HEALTH INFORMATION SEEKING BEHAVIOUR OF GUARDIANS OF BLIND CHILDREN LIVING IN THE RURAL FREE STATE

By

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DECLARATION

I, Molebogeng Simphiwe Motseke, hereby declare that this dissertation submitted for the degree MA (Communication Science) at the University of the Free State, is my own independent work. I further declare that this dissertation has not been previously submitted to any other institution of higher education for the purpose of obtaining a degree. I am also aware that the copyright is vested in the University of the Free State.

Motseke

Molebogeng Simphiwe Motseke

02 December 2019

DEDICATION

I dedicate this dissertation to myself, Molebogeng Simphiwe Motseke.

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ABSTRACT

Disabilities related to sight are the most common in South Africa and commonly afflict South African children (Lehlola, 2005; 2014; DSD, DWCOD & UNICEF, 2014). In addition to normal parenting tasks, guardians of children living with disabilities are faced with the need to manage uncertainties about their children's medical, motor, intellectual and social prognosis (Barnett et al, 2003, Gona et al., 2011). Some of these uncertainties can be managed through seeking health information, which can include disability-specific information and information about specialised support that the children may need to ensure optimum development (Eleweke et al., 2008). It is, however, well documented in the literature that guardians of children living with disabilities have unmet health information needs and that these needs are worsened in rural areas by factors including poverty, lack of education, cultural beliefs and limited access to healthcare resources (Sloper, 1999; Rahi, Manaras, Tuomainen & Hundt, 2004; Jackson, Baird, Davis-Reynolds, Smith, Blackburn & Allsebrook, 2007; Skinner & Skilfkin, 2007; Lorenzo, van Pletzen & Booyens, 2015).

The culture-centred approach (CCA) to health communication focuses on listening to the voices of cultural members and allowing them to enter into communicative processes by voicing alternative perspectives of health that are relevant to their context (Dutta, 2008). Adopting the tenets of the CCA, this study sought to explore the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas of the Free State province and learn from them how to best meet their health information needs regarding their children's blindness. The objectives of this study were to (1) identify the role that cultural beliefs play in the guardians' perception of the causes of their children's blindness, (2) identify the source(s) of health information that the guardians commonly used and (3) determine the health information source(s) that the guardians preferred and whether the reasons for those preferences were culturally bound.

Individual, face-to-face, semi-structured, in-depth interviews with 22 guardians of blind and partially blind children who live in rural areas of the Free State province revealed that the guardians' cultural beliefs shaped how they perceived the causes of their children's blindness, which in turn influenced their eye-care seeking behaviours and decisions to seek health information. The source of health information that the guardians commonly used was face-to-face communication between themselves and members of their families and communities, religious leaders, traditional healers, allopathic healthcare practitioners and educators from the mainstream schools that their children formerly attended. The source of health information that the guardians preferred the most was face-to-face communication in their native language at central locations within their communities such as at the local clinics, churches, schools, libraries and community halls. This study found that this preference was not culturally bound but rather influenced by the guardians' literacy levels, socio-economic status and the accessibility of resources available to them.

The findings of this study also highlight the importance of understanding the influence of the three key tenets of the CCA – culture, structure and agency- on the guardians' health information seeking behaviour. An intersectional analysis of culture, structure and agency revealed that these tenets both enable and constrain the guardians’ health information seeking behaviour. This study argues that this understanding may help increase the guardians’ access to and use of health information by allowing for the creation of culturally relevant health information material and the provision thereof through platforms that are commonly used by and easily accessible to the guardians.

Keywords: *Health communication, childhood blindness, health information seeking behaviour, eye-care seeking behaviour, culture-centred approach.*

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CHAPTER ONE

INTRODUCTION

Background

The disclosure of a child's diagnosis of disability is an overwhelming experience for guardians, which often results in new responsibilities (Perryman, 2005; Kandel & Merrick, 2007). In addition to normal parenting tasks, guardians of children living with disabilities are faced with the need to manage uncertainties about their children's medical, motor, intellectual and social prognosis (Barnett et al., 2003; Gona et al., 2011).

Some of these uncertainties can be managed through seeking health information, which can include disability-specific information and information about specialised support that the children may need to ensure optimum development (Eleweke et al., 2008). The guardians' health information seeking behaviour is often influenced by their beliefs regarding the causes of the children's disability. These beliefs are often a result of overarching societal beliefs and values, and include elements that are economic, political, social and spiritual (Eleweke et al., 2008). Guardians who believe that their children's disability was caused by biological variables are likely to seek bio-medical information, while those with a fatalistic view are more likely to accept their children's disability as fate (Ravindran & Myers, 2012). Those who believe that the disability was caused by environmental factors may seek information on behaviourally-based interventions (Ravindran & Myers, 2012), while those who believe that it was a result of a curse or punishment may be reluctant to use - on the child – resources they believe are scarce such as money and nutritious food (Gilbert, 2007).

Health communication typically flows from guardian to child (Williams et al., 2016), and aims to improve health outcomes by sharing health-related information (Schiavo, 2007). Eleweke et al. (2008) stress the importance of providing guardians of children living with disabilities with relevant and useful information. It is, however, well documented in the literature that guardians of children living with disabilities have unmet health information needs, which are worsened in rural areas by factors including poverty, lack of education, cultural beliefs and limited access to healthcare resources (Sloper, 1999; Rahi, Manaras, Tuomainen & Hundt, 2004; Jackson, Baird, Davis-Reynolds, Smith, Blackburn & Allsebrook, 2007; Skinner & Skilfkin, 2007; Lorenzo, van Pletzen & Booyens, 2015)

Disabilities related to sight are the highest in South Africa (Lehlola, 2005, 2014) and commonly afflict South African children (DSD, DWCOD & UNICEF, 2014). The Free State province has the highest proportion of persons living with severe (2.8%) and mild (13.8%) sight difficulties (Lehohla, 2014). The global initiative - 'VISION 2020: the Right to Sight' - identified childhood blindness as one of the five key areas for action and aims to reduce the prevalence of blindness in children due to treatable and preventable causes by the year 2020 (WHO, 2007). Health communication, which is an important component of patient care, can play a multifaceted role in improving the health of individuals (Nazione et al., 2013; Valero-Garcés, 2014). Williams et al. (2016), however, affirm that factors such as culturally inappropriate material, health literacy, access to healthcare, and the low prioritisation of health due to competing economic demands make it challenging for health communicators to effectively engage with economically-disadvantaged communities. This study will focus on childhood blindness and will be conducted in rural areas of the Free State province.

Research problem and objectives

The aim of this study is to explore the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas of the Free State province and suggest alternatives to the current ways of making health information available to these guardians.

The objectives of this study will be to:

a) Identify the role that cultural beliefs play in the guardians' perception of the causes of their children's blindness.
b) Identify the source(s) of health information that the guardians commonly use.
c) Determine the health information source(s) that the guardians prefer and whether the reasons for those preferences are culturally bound.

The field of health communication is grounded on the assumption that health communicators need to gain ample insight about their target audiences and that this information informs their communication approach (Bernhardt & Cameron, 2008). Kreuter and Wray (2003) affirm that the more knowledgeable health communicators are about the intended recipients of their messages, the more relevant those messages will be. This study highlights the importance of understanding the influence of the three key tenets of the culture-centred approach (CCA) to health communication - culture, structure and agency - on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas, and argues that this understanding may help increase their access to and use of health information by allowing for the creation of culturally relevant health information material and the provision thereof through platforms that are commonly used by and easily accessible to the guardians.

Culture, which is created by the daily practices of members of a community, refers to the local contexts within which health meanings are constituted and negotiated (Dutta, 2008). Cultural beliefs, values and practices greatly influence an individual's understanding of health and subsequently shape their behaviour (Dutta, 2008; Tan, 2016). Because of its influence on an individual's attitudes, perspectives, knowledge creation and sharing of meaning (Dutta & Basu, 2007; Tan, 2016), this study asserts the need for understanding the role that culture plays on the health information seeking behaviour of guardians of blind and partially blind children living in rural areas.

Structure refers to aspects of social organisation which enable and/or constrain an individual's capacity to engage in health-related behaviours (Dutta, 2008). This includes elements which are vital to the individual's healthcare such as food, shelter, transportation and medical services (ibid). Structure is deeply connected with the availability of material resources and influences the daily healthcare choices of members living in marginalised communities (ibid). Dutta (2008) argues that structure is simultaneously enabling and constraining as it determines the range of healthcare choices that are available or unavailable to individuals and thus limits healthcare in marginalised settings. On the other hand, structure challenges the frameworks within which health is constructed and thus creates opportunities for change (ibid). Structure can be used to determine whether or not, and the extent to which, guardians of blind and partially blind children living in rural areas are constrained; whilst also aiding in challenging the frameworks within which health is constructed and creating opportunities for change.

Agency is understood as an individual's ability to act in their own interests, to make choices and to participate actively in working with and/or challenging the structures that constrain their lives (Dutta, 2008; Sheik, 2013). An individual's ability to act is, however, subject to available resources (Sheik, 2013), which could in turn have an influence on the health information seeking behaviour of guardians of blind and partially blind children living in rural areas.

The intersection of these key tenets of the CCA creates openings which allow for the voices of marginalised communities to be heard, constructs discursive spaces where erasures in marginalised settings are interrogated, and offers opportunities for engaging in dialogue with and co-constructing the voices of those who have traditionally been silenced (Dutta, 2008). Based on the background presented, the culture-centred approach (CCA) to health communication is an effective framework for understanding the health information seeking behaviour of guardians of blind and partially blind children living in rural areas of the Free State province in South Africa.

Structure of the dissertation

This dissertation is organised into 6 chapters. Chapter 1 briefly explains the background, research problem and objectives of this study, and outlines the structure of the dissertation. Chapter 2 provides a critical review of the literature on topics that are relevant to this study. Chapter 3 focuses on the theoretical framework underpinning this study. Chapter 4 details the methodology used for this study. Chapter 5 covers the findings of this study. Chapter 6 concludes the dissertation by discussing the findings, providing recommendations, highlighting the limitations of this study and suggesting ideas for future research.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This study seeks to explore the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas of the Free State province and suggest alternatives to the current ways of making health information available to these guardians.

Bourne et al. (2017) reported that 2015 global data revealed that an estimated 217 million people have moderate to severe visual impairment and of those, 36 million are completely blind. In South Africa, the most common type of disability is related to sight (Lehlola, 2005; 2014), and commonly afflicts South African children (DSD, DWCOD & UNICEF, 2014). Despite the fact that up to 80% of global blindness can be treated or prevented (WHO, 2013), the number of blind people continues to increase. Childhood blindness is one of the focal areas of the global initiative ''VISION 2020: The Right to Sight'' which was launched in 1999 (WHO, 2007). This initiative aims to eliminate avoidable blindness by the year 2020 and to prevent the projected doubling of avoidable visual impairment between the years 1990 and 2020 (ibid).

The involvement of guardians is pivotal for the treatment and prevention of childhood blindness (WHO, 2007). As primary care givers and decision makers regarding their children's healthcare needs and the seeking of related healthcare services, guardians play an essential role in the control of childhood blindness (Glascoe, 2003; Kumar et al., 2013). Scholars suggest that the eye-care seeking behaviour of guardians plays a crucial role in reducing the prevalence of blindness in children, which is sometimes due to treatable or preventable causes (Balasubramaniam et al., 2013). Various scholars have additionally found that knowledge of how guardians perceive ocular ailments is important in helping to understand their eye-care seeking behaviour (Abubakar & Ajaiyeoba, 2001; Ebeigbe & Emedike, 2017).

Information is vital for guardians as they raise young children and equip older ones for independence (Gibson, Kaplan & Vardell, 2017). Access to information enables guardians of children with disabilities to take an active role in their decision-making processes, and in the treatment and rehabilitation of their children (Hummelinck & Pollock, 2006; Al-Daihani & Al-Ateeqi, 2015). In order for guardians to perform this role efficiently, it is important that they are aware of their information needs and that they are able to access and make appropriate use of relevant information (Al-Daihani & Al-Ateeqi, 2015). Numerous scholars have affirmed that the guardians' decisions about where to look for information are influenced by their information needs - which differ among guardians, change over time, and are influenced by their individual contexts (Hummelinck & Pollock, 2006; Al-Suqri & Al-Aufri, 2015; Gibson, Kaplan & Vardell, 2017; Alsem et al., 2017).

This chapter will provide a review of the literature in the area of childhood blindness and on how beliefs and taboos influence the perception of blindness in rural areas. This includes perceptions about the causes of blindness as well as the treatment, prevention and cure of blindness and ocular ailments. This chapter also reviews the literature on the eye-care seeking behaviour of people living in rural areas, the utilisation of eye-care services in rural areas, the information needs and information seeking behaviour of guardians of children living with disabilities, as well as the information sources that are used by these guardians. This chapter also examines the literature dealing with the influence that sociographic and demographic factors have on the various topics covered in this study, the role of health communication and the role of culture in health communication.

Childhood blindness

Africa, where 10% of the global population lives, is home to approximately one-quarter of the world's blind children (Gilbert, 2007). Majority of the children who become blind in developing countries die within a few years after losing their eyesight (Gilbert & Foster, 2001). These children die from systemic complications of the blindness-causing condition (ibid). These conditions include vitamin A deficiency, congenital rubella syndrome, measles, meningitis, prematurity and other inherited syndromes (ibid). The major causes of blindness in children vary widely among regions and are mainly determined by socioeconomic development and the availability of primary healthcare and eye-care services (Gilbert & Foster, 2001; Gilbert, 2007). Childhood blindness does not only impact the children's development, education, quality of life and future work opportunities, it also has dire social and economic consequences on the family (Kumar et al., 2013). Another reason for early mortality in blind children is that poor parents find it more difficult to provide care for their blind children than they do for their sighted siblings (Gilbert & Foster, 2001).

Although childhood blindness comprises of only 4% of the total global blindness (Pascolini & Mariotti, 2012), it is recognised as a worldwide priority because of (a) the number of 'blind years' experienced by the children, (b) the fact that many of its causes are treatable or preventable, and (c) the availability of effective interventions (WHO 2000; Gilbert & Foster, 2001; Kong, Fry, Al-Samarraie, Gilbert & Steinkuller, 2012).

Most blind children are either born blind or become blind before the age of 15 and thus have a lifetime of blindness ahead of them (WHO, 2007). The term 'blind years' refers to the expected number of years a person will live without vision (WHO, 2007), and blind children live more 'blind years' than blind adults (Ebeigbe & Emedike, 2017). Gilbert et al. (2003) reported that an adult who loses their sight due to age related cataract will, on average, live for approximately 5 years before dying, whereas a child who loses their eyesight at the age of 5 may live for up to 50 years. Kong et al., (2012) affirm that these 'blind years' are costly because of the resources required - from both the healthcare system and the blind children's families. These resources include costs for running medical and allied health services, costs associated with transportation and possible home modifications, as well as additional attention and security (WHO, 2007).

The World Health Organisation (2007) found that nearly 50% of the estimated 1.4 million cases of blindness in children below the age of 15 years could have been avoided. Research on childhood blindness shows that childhood blindness is not only treatable or preventable, but that blind children's eyesight can also be restored (Ebeigbe & Emedike, 2017; Kumar et al., 2013; Balasubramaniam et al., 2013, Gilbert & Foster, 2001). Gilbert and Foster (2001) learned that the early treatment of glaucoma and retinopathy of prematurity (ROP) could prevent blindness in children; that blindness causing conditions such as measles infections, ophthalmia neonatorum, vitamin A deficiency, congenital rubella syndrome and the use of harmful eye medication remedies could be entirely prevented; and that eyesight can be restored if blindness is due to cataract and selected cases of corneal scarring.

Interventions aimed at the treatment and prevention of blindness in children include increasing awareness and encouraging the use of primary eye-care services; avoidance of harmful traditional practices to prevent corneal scarring; ocular prophylaxis of newly born babies to prevent neonatal conjunctivitis; measles immunisation to prevent corneal scarring; rubella immunisation; nutrition education; food supplementation and fortification of commonly eaten food with vitamin A to control vitamin A deficiency (WHO, 2007).

Beliefs regarding the causes of blindness in rural areas

The literature centers on the biomedical dimensions of how blindness is understood. Globally, the leading causes of blindness have been identified as cataract, uncorrected refractive error, glaucoma, age-related macular degeneration, corneal opacity, trachoma and diabetic retinopathy (Flaxman et al., 2017).

