath and Barber (2011:3), who state that patients need information relating to their condition and the likely outcomes with or without treatment, at the right time and in an accessible font. They further stated that for people with visual impairment the nature of their condition can serve as a barrier to information.

iv. The individual social role

People need information for different reasons depending on the role they play in society. The reviewed literature found that participants need information about their disabilities as a way of coping with life activities (Williamson, Schauder & Bow, 2000). The findings reveal that mothers of CWA, including the researcher, searched for information on albinism to attend to the needs of their children appropriately. This includes skin and eye-related information, information on the type of school their children can attend, and effectiveness of different sunscreen lotions.

v. Information seeking strategies

Additionally, Wilson's model recognised the following types of search behaviours: passive attention, passive search, active search and ongoing search (Wilson, 1997:562). Participants confirmed receiving information from listening to the radio, watching television and reading newspapers (passive search), and actively searching for information from sources such as the

internet and interpersonal sources such as healthcare professionals, friends, family members and neighbours (active search).

6.4 Moore's (2002) model of social information needs

Moore's model comprises six dimensions of social information namely function, cluster, users, form; agents and mechanisms. Of these dimensions only three formed the basis for the analysis of this study namely: function, form, and agents.

6.4.1 Function

Function is one of Moore's (2002) components, this component emphasises the reasons why people need information. For this study this component was found necessary to understand the information needs of PWA mainly, information for citizenship and information for consumption.

a. Information for citizenship

Moore (2002:298) states that people need access to the information that will enable them to play their full part as active citizens, making democratic choices, holding organisations of all kinds to account, and exercising their rights and responsibilities as members of the society. Tilley (2009:65) explains that – in addition to the information needs that they share with everyone – people with physical disabilities need information that is relevant to their position as disabled people.

This study identifies that PWA need information related to their condition. This includes information on how to take care of their skin and eyes; on how to apply for the disability grant; information on the type of soaps, sunscreen lotions, body cream to use; and the types of clothes to wear. Furthermore, basic information required by PWA includes where to access aids such as hats, UV- protective clothes as. Similarly, information on understanding what albinism is and that PWA are human beings, were recognised as essential by key informants.

b. Information for consumption

In addition, parents of children with albinism acknowledge seeking information on the kind of schools that their children can attend, because information supports them to make informed decisions as users. This is essential, as it will adequately inform them about a range of schools and type of support services available at each school. It is also important to know the advantages and disadvantages of placing children in different schools. A number of

interviewees expressed needing information on how to protect themselves better, the type of clothing to wear (for example, the specific textile) and the effectiveness of different sunscreen lotions, especially the SPF contained in the sunscreen. It is emphasised that people need access to information as users, otherwise they lack the power to choose and, through their choices, to influence ways in which society is organised and goods and services are provided (Moore, 2000:64).

6.4.2 Form

Form is another component of Moore's model of social information needs. This component focuses on the kind of information that people need. For this analysis, the following themes were considered; environmental scanning and answers to questions.

a. Environmental scanning

Moore reported that people need information to help them build an understanding of the world in which they live and, by so doing, people seek, absorb and process many different types of information (Moore, 2002). The findings showed that participants absorbed and sought information from different sources, both formal and informal, such as friends, family, healthcare professionals, parents, and teachers, and mostly the internet, as well as radio, television and many more other sources.

On the other hand, interviewees mentioned that those from whom they seek information are sometimes rude to them and are unapproachable. Previous studies established that children with albinism are not as handicapped by the physical condition of albinism as they are by the environment, (Gaigher, Lund & Makuya, 2002:3). Rude staff members and poor service delivery were observed by (Nakuta & Mnumbi-Mchombu, 2013:343). Similarly, all participants indicated that there are occasions when they are not provided with information on disabilities as those who possess such information regard them as non-disabled. This was found by this study, despite the Namibian government's classifying PWA as disabled.

b. Answers to questions

Furthermore, Moore stated that people need to be able to get answers to specific questions that bother them. Participants wanted answers to questions, such as what albinism is, why they are white and not black like others, and why do they have poor eyesight. A parent participant wanted to know why and how she got a child with albinism. The researcher

explained that for the first two weeks after her child's birth she too had many 'why' questions.