People living in rural areas, however, have their own beliefs regarding the causes of blindness, which subsequently influences their health information seeking behaviour. Numerous scholars affirm that it is important to understand the beliefs of these rural dwellers, as this understanding could help enhance their utilisation of eye-care facilities, and also aid with the planning and implementation of blindness prevention initiatives that are not only affordable, but are also acceptable to the people (Nwosu, 2002; Ashaye, Ajuwon & Adeoti, 2006; Olatunji, Adepoju & Owoeye, 2015). This study additionally suggests that understanding the beliefs of guardians of blind and partially blind children who live in rural areas regarding the causes their children’s blindness, and the influence of these beliefs on their health information seeking behavior, may help increase their access to and use of health information.

The literature reviewed shows that the perceptions of the causes of blindness in rural areas have not changed much over the years. In a study on the beliefs and attitudes to eye disease and blindness in rural Anambra State- Nigeria, Nwosu (2002) found that blindness was mainly caused by filariasis, germs and enemy poison. Other causes of blindness included inheritance, swearing to false oath, entering an evil forest, and evil spirits. Some respondents stated that they were not certain of the causes of blindness. It is worth noting that the study was conducted in onchocerciasis (river blindness) endemic communities, which could be the reason for filariasis being cited as the major cause of blindness (Nwosu, 2002).

In another study on the perception of blindness and blinding eye conditions in Nigeria, Ashaye, Ajuwon and Adeoti (2006) conducted focus group discussions with partially and completely blind male and female respondents from two rural communities. These respondents identified the two major causes of blindness as onchocerciasis, and cases where an individual’s eyes are open but the person is unable to see. Other listed causes of blindness were conjunctivitis, smallpox, and violation of pregnancy taboos which could lead to eye diseases in the unborn baby. To supplement their data, these scholars did in-depth interviews with traditional healers and patent medicine sellers who were the major providers of eye-care services in the two rural communities. These interviews revealed that the respondents believed that supernatural means, onchocerciasis, situations in which excessive sweat gets into the eyes of farmers, and germs that are believed to live naturally in one's body were the main causes of blindness. Other causes of blindness identified by patent medicine sellers were poor feeding, measles, walking in the heat of the sun, aging and farm-related injuries (Ashaye, Ajuwon & Adeoti, 2006)

A third study conducted in Nigeria on a rural community's perception and attitude concerning blindness in adults revealed that the consumption of certain types of food, and supernatural forces were believed to be the major causes of blindness (Olatunji, Adepoju & Owoeye, 2015). Other causes of blindness cited by the respondents were aging, onchocerciasis, germs, eye trauma, long term exposure to smoke, long-term spectacle wear, prolonged ocular itching, evil whirlwind and disobedience. Another belief was that blindness was hereditary (ibid). Ofosu et al. (2018) in Ghana similarly found that ocular ailments and subsequent blindness were believed to be caused by old age, injury, drinking contaminated water, sweat entering eyes during diving or working on farms and conjunctivitis.

Traditional beliefs and taboos

There are various traditional beliefs and taboos regarding the causes of blindness which are passed from generation-to-generation in rural settings. These beliefs involve the consumption of certain foods and the involvement of supernatural forces. For example, in a 2006 study, Ashaye, Ajuwon and Adeoti found that respondents from a rural community in Nigeria believed that the excessive consumption of carbohydrates and food seasoning caused itching of the eyes. This, in their view, resulted in blindness. Nine years later, Olatunji, Adepoju and Owoeye (2015) found that individuals living in rural areas in Nigeria believed that the consumption of certain food such as groundnut, roasted cassava flakes, vegetable oil and okra could cause blindness. Ofosu et al. (2018) additionally found that some rural dwellers in Ghana believed that eating too much gari (powdered foodstuff) and cocoyam caused blindness.

Ashaye, Ajuwon and Adeoti (2006) also found that some respondents believed that a person became blind due to supernatural means after engaging in a bitter quarrel with a neighbour. Specifically, they believed that an aggrieved neighbour could contact a healer who would make a "charm" on their behalf. The charm – which was worn as a ring and displayed so the victim could see it - had the power to cause the intended victim to lose their eyesight immediately. Olatunji, Adepoju and Owoeye (2015) confirmed that the belief that blindness is caused by punishment from supernatural forces is common in most rural areas in Africa, where there is a strong belief in evil powers and deities. Similar findings were made by Ashaye, Ajuwon and Adeoti (2006), and Nwosu (2002). A study in Papua New Guinea also revealed that vision impairment was attributed to witchcraft and it was believed that the perpetrator would seek to 'spoil' one's eyes as a means of seeking revenge or in order to punish them. Such a belief may result in individuals being reluctant to accept modern preventative and/or therapeutic options, or hinder them from seeking or accepting proper and timely eye-care (Olatunji, Adepoju & Owoeye, 2015)

Beliefs regarding the treatment, prevention and cure of blindness and ocular ailments in rural areas

According to several scholars, rural residents with ocular ailments make use of various treatment methods. These methods include the use of allopathic treatment, a combination of allopathic treatment and religious and/or traditional interventions, or the exclusive use of traditional interventions (Otomoye et al., 2013; Olatunji, Adepoju & Owoeye, 2015; Maregesi et al., 2016; Ofosu et al., 2018). Many of these individuals, however, resort to self-medication and the use of traditional eye medicine (TEM) – which is found to be common practice in rural areas in Tanzania, Nigeria, Ghana, Pakistan, India and South Africa (Ashaye, Ajuwon & Adeoti, 2006; Ukponmwan & Momoh, 2010; Iqbal et al., 2012; Olatunji, Adepoju & Owoeye, 2015; Maregesi et al., 2016; Rakoma, 2017; Ofosu et al., 2018) and is attributed to reasons such as inaccessibility, non-availability and high costs of transportation and medical services (Ukponmwan & Momoh, 2010). Omotoye et al. (2013), for instance, found that only 137 (23%) of 588 rural dwellers made use of allopathic eye-care services while 451 (77%) resorted to alternative eye therapy.

Although products used for the production of TEM differ from country to country (Iqbal et al. 2012; Maregesi et al., 2016), the use of similar products has been reported in various studies. Chemical substances and plant products are of frequent use in Pakistan, where Iqbal et al. (2012) found galena-lead sulphide to be the most used, followed by honey. Other products used include alum, turmeric paste, cold water, hot fomentation, olive oil, rose water, black pepper, ice cubes and goat milk (ibid). Products used in India included honey, rose water, alum water, milk, plant juice, saline water, breast milk, turmeric, jiggery, garlic, goat's milk, powdered horn of deer, excreta of donkey, lemon juice, turpentine, coconut oil, warm tea leaves, ginger juice, onion juice, mustard oil, carom seeds and leaf extracts (Gupta, et al. 2017). A majority of TEM products used in Tanzania were herbal preparations, and some products included animal waste (Maregesi, et al. 2016). Ukponmwan and Momoh (2010) found that many of the respondents in Nigeria used plant extracts, breastmilk, religious items, urine, soot and alcohol. Other studies carried out in Nigeria reported that TEM products used included substances such as battery fluid, eye pencil, palm wine (Olatunji, Adepoju & Owoeye, 2015), holy water, salt solutions, petrol/kerosene, human urine, tobacco powder (snuff) (Nwosu, 2002), and clean water (Ashaye, Ajuwon & Adeoti, 2006). A study from Ghana reported the use of breast milk, salt water, antimony powder, shea butter, seawater, tobacco snuff, herbs and drinking a mixture of malt and tomato puree (Ofosu et al., 2018). The use of herbal concoctions, cassava extracts and water was reported in many of the studies (Nwosu, 2002; Ashaye, Ajuwon & Adeoti, 2006; Olatunji, Adepoju & Owoeye, 2015). Rakoma (2017) similarly found that TEM products used in South Africa included urine, breast milk, herbal mixtures, sugar and water, salt and water, anointed water and anointed tea.

Individuals in rural areas make use of herbal medicine mainly because it is easy to access and because of the high cost of allopathic pharmaceuticals and healthcare services (Pendola et al., 2008). Researchers have learned that any part of the plant may be used to make herbal medicine (Ukponmwan & Momoh, 2010; Maregesi et al., 2016). This includes the roots, stem, flowers or fruit, shoot, latex, leaves and the seeds (ibid). The plant used may be ground and used as a paste, or diluted with a liquid such as alcohol, water or breast milk and then used as an eye drop (Ukponmwan & Momoh, 2010). The plant may also be boiled in water and the juice used after cooling (Nyenze, Iiako & Karimurio, 2007). Fresh leaves of the plant may be squeezed and the juice used as eye drops. Or the leaves of the plant may be chewed and the juice put into the user's conjunctival sac (Nyenze, Iiako & Karimurio, 2007). The root, stem or leaves of the plant may also be dried, ground and mixed with liquid or other herbs and then applied to the eye (Ukponmwan & Momoh, 2010).

Many people living in rural areas in Africa believe that diseases are caused by not conforming to traditional societal rules or by breaking taboos, and therefore tend to consult their elders or a traditional healer in an event of an ocular ailment (Ukponmwan & Momoh, 2010). Traditional healers however prefer to use substances that cause pain and irritation as they are believed to be therapeutically effective, and are perceived as more potent by both the traditional healers and the users (Ukponmwan & Momoh, 2010; Ebeigbe, 2013; Maregesi et al., 2016). These substances include donkey and cow dung, lizard droppings, bird urine, snail shells, human sputum and python's excreta (Maregesi et al., 2016; Baba, 2005). Consequently, Maregesi et al. (2016) found that the use of animal waste products, which are normally contaminated with pathogenic microbes, often leads to blindness. Similar findings were documented by Nwosu, (2002), Ashaye, Ajuwon, and Adeoti (2006), and Olatunji, Adepoju and Owoeye (2015). Ashaye, Ajuwon and Adeoti (2006) additionally found that the traditional healers who participated in their study believed that blindness was curable and claimed they had cured it before. However, these healers affirmed that blindness caused by supernatural means was the most difficult to cure, and that in order to cure this type of blindness the affected person had to report it early and be able to identify the person who made the charm that caused them to lose their eyesight.

The use of traditional and allopathic medicine

Globally, the demand for traditional medicine is increasing (WHO, 2013). The World Health Organisation (2013) affirms that traditional medicine is an important and often underestimated part of healthcare. Many countries have their own traditional ways of healing, which are firmly rooted in their culture and history (WHO, 2013). Traditional healing does not only seek to alleviate physical symptoms but also to re-integrate the person with their community, the earth and spiritual world (Ross, 2010). Allopathic healing, on the other hand, seeks to alleviate physical symptoms through appropriate medical, surgical and chemical interventions that are believed to be scientific, rational and empirical (ibid).

Numerous scholars have found that individuals make use of both traditional and allopathic medicine in times of ill-health (Dutta-Bergman, 2004; Wreford, 2008; Nyathirombo, Mwesingye & Mwaka, 2012; Saunderson, 2013; Nortjé & Albertyn, 2015). Nyathirombo, Mwesingye and Mwaka (2012), for instance, found that 70% of their respondents made use of traditional eye medicine (TEM) and allopathic medicine simultaneously. Many of these respondents, however, sought allopathic medicine when traditional medicine - which was their first choice - failed to produce the desired outcome (ibid). Nortjé and Albertyn (2015), in contrast, found that majority of their respondents made use of allopathic medicine to manage their children's pain, and only made use of traditional medicine as a last resort.

Eye-care seeking behaviour of people living in rural areas

Studies show that a majority of individuals with ocular ailments living in rural areas first seek traditional methods of treatment (Nwosu, 2002; Nwosu and Obidiozor, 2011; Omotoye, et al., 2013; Gupta et al., 2017). Nwosu (2002), for instance, found that 286 (35%) of 814 respondents with ocular ailments made use of self-medication. Those who consulted an ophthalmologist did so only after remedies from other healthcare practitioners did not produce the desired outcome. Other healthcare practitioners consulted included the chemists, general practitioners, opticians, nurses and herbalists. Similarly, Gupta et al. (2017) reported that 307 (14%) of 2 160 respondents did not consult with an ophthalmologist. Of the 307, 140 (46%) made use of home remedies and did not consult with anyone for their ocular ailments, while 138 (45%) visited traditional healers, non-registered practitioners, drug stores and pharmacists.

Children with ocular ailments often rely on their guardians to provide for their eye-care needs (Gilbert, 2007). The eye-care seeking behaviour of guardians of blind children can be influenced by several factors (WHO, 2007). These factors include their lack of awareness about childhood blindness related preventive measures and the fact that the vision of blind and partially blind children can often be improved; competing demands for scarce resources within the family; a shortage of paediatric eye-care professionals; and barriers to accessing services such as distance, cost, and fear (WHO, 2007) which could be worsened in rural areas.

The utilisation of eye-care facilities in rural areas

Researchers found that non-availability, non-accessibility and non-affordability influence the utilisation of eye-care facilities in rural areas (Ntsoane & Odutan, 2010; Omotoye et al., 2013). The availability of eye-care facilities in rural areas however does not necessarily guarantee usage by the community. Omotoye et al. (2013) affirm that the negative attitudes that people have towards existing eye-care facilities often result in low acceptance and low utilisation. Olatunji, Adepoju and Owoeye (2015) found that over 90% of 290 rural dwellers were aware of an available eye-care facility but it remained underutilised. Those who did not make use of the eye-care facility stated their reasons as a fear of a poor outcome, perceived waste of time, unfriendly clinic staff and costs (ibid). Ashaye, Ajuwon & Adeoti (2006) similarly learned that individuals with eye-related problems did not make full use of available healthcare facilities because they perceived it as a waste of time, felt they would receive wrong information, did not know who to contact in the hospital and felt the transportation costs were too high. Omotoye et al. (2013) found that 1 069 (86%) of 1 236 rural dwellers had never made use of the existing eye-care facility due to a lack of awareness, and the cultural belief that eye disorders should not be treated in order to avoid blinding the eyes. Consequently, Omotoye et al. (2013) affirm that the non-utilisation of eye-care facilities could lead to an increase in the prevalence of blindness that is due to avoidable and preventable causes.

Peters et al. (2008) argue that an individual's utilisation of healthcare services is influenced by the four dimensions of access to healthcare services which are geographic accessibility, availability, financial accessibility and acceptability. These researchers identified geographic accessibility as an important part of accessing healthcare services. They found that individuals need good roads - which are scarce in poor areas of developing countries - in order to go to healthcare facilities. They also found that remote healthcare centres required individuals to spend more time and money to travel to the facilities. These travel related expenditures and the lack of good roads became obstacles to obtaining healthcare. Availability acts as an obstacle to obtaining healthcare for individuals living in poor areas of developing countries and refers to the individual's opportunity to access the healthcare service as and when needed (Peters et al., 2008). Individuals living in rural areas often face both geographic and economic barriers when accessing services (Ademola-Popoola & Owoeye, 2004). Peters et al. (2008) found financial accessibility, or affordability, to be amongst the most important determinants of access. They identified both direct and indirect costs as obstacles to obtaining healthcare. Direct costs include the costs of the healthcare service, while indirect costs are made up of transportation, food and accommodation costs as well as the cost of time for both the individual and those who may accompany them (ibid). Gilbert (2007) for instance found that in many cultures women needed to be accompanied by a male head of household, which increased the number of those who have to travel and thus added to their healthcare expenditures. Acceptability, according to Peters et al. (2008), involves the health service providers' responsiveness to the social and cultural expectations of the individual and their communities. Not surprisingly, these researchers found that measuring acceptability of health services depends on local contexts.

The influence of the aforementioned dimensions of access on the utilisation of eye-care facilities in rural areas can be seen in a number of studies (Burnett et al., 2016; Gupta et al., 2017; Rakoma, 2017). Gupta et al. (2017) found that the respondents of their study did not utilise ophthalmic services because of economic constraints, the distant location of the healthcare facilities, being discouraged by objections raised by older family members; the provision of acceptable services by local traditional healers and not deeming the ocular ailment as a priority. Ashaye, Ajuwon and Adeoti (2006) however found that many individuals relied on alternative sources of eye-care in rural areas due to a lack of eye-care facilities. These alternative sources include individuals who serve as frontline health workers in these areas, such as traditional healers and patent medicine sellers (ibid).

Health information needs, health information seeking behaviour and health information sources

Guardians of children living with disabilities can manage uncertainties about their children's medical, motor, intellectual and social prognosis by seeking health information - which can include disability-specific information and information about specialised support that the child may need to ensure optimum development (Barnett et al., 2003; Eleweke, et al. 2008).

These guardians need access to relevant health information in order to make sure that their children's health improves (Lwoga & Mosha, 2013). However, lack of access to health information remains a major barrier in developing countries (Watts & Ibegbulam, 2006).

Bates (2002) identified four types of information seeking activities which are: searching, monitoring, browsing and being aware. Searching refers to when an individual actively seeks out information to address an already identified and known information need. Browsing occurs when the individual actively collects information but with a purpose that is unclear or not yet known. Monitoring is when the individual is on the lookout for information but has not yet identified a particular information source. Being aware involves the individual passively receiving information they did not know they needed. As a means of managing uncertainties regarding their children's blindness, guardians of blind and partially blind children living in rural areas could actively seek out (searching) health information by going to the clinic or the hospital, consulting a traditional healer, priest, trusted family member or a friend to enquire about an already identified health information need. These guardians could go through (browsing) newspaper and magazine articles, the internet, posters and pamphlets in order to find health information regarding their children's blindness but with no particular health information need in mind. These guardians could be on the lookout (monitoring) for radio advertisements, newspaper and magazine articles, television programs or information during consultations with doctors and nurses pertaining to their children's blindness. They could also take notice (being aware) of the information being shared during personal conversations, advertised over the radio and/or television or made available in public spaces regarding their children's blindness. Baba et al. (2017) affirm that difficulties in finding information can result in feelings of anxiety, confusion and alienation for guardians of children living with disabilities.

Humphreys (2000) found that rural dwellers made use of various sources of health information in order to find out about healthcare services. These sources include healthcare providers, family, friends and mass media. Humphreys (2000) discovered that those who lived in smaller rural communities with fewer healthcare services depended more on mass media than those who lived in larger communities with better healthcare services. Also, family and friends played a more significant role in smaller, close-knit communities than in larger communities. Additionally, Humphreys (2000) highlighted that General Practitioners play an important role in rural areas as both a provider of care and as a source of health information. Gupta et al. (2017) found that when seeking eye-related health information, 1,588 of 2,160 (74%) rural dwellers turned to their neighbours, relatives and traditional healers for the information, 365 (17%) went to the hospital and healthcare workers, 116 (6%) spoke to patients with similar ocular ailments, 86 (4%) made use of newspapers, books and pamphlets, 53 (2%) listened to the radio or watched the television, while 7 (0.5%) spoke to school teachers. Seven percent of the respondents either made use of multiple sources or did not seek any eye-related health information from any source. Rakoma (2017) found that 68% of the participants sought eye-related health information from healthcare workers, 29% sought it from their family members, 2% from traditional healers while 1% made use of other sources. Interestingly, of those who made use of traditional eye medicine (TEM), 61% sourced information from their family members, 30% from healthcare workers, 6% from traditional healers and 3% from other sources. Those who did not make use of TEM sourced information from healthcare workers (ibid). While seeking information, an individual's decision to act in a particular way is influenced by a number of factors (Boyd, 2004). These factors include the information that the individual has access to, the information that they receive, their trust in the information source, perceived quality, and the manner in which they make sense of the information (ibid). For instance, guardians of blind and partially blind children living in rural areas may have access to health information regarding their children's blindness but may disregard the information because they do not trust the source.

Many studies have been conducted to determine the information needs and information seeking behaviour of, as well as the information sources used by, guardians of children with various disabilities. These studies include a qualitative analysis of the information needs of parents of children with healthcare needs conducted in the United Kingdom (Jackson et al., 2007); a study in Tanzania on the information seeking behaviour of parents and caregivers of children with mental illness (Lwoga & Mosha, 2013); a study on the information seeking behaviour of parents of children with disabilities in Kuwait (Al-Daihani & Al-Ateeqi, 2015); information seeking by parents of children with physical disabilities in the Netherlands (Alsem et al., 2017); and a case study in Malaysia on the information needs and barriers encountered by guardians of children with severe disabilities (Baba et al., 2017). It is worth noting that none of these studies focused solely on guardians who live in rural areas, which is the focus of this study.

Jackson et al. (2007) reported that parents of children with healthcare needs in the United Kingdom had information needs concerning their children's medical condition and symptoms, its management, related tests and treatments, waiting times, accessing services, and care guidelines to share with other family members or with their children's school. These parents stated that they had sought information independently and that they did so mainly when they felt that they had not received enough information from their healthcare professionals. These guardians sought information from the internet - which in some cases did not satisfy their information needs - collected leaflets, and made verbal queries with healthcare professionals, condition-specific organisations, schools, and friends. These parents highlighted the need for the contact telephone number of a healthcare professional in order to obtain further information when required. They also expressed that they preferred information to be delivered verbally on a one-on-one basis by a healthcare professional and to have it supplemented by accessible, written material they could refer to.

Parents of children with mental illness in Tanzania expressed a need for health information on their children's nutrition, treatment, health education, physical fitness, causes of the disease, prevention, prognosis and diagnosis (Lwoga & Mosha, 2013). Lwoga and Mosha (2013) found that parents needed access to health information from various health information sources in order to supplement the verbal medical information they received. These parents identified the internet as their commonly used source of health information, followed by printed books, television, verbal discussions with families, newspapers and/or magazines, the radio, leaflets, CDROMs, printed journals, healthcare professionals, videos, and information specialists and/or librarians. Interestingly, most television channels in Tanzania broadcast health television programmes free of charge in Swahili, which is a language that is predominantly spoken in the country, and television ranked third as the most commonly used source of health information (ibid).

Al-Daihani and Al-Ateeqi (2015) found that the parents of children with disabilities in Kuwait expressed a need for information during and after diagnosis. A majority of the parents stressed the need for information during diagnosis and stated that they were interested in information regarding the children's education, medical condition, and growth and development. After diagnosis, the parents expressed a need for information on benefits available from the government, information on how to develop the children's resilience, and on how to communicate with the children. The parents viewed doctors as their most preferred source of information, followed by books, and social workers. Internet forums, support groups and social media applications were identified as the least preferred sources of information. This could be attributed to the fact that these resources were not available in Arabic, which was the parents' first language. Another reason could be that parents were unaware of the availability of these resources and how to make use of them (Al-Daihani & Al-Ateeqi, 2015).

In their study on information seeking by parents of children with physical disabilities in the Netherlands, Alsem et al. (2017) found that the parents experienced difficulties in finding the information they needed and that they had many information needs which were not met. These parents needed medical information about their children's disabilities, rehabilitation-related information and experience-based knowledge. Medical information includes information about the children's diagnosis, prognosis and medical therapy options. Rehabilitation-related information includes information on the specific requirements of the child and services available to both the child and the parent. Finally, experience-based information includes information about day-to-day care and the home experience. These parents sought medical and rehabilitation-related information mostly from healthcare professionals and from the internet, whereas experience-based information came mainly from exchanges with peers – both in person and through the internet. The researchers found that most parents sought information from multiple sources and compared the information from the various sources for trustworthiness. These parents also expressed how changing situations resulted in new information needs, which in turn, resulted in new information seeking strategies (ibid).

Baba et al. (2017) found that guardians of children living with severe disabilities in Malaysia needed information on their children's diagnosis, its management (treatment options, drug action and potential side effects) and the expected outcomes of treatment. The guardians stated that they needed information in order to be able to take control of their situation, to make decisions for their children and for themselves, and to be able to access support. In addition to verbal information, the guardians stressed the need for written information as it would help them remember the information that was obtained from the healthcare professionals. These researchers reported that the guardians encountered information-related barriers which prevented them from receiving appropriate information timeously.

These barriers included costly reading material and the use of web-based resources. The guardians acknowledged that they get got important information from reading material such as newspapers and magazines, and that they found the reading material helpful because it contained pictures and stories about children with disabilities and about how guardians could provide good care. However, the guardians stated that information in these reading materials did not reach them on time because they could either not afford it and had to rely on reading material left at the care center by other guardians, or they could afford to purchase the reading material only once in a while as they would rather spend the money on more important things like the children's diapers and special milk. Lack of time, and limited experience and knowledge of the use of technology prevented the guardians from searching for appropriate information. The guardians stated that they did not have the time to flitter through and search for appropriate information regarding their children's disability because they needed to care for the child. Limited experience in the use of communication technologies hampered effective information searching and produced inappropriate results, which led to disappointment and a waste of time (ibid).

The influence of sociographic and demographic factors

Numerous studies found that guardians of children living with disabilities have unmet health information needs, which tend to be greater in rural areas due to factors such as poverty, lack of education and limited access to health resources (Rahi, Manaras, Tuomainen & Hundt, 2004; Jackson et al., 2007; Skinner & Skilfkin, 2007; Lorenzo, van Pletzen & Booyens, 2015). Gilbert (2007) reported that sociographic factors such as poverty and low levels of socio-economic development are important risk factors that influence the prevalence of childhood blindness in developing countries. Gilbert (2007) also found that low levels of development resulted in low levels of education among mothers, poor primary healthcare, and engagement in potentially harmful cultural practices. Consequently, poor primary eye-care and clinical services for children resulted in children with treatable and preventable causes of blindness remaining blind (ibid).

Education and age as demographic factors also have a significant influence on the guardians' health information seeking behaviour. Lwoga and Mosha (2013) reported that an individual's level of education greatly influences their selection of health information sources and identified it as the main problem that hindered Tanzanian guardians from seeking health information. These researchers found that the majority of the respondents in their study had no college or university education and consequently struggled to make sense of the English language, which was the language used in most of the health information available on the internet and printed material.

Research also suggests that an individual's level of education is an important determinant of their beliefs regarding the prevention of blindness, their preferred treatment method, and their acceptance of surgical interventions (Olatunji, Adepoju & Owoeye, 2015). In a Nigerian rural community where majority of the residents had limited education, Olatunji, Adepoju and Owoeye (2015) found that individuals who attained higher levels of education believed more in the prevention of blindness than those with less education. Measures for preventing blindness were stated as regular hospital visits, the consumption of good food, spiritual means, and the use of drugs (ibid). Although one's educational level had a significant influence on their preferred method of treatment, Olatuji, Adepoju and Owoeye (2015) found that despite the high illiteracy rate, majority of the respondents preferred allopathic methods of treatment, others preferred spiritual interventions, and traditional methods were the least preferred. This could, however, be attributed to the existence of an eye-care facility that was accessible to the community, the possibility of the community members being exposed to eye health education at the clinic, and the presence of churches and Muslim clergy's that were within the reach of the community where community members could seek solution in prayers**.**

Olatunji, Adepoju and Owoeye (2015) also found that individuals who attained higher levels of education had a more positive attitude towards eye-related surgical intervention than those with lower levels of education. Fear was cited as the most common reason for refusing eye surgery, followed by poor outcome, and the belief that surgery was not necessary as it was the will of God or because the individual would be able to cope (Olatunji, Adepoju & Owoeye, 2015). Rotchford et al., (2002) similarly reported that surgery was associated more with risks than with ineffectiveness, and that that surgery was viewed as a last resort. These researchers found that a majority of the respondents feared surgical intervention, doubted that surgery would restore their eyesight, and felt there was no need for surgery. Fear of surgery resulted from the belief that one could die during surgery, or that patients could be given a drug that would make them sleep forever. Contrary to the findings of Olatunji, Adepoju and Owoeye (2015), Nwosu (2002) reported that even though only a small portion of the respondents had post-primary education, a majority believed that surgical interventions to were useful. Nwosu and Obidiozor (2011) reported that the use of traditional eye medicine was greater in individuals without any formal education than those who had attended at least primary school, while Omotoye et al. (2013) found that people with formal education were more likely to use eye-care facilities than those who had no formal education. Additionally, Omotoye et al. (2013) affirmed that individuals who had formal education had greater eye-care seeking behaviour, which could be attributed to their greater knowledge, higher socioeconomic class and higher financial resources.

Gibson et al. (2017) identified the child's age as an important factor that influences the guardians' information source selection. These researchers found that the parents' selection of information sources changed as the child aged. For instance, parents of autistic children aged 1-12 identified therapists as their frequently used information source, followed by other parents of individuals with Autism Spectrum Disorder (ASD). For parents of children aged 13-17, other parents of individuals with ASD were their mostly used source, followed by doctors. Parents of individuals 18 years and older made frequent use of local organisations, followed by doctors. Social workers and local libraries were the least used sources of information. Interestingly, information source selection decreased in general as the child grew older. The researchers were not clear whether the parents' information source selection decreased as a result of a reduction in their information needs, reduced availability of information to parents of teenagers and adults, or a combination of both. Al-Daihani and Al-Ateeqi (2015) similarly found that the parents' information needs change as their child grows and develops. Al-Daihani and Al-Ateeqi (2015) reported that individuals between the ages 25-35 placed a significantly higher value on information sources when compared to individuals between the ages 36-55. Nwosu and Obidiozor (2011), on the other hand, found that older individuals were more likely to make use of TEM than those who were younger.

The role of health communication

Williams-Piehota, et al., (2010) found that health promotion initiatives rarely address the specific healthcare needs of individuals living with disabilities. An evaluation of health communication materials for individuals with disabilities conducted in the USA revealed that individuals who were deaf or hard of hearing, blind or had low vision, and those who had a physical disability expressed a need for treatment-related information and information on mental health to be included in health communication materials designed for individuals living with disabilities. Focus group interviews with respondents aged between 25 and 64 revealed that these respondents preferred to receive health information from their healthcare providers, the internet, family, friends and print materials. Despite healthcare providers being their preferred source of health information, a majority of the respondents said they had difficulties communicating with their healthcare providers, did not trust their healthcare providers and felt their healthcare providers rarely understood their individual disabilities and how those disabilities might affect their access to, or receipt of, healthcare information or services.

Children living with disabilities face similar challenges. These children, however, are often unable to articulate their health information needs and often rely on their guardians to satisfy these needs. Health communication, which is an important component of patient care (Nazione et al., 2013), typically flows from guardian to child (Williams et al., 2016), and aims to improve health outcomes and one's quality of life by sharing health-related information (Schiavo, 2007; Pimal & Lapinski, 2009).

Hawkins et al. (2008) affirm that health communication can be grouped into three categories which are mass communication, targeted communication and tailored communication. Mass communication involves sending identical messages to undifferentiated and relatively large audiences; targeted communication allows separate audience segments to benefit from a shared meaning; while tailored communication involves producing a message that is matched to the needs and preferences of individuals.

This study suggests that health communication strategies should be tailored to the situational environments of guardians of blind and partially blind children living in rural areas. Hawkins et al. (2008) define tailoring as a means of creating communication that is individualised for the receivers, with the expectation that this individualisation will lead to larger intended effects of the communication. Tailored health communication allows health communicators to customise the source, message and channel of health communication to a given individual, which may in turn maximise the relevance of the health communication to that particular individual (Kreuter & Wray, 2003). Kreuter and Wray (2003) found that individuals are more likely to perceive health information as relevant if it is seen as responding to their particular circumstance and life experiences. Also, Williams-Piehota, et al. (2010) confirm that individuals are more likely to make use of health information material if the material resonates with them. Williams et al. (2016) affirm, however, that factors such as culturally inappropriate materials, health literacy, access to healthcare, and the low prioritisation of health due to competing economic demands make it challenging for health communicators to effectively engage with economically-disadvantaged communities.

Schaivo (2007) affirms that, in health communication, the target audience actively participates in the process of analysing the health issue and finding solutions which are cost-effective and culturally appropriate. In this regard, it is important to highlight the importance of culture since it affects how individuals react to and interact with health information (Betsch & Bohm, 2016). It is therefore important to understand the cultural characteristics of a given group, as this can enable health communication programs and services to be customised to better meet the needs of these individuals (Kreuter & McClure, 2004).

The culture-centred approach (CCA) to health communication, which is discussed in detail in chapter 3, stresses the need to develop respect for the capability of members of marginalised communities to define their health needs and to seek out culturally appropriate solutions that fulfill these needs (Dutta & Basu, 2011). This approach emphasises the voices of members of subaltern communities, examines the ways in which these voices have been erased by the dominant discourses of health communication and suggests alternatives to these dominant discourses by engaging with the voices of members of these communities (Dutta, 2008). Through engaging with guardians of blind and partially blind children who live in rural areas of the Free State province, this study seeks to explore their health information seeking behaviour concerning their children's blindness and suggest alternatives to the current ways of making health information available to these guardians.

The role of culture in health communication

Communication, which is the shared exchange of messages among cultural members (Dutta, 2008), can be a powerful tool that can help meet public health objectives (Kreuter & Haughton, 2006). Dutta (2008) argues that the dominant approach to health communication takes culture for granted in its assumptions about the role of the biomedical model in problematising health and in proposing solutions to health problems. Kreuter and McClure (2004) suggest that recognising culture as an important factor in public health and health communication can potentially contribute to the development of new and more effective strategies, which can help eliminate health disparities.