Reviewed literature confirmed that these kinds of questions are common among those affected by albinism and their family members. Parent participants in Brocco's (2015) study specifically wanted to know 'how did it happen' after the birth of their son with albinism. Furthermore, interviewees with albinism wanted information as to where to access aids such as hats, clothes and sunscreen could be acquired, and how to apply for the disability grant.

6.4.3 Agents of information

Moore (2002) identifies three agents of information, each of whom initiates an information activity. These are the information seekers, providers, and processors.

a. Information seekers

An interviewee who was never interested in acquiring information on albinism pointed out that he survives by God's grace, while another one felt he has picked up enough information on albinism through experience and living with the condition.

From a participant's comments it was clear that interviewees actively sought information to meet their information needs. The researcher claimed:

Seeking for information on my daughter's vision was more triggered by the fact that she could not follow objects within the first three months. I sought for information on my daughter's vision from the paediatrician, who referred me to an ophthalmologist.

Similarly, organisational participants indicated that when PWA come to the organisations they seek different types of information, such as information on how to apply for a disability grant and information on skin cancer. However, some interviewees acquired information from different sources such as parents and teachers, nurses and healthcare professionals. The findings also revealed that interviewees passively absorb information through radios and television.

b. Information providers

Even though PWA have needs related to their condition, a majority of those interviewed indicate that information is not available in appropriate formats and fonts. The study cites Moore (2000:52), who explains that those who provide services and facilities that are used by people with visual impairment – along with everyone else– need to take greater account of

the importance of providing information in formats that can be used by people with little or no sight. Thus, information providers should be made aware that persons with physical disabilities need access to information services that are designed to meet their information needs (Tilley, 2009:73). The study identified healthcare professionals such as dermatologists and ophthalmologists as the providers of skin- and eye- related information, as well as SINASRA and NAAT, and other sources such as family members, friends, and neighbours, as providers of social care information.

c. Information processors

All participants in the study mentioned different people who help them with the processing of information such as spouses, parents, neighbours, friends, nurses and healthcare professionals and other siblings with albinism. Healthcare professionals (Doctors, nurses, dermatologists, and ophthalmologists) were the providers of information related to eye and skin of PWA.

6.5 Conclusions

The aim of the study was to investigate the information needs of PWA and parents of CWA using Moore's model of social information needs and Wilson's model of information behaviour as the theoretical framework guiding the study. The study concludes that PWA have information needs related to their condition, basic needs such as shelter, and other information needs such as how to obtain national documents. For PWA, information plays a crucial role in making informed decisions and choices about products and services available. Without information, they lack the power to exercise their democratic rights and will not be aware of their surroundings. 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.

On matters of information services, organisational participants indicated that they offer different information services to people with albinism. These include advising PWA on the type of clothing to wear and how to apply sunscreen lotions and so forth. Furthermore, these organisations make use of different platforms to disseminate information to PWA. However, some of the platforms were found to be ineffective resulting in the failure of participants to be aware of the existence of the organisations and to make use of the available services.

The study concluded that participants make use of both purposively and incidentally modes of acquiring information. Sources such as the internet, radio, television and healthcare professionals, family members, friends, and neighbours were mostly preferred by participants as the main sources of information. Newspapers and radio though preferred by some PWA were criticised for not being informative and not communicating the needed information to the participants.

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

6.6 Contribution of the study to the field of knowledge

As it has been mentioned in Section 1.2.3, this study serves as a reference point to provide a baseline to future studies on the same topic in other parts of Namibia especially in Ohangwena and Kavango East and West regions. Moreover, evidence of literature searches presented in annexure A also indicates that there is no known study on the information needs of PWA in Namibia, Africa and world at large; hence this study can fill the gap.