Culture is dynamic, transformative and constituted through the voices of cultural members (Dutta, 2008). Kreuter and Haughton (2006) found that culture can, directly or indirectly, influence an individual's health-related beliefs, decisions, priorities, and behaviours. These researchers acknowledge, however, that culture is but one of the many factors that influence an individual's health-related beliefs and actions and affirm that there are other factors that can have an impact on these health-related beliefs and actions. These factors are individual, environmental and/or socioeconomic, and can have both independent and synergistic effects with culture (Kreuter & Haughton, 2006).

The culture-centred approach (CCA) to health communication pays attention to how members of communities construct meanings about health and illness, and provides a premise for understanding the various perspectives on illness and its treatment and on how culture influences these perspectives (Dutta, 2008). This approach also highlights the need to listen to the voices of cultural members in suggesting culture-based health solutions (Dutta & Basu, 2008).

A culture and its approaches to illness, curing and healing are understood through the lived experiences of its members (Dutta, 2008). These lived experiences are shaped by what the culture sanctions as knowledge, the values attached to it and how culture is used as a resource in the daily lives of its members (ibid). Cultural beliefs, values, and practices greatly influence an individual's understanding of health and subsequently shape their behaviour (Dutta, 2008; Tan, 2016). These beliefs, values and practices are also contextual, and health meanings become localised within these contexts (Dutta & Basu, 2011). For instance, a study conducted in rural Bengal, India, revealed that nature was central to the Santalis' understanding of health and that for them health coincided with an individual's ability to live in harmony with nature (Dutta-Bergman, 2004). The researcher learned that the Santali people understood health through the intersections of culture, structure and agency. They believed that illnesses and diseases were caused by spirits that entered an individual's body when the natural processes were disturbed and that they could only be cured by removing the spirits from the body through acts of exorcism conducted by a traditional healer. Instead of being crippled by their multiple structural barriers, the Santali people demonstrated agency and found other means of survival. These included saving up enough money in order to access allopathic medicine or opting for alternative, more affordable options such as the use of homeopathic medicine, praying at the local Hindu temples to the Hindu goddess Kali and making special offerings to the goddess. These Santali affirmed that although they believed in the healing powers of both allopathic and homeopathic treatment, they strongly believed that these forms of treatment did not address the actual causes of illnesses and diseases, and that in order to completely heal – one needed to supplement modern medical treatment with religious rituals that appeased the spirits and the Gods.

Culture is also linked to social structures and the way in which resources are allocated in communities as these factors greatly influence how the members of such communities create meaning within the context of their lived experiences (Dutta, 2007). Dutta (2008), for instance, found that treatment options during times of ill-health are determined by a complex process of meaning-making, which is influenced by the structural resources available to the individual and their family. Although children have the highest priority over the available resources in times of ill-health (Dutta, 2008), Gilbert (2007) found that guardians who believe that their children's disability was a result of a curse or punishment may be reluctant to spend scare resources, such as money and nutritious food, on the child. Social structures have an economic effect on marginalised communities, which impacts their daily experiences of securing access to resources (Dutta, 2014). For instance, a study on the role of the family in maintaining and promoting the health of rural Australians revealed that healthcare services were not available locally for these rural dwellers. This meant that they had to travel long distances in order to access the services (Humphreys, 2000). Humphreys (2000) found that other barriers that prohibited these rural dwellers from making use of healthcare services included the amount of time that was required away from home and/or work, the cost of the healthcare services, transportation difficulties, and not knowing where to go to seek help.

Dutta-Bergman (2004) found that the choice of medical treatment for individuals who lived in a poor community in India was not defined by the individual's belief that one treatment option was better than another. Rather, it was influenced by the amount of money the treatment would require, the seriousness of the disease, and the amount of time the visit would take. Dutta (2008) similarly reported that parents from a rural community in India made use of various treatment options during times of ill-health and that their choice was dependent on the location of the patient in the family structure, the nature of the illness, and the price of the treatment and other resources needed to secure the treatment, such as time and transportation. Another study focusing on the healthcare preferences of rural dwellers in Nepal revealed that rural dwellers sought healthcare from traditional healers first before visiting other healthcare workers because the traditional healers were more easily accessible (Shimobiraki & Jimba, 2002).

Airhihenbuwa et al., (2014) suggest that an understanding of how individuals make their health-related choices will help provide insight into how they maintain their health and function regardless of their limitations. A study conducted in India that sought to understand how rural men engage with their available structural resources and how they enact agency by formulating communicative strategies within their constraints to take care of their health needs and those of their families revealed that structure was conceptualised as a constraint on agency (Dutta & Basu, 2008). The respondents of this study stated that even though they wanted to achieve good health, they were unable to do so because of structural barriers such as financial resources, and a lack of geographic and material access. These respondents indicated that a good doctor would charge a lot of money and that they would therefore consult with the nearest homeopathic doctor as these doctors had affordable consultation fees and also included the medication required to treat the ailment. When the homeopathic medicine did not work, these respondents would visit the local pharmacy because the pharmacist did not charge for the consultation. These respondents cited mistreatment, the unavailability of medicines and the amount of time lost during visits to the hospital as their reasons for not making use of the local hospitals. Dutta and Basu (2008) also found that even though the respondents were aware that local medicine sellers did not have a medical degree, they still made use of their services and regarded them as doctors because of affordability. The researchers maintained that agency is enacted in the respondents' conscious choice to make use of the services of the affordable medical seller. In fact, the respondents' choices showed that they were able to make sense of the resources available to them and make optimal use thereof (Dutta & Basu, 2008).

Summary

This review of the literature revealed a number of factors that influenced the eye-care seeking behaviour of individuals living in rural areas. These factors included beliefs regarding the causes, treatment, prevention and cure of blindness and ocular ailments; interactions with other people; perceptions about the availability of eye-care services; as well as geographic and economic barriers such as distance and cost. These factors need to be considered when seeking to understand the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas as these factors may possibly have an influence on their preferred sources of health information.

A review of the literature affirms that the influence of friends and family members on the decision making of rural dwellers should not be underestimated. Gupta et al. (2017) found that respondents with eye problems did not make use of ophthalmic services due to objections raised by older family members and that many turned to their neighbours and relatives to seek eye-related health information. Ukponmwan and Momoh (2010) reported a high prevalence of the use of traditional eye medicine (TEM) that the respondents received from their neighbours and relatives. In addition, Nswou (2002) uniformly found that the respondents had a negative attitude towards surgical interventions because of poor outcomes observed in cases involving friends and relatives. Omotoye et al. (2013) stress the importance of understanding the attitudes and beliefs of individuals and argue that these individuals must have a positive attitude towards eye-care facilities and providers in order to increase utilisation and reduce the prevalence of blindness that is due to treatable and preventable causes.

Culture also plays a key role in an individual's choice of treatment. In health communication, the target audience actively participates in the process of analysing the health issue and finding solutions which are cost-effective and culturally appropriate (Schaivo, 2007). Traditional healers are often the first point of consultation in rural areas as they are accessible and are able to tell whether diseases are caused by evil spirits or not (Shimobiraki & Jimba, 2002). Ukponmwan and Momoh (2010) stressed the need for traditional healers to refer patients with ocular complaints to the hospital as traditional healers have been found to make use of harmful eye practices which may exacerbate ocular ailments. Similarly, Gilbert and Foster (2001) identified a need for trained community-level health workers to be able to identify children who need referral for ophthalmological assessment and treatment. This could help combat the prevalence of childhood blindness due to treatable and preventable causes.

Numerous studies on children living with varying disabilities reported similar findings about the health information needs of guardians (Jackson et al., 2007; Lwoga & Mosha, 2013; Al-Daihani & Al-Ateeqi, 2015; Alsem et al., 2017 and Baba et al., 2017). These health information needs included the need for disability-specific information as well as information about specialised support that the children may need. Healthcare professionals were viewed as the preferred source of information. Respondents in these studies indicated a preference for written information in order to supplement the verbal information communicated by healthcare professionals. The studies also indicated that the lack of information available in the guardians' first language is a concerning barrier to health information. Moreover, computer illiteracy and lack of access to a computer and the internet are barriers to accessing health information in some countries (Mnubi-Mchombu, 2013). Thus, researchers felt that it was important to acknowledge the internet as a source of information for parents of children living with disabilities (Alsem et al., 2017). Porter (2009) and Gibson et al. (2017) for instance agreed that given the abundance of information and ease of access, the internet affords users the opportunity to find answers to health-related queries as and when they arise. Sociographic and demographic factors such as poverty, lack of education, limited access to health resources, and age also proved to influence the type of information that parents and guardians seek or have access to; as well as their utilisation of available eye-care facilities. These factors should therefore be taken into account when investigating the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas.

Ultimately, the review of the literature supports the need for this study. In order to develop successful health communication programmes, it is not only important to both understand and involve target audiences, but to also understand what their needs are (Schiavo, 2007). Alsem et al. (2017) affirm that in order to improve the way in which the information needs of parents are met, their preferences must be known. Maepa (2000) concurs that understanding the kind of information users need, and how they search for it, will lead to improvements responsive to their needs. This study therefore seeks to answer the following research questions: (i) what role do cultural beliefs play in the guardians' perception of the causes of their children's blindness? (ii) which source(s) of health information do the guardians commonly use? and (iii) which source(s) of health information do the guardians prefer the most? and are their reasons for their preferred health information sources culturally bound? Kreuter and Wray (2003) affirm that the more knowledgeable health communicators are about the intended recipients of their messages, the more relevant those messages will be.

Through dialogues with cultural members, the CCA to health communication allows for engagement with the locally situated nature of healthcare experiences, which are articulated through thick descriptions of the lived experiences of community members (Dutta-Bergman 2004; Dutta and Basu, 2007; Dutta, 2009; Dutta et al., 2018). This approach allows for participatory spaces to be created and sustained which afford health communicators the opportunity to listen to the voices of members of marginalised communities, engage with their agency and create transformative opportunities through the co-construction of narratives (Basu & Dutta, 2008). Through listening to the voices of guardians of blind and partially blind children who live in rural areas of the Free State province, this study sought to create transformative opportunities by generating knowledge and contributing towards creating culturally relevant health communication strategies for communities in rural areas in South Africa.

CHAPTER THREE

THEORETICAL FRAMEWORK

Introduction

The culture-centred approach (CCA) to health communication focuses on listening to the voices of cultural members and providing an understanding of the health meanings and experiences of subaltern communities (Dutta & Basu, 2007; Dutta, 2008). Subaltern communities are communities located at the margins of mainstream society and decision making, which have been erased from dominant discursive spaces (Dutta, 2018). Grounded on the CCA to health communication, this study focuses on the intersections between culture, structure and agency to understand the influence of these tenets on the health information seeking behaviour of rural guardians of blind and partially blind children. The CCA to health communication suggests a critical analysis of these tenets as they play a crucial role in how communities understand and experience health and illness (Dutta, 2008). Dutta (2008) affirms that the CCA to health communication allows for engagement with members of subaltern communities and enables them to enter into communicative processes by voicing alternative perspectives of health that are relevant to their context. Dutta (2008), furthermore, stresses the need to listen to the voices of members of subaltern communities and argues that it allows for exploring the possibility of various approaches to healing that do not lie within the biomedical model but may engage with it.

South Africa is characterised by major inequalities which stem from the political history of the country (Delobelle, 2013). The country's healthcare system is divided into public and private healthcare. Overused and under-resourced, the government-run public healthcare sector caters for the wellbeing of the majority of the South African population and predominantly serves Black members of the population (Delobelle, 2013; Mahlathi & Dlamini, 2015). The private healthcare sector on the other hand offers world-class, high-quality facilities for the minority that are able to pay for privatised healthcare services, which are often located in urban areas of the country (Delobelle, 2013; Mahlathi & Dlamini, 2015).

Although South Africa's Constitution (section 7 of the Bill of Rights) guarantees every citizen access to healthcare services, many individuals - particularly those who live in rural areas - face disheartening access-related challenges. These challenges are instigated by factors borne from the Apartheid regime, which gravely affected health and healthcare services in South Africa. These factors include racial discrimination, income inequalities and spatial segregation (Coovadia et al, 2009; Abel, 2016).

Since 1948, Black South Africans were subjected to exploitative and exclusionary laws and policies that separated them on the basis of race (Scrubb, 2011). In order to segregate all aspects of society, the then Afrikaner-led Apartheid government developed a system known as the Bantustans or Homelands, and forcefully relocated Black South Africans to - mostly rural - designated areas that were separate (and often quite far) from those of White South Africans (Scrubb, 2011; Abel, 2016). The Bantustans were typically characterised by a scarcity of resources and each Bantustan was responsible for the control and monitoring of its healthcare system (Kon & Lackan, 2008). Healthcare in the Bantustans was mainly provided by non-profit missionary hospitals and overseen by local elites (Scrubb, 2011). Due to a lack of oversight and regulation by the government, healthcare services in the Bantustans ignored quality-of-care guidelines and allowed for the abuse of Black South Africans who made use of these services (Kon & Lackan, 2008).

The Apartheid regime, therefore, legitimised subalternity and created the conditions of marginalisation that still exist today. Despite the fall of Apartheid in 1994, the majority of Black South Africans still live in disadvantaged communities that are located in the poorest regions of the country and remain vastly underserved (Kon & Lackan, 2008). These former Bantustan areas are still daunted by overcrowding, poverty, unemployment and limited access to basic resources (Strickland-Munro, Allison & Moore., 2010).

With this background in mind, the goal of the CCA to health communication is to create discursive spaces in subaltern communities by highlighting the limitations in current health communication practices. The CCA approach also seeks to interrogate, theorise and formulate participatory communication strategies that will adequately represent the voices of subaltern members and bring forth appropriate theories of health and wellbeing (Dutta, 2018). This is why this study sought to engage with members of rural communities to provide new ways of thinking about health communication in rural areas and bring forth alternative possibilities for the provision of health information that better meet their needs.

The role of Culture, Structure and Agency

Culture

The CCA to health communication stresses the importance of culture in health communication practices and focuses on building theories and applications from within subaltern communities (Dutta, 2007). Culture is understood as both static and dynamic, and reflects the shared values, practices, and meanings that are negotiated in communities (Dutta, 2018). Not only does culture impart its values to a community; it also simultaneously co-creates opportunities for transforming these values over time as it responds to local, national, and global shifts in economics, politics, and communication flow (Dutta, 2018). Culture is influenced by tradition and current structures, and is articulated in the meanings that are co-constructed by members of communities (Dutta, 2007; Dutta, 2008; Dutta & Basu, 2011). In other words, these meanings are located within the local context of the culture (ibid). Dutta (2008) argues that health is a resource that is possessed not only by the individual but by the community as a whole, and defines the community as a geographical space within which an individual and their family resides. The basic material resources that a community has constitute its capacity (ibid).

Narratives of health become meaningful when understood in terms of culture (Dutta, 2008). The CCA suggests that culture is preserved and transformed through stories (Duta, 2008). Community members share stories and these stories offer lessons about health, about what it means to be healthy, what it means to be ill, and what actions an individual ought to take in response to illness (Dutta, 2008). Stories also allow for new meanings of health to be articulated and for change to take place by introducing new possibilities into the discursive space (ibid).

This study explored how guardians of blind and partially blind children who live in rural areas make meaning of their children's blindness and of their own health information seeking behaviour based on the values, beliefs and practices of their culture and of the culture that exists in the communities where they live.

Structure

Structure refers to aspects of social organisation which enable and/or constrain an individual's capacity to engage in health-related behaviours (Dutta, 2008). This includes elements that are vital to the individual's healthcare such as food, shelter, transportation and medical services (Dutta, 2008). Structure also refers to the communicative resources that enable and/or constrain access to resources (Dutta, 2014). This includes communicative rules, processes, roles and rituals that create the realms of participation and representation (ibid). Dutta (2008) suggests that structures include micro-level, meso-level and macro-level resources. Examples of micro-level resources include medical services, communication channels, modes of transportation and health enhancing resources such as food, clean spaces and spaces for exercising. Meso-level resources include media platforms, civil society organisations and the implementation of policies. Macro-level resources include national and global health organisations, as well as national and international political actors and points of policy formulation (Dutta, 2008). Structures do not only shape the material resources that communities have access to, but they are also shaped by the participation of communities in processes of change (Dutta, 2014). The CCA highlights that community members actively participate in making sense of, interacting with and seeking to transform the social structures that encompass them (Dutta & Basu, 2011).

Structures play a significant role in the health experiences of individuals, particularly those who live in marginalised communities (Dutta, 2007). Marginalised communities are described as communities that have limited access to basic healthcare resources and mainstream communication platforms that share health information and enable community members to articulate their questions and concerns (Dutta, 2008). In addition, marginalised communities in South Africa are typically characterised by an inadequate provision of basic services such as housing, water, electricity and sanitation, with many areas using the bucket system and pit-toilets (Amnesty International South Africa, 2018). Dutta (2008) asserts that structures are deeply connected with the availability of material resources and influence the daily healthcare choices of members living in marginalised communities. Structures interact closely with an individual's cultural context to circulate meanings and to represent agency at individual, relational, familial, and community levels (Dutta, 2014). Dutta (2014) posits that structures limit and enable access to resources. Structures determine the range of healthcare choices that are available or unavailable to individuals, and consequently limit the opportunity for securing healthcare in marginalised settings (Dutta & Basu, 2011; Dutta, 2008). Dutta-Bergman (2004) found that communities that have access to multiple health-related resources are able to better sustain the health of their members. Therefore, the options sought out by members of marginalised communities are informed by their structural condition of being deprived of resources (Dutta, 2008).

Although it is important to recognise the relevance of the biomedical model in delivering effective solutions, Dutta (2008) argues that the basic resources of the biomedical system are often inaccessible to individuals who live in resource deprived communities. Structures constrain and limit the possibilities of health among members of marginalised communities by limiting healthcare resources, communicative resources and other critical resources that are available to members of privileged communities (Dutta, 2008). The conditions in marginalised communities are sustained through the unavailability of communication channels, as well as the circulation of discourse that continues to stigmatise communities that are underserved - thus justifying their location at the margins of healthcare systems (Dutta, 2008).

As alluded to in the literature review, accessibility is crucial for the utilisation of healthcare services, particularly in rural areas. This study explored the influence of various structures on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas. These structures include the physical location of healthcare service, financial resources, transportation and travelling related costs, as well as the accessibility of local providers of healthcare and health information.

Agency

Agency is an individual’s ability to act in their own interests, to make choices and to participate actively in working with and/or challenging the structures that constrain their lives (Sheik, 2013; Dutta, 2008). An individual’s ability to act is, however, subject to the resources available to them (Sheik, 2013). Individuals make use of cultural resources to navigate the structures they find themselves in (Dutta, 2014). The structures within which resources are organised not only constrain an individual’s ability to act, but they also offer a framework for challenging and transforming these structures (Dutta, 2014). Cultural members enact their agency through culturally situated meanings in the realm of the dysfunctional structures that constitute their lives (Duta & Basu, 2008). Dutta and Basu (2008) confirm that the CCA emphasises the understanding of the existing forms of participation in communities that have been traditionally treated as devoid of agency, and stresses that participatory forms of communication have long existed in marginalised settings.

Dutta (2014) affirms that agency can be understood in terms of the daily forms of meaning making that develop creative strategies of addressing the structural barriers that are experienced by individuals, their families and communities. These individuals, their families and communities actively participate in a number of actions that directly challenge the structures that constrain their lives, and they simultaneously work with the structures in finding healthful options (Dutta & Basu, 2011). Having trust in the provider is important as relationships of trust enact agency and help provide ways of coping in resource deprived communities (Dutta & Basu, 2008). Dutta (2008) concurs that community members that reside in settings where they are unable to access resources often discuss ways of challenging the structures that constrain their lives, with the goal of obtaining better resources. For instance, service delivery protests are common practice in South Africa by communities that feel that the government is failing to provide adequate services.

As discussed in the previous chapter, some communities enact agency in the way they choose to access limited health resources (Dutta and Basu, 2008). Dutta and Basu (2008) found that the respondents of their study preferred to make use of local medicine sellers because they were often members of the communities and could therefore be trusted. As a result, the respondents also relied on the local medicine sellers to provide them with health information. The researchers also learned that agency was also enacted in familial networks, where health decisions were made. Consistent with these findings, Dutta and Basu (2007) affirm that communities that have stronger social ties and higher levels of reciprocal trust among their members are able to better mobilise the resources for optimal health and are more likely to have better health results. Dutta (2008) concurs that members in such communities find greater access to health resources and are also more likely to experience increased social support and reduced levels of stress.

Dutta (2008) also stresses the need for health communicators to pay attention to how members of resource deprived communities are marginalised by the constitution and application of the biomedical model. The biomedical model denies members of resource deprived communities access to the basic infrastructures of biomedicine (ibid). It also marks their local or cultural choices as ''primitive'' on the basis of its own scientific rational standards (ibid). Dutta (2008) argues that the universalistic and exclusive logic of the biomedical model needs to be disrupted in order to create a meaningful discursive space for understanding the health choices of cultural members who survive within very limited structural resources. This is why this study explored how rural guardians of blind and partially blind children enact agency despite the limitations present in their environments.

Strengths of using the culture-centred approach (CCA) for this study

Guardians of blind and partially blind children who live in rural areas have limited access to healthcare and communicative resources. These guardians' voices have also been rendered silent through mainstream platforms of society. The CCA to health communication is an ideal theoretical framework for this study as it allows for the co-creation of legitimate spaces that recognise and represent silenced voices (Dutta, 2008). Additionally, dialogue is central to the CCA and creates communicative spaces for gathering input from community members in the creation and development of communication solutions that are relevant to their context (Dutta, 2008; Dutta, et al., 2016). The CCA enabled the researcher to engage in dialogue with the guardians and learn from them how to best meet their health information needs regarding their children's blindness, and also suggest alternatives to the current ways of making health information available to these guardians.

Summary

Every community prevents and manages diseases through its own understandings and beliefs (Omotoye et al., 2013). Dutta (2008) stresses that engaging with the biomedical model from a cultural perspective allows for an understanding of the various ways in which health, illness and healing are conceptualised.

The CCA to health communication enables health communicators to look at how mainstream health organisations marginalise the health experiences of members of under resourced communities, and how culture influences physician-patient relationships (Dutta, 2008). The perceived nature of these relationships can have an influence on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas because of the perceived level of trust between the guardians and the source of health information. Culture also has an influence on an individual's attitudes, perspectives, knowledge creation and sharing of meaning (Dutta & Basu, 2007; Tan, 2016), and therefore plays an important role in understanding the information seeking behaviour of these guardians. Although a lack thereof limits access and utilisation, structures also challenge the frameworks within which health is constructed and therefore create opportunities for change (Dutta, 2008, Dutta & Basu, 2011). The prospect of change necessitates an understanding of the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas as this understanding could help tailor health communication strategies to the situational environment of these guardians and help better meet their health information needs. By engaging in questions of agency, the CCA allows for the voices of members of marginalised communities - who have been silenced by mainstream media platforms and lack of access to health structures – to be heard and creates opportunities for social change in the healthcare system (Dutta, 2008).

CHAPTER FOUR

METHODOLOGY

Introduction

This study was qualitative in nature and followed a culture-centred approach (CCA) to health communication. Qualitative research enables the researcher to describe, explore and understand phenomena from the perspective of the participants (Noble & Smith, 2014). It involves understanding the human experience in specific settings and focuses on the participants' emotions, behaviours and lived experiences (Rahman, 2017). In qualitative research, the depth of the data collected is more important than recruiting large samples (Noble & Smith, 2014) which is why only 22 guardians of blind and partially blind children who live in rural areas of the Free State province were recruited for this study. Qualitative research also allows the researcher to ascertain how meanings are shaped through and in culture (Corbin & Strauss, 2015). Essentially, this study used qualitative means in order to explore the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas and suggest alternatives to the current ways of making health information available to these guardians.

Health communication scholars and practitioners stress the need for understanding human behaviour through the prism of theory (Rimal & Lapinski, 2009). Using the CCA to health communication, this study sought to generate knowledge through the lived experiences of rural guardians in order to understand their health information seeking behaviour concerning their children's blindness. The CCA to health communication, which is concerned with the voices of members of subaltern communities in discussions of health, focuses on creating discursive spaces that interrogate the erasure of these voices and offer opportunities for co-constructing culture-centred solutions to health-related problems (Dutta, 2008; Acharya & Dutta, 2013). Dutta (2007) affirms that the voices of community members are central to the articulation of health problems and corresponding solutions. The three key tenets of the CCA - culture, structure and agency - were critically analysed through the use of individual, face-to-face, semi-structured in-depth interviews. Acharya and Dutta (2013) maintain that the intersections between culture, structure and agency create opportunities for listening to the voices of members of subaltern communities, whom have been rendered silent through mainstream platforms of society.

This study sought and obtained ethical clearance from the Ethics Committee of the University of the Free State, Faculty of Humanities (appendix C) and thus adhered to sound ethical standards. Permission to work with Bartimea and Thiboloha Schools for the Deaf and Blind was sought from (appendix D and E) and granted (appendix F and G) by the Principals of the respective schools. The guardians of the blind and partially blind children gave consent to participate in this study.

Recruitment and sampling

The researcher had briefing sessions with guardians of blind and partially blind children who live in rural areas of the Free State province whose children attended either Bartimea or Thiboloha School for the Deaf and Blind. The briefing sessions were held during a parent-teacher meeting at each school and the researcher distributed a list where the guardians who were interested wrote their contact details. 35 and 30 guardians showed interest from Bartimea and Thiboloha schools respectively. The researcher then made telephonic contact with the guardians and selected them based on the selection criteria stipulated for this study. Many of the guardians who were interested in participating in this study were not eligible because they either did not reside in a rural area in the Free State province or their children were not blind or partially blind. 40 guardians were eligible to participate in this study and data saturation was reached after interviews with 22 guardians. Data saturation refers to a point at which new data becomes repetitive of data already collected, and does not lead to any new emergent themes (Sandelowski ,2008; Given, 2016).

Purposive sampling was used for this study. Purposive sampling is a process of deliberately selecting participants based on the qualities they possess (Etikan, Musa & Alkassim, 2016). With purposive sampling, the researcher first determines what needs to be known and then finds individuals who are willing to, and can, provide the needed information (Bernard, 2002). These individuals are selected based on the purpose of the study and it is expected that each participant will provide valuable information that is unique and rich (Etikan, Musa & Alkassim, 2016). Specifically, this study made use of homogeneous sampling, which is a form of sampling that focuses on individuals who share specific characteristics or similar traits (*ibid*). The sample for this study comprised of a total of 22 guardians of blind and partially blind children who live in rural areas of the Free State province. These guardians were selected on the basis that they have blind or partially blind children and live in a rural area, and they would therefore be able to provide information on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas - based on their lived experiences.

Participants

The guardians’ information is indicated in the figure below.

	Gender and age of guardian	**Race of guardian**	**Ethnicity of guardian**	**Employment status of guardian**	**Highest level of education of guardian**	**Relationship to child**	**Gender and age of child**	**Child's disability and medical condition**
Guardian 1	Female (45)	Black	Xhosa	Employed	High School (Grade 12)	Aunt	Female (13)	Partially blind
Guardian 2	Female (47)	Black	Sotho	Unemployed	High School (Grade 11)	Mother	Male (13)	Partially blind and has albinism
Guardian 3	Female (66)	Black	Sotho	Pensioner	Primary School	Grandmother	Male (13)	Partially blind and has albinism
Guardian 4	Female (33)	Black	Sotho	Unemployed	High School (Grade 10)	Mother	Female (12)	Partially blind
Guardian 5	Female (37)	Black	Sotho	Unemployed	High School (Grade 11)	Mother	Female (9)	Partially blind and has albinism
Guardian 6	Female (39)	Black	Zulu	Employed	High School (Grade 12)	Mother	Female (12)	Partially blind and has hydrocephalous
Guardian 7	Female (62)	Black	Sotho	Pensioner	Primary School (Grade 3)	Grandmother	Male (18)	Partially bind
Guardian 8	Female (50)	Black	Sotho	Unemployed	Primary School (Grade 7)	Mother	Female (12)	Partially blind

Guardian 9	**Female (38)**	**Black**	**Sotho**	**Unemployed**	**High School (Grade 12)**	**Mother**	**Male (13)**	**Partially blind and has albinism**
Guardian 10	Female (29)	Black	Xhosa	Unemployed	High School	Mother	Female (7)	Child is partially blind and has glaucoma
Guardian 11	Female (38)	Black	Sotho	Unemployed	High School	Mother	Female (11)	Child is partially blind
Guardian 12	Female (31)	Black	Sotho	Employed	High School (Grade 11)	Mother	Male (12)	Child is blind
Guardian 13	Female (35)	Black	Sotho	Unemployed	High School (Grade 12)	Mother	Male (10)	Child is partially blind and has albinism
Guardian 14	Female (42)	Black	Sotho	Employed	High School (Grade 12)	Mother	Female (9)	Child is blind and has a brain tumour
Guardian 15	Female (42)	Black	Sotho	Unemployed	High School (Grade 12)	Aunt	Male (15)	Child is partially blind and has albinism
Guardian 16	Female (35)	Black	Sotho	Unemployed	High School	Mother	Female (9)	Child received an eye donation and is partially blind
Guardian 17	Male (37)	Black	Sotho	Employed	High School	Father	Male (9)	Child is partially blind

Guardian 18	Female (50)	Black	Sotho	Unemployed	Primary School (Grade 4)	Mother	Female (21)	Child is blind
Guardian 19	Female (56)	Black	Sotho	Employed	Primary School (Grade 7)	Grandmother	Male (13)	Child is partially blind and has albinism
Guardian 20	Female (65)	Black	Tswana	Pensioner	Primary School	Grandmother	Male (7)	Child is partially blind and has albinism
Guardian 21	Male (36)	Black	Sotho	Employed	High school (Grade 12)	Father	Male (7)	Child is blind and has a tumour
Guardian 22	Female (37)	Black	Sotho	Unemployed	High School (Grade 10)	Mother	Female (16)	Child is partially blind

Ethical considerations

Permission and consent

Permission to work with Bartimea and Thiboloha Schools for the Deaf and Blind was obtained from the Principal of each school. The consent forms for the guardians were made available in English (appendix H) and Sesotho (appendix I), and were at a readability level appropriate for the guardians. The researcher went through the consent forms with the guardians and provided additional explanations where needed. The researcher made the guardians aware that the information that they gave in this study would not be linked to their names or to those of their children. The researcher also told the guardians that they did not have to participate in this study if they did not want to, and that their children would not be disadvantaged at their schools if they decided not to participate in this the study. In addition, the researcher informed the guardians that they could choose whether or not to answer specific questions and that they could choose to stop participating in this study at any time without having to provide an explanation. The researcher included the contact details of her supervisor in case the guardians had any questions and/or complaints. Furthermore, the researcher made provision for verbal agreement by audio-recording the entire consent process, including the guardians' agreement to partake in this study.

Confidentiality

The identities of the guardians were protected through confidentiality. This was ensured by referring to the guardians as ''guardian'' in the study and by not including the names of the children that were mentioned during the interviews. The names of the guardians, as well as those of their children were unlinked from the data gathered for the study. The transcribed data was stored on a password-protected computer and was available only to the researcher and her supervisor.

Data collection

Data for this study was collected by means of a tape recorder through individual, face-to-face, semi-structured, in-depth interviews with 22 guardians of blind and partially blind children who live in rural areas of the Free State province.

Interviewing is defined as a two-way conversation between the interviewer and the interviewee with the aim of collecting in-depth information regarding an issue of mutual interest (Alshenqeeti, 2014; Morris, 2015). Rossetto (2014) suggests that participating in qualitative research interviews can be beneficial for both the participants and the researcher. Such interviews, Rossetta (2014) suggests, can be inherently therapeutic for the participants as they offer a space for catharsis, and afford the researcher the opportunity to make a positive difference in the lives of the participants. Although Bahn and Weatherill (2013) argue that interviews that focus on sensitive issues may have an increased probability of causing distress to the interviewees, they do acknowledge that many interviewees enjoy being able to tell their story. Many of the guardians of this study expressed that it was their first time speaking to someone about their children's blindness and that they appreciated the opportunity.

Morris (2015) affirms that semi-structured, in-depth interviews are usually an appropriate method for sensitive topics. In-depth interviews allow the researcher to get as much relevant information as possible in the allocated time, follow up on the responses of the participants, probe and discreetly direct the conversation. The in-depth interviews for this study were conducted at the guardians' homes, in Sesotho (their home language) and at a time chosen by them. The length of the interviews ranged between 30 minutes to 1 hour and 30 minutes, and the interview schedules were made available in English (appendix A) and Sesotho (appendix B).