Civil societies that deal with issues of albinism found in most African countries and other stakeholders such as the Ministry of Health and Social Services, Ministry of education, Arts and Culture, Gender equality and Child Welfare and Ministry of Justice and the department of Disability Affairs in the Office of the Vice President will also benefit from the findings of the study in terms of service delivery to PWA. The study found that most PWA in the Khomas region are unaware of the existence of SINASRA and NAAT, as such they do not benefit from the services offered by these organisations. In this light, the study provides recommendations on how these limitations can be addressed in Namibia and the rest of the world. The findings can be useful to researchers investigating the health information needs, social information needs and educational related information needs of PWA.

The knowledge gained by the researcher during the process of investigation has empowered her to understand the ‘why’ questions she endured after the birth of her daughter. She became a mother who is able to stand up for albinism issues and be able to explain to others what albinism is and what it is not. She will also be able to empower PWA who find the going tough and motivate other parents to consider their children as normal human beings who have a condition. The researcher emphasises to the parents of CWA that they should use the negativity associated with albinism and turn it into something positive. As the saying goes that ‘when someone is throwing stones at you, take those stones and build a house for yourself’. Additionally, the positive views expressed by parent participants can also be used by other women who find themselves in the same situation as coping mechanism.

Another important aspect of this study is the methodology used. The study made use of auto-ethnography in addition to interviews to give a personal account of the researcher with regard to albinism. In Section 4.3.3 Anderson and Fourie (2015) acknowledged that this method has appeared in health science literature, but it has been much neglected in information science studies. Certainly, writing about personal experiences has not been a norm in information

science (Guzik, 2014). Hence the study will add to the existing literatures that have applied this methodology in information science studies.

6.7 Recommendations

6.7.1 Study's recommendations

This section provides a basis for recommendations based on findings of the study.

a. Information booklet

Expectant mothers in most cases are caught off guard as some type of disabilities such as albinism cannot be detected by the sonar during the pregnancy. Thus it is of utmost importance for health facilities in Namibia and elsewhere in the world to have support mechanisms in place for mothers giving birth especially to children who are born with any kind of disabilities.

The ministry of health and social services and relevant stakeholders should come up with a booklet providing mothers of unborn children with information on different types of disabilities that might affect the unborn babies. Such information will prepare mothers mentally and prepare them to expect the negative and positive results of childbearing.

b. Open day

The findings indicated that most of the participants were not aware of the existence of SINASRA and NAAT, and had never met those in charge of these organisations. It is, therefore, of utmost importance for the two organisations to reach out to PWA through initiatives such as open days. These will bring PWA together to know each other, have fun, share information, and stories of hope, all with the aim of getting rid of the isolation and stigma suffered by PWA and create a sense of belonging.

c. Sensitisation meetings

The findings indicate that one of the organisations does share information through face-to-face meetings, which are regarded as effective platforms to reach out to PWA and the community at large. Sensitisation meetings with the aim of raising awareness on albinism and educate society on issues affecting PWA thus need to be created. The meetings will also address the issue of the lack of awareness of the existence of NAAT and SINASRA, and share information on how PWA can benefit from these organisations.

d. Create social media platforms to share information

The creation of social media platforms should be another way of getting rid of isolation by bringing PWA together on one platform, because knowing others in the same situation is helpful. However, the WhatsApp pages, for example, should be in a language accessible just to make sure that nobody is left out.

e. Counselling services

The findings also revealed that some participants need counselling services, NAAT and SINASRA, together with the Ministry of Health and Social Services see to it that psychologists and social workers are placed at the regional councillor's offices to attend to community members, including PWA, who require this kind of services.

6.7.2 Recommendations for future research

The study only assessed the information needs of PWA, parents of CWA, and children with albinism in Khomas region, an urban area. However, it is anticipated that there is a need to conduct further studies on the information needs of PWA in other regions that represent rural settings, such as Ohangwena and Kavango East and West regions, as they are the poorest regions in Namibia and, according to the Namibia Census of 2011, the majority of PWA reside in these regions. This will be done to determine if there is a difference between the information needs of PWA in the urban and the rural areas.

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Annexure A: Evidence of literature searches

Databases	Keywords used/Search strategies	Results
<ol style="list-style-type: none"> 1. Google Scholar 2. EBSCOHOST: Academic search complete, <i>Library, Information Science & Technology Abstracts</i>, e-journals, Master file Premier 3. Science Direct 4. E books 5. JSTOR 6. Emerald 7. Sabinet African Electronic Publications (SA ePublications) 	<p>Information needs AND albinism, Information seeking behaviour AND albinism. Information AND needs AND albinism.</p> <p>Information behaviour, AND albinism.</p>	<p>The keywords given in the table were used to search for information needs of PWA in different databases. However, when the search was conducted a lot of articles which were retrieved are about the information needs of people with visual impairment, articles about albinism and health issues. Articles about the attacks and killings of PWA in Africa and articles about albinism in general. Articles addressing information needs of PWA specifically were not found.</p>

Annexure C: Interview guide for people with albinism

Date: _____

Record the time: _____

Thank you for your time once again and for your participation in this study. As I mentioned earlier, I am Anna Ngula, a mother of two children with albinism, a girl born in 2013 and a boy born in 2016. Please tell me about yourself.

1. Demographic information

1.1 How old are you?

1.2 What is your gender?

1.3 What is your highest educational qualification?

1.4 In which constituency do you live in Khomas region?

I am now going to ask you a few questions about your information needs as a person with albinism.

2 Information needs

2.1 Let us start with the time when you realised that you have albinism. Please share with me how you felt when you realised that you have albinism?

2.2 At the time when you were aware that you have albinism, what information did you want to know?

2.3 What questions about your condition did you have? Were there specific answers you were looking for? If 'yes' what sort of answers were you looking for?

2.4 As a person with albinism can you describe your daily living experiences? In view of your daily living experiences, what information would you say you need regularly?

2.5 As a person with albinism do you have any concerns, uncertainties and worries? If 'yes', what information do you think you need to address these concerns, uncertainties and worries?

2.6 What are the things that you aspire to achieve in life? What information do you think you need to be able to achieve them?

We are now moving onto questions related to how you find information that you need to assist you with albinism

3 Mechanisms used to seek information

- 3.1 Where do you find information that helps you to care for your condition? Or helps you to cope better with your condition?
- 3.2 Who encourages, helps or supports you when you are looking for information?
- 3.3 Who helps you to cope with and manage your condition?
- 3.4 What challenges, if any, do you experience when you are trying to find information related to albinism?
- 3.5 How do you think the community, the nation or the government could assist in meeting the information needs of people with albinism?

I am now going to ask you questions about organisations that assist people with albinism in the country

4. Awareness of organisations for PWA

- 4.1 Are you aware that there are organisations for people with albinism in the country?
- 4.2 Which of these organisations do you know?
- 4.3 How did you know about these organisations?
- 4.4 Are you a member of any these organisations? If 'yes', which one/s?
- 4.5 What was the main reason for joining this organisation/these organisations?
- 4.6 What services and support do you get from these organisations? If the response was 'no' for 2.4, will you please share with me your reasons for not joining of any these organisations?

Now we have come to the end of our discussion, do you have any comments or questions related to our discussion?

Thank you very much for your time and participation in this study. Please feel free to contact me if you have questions related to our discussion today. Here is my business card.

Record the time: _____

Annexure D: Interview guide parents of children with albinism

Date: _____

Record the time: _____

Thank you for your time once again and for your participation in this study. As I mentioned earlier, I am Anna Ngula, a mother of two children with albinism, a girl born in 2013 and a boy born in 2016.

I am going to start by asking you questions about yourself

Demographic information

- 1.1 How old are you?
- 1.2 What is your gender?
- 1.3 What is your highest educational qualification?
- 1.4 In which constituency do you live in Khomas region?
- 1.5 How many children with albinism do you have?
- 1.6 How old is your child/are your children with albinism?
- 1.7 Were your children born in hospital or at home?

I am now going to ask you a few questions about the information that you needed and still need since giving birth to a child or children with albinism.

2. Information needs

- 2.1 Let us start with the time you gave birth to a child with albinism. Would you please share with me how you felt when you realised that your child has albinism?
- 2.2 When you became aware that your child has albinism, what information did you want at that time?
- 2.3 What information did you need as your child grew up?
- 2.4 What information do you need now?
- 2.5 As a parent of a child with albinism can you describe your daily experience about your child's condition?
- 2.6 What kind of support do you and your child with albinism need?