The issue of accuracy and the degree to which the interviewees' account reflects the social reality make in-depth interviews limiting (Morris, 2015). The issue of accuracy was however not a factor for this study as the guardians were able to accurately recall their exact feelings and behaviour around the time of diagnosis, even though it was many years ago. Other weaknesses of in-depth interviews are that they are potentially time-consuming and expensive; accessing the interviewees may be difficult; transcribing of the interviews can be time-consuming or costly; and although the data collected can suggest a definite pattern, it can however not be generalised to a larger population. Boyce and Neale (2006) concur that conducting, transcribing and analysing in-depth interviews can be time-intensive; the interviewer needs to be appropriately properly trained in interviewing techniques; and the results are not generalisable because small samples are usually chosen. Similar challenges were faced with this study.

In-depth interviews however allow the researcher to access rich personal data (Morris, 2015). Other strengths of in-depth interviews are that they enable the researcher to understand the interviewees' context and motivations; allow the interviewees to express what is important to them; and allow the interviewer to probe and obtain additional information by observing the body language and intonation of the interviewees (Morris, 2015). Boyce and Neale (2006) affirm that in-depth interviews provide much more detailed information and a more relaxed atmosphere in which to collect data, as opposed to other data collection methods.

It is interesting to note that the guardians from Thiboloha School for the Deaf and Blind in Qwa Qwa were initially skeptical of the researcher. This may be because the researcher is not from Qwa Qwa and was viewed as outsider. In order to build rapport with the guardians, the researcher visited the school twice during the parent-teacher meetings and had conversations with the guardians about the research. Guardians from Bartimea School for the Deaf and Blind in Thaba Nchu, on the other hand, were immediately receptive of the researcher. This may be because the researcher is from Thaba Nchu and the guardians felt that they could trust her.

Once rapport was built, all of the guardians felt comfortable with sharing their experiences with the researcher and they all invited her to their homes for the interviews. For the convenience of the researcher, some guardians offered to meet at the schools for the Deaf and Blind or at the local clinics as these locations were central and easy to locate. The researcher however kindly declined the offer and the guardians warmly welcomed the researcher into their homes. The researcher's social privilege of being a university student made her a credible source and increased the level of trust from the guardians.

Data analysis

The researcher made use of thematic analysis to analyse the data. Thematic analysis, as explained by Braun and Clarke (2006), is a method for identifying, analysing, and reporting patterns/themes within data. Specifically, the researcher analysed the data through coding which according to Brink, van der Walt and van Rensburg (2012) is finding patterns and producing explanations using both inductive and deductive reasoning to categorise the data into segments.

The researcher familiarised herself with the data by listening to the audio-recordings and reading the transcribed interviews. The researcher did this twice for each interview and made notes on points of interest. The researcher used descriptive codes in the early phases of data analysis, followed by interpretative and explanatory codes. The researcher then used deductive reasoning to categorise the data into segments. Six themes emerged from the data, which are (1) reaction to blindness diagnosis, (2) guardians' coping strategies (3) beliefs about the causes of blindness, (4) eye-care seeking behaviour, (5) health information seeking behaviour and (6) role of schools in supporting blind and partially blind children and their guardians.

Some of the codes used for this study are illustrated in the figure below:

Codes	Descriptive codes	Explanatory code
Emotions displayed during interview	Helplessness Sad Overwhelmed Cried	The guardians were heavy hearted, overwhelmed, sad, felt helpless and some cried during the interviews. They displayed a desperate need to know what the actual cause of their children's blindness was, and what they could do as guardians to help their children as they grow older and transition into various stages in life.
Comfort	God's will Other blind children Sense of belonging for children	The guardians took comfort in believing that the child's blindness is God's will. They also found comfort in seeing other children with similar conditions at health care facilities and at the schools for the deaf and blind. This made them realise that their children are not the only ones.
Denial	Seeks multiple opinions Enrolled child at mainstream school Does not view child as blind	The guardians were in denial and sought multiple opinions after the disclosure of their children's blindness. They were also in denial of the fact that the children were partially blind and therefore enrolled them in mainstream schools. They also did not consider their children as blind because the children could still see, read, write and do things for themselves, despite the difficulty.
Hopeful	Child will see again God will answer prayer	The guardians were hopeful that the child's eye-sight could be restored and therefore consulted with multiple medical doctors, considered surgery, prayed, made use of holy ointment and holy water, went to the church for healing, appeased the ancestors, performed traditional rituals and consulted with traditional doctors.
Acceptance	Struggled Even now Depends on perceived cause Other medical conditions School for the Blind and deaf	The guardians struggled to accept that their children's blindness, some still haven't accepted. Their ability to accept was greatly influenced by their perceived cause of blindness. Those who believed it was the will of God were more likely to accept than those who believed it was due to witchcraft. Guardians of children with secondary medical conditions were more accepting of blindness. The guardians also could not accept that the children had to leave home/mainstream schooling and go to a school for the deaf and blind.
Coping mechanism	Encouraging children to swear Multiple stakeholders Avoidance Not completely blind	The guardians found various means of coping, for both themselves and the children. These include encouraging the child to swear at other children when they tease them, seeking multiple opinions, according social interactions and taking solace in the fact that at least the child is not completely blind.
Prayer	For guardians and children For cure Takes time	The guardians prayed for acceptance and strength, for both themselves and the children. They also prayed for a cure, and although prayer did not seem to bear results, some still believed that God will ultimately hear and respond to their prayers and were not disheartened because they believed that prayers do not get answered immediately.

Community	Accepting Unaccepting Weary of intentions	The guardians felt happy and a part of the community when members in their community accepted their children and their children played harmoniously with other children within the community, or felt ostracised when their children were made to feel different and unwelcome. Their children would get teased by other children within the community and the parents of these children would turn a blind eye and not reprimand their children. The guardians were also weary of the intentions of those who took an interest in helping to restore their children's eye-sight
Family	Supportive family gives hope and helps with acceptance Paternal family blamed mother for child Believed that blindness was due to not practicing certain traditional practices	Majority of the guardians received emotional and financial support from their family members, which helped them accept their children's blindness. The children's maternal family was more supportive than the paternal family. The paternal family blamed the mother for giving birth to a blind child and bringing such into the family. The paternal family believed that the children's blindness may have been caused by not performing certain traditional rituals and insisted on performing traditional rituals for the child. These rituals include acknowledging the child and bringing them forth to their ancestors.
Beliefs in ancestors and traditional rituals	Mostly didn't believe Family influence Rituals	Many of the guardians did not believe in ancestors and traditional rituals and therefore did not perform any. Those who performed the rituals did so because of influence from the family. The rituals that were performed were mainly to acknowledge the child and seek guidance and answers from the ancestors.
Fear of conceiving again	Wanted to abort child Won't not love blind child anymore Won't give enough attention	The guardians expressed concerns about conceiving again. They feared that they wouldn't love their blind children anymore or they won't be able to give them enough attention. They feared that the new child would have the same condition as the blind child. They also had concerns about who would take care of old child when they are busy with going to the clinic for new child.
Eye-care interventions	Religious leader, traditional healers and allopathic doctors	The guardians sought religious, traditional and allopathic eye-care interventions. This included visiting traditional healers, allopathic doctors and religious leaders.
Spectacles	Struggled to/did not get from public hospitals Got them privately	The children never received spectacles from the hospitals, and those who did, waited for a very long period of time. The children also had their spectacles for a long period time, the parents were aware that the spectacles were long overdue for renewal but it could be that they were discouraged processes and long waiting period at the hospitals, and the high costs of getting the spectacles privately.
Eye surgery	Against it Child will go blind either way, does or doesn't do surgery	The guardians were against eye surgery because of the sensitive nature of the eye, and there was a general belief that surgery would cause the child to go blind. There was a fear that if grown people can go blind after surgery, then what about a child. Those who were for eye surgery believed that the child might go blind either way, so might as well give surgery a shot.

Trustworthiness

The researcher proved trustworthiness through establishing credibility, transferability, dependability and confirmability, which are discussed below.

Credibility

The researcher ensured credibility through member checking, which Shenton (2004) explains as the process of going through the transcripts with the participants to verify if the data was accurately captured and whether the meanings formed were representative of their views. For this study, before analysing the data, the researcher made summaries of each interview, contacted the guardians telephonically, went through the summaries and had the guardians confirm that the data was captured accurately and that the meanings formed were representative of their views.

Transferability

Transferability refers to the extent to which results apply to other similar situations (Bless, Higson-Smith, & Sithole, 2013). The researcher ensured transferability by giving detailed descriptions of the context in which the data was collected and about the guardians.

Dependability

In order to ensure dependability, the researcher provided details on the implementation of the research design and data gathering. Providing sufficient descriptive data will allow comparison and enable future researchers to repeat the work and obtain similar results (Shenton, 2004 & Golafshani, 2003). The researcher also ensured dependability by developing an interview protocol. An interview protocol is a set of instructions that ought to be followed for every interview, which guarantees consistency between the interviews and increases the reliability of the findings (Boyce & Neale, 2006). These instructions include what the interviewer ought to say to the interviewees when setting up for, beginning and concluding the interviews; as well as what the interviewer ought to do during and after the interviews (Boyce & Neale, 2006). For this study, while setting up for the interviews, the researcher exchanged pleasantries with the guardians and thanked them for agreeing to meet. When beginning the interviews, the researcher read through the consent forms together with guardians and made them aware that the interviews were being audio-recorded. During the interviews, the researcher maintained eye contact with the guardians and appeared interested in what they were saying. In addition, the researcher avoided yes/no and leading questions, and was mindful of not imposing her personal opinions on the guardians. The researcher also took mental notes regarding the body language and intonation of the guardians and checked the audio-recorder to ensure that the interview was being recorded. Upon concluding the interviews, the researcher thanked the guardians for their time, asked them if they had any questions and whether they wanted to have the results of the study presented to them. After the interviews, the researcher ensured that the interviews were saved on the audio-recorder, wrote down the mental notes she made during the interviews and summarised key information for each interview.

Confirmability

Confirmability was ensured through acknowledging the beliefs underpinning the decisions made and methods adopted by the researcher (Shenton, 2004). The researcher was mindful of and made sure that her interpretations of the findings were grounded on the data and not based on her own viewpoints or preferences. The researcher also made use of an audit trail, which required her to provide a complete set of notes on decisions made during the research process, sampling, emergence of the findings and her reflective thoughts (Korstjens & Moser, 2018).

Summary

Data for this study was collected through individual, face-to-face, semi-structured, in-depth interviews that were conducted in Sesotho. The data was then translated into English and analysed using thematic analysis. The researcher adhered to ethical standards and tried by all means to mitigate harm for both herself and the guardians.

The researcher made arrangements with qualified Social Workers from Bartimea and Thiboloha Schools for the Deaf and Blind for free consultations for the guardians who experienced distress as a result of the interviews. The researcher also made arrangements with the guardians, Bartimea and Thiboloha schools, and the Free State Departments of Health and Education for a presentation of the results.

CHAPTER FIVE

FINDINGS

Introduction

The culture-centred approach (CCA) stresses the need for dialogue with, and the creation of spaces for marginalised cultural voices. This study followed a culture-centred approach to health communication and sought to explore the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas of the Free State province and suggest alternatives to the current ways of making health information available to these guardians. Health information, in the context of this study, refers to blindness-related medical information and information about specialised support that the blind and partially blind children may need.

The researcher conducted individual, face-to-face, semi-structured, in-depth interviews with 22 guardians of blind and partially blind children who live in rural areas of the Free State province in South Africa. The interviews were conducted in Sesotho and held at the homes of, and at a time chosen by, the guardians. The guardians were made up of fourteen mothers, four grandmothers, two aunts and two fathers. It is worth noting that factors such as death, close familial ties and migrant work make it common for females to be primary carers of children in South Africa. The children whose guardians were interviewed were either completely blind, had sight in only one eye, or had very little sight in both eyes. Each of the 22 guardians had one child that was either blind or partially blind. Four of the 22 children were blind and 18 were partially blind. Of the 18 that were partially blind, four were completely blind but their eyesight was restored through either eye donation, surgery or traditional eye-care interventions. Some of the children had other medical conditions which were perceived to have been the cause of their blindness such as albinism, glaucoma, tumours, pre-existing eye/ear medical problems, Human Immunodeficiency Virus (HIV) and hydrocephalous.

The guardians and their children were all Black and from several cultural groups. Eighteen were Sotho, two were Xhosa, one was Zulu and one was Tswana. The guardians were aged between 29 and 66, and all had formal schooling with high school certificates being the highest qualification achieved. The majority of the guardians were unemployed, and their monthly income ranged from 1 700 to 5 000 Rands. Their source of income was mainly the children's disability grant together with either a wage, salary, pension grant or social grant. Some of the guardians generated an income from selling food and sweets at the local schools and surrounding areas.

The interviews yielded six themes and highlighted the influence of the three key tenets of the CCA - culture, structure and agency - on the health information seeking behaviour of the guardians. The interviews explored how the guardians made meaning of their children's blindness based on the values, beliefs and practices of their culture and of the culture that exists within their communities, as well as its influence on their eye-care and health information seeking behaviour regarding their children's blindness. The guardians expressed feeling heavy hearted, overwhelmed, sad and helpless regarding their children's blindness. Some of the guardians cried during the interviews and the researcher referred them to the Social Workers at their children's schools for support. Most of the guardians stated that they did not have any family history of ocular ailments and those who had a family history of ocular ailments indicated that they either had poor vision and wore spectacles, or had general eye problems such as dryness, itchiness and redness of the eyes, although none of these conditions led to blindness. All of the guardians expressed that their children were the only ones who were blind in their families and in their communities.

The themes that emerged from the interviews, as well as the three key tenets of the CCA, will be discussed in the section below. These themes were (1) reaction to blindness diagnosis, (2) guardians' coping strategies (3) beliefs about the causes of blindness, (4) eye-care seeking behaviour, (5) health information seeking behaviour and (6) role of schools in supporting blind and partially blind children and their guardians.

Theme one – Reaction to blindness diagnosis

The guardians, their families and their communities expressed varying reactions to the children's diagnosis of blindness. These reactions included hurt, shock, disbelief, uncertainty, anxiety, acceptance, supportiveness, blamefulness, pity and scorn.

Many of the guardians struggled to come to terms with their children's diagnosis of blindness and some expressed feeling shocked, hurt and suicidal. Most of the guardians' shock stemmed from the sudden nature of their children's blindness and fact that their children were the first in their families and the only ones in their communities (that they knew of) who were blind. Many of the guardians felt hurt by the fact that their children would be faced with a life-time of mobile and social difficulties, while first-time parents were hurt that their first-born children had a disability. One mother particularly expressed feeling suicidal upon diagnosis.

> *Yho, death seemed like the only solution, for the both of us [mother and child]. I couldn't accept it. Yho *silent* I had satanic thoughts of throwing myself, together with the child, down the stairs. They [doctors and nurses] saw that I was not okay. I was crying. I was devastated. I didn't know what to do. I had stupid thoughts at that time, and then they called these people…what do you call them? Social Workers. They tried talking to me, but I didn't find whatever they were saying helpful. I was asking myself why? Why did such have to happen to the child? - Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind and has a brain tumour]*

Many of the guardians struggled to accept their children's diagnosis of blindness and some indicated that they still have not come to terms with the fact that their children are blind.

> *At first it was difficult for me to accept my child's situation, I was ashamed of her. I was afraid of walking around with her. I kept asking myself why me? It really hurt me because she is my first-born child. I even had regrets at some point. I asked myself why did I have a child in the first place because now the child is giving me problems. -*

> *Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*
>
> *It was painful. It was painful because I never thought that when I have a child, I'd have a child who can't see. I was always crying, I don't want to lie. I was always crying. I couldn't even talk [about the child's blindness] like I am talking to you now, I would cry. I used to cry, even in the taxi. Wherever I went with him, I didn't like it if people asked me "is this child blind?" I would get very hurt. It took me a very long time to accept. – Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*
>
> *It was very difficult for me to accept, even now. It's still difficult for me to accept. He does everything slowly. At times I just get that feeling where I want to say to him "Do it like this. Do it quickly!". It's not easy. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

It is worth noting that the guardians whose children had other medical conditions which were thought to be the cause of the children's blindness seemed to be more accepting of their children's diagnosis of blindness. These medical conditions included albinism, glaucoma, tumours, pre-existing eye/ear medical problems, Human Immunodeficiency Virus (HIV) and hydrocephalous.

Many of the guardians also expressed feeling uncertain about their children's futures and anxious about having their children leave home and residing at the schools for the Deaf and Blind. Many of these guardians were concerned about the kinds of lives that their children would lead and wondered if their children would manage living with blindness. Many of the guardians were particularly concerned about who would help care for their blind children should they pass away.