We are now moving onto questions related to how you find information that you need to assist your child with albinism.

3. Mechanisms used to seek information

- 3.1 Where do you find information that help you to care for your child with albinism or that help you to cope better with the condition of your child?
- 3.2 Who encourages you or supports you when you are looking for information?
- 3.3 Who helps you to cope with and manage the condition of your child?
- 3.4 How does your family cope with and manage the condition of the child with albinism?
- 3.5 What challenges do you experience when you are trying to find information related to albinism?
- 3.6 Which services would you suggest or recommend for people with albinism particularly related to their information needs

I am now going to ask you questions about organisations that assist people with albinism in the country.

4. Awareness of organisations for PWA

- 4.1 Are you aware that there are organisations for people with albinism in the country?
- 4.2 Which of these organisations do you know?
- 4.3 How did you know about these organisations?
- 4.4 Which of these organisations are you a member of?
- 4.5 What was the main reason for joining these organisation/these organisations? / Why are you not a member of any organisation?
- 4.6 What services and support do you and your child get from these organisations? (I will not ask this question to the parent that is not a member of an organisation.)

Do you have any comments or questions related to our discussion?

Thank you very much for your time and participation in this study. Please feel free to contact me if you have questions related to our discussion today. Here is my business card.

Record the time: _____

Annexure E: Interview guide for key informants

Date: _____

Record the time: _____

Thank you for your time once again and for your participation in this study.

I am going to start by asking you questions about your organisation

Section A: Background information

1. What is the name of the organisation?
2. When was it established?
3. What is the primary objective of this organisation?
4. What are the major activities of your organisation?
5. What is your role in this organisation?

I am now going to ask questions about information needs and information services for PWA

Section B: information provision

6. What kind of services do you offer to PWA in Khomas Region?
7. How do you raise awareness of your organisation and its services to PWA in Khomas Region?
8. How do you ensure that information about the services you offer reaches PWA in Khomas Region?
9. Besides English, which other languages do you use to disseminate information to PWA?
10. What challenges do you experience when disseminating information to PWA in Khomas Region?
11. When PWA come to your organisation which information do they look for?
12. In your opinion, what are the information needs of PWA in Khomas Region?
13. In your opinion, which sources of information, related to their condition, do PWA in Khomas Region use?
14. Do you have any suggestions or recommendations for information services of PWA in Khomas Region or Namibia in general?
15. Do you have any comment or question related to our discussion?

Thank you very much for your time

Annexure F: Interview guide for people with albinism translated in Oshiwambo

Esiku lyomapulapulo: _____

Ethimbo: _____

Tangi unene sho wimangulula kinaku gwanithwa yoke opo wu kuthe ombinga. Ngashi shali sha tseyitwa petameko edhina lyandje ongame Anna Ngula nondili ndina aanona yaali omukadhona avalwa mo2013 noshowo omumati avalwa mo2016, noyeli taya lumbu nuulema woshipa

1. Demographic information

1.1 Owuna omvula ngaapi?

1.2 Owuna omvula ngaapi?

1.3 Ondondo yoye yopambanda melongo

1.4 Ohokala moshitopolwa shinipo mo Khomas Region?

Ngashingeyi otandi ke kupula omapulo genasha nomahangano nga haga kwathele aanulema yoshipa moshilongo.

Andi kapula omapulo genasha nuyelele mbu wa li wa pumbwa onгаа omuntu ena uulema woshipa

2. Uyelele mbu wali wapumbwa

2.1 Natu tameke nethimbo shi wa dhimbulula kutya owuna uulema woshipa. Oto vulu oku lombwelandje kutya owali wu vite ngiini shi wa dhimbulula kutya owuna uulema woshipa.

2.2 Pethimbo mpono shi wa dhimbulula kutya owuna uulema woshipa, uyelele wuni kwa wa pumbwa pethimbo mpono?

2.3 Omapulo geni kwali wuna shinasha nonkalo yoye? Opuna omayamukulo ko ndandalunde ngaa kwali wahala gayamukulwa? ‘Ngele osho’ omayamukulo geni wali wahala gayamukulwa?