> *I didn't feel good about the fact that his sight was diminishing, and I was worried about who is going to help him once he can't see at all and who would take care of him should God decide to end my life. And even when I am still alive, he is a boy and I won't really be able to escort him to the toilet and things like that. He would require a male carer. – Guardian 7: Grandmother, age 62 [child is an 18-year-old youngster who is partially blind]*
>
> *Tjooooo I was very skinny. It [weight loss] was due to stress about what kind of life is the child going to live? How will this child manage? – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

The guardians' anxiety about having their children leave home and residing at a School for the Deaf and Blind was driven by the fact that the children were still young and the guardians worried about whether they would be able to take care of themselves or attend to their personal hygiene needs.

> *I cried. I cried a lot. I was not happy. It's painful. You are already used to having the child around and then all of a sudden they can't see, and they have to leave [and reside*

> *at the School for the Deaf and Blind]. My heart was really painful. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*
>
> *I was worried. I still do worry a lot about how she will manage when she grows older and starts things like her [menstrual] period. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*

These guardians also stated that, although the schools for the Deaf and Blind had caretakers who looked after their children, they constantly worried about whether their children took their medication as required for their chronic conditions (HIV, epilepsy, glaucoma and hydrocephalus).

The families' reaction to the children's diagnosis of blindness played a pivotal role in aiding the guardians to come to terms with their children's disability. Although shocked and hurt, the families generally tended to rally around the guardians and the children, which helped the guardians feel supported.

> *They supported me. They were also hurt but they were able to put me well. - Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*
>
> *Ai, they were a little hurt but they accepted. They said that it's painful but there's nothing that can be done because she was given to me by God, and I accepted that ''it's a gift from God''. I accepted. – Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *They accepted and made peace with the fact that this is how the child was born. They also tried to make me accept it and make peace with it, up until I eventually came to terms with it. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

In a few cases, the families reacted negatively to the children's diagnosis of blindness and their reaction led to the guardians feeling even more hurt and isolated. Many of the negative reactions were from the children's paternal families, who believed that the mothers were the cause of the children's blindness since there were no other blind persons in their families. This resulted in strained relations between the parents, and between the mothers and the children's paternal families.

> *The only person who gave me problems was the child's father. He changed after the child had problems with her eyes. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*
>
> *His father's side of the family on the other hand, I can't say that they had accepted it because even his father spent about a year without communicating with us. I just told myself that this is my child and I have to accept whatever people are saying and give him love. It does not matter what outside people say, this is my child. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

> *My in-laws said that they do not have blind children in the family and I am the one who came with blindness. This made me feel hurt, very hurt. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

The communities' reaction to the children's diagnosis of blindness had a significant impact on the guardians' sense of belonging. Many of the guardians indicated that their communities reacted positively to their children's blindness. The communities treated the guardians' children in the same way as they treated all the other children within the community, and the children all played together in harmony. The community members generally reprimanded their children when they mocked the blind children and they assisted the children whenever necessary. Some community members empathised with the guardians and others admired the guardians for taking such good care of their children. These positive reactions caused the guardians, as well as their children, to feel supported and accepted.

> **Smiles* The community is okay. They are truthfully treating him well. There aren't any bad things. It made me to also treat him well and take care of him. – Guardian 9: Mother, age 38 [child is a 13-year-old boy who is partially blind and has albinism]*

> *They have accepted her. They treat her well. When she can't see something, they help her. The elders reprimand the small children when they call her names. They treat her very well. I feel happy. I honestly feel happy. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*

> *To tell you the truth, they didn't treat him badly. They treated him like any other person. He is loved by everyone, and the other children have never excluded him, they play well with him. He is also an open person, you shouldn't whisper and ask others if he's blind, he wants you to ask him if he can't see and what is wrong with his eyes and he will tell you himself. Even where we have moved to now, they have accepted him and all is well. It makes me happy to know that my child is not excluded. – Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*

There were, however, some communities that were not supportive. This lack of support manifested through the children refusing to play with their blind peers. In some cases, the blind children were mocked while adults watched and failed to reprimand the unkind behaviour. These negative reactions from the community caused the guardians, as well as their children, to feel hurt and unwanted.

> *The elders pitied her and the children used to tease her because she couldn't see and it would hurt me a lot. - Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*

> *They would laugh. It was something like a joke to them. The child was even afraid of going outside and playing with the other children. She was always indoors and it made me feel like I am a bad parent. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*

> **Eyes teared up* People would always tease her, saying that she is blind and things like that. I did not take it well, it would really hurt me. I didn't like it. Even when she'd be playing with other children and they would say to her that "you are blind" it wouldn't sit well with me. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

Theme two - Guardians' coping strategies

Many of the guardians struggled to cope with the children's diagnosis of blindness and the challenges that came with raising children that are blind. As a means of coping, these guardians sought the support of multiple stakeholders. They went to family members for counsel, their churches for religious guidance, and traditional healers and allopathic healthcare practitioners for the causes and cure of their children's blindness.

Another coping strategy that many of the guardians employed was prayer and trusting that their children's blindness was God's will. These guardians took solace in believing that God had done His will and trusted that God would handle the situation. Many of these guardians expressed that they prayed for strength and guidance, and stated that it was through prayer and their faith that they were able to accept their children's blindness. Some guardians stated that they prayed for God to restore their children's eyesight and that they believed that God would one day hear their prayers.

> *Every day we would say that prayer came first, we need to pray so that God can see how to help with the child's eyesight. […]. And then I told my child that she should just accept that she is blind and that one could say that God showed His favour upon her because she is not completely blind. She can still see, even if it's not far. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

> *It is God's doing. He gave me a child who is blind. That's how I came to accept, I have that belief that it is only God. […] He [guardian's uncle] also said that we need to accept this; he said "it was God's wish to give you such a child. We can't choose for God who he should give this child to and give you a different one". – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *I know God has done this and he will correct it. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

Some of the guardians struggled to cope with their blind children being mocked by the other children and they, as a means of coping, encouraged their children to stay indoors or to swear at the children who mocked them.

> *It was very saddening. I even encouraged her to stay indoors. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *It [the teasing] continued up until I told my child that she should swear at them [children in her community]. I told her that I know that what I am doing is not right but we can't have that she gets teased every time she plays with them and their parents seem to enjoy it, so I told her to swear at them. Ever since I told her to*

> *swear at them, the teasing has never happened again. I said to her "you should swear at them!" and the swear word that I told her to use was a very bad one and she used to do it. This one time she swore at one of the children in front of the child's mother and the mother kept quiet. I was just waiting for that parent to come to me. I was going to ask her how she would feel if it was her child that was constantly being teased. They do not reprimand their children, they just laugh, so I gave my daughter permission to swear at them. […]. Thereafter they stopped teasing her and she was able to play nicely with them. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

While most communities were supportive, the guardians who lived in communities where they and their children were not accepted tended to withdraw from social activities in the communities and refrained from building and nurturing relations with members of their communities as a means of coping.

Many of the guardians also expressed that they feared conceiving again. These guardians feared that their next children could also be blind or have the same medical conditions as their elder siblings, such as albinism or hydrocephalus. Some of the guardians indicated that they feared that if they were to have other children, they might not love their blind children in the same way, especially if these children were to be born without any form of disability. Other guardians feared that if they had other children, they might not be able to attend to the needs of their blind children such as accompanying their blind children for their eye examinations, or personally taking them to and collecting them from their schools during school holidays. As a means of coping with their fears, some of the guardians decided not to have more children. Those who had more children used prayer, traditional rituals and regular eye examinations as mechanisms to cope with their fears.

> *I felt that I did not want to have other children. I have a child that has a problem, who would take care of him while I go back and forth for pregnancy related check-ups, what would I do? – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*
>
> *Yhoooo I was afraid. I was afraid that history would repeat itself and I'd have another child who is like my first-born child. – Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *I do not want to have another child. They might be born blind. It seems to me that this is hereditary. I have severe eyesight problems and my child is partially blind. We seem to have inherited it from my grandmother. So no, I do not want to have another child. They might be born blind. – Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*
>
> *I really felt bad for falling pregnant. I wondered how could I have another child whereas my child has eye problems and needs love? What if it happens that I stop loving her? I asked myself such questions. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

> *I was afraid, I even went to the hospital to ask if this condition is not contagious. She [second born child] also had eye problems after birth, she had discharges coming out of her eyes. I took her to the doctor when she was 2 months old but he said that her sight was fine. I also took her to Bloemfontein when I took her sister for treatment and the doctors said she is still fine. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

Theme three – Beliefs about the causes of blindness

Many of the guardians, their families and their communities had firmly held beliefs regarding the causes of blindness, which influenced the guardians' eye-care seeking behaviours and their decisions to seek health information.

Some of the guardians did not know what caused their children's blindness, others thought that it could have been hereditary or that it was caused by alcohol, difficulties experienced during labour or the children's medical conditions, which included albinism, glaucoma, tumours, pre-existing eye/ear medical problems, HIV and hydrocephalous.

> *Blindness is hereditary. I don't believe that it is something that is man-made. My grandmother was partially blind and lost her eyesight completely during her pension years and as you can see, I too have problems with my eyesight [guardian wore spectacles with a very thin lens]. – Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*
>
> *I think it's because her mother drank a lot of alcohol. Her mother passed away. She used to drink a lot. I think that's the cause. But also, the child's grandfather from her father's side also has an eye problem so she could have also gotten it from there. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*
>
> *I think it was the nurses' fault because I think they hurt the child during that time when they were trying to pull her out and she'd go back in [to the womb] and they'd try to pull her out but she'd go back in. Remember I told you that we noticed handprints on the child's head and face after she was born. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*
>
> *I think that maybe it's in their nature because he is an albino. - Guardian 15: Aunt, age 42 [child is a 15-year-old boy who is partially blind and has albinism]*
>
> *I can't be certain. I could say that it was caused by the fact that he is [HIV] positive. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*
>
> *It seems to me that it was caused by her condition: hydrocephalus. I don't know. It's just what I think. But then I sometimes think to myself that she inherited it from me because I also have an eye problem. – Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*

Many of the guardians believed that their children's blindness was due to God's will and that God would restore their eyesight or give them enough strength to accept His will. Some guardians expressed that they believed that God was just testing their faith and that they needed to be steadfast in prayer and God would provide the necessary guidance. Others referred to a scripture in the Bible about a blind person and stated that blind people existed, even in biblical times.

> *I believe that it is God's will. You could be born blind, or you could be with sight and lose it as time goes by. – Guardian 7: Grandmother, age 62 [child is an 18-year-old youngster who is partially blind]*

> *My belief is that, it is through God that you get a child that is different. I have accepted that…My belief is that it is God who gave me a child who is blind. It is not through my wisdom that I could dictate to God which kind of child he should give to me. It is God's doing. He gave me a child who is blind. That's how I came to accept, I have that belief that it is only God. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *Blindness is not something new, there was a blind person even in the Bible whom we read about on Sundays at Bartimea [School for the Deaf and Blind]. So, I think that the things that happened during those times can still happen in this day and age. – Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*

Other guardians believed that their children's blindness was caused by the evil deeds of other people, ancestral spirits or that it resulted from not following the correct traditional practices.

> *There is also an influence of the evil deeds of others. You'd find that the one minute things are like this, and the next they are not. I believe this because she couldn't see at all when she went to Thiboloha [School for the Deaf and Blind] and had to use her hands to feel around, but right now she can see, even though she's near-sighted. So you'd find that it's because of the evil deeds of others, because when she's home, even if it's for a few days, her sight deteriorates. She won't finish an entire week here without her sight becoming worse. She'll start using her hands to find her way around. At times you'd find that she can't see during the day but then she sees at night. Sometimes she can't see at night but then she sees during the day. I don't understand how her eyes change with the weather in such a manner. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *The way that I delivered this baby was very suspicious. I believe that there is something that I stepped on when I was pregnant. The child came out being red and had red eyes. I took her to the traditional healers and they said that I had stepped on something while I was pregnant, on the other side the doctor said that it was an infection. I think that it is something that I had stepped on. I had a very difficult labour and I had an operation. – Guardian 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]*

> *But then again I also think what caused it was because I stopped breastfeeding her. All these things started happening after I stopped breastfeeding her and cut her hair [a common practice in many South African Black cultures]. I applied aloe on my breast,*

> *like with all the other children, I applied aloe so that she could find it bitter and stop breastfeeding. Which is why I think that a mother's milk is the best because it protects a child from things because this happened after she stopped breastfeeding. – Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind and has a brain tumour]*

Many of the guardians' families held beliefs that were similar to those of the guardians, which reflects how beliefs are transmitted from one generation to the next. The families too believed that their children's blindness was hereditary, something that just occurred, was due to the will of God, caused by spiritual attacks, ancestral spirits, the evil deeds of other people and not following the correct traditional protocols.

> *They also believe that blindness is something that just occurs. Sometimes it just occurs without one knowing what happened. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*
>
> *They are Christians so they believe it is God's doing. – Guardian 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]*
>
> *They believe that it is witchcraft, they wanted me to take her to a traditional healer so that she can get traditional medicines. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind]*

Many of the guardians had not spoken about nor were aware of the beliefs held by their communities regarding the causes of blindness. Those guardians who spoke about or were aware of the community's beliefs stated that their community believed that blindness was something that just occurred or that it was due to the evil deeds of other people and advised the guardians to seek religious and traditional eye-care interventions.

> *They too believe that it's something that just occurs. You'd find that a child can have a disability whereas there's no-one else in the family with a disability. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*
>
> *They would say things like maybe I had a quarrel with so and so, and so and so did this and that…jealousy and things like that. – Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind and has a brain tumour]*
>
> *They believe that it is witchcraft and that I must attend prayer sessions and use holy oil and my child will be cured. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*
>
> *They gave advice about taking her to a church that heals people or to traditional doctors. I went to many people until I got tired. – Guardian 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]*

Theme four – Eye-care seeking behaviour

The guardians' decision to seek eye-care was motivated by the noticeable signs and symptoms that the children presented or the children's ocular complaints. The children presented signs of photophobia and their eyes reddened. The younger children would cry a lot, get frightened by seemingly sudden movements, and not be responsive when objects were placed or moved in front of their faces. The older children would frequently press their eyes together as though they were struggling to see, slightly tilt their heads when being spoken to, constantly rub their eyes, sit very closely to the television, hold cellular devices very closely to their faces, move their faces very closely to their books when reading or writing, bump into furniture, walk into doors and walls, struggle to locate items and take longer than normal to complete tasks. The children also tended to have poor handwriting and struggled to complete class activities at their mainstream schools. The children's ocular complaints included that their eyes felt painful, dry, itchy or had a burning sensation, or that they could not see their teachers' handwriting on the chalk boards at their mainstream schools.

Many of the guardians first consulted with their families and sought the family's advice before they sought help regarding their children's eye condition. The guardians stated that they first consulted with their families because they needed advice from their elders, wanted to make a family decision regarding the children's eye-care, and that they needed emotional support.

Many of the guardians consulted with their grandmothers, mothers or aunts as they either lived together with these elders or they lived within close proximity and had close bonds.

> *I spoke to my husband's aunt and my aunt […] [because] she [husband's aunt] was the one who I spent most of my time with since my aunt was mostly at work and would come back home late at night, but my husband's aunt was always around, and then I realised that I needed to show her the problem that I have noticed with the child since she was the one who would bathe the child. – Guardian 4: Mother, age 33 [child is a 12-year-old girls who is partially blind]*

> *I spoke to my uncle's then girlfriend [because] we were close and she understood me. - Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*

Some of the guardians consulted with their spouses or family members that they lived with in order to make a joint decision regarding the children's eye-care. In cases where they held differing views, the final decision was made by an elder in the family or the father of the child.

> *I spoke to his father, we were not staying together at that time. I spoke to his father and told him how the child was behaving […] [because] he was a supportive person at that time, which is why I was able to open up to him. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

> *I spoke to my mom and I asked her to have a look at the child's eyes [because] I noticed that they were changing and she said no, it's a discharge that occurs when a child is still small, she'll be okay as time goes on. I should just pour breastmilk into her eyes,*

> *the milk will cleanse it. Only to realise that the more I poured the breastmilk, the worse the eyes become. She then said that I should take the child to the [allopathic] doctor – Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*
>
> *I spoke to my grandmother, and then we took the child to the [allopathic] doctor. I thought that this could have been caused by traditional herbs that we normally give to babies and that she would be alright after some time but my grandmother said that no, there were no traditional herbs that were put inside her eyes and that we must take her to the [allopathic] doctor. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*
>
> *We spoke about it as a family. I spoke to my brother, and the child's father was also there when we spoke about it. His father picked him up and looked at him and he cried saying that his child can't see, what could be wrong, and I said I do not know, and then we took him to traditional healers. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

Some of the guardians expressed that they consulted with their families because they needed emotional support.