2.4 Onga omuntu ena uulema woshipa onkalo yoye yesiku kehe oyili ngiini? Monkalo yoye yesiku kehe uyelele wuni hokala wa pumbwa unenene esiku kehe.

2.5 **Onga omuntu ena ulema woshipa opuna sha mbela se ku limbilika? “Nangele osho” uyelele wuni wapumbiwa oku ku kwatha mo momalimbibili nagno?**

Ngashingeyi otandi kapula omapula kombinga yoku mona uyelele opo wu kwathele okanona koye hoka kena uulema woshipa.

3. Oho kongo uyelele ngiini?

- 3.1 Openi ho adha uyelele tawu ku kwatha opo wusile okanona koye oshimpwiyu, nenge hawu kutha opo shi kukalele oshipu okusila
- 3.2 Olye he ku tsu omukumo nenge he ku kwatha ngele to kongo uyelele?
- 3.3 Olye he ku kwatha okusinda omashongo nokusila onkalo yokanona koye oshimpwiyu?
- 3.4 Ezimo lyoye ohali konditha ngiini omashongo nokusila onkalo yokanona koye oshimpwiyu?
- 3.5 Oho tsakaneke omaudhigu gashike moku konga uyelele wunasha nuulema woshipa?
- 3.6 Oprograma dhinipo wu uvite kutya odha pumbiwa okupewa aantu mba yena uulema woshipa uunene shinasha nomawuyelele ngaa yapumbwa.

4. Uyelele wunasha nuulema woshipa

- 4.1 Owe tseya tuu kutya opuna omahangano haga kwathele aantu mba yena uulema woshipa moshilomgo?
- 4.2 Genipo gomo mahangano ngano wushi?
- 4.3 Genipo gomo mahangano ngano wushi?
- 4.4 Owuli oshilyo sha limwe lyo momahangano ngaano? *Ngele osho* olinipo?
- 4.5 Omolwashike wuli oshilyo shehangano nenge shomahangano ngaano?
- 4.6 Komahangano ngano ohomonoko omakwatho no sapota yashike??
- 4.7 *Ngele eyamukulo lyoye mo 2.4*, olyali no omolwashike kuli oshilyo shomahangano ngano?

Owuna omapulo gagwedhwapo shina nashi kwali tatu popi?

Tangi unene showakutha ombinga mo study djika. Ngele owuna omagwedhelepo kombinga yashi twa popi nena.

Ethimbo: _____

Annexure G: Interview guide for parents of children with albinism translated in Oshiwambo

Esiku lyomapulapulo: _____

Ethimbo: _____

Tangi unene sho wimangulula kinaku gwanithwa yoke opo wu kuthe ombinga. Ngashi shali sha tseyitwa petameko edhina lyandje ongame Anna Ngula nondili ndina aanona yaali omukadhona avalwa mo2013 noshowo omumati avalwa mo2016, noyeli taya lumbu nuulema woshipa.

Otandi ka Tameka tepula omapulo kombinga yoye mwene.

1. Demographic information

- 1.1 Owuna omvula ngaapi?
- 1.2 Ngoye omunkiintu nenge omulumentu?
- 1.3 Ondondo yoye yopambanda melongo
- 1.4 Ohokala moshitopolwa shinipo mo Khomas Region?
- 1.5 Owuna uunona uungapi wuna uulema woshipa?
- 1.6 Uunona woye mbu wuna uulema woshipa owuna omvula ngaapi?
- 1.7 Uunona woye owa valelwa kegumbo nenge omoshipangelo?

Ngashingeyi otandi ke kupula omapulo genasha nomahangano nga haga kwathele aanulema yoshipa moshilongo.

Andi kapula omapulo genasha nuuyeleele mbu wali wa pumbwa pethimbo wa mono okanona nuuyeleele mbu wuli wa pumbwa natango sho wuli omuvali gokanona nenege guunona wuna uulema woshipa.

2 Uuyeleele wuni wali wapumbwa

- 2.1 Natu tameke nethimbo shiwamono okanona kena ulema woshipa. Owali wu uvute ngiini shi wa dhimbulula kutya okanona koye okena uulema woshipa?
- 2.2 Shi wa dhimbulula kutya okanona koye okena uulema woshipa, uuyeleele wuni kwa wa pumbwa pethimbo mpono?
- 2.3 Shokanona koye taka ende ta ka koko uuyeleele wuni wuli wa pumbwa?
- 2.4 Uuyeleele wuni wa pumbwa ngashingeyi?
- 2.5 Onga omuvali gokanona kena uulema woshipa, onkalo yoye yesiku kehe oyatya ngiini unene ngele tashiya konkalo yokanona koye.
- 2.6 Omakwatho genipo ngoye onгаа omuvali nokanona koye mwa pumbwa?

3 Oho kongo uyelele ngiini?

- 3.1 Openi ho adha uyelele tawu ku kwatha opo wusile okanona koye oshimpwiyu?
- 3.2 Olye he ku tsu omukumo nenge he ku kwatha ngele to kongo uyelele?
- 3.3 Olye he ku kwatha okusinda omashongo nokusila onkalo yokanona koye oshimpwiyu?
- 3.4 Ezimo lyoye ohali konditha ngiini omashongo nokusila onkalo yokanona koye oshimpwiyu?
- 3.5 Oho tsakaneke omaudhigu gashike moku konga uyelele wunasha nuulema woshipa?
- 3.6 Oprograma dhinipo wu uvite kutya odha pumbiwa okupewa aantu mba yena uulema woshipa uunene shinasha nomawuyelele ngaa yapumbwa.

4 Uyelele wunasha nomahangano guulema woshipa

- 4.1 Owa tseya tuu kutya opuna omahangano haga kwathele aantu mba yena uulema woshipa moshilomgo?
- 4.2 Genipo gomo mahangano ngano wushi?
- 4.3 Omahangano ngaano owega tseya ngiini?
- 4.4 Momahangano ngaano olinipo wuli oshilyo?
- 4.5 Omolwashike wuli oshilyo shehangano nenge shomahangano ngaano / omolwashike ino joina ashike kehe ehangano?

Komahangano ngano ngoye no mumoye ohamunoko omakwatho no sapota yashike?

Owuna omapulo gagwedhwapo shina nashi kwali tatu popi?

Tangi unene showakutha ombinga mo study djika. Ngele owuna omagwedhelepo kombinga yashi twa popi nena.

Ethimbo: _____

Annexure H: Ethical clearance



Library and Information Studies Centre
University of Cape Town
Upper Campus

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Tel: +27 (0) 21 650 4546 Fax: +27 (0) 21 650 2529
E-mail: lisc@uct.ac.za
Internet: www.lisc.uct.ac.za

Ref. no.: UCTLIS201706-07

03 July 2017

Dear Ms Ngula

I am pleased to inform you that ethical clearance has been granted by the Ethics Review Committee of the Library and Information Studies Centre on behalf of the Humanities Faculty of the University of Cape Town for your Master's study entitled: *Information needs of people with albinism (PWA) in Khomas Region, Namibia*.

I wish you well with your study.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Michelle Kahn'.

Ms Michelle Kahn

Chair, Department (LISC) Research Ethics Committee

Annexure I: proof of approval to conduct research in khomas region



KHOMAS REGIONAL COUNCIL

Tel No. : (061) 2924300
Fax No.: (061) 220317

Khomas Regional Council
P.O. Box 3379
WINDHOEK

Our Ref:
Your Ref: 8/3/1
Enquiries: MNL Enkono

07 July 2017

Mrs. Anna Ngula
P O Box 99525
Windhoek

APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH PROPOSAL IN KHOMAS REGIONAL COUNCIL (ALL CONSTITUENCIES)

1. Reference is made to your letter dated 06 July 2017 in the above regard.
2. This letter serves to inform you that, approval had been granted to conduct your reach at the Khomas Regional Council for educational purpose to fulfill the study requirement toward obtaining the Masters in Library/ Inf Science.

Yours sincerely,


CLEMENT M. MAFWILA
CHIEF REGIONAL OFFICER