> *I went home in order for them to help me make sense of the child's situation […] [because] there is no-one else that could have been able to provide me with the kind of support that I needed better than my siblings and my mother. - Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind and has a brain tumour]*
>
> *I went home and I told them it seems like this child can't see […] [because] I was surprised, wondering why his are eyes like this, why are they not opening and I needed their support. Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*

After consulting with family members, all of the guardians sought religious, traditional and/or allopathic eye-care interventions in order to find out what could be wrong with, or in an attempt to restore, their children's eyesight. All guardians either started with or ultimately resorted to the use of allopathic eye-care interventions. Allopathic healthcare in South Africa is provided through private and public healthcare services. Due to their socio-economic status, many of the guardians made use of public healthcare services, which are provided free of charge at public clinics and hospitals. Given the structure of the provision the healthcare services in South Africa, many of the guardians started at their local clinics, which referred them to their district hospitals. The district hospitals then referred them to either National or Pelonomi regional hospitals in Bloemfontein which, depending on the severity of their children's condition, referred them to Universitas academic hospital in Bloemfontein.

> *Yes, it was before we went to the clinic. We took him to a traditional healer. The doctor was a young man, he passed away. The medicine that he used in the child's eyes seem to have brought a bit of his sight back, I am certain of that. The child was completely blind because he wouldn't react when I waved my hand past his eyes, and*

> *he would walk straight into things. After that young man used his medicine, that's when the child had a bit of eyesight again. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *They [family members] observed her and tried all that they could. They took us to different churches and the priests would tell us that it's due to evil spirits; she'd be okay. Up until I realised that nothing is happening and we started going to allopathic healthcare practitioners. I started at the clinic, and they referred me to the hospital, the hospital referred me to Pelonomi [regional hospital] and Pelonomi referred me to National hospital. And that's when we found out that she was permanent[ly blind]. There was nothing they could do to help. She's blind, irreversibly blind. – Guardians 14: Mother, age 42 [child is a 9-year-old girl who is blind]*

> *They [family members] told me to take the child to a private doctor. The private doctor checked her and gave us medication and we used it. Her eyes became worse and then I took her to National [regional] hospital in Bloemfontein. They examined her at National hospital and they found that her eyes were damaged, she had sores inside her eyes. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*

Many of the guardians did not seek a second opinion after their children were diagnosed with blindness. This was influenced by the structure of the South African public allopathic healthcare referral system, which referred the patients from one healthcare facility to the other before receiving the ultimate diagnosis. Some of the guardians' decision to not seek a second opinion was influenced by a lack of financial resources and the assumption that children's other existing medical conditions may have be the cause of their blindness.

> *No, I did not. From Moroka [district] hospital they referred us to National [regional] hospital and when we got to National hospital, it was confirmed that the child indeed has eyesight problems. – Guardian 4: Mother, age 33 [child is a 12-year-old girls who is partially blind]*

> *No, I didn't. They checked her out at National [regional hospital] and they sent her to Universitas [academic hospital] for a scan and they told us that she's blind. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*

> *I did not look for a second opinion, I just accepted. I didn't have enough money to try other options. - Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*

> *No, I just accepted because they explained that albinos can't see far. – Guardian 5: Mother, age 37 [child is a 9-year-old boy who is partially blind and has albinism]*

Those guardians who sought a second opinion either asked to be referred from a district to a regional hospital, made use of private healthcare services, or resorted to the use of allopathic healthcare services after religious and/or traditional eye-care interventions did not bear the desired outcome.

Many of the guardians stated that they did not use eye medicine for their children's eyes. Their reasons were influenced by the incurable nature of their children's eye condition and the fact that the children did not have any ocular complaints.

> *He hasn't used any medicine. We were told that his condition is incurable. If I still remember the [allopathic] doctor's explanation correctly, they said that he does not have the black part, like I have. There's a hole inside his eye. He doesn't have any pigments inside his eye. He doesn't have both of them [pupil and iris] inside his eye. . – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

> *No, he never used any. He hardly ever complained about them being painful or anything along those lines. – Guardian 9: Mother, age 38 [child is a 13-year-old boy who is partially blind and has albinism]*

Those who made use of eye medicine used religious, traditional or allopathic eye medicine in the form of eye drops or eye ointment.

> *We used ointment we received from the church. We rubbed it around her eyes. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *They would give him eye drops at the clinic and at other times give him the ointment. The traditional healer gave us traditional medicine that we would use in his eyes as drops, which helped restore his sight. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *We used treatment from the [allopathic] doctor. They [allopathic doctor] had explained to me that my child has glaucoma. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

Many of the guardians' families did not make suggestions regarding eye medicine for the children. Those who made suggestions, suggested that the guardians make use of traditional eye medicine, which was influenced by their beliefs regarding the cause of their children's blindness.

> *They recommended traditional medicine but I refused to use it. I do not want to put things in my child's eyes. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

> *They had suggested that I take him to a traditional healer and he was given medication. He was still very young. They thought that maybe he was blind due to the evil deeds of other people. We used it [traditional medicine] that time only, orally. We didn't put anything into his eyes. – Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*

Many of the guardians' communities did not make suggestions regarding eye medicine for the children. This was influenced by their lack of awareness regarding the children's eye condition and not having close ties with the guardians.

> *The people in the street I stay in mind their own business. They do not have that thing of building each other up or intervening when a person has a certain problem. Everybody just lives their own life. - Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*

> *I was able to get an opportunity to be close to people who are a part of an association that's for people with Albinism who have eye problems, so they are the ones who usually tell me what to do, and they also helped me to come to terms with it and accept that this is for a lifetime. I was in a taxi with this other lady [with albinism]. I actually found her in the taxi. I was with my son and she said ''you have such a beautiful child, could you please give me your number so that we can chat''. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

Some of the guardians tried different approaches to cure their children's blindness. This included the use of food, religious, traditional and allopathic eye-care interventions.

> *I gave him food that help with eyesight such as carrots and spinach. – Guardian 7: Grandmother, age 62 [child is an 18-year-old youngster who is partially blind]*

> *We used medication we got from the hospital. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *We tried surgery, used [allopathic] medicine and got him spectacles. – Guardian 17: Father, age 37 [child is a 9-year-old boy who is partially blind and has glaucoma]*

> *We used to pray because just like you know, there is no parent who would love for their child to have a disability. It's the same as when you are sick, you know that your parent would not be happy that you are sick. They won't just sit back and say ''she'll be alright''. […]. Her sight never became better; we prayed to God up until we accepted that there's nothing more that could be done because even the doctors couldn't succeed. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

Some of the guardians' families had an influence on the type of cure that the guardians sought for their children's blindness, which included the use of religious, traditional and allopathic eye-care interventions.

> *We performed that ritual I told you about [slaughtering goat and putting a bracelet made of goat skin on the child] thinking that his eyesight would come back but he is still like that. We visited the gravesites of our elders who have passed on. We also went to his late father's resting place thinking that there would be something different and he may be able to see from wherever he is and show us what we need to do for the child to see. But there's no solution. Truthfully, there is no solution. The*

> *people who have passed on have passed on. They are dead quiet. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *Her father's side of the family said that they needed to take her to somebody's gravesite somewhere but I refused. Other family members said that I should allow them to take her to the gravesite, maybe she'll be better. I went there with her because my relationship with her father was still okay at that time but there was no difference. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*

A few of the guardians' communities made suggestions on how to cure the children's blindness. These included performing traditional rituals and taking the children to church for prayer.

> *I don't go to church. The lady I work with attends ZCC [Zion Christian Church] and then she said I should go with her to church, the child will get help and then we went and he drank those things he got from the church but they didn't do anything to him. He is still like that. - Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*

> *There is this other woman who would take her to her church saying that they will pray for her, and I would allow my daughter to go. I would allow her to go because you know when things are difficult prayer helps and there is one God. It's okay if she goes to that woman's church, and it is okay if she goes to my church. She would say "borrow me your child so that I can take her to church and have them pray for her eyes". – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *It was only recently that the owner of the transport he uses [to school] invited us to her church but we never went. I knew that they might give me oils and tell me to apply it on the child. Those things could end up damaging the child even worse. I have accepted what he is and there is never going to come a point where I change and stop accepting. I don't want people to provide me with remedies. This child just needs to go to his appointments at the eye specialist, and that's final. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *Some wanted to take the child to their churches stating that the pastors at their churches heal people. I never agreed. I am the type of person that when you talk a lot, and say nasty things that make one angry, I won't get along with you. I would wonder why this person would want to take my child to church to get healed, whereas I can tell that they are just being pretentious and it's not that they love me. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

Many of the guardians experienced numerous challenges while seeking eye-care for their children which included stress and a lack of emotional and financial support. Their limited financial resources were particularly challenging because they often had to travel back and forth between healthcare facilities. Many of the guardians were unemployed and they stated that they at times needed to borrow money from family members and friends or from loan sharks in order to see to the eye-care needs of their children. The guardians expressed that they needed money to travel to the various churches they sought assistance from; to travel to and consult with the traditional doctors; to perform traditional rituals which at times required cattle to be slaughtered and traveling to sacred places; to travel to the public clinics and hospitals, to travel to and consult with private healthcare practitioners, to purchase spectacles for their children and food that is good for the children's eyesight. Some guardians expressed that they did not have any emotional support as their close family members had either passed away or stayed far from their homes.

> *I stressed a lot about the child. I would wonder why did I give birth to a child that is like that. Transport was also a problem because I was unemployed at that time and there was nobody who was employed in the family. We lived off of my grandmother's pension grant. - Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*

> *My biggest problem was going up and down [back and forth between the healthcare facilities]. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *Transport from here [home] to Manapo [district hospital] and you'd get a date for whenever and have to go back again. This resulted in financial problems. The money he got for his disability grant was still very little back then. At times you'd find that I do not have money at the time of the date that has been set and I would have to borrow it in order for me to catch a taxi and take the child because I wanted him to also have a life. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *Money was a problem. She only started receiving a disability grant when she was 5 years old, and it was only 500 Rands at that time. Her father was the only one employed and the money he earned was not enough and we would go to bed hungry, but it didn't matter because it was for our child - Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*

> *I didn't have any form of support. My mother had already passed away when I had my child. I lived with my grandmother and she was already quite old and had her own problems with her eyesight. Her father's side of the family didn't care about us. I would use some of my grandmother's pension money to commute to the hospital. - Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*

Those guardians who did not experience any challenges attributed it to the fact that they were employed, received assistance from their employers or spouses, or that their spouses had the children covered on their medical aid and they were able to use private healthcare services.

> *I never experienced any financial problems because my relationship with her father was still okay at that time. He was very supportive from when she was born, right up until we separated. Right now I am independent; I use my salary and her grant to help make ends meet. I don't want to lie, everything went well during that time. I did not*

> *have any challenges. My family was also supportive, although financially it was difficult. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *Everything went well. We didn't have a problem with going to the doctors because we had medical aid during that time. The challenge only began recently. He got removed from the medical aid. I didn't struggle at all back then. When his spectacles were due to be renewed, I'd take him to an optometrist to get new ones. Right now things are difficult. He [the father] even comes home after 2 to 3 months. He would just appear out of nowhere. He is no longer close with his children. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

Theme five - Health information seeking behaviour

None of the guardians actively sought blindness-related medical information. Their reasons for not seeking such information were driven by acceptance, fear and a lack of awareness.

Many of the guardians stated that they had accepted their children's blindness and therefore did not see the need to look for blindness-related medical information.

> *I didn't want to know about blindness because I already have a child who is blind and it won't change anything. Maybe if she was still young then maybe I would want information about blindness but because she is already grown, I have accepted her and it even feels like she can see to me. I have accepted that my child is blind and that her blindness is what God has given her up until she leaves this world – Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*
>
> *The doctors told me that she's not going to see and they explained, and I didn't look for any more information. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*
>
> *I think it never occurred to me because I accepted the child's condition quickly, which maybe stopped me from wanting to find out more about blindness. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

Some of the guardians feared that actively seeking blindness-related medical information would make them feel worse about their children's blindness. Other guardians feared that they would find information that would stress the need for eye-related surgical interventions and that these interventions might further worsen the children's eyesight or result in death

> *Won't looking for it make me feel hurt even worse? – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*
>
> *They might tell me that they want to cut his eye, and damage my child. No way *chuckles*. - Guardian 3: Grandmother, age 66 [child is a 13-year-old boy who is partially blind and has albinism]*

What is tragic is that some of the guardians were not aware of the need to seek blindness-related medical information. In fact, many indicated that it never occurred to them to look for such information.

> *It is not something I ever thought of doing. – Guardian 7: Grandmother, age 62 [child is an 18-year-old youngster who is partially blind]*
>
> *I did not even know that there are people who can't see when I was growing up. I grew up and got to this age without ever seeing people who are blind. The first time I saw a blind person was with my child […]. Such [blindness] had never happened before. I would always wonder on my own but it never came to me that I should look into A, B and C. It never actually crossed my mind. Guardian 12: Mother, age 31 [child is a 12-year-old boy who is blind]*
>
> *I don't know that I had to look for such, I do not know. I just listen to what his doctors at National [regional hospital] and the school say. I don't know what I ought to do when it comes to matters concerning his blindness. - Guardian 20: Grandmother, age 65 [child is a 7-year-old boy partially blind and has albinism]*
>
> *I honestly never looked for information. I am uneducated, where would I look for the information? - Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*

When asked what kind of health information they would like to search for regarding their children's blindness, many of the guardians expressed that that they would like to know about the causes of, and possible cure for blindness, if their children's eyesight would worsen over time, and how they ought to handle their children.

> *I would like to know what caused the child's blindness, and where does blindness come from - how does one become blind. That is all I would like to know. – Guardian 5: Mother, age 37 [child is a 9-year-old girl who is partially blind and has albinism]*
>
> *I would like to know what caused her blindness, without me making the assumption that it's caused by her condition [hydrocephalous]. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *I would like to know what blindness is and how does a person become blind. Some people are born with sight and then lose it at some point but I am not interested in knowing about such because my child was born blind. The thing I would like to know is why and how does a child get born blind, or is it God's creation? - Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*
>
> *I would like to know what causes blindness. And if it happens that you go blind, will you be able to see again after being treated or will you be blind for the rest of your life? – Guardian 7: Grandmother, age 62 [child is an 18-year-old youngster who is partially blind]*

> *What causes blindness, whether she will end up being [completely] blind - things like that. And what I must do if her condition gets worse. How will I cope if she becomes completely blind and how will I support her. - Guardian 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]*
>
> *I would like to know if there's anything that can be done to help restore my child's eyesight and help him see clearly. - Guardian 20: Grandmother, age 65 [child is a 7-year-old boy partially blind and has albinism]*
>
> *I would like to know if there's anything that can be done to restore his eyesight but it hurts because I am not hopeful that something can be done that can help the child to be normal. I would also like to know about the possibility of eye donations. - Guardian 17: Father, age 37 [child is a 9-year-old boy who is partially blind and has glaucoma]*
>
> *About how I should handle a child that is blind. What I want to know is how I should raise my child when he is like this. How I should handle him. That's what I wish to know. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*
>
> *I would also like to know how to live with a blind person. Yes, I am learning as we go. I see that ''oh, this is how we can do this'' but if there's another way of doing the exact same thing then I would like to know. At some point, government officials were here and they said that this house should not be like this for a child that is blind, it should have been in a certain way. In a way that can accommodate her so that she too can be able to do things on her own. We should have told the builders and had it built in a specific way. - Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind]*

Many of the guardians, however, actively sought information about schools that would be able to accommodate and cater for their children's visual needs. They did so after they were made aware of the existence of such schools through the radio, by allopathic healthcare practitioners, educators, and members of their families and communities who knew (of) parents whose children attended these schools or knew (of) people who lived nearby these schools.

> *I heard from the radio about Bartimea [School for the Deaf and Blind]. I then went there and found out if they would be able to take my child and what my chid would need in order to get accepted to the school. Guardian 5: Mother, age 37 [child is a 9-year-old boy who is partially blind and has albinism]*
>
> *I heard from a neighbour of mine that there is a school for blind children in Thaba Nchu. My neighbour saw it when he was visiting his relative who stays near the school. - Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*
>
> *I was told by the teachers at the local school that my child needed to go to a school that would be able to accommodate her. I knew that my child did not belong in a*

> *mainstream school but I kept her there, although she was not performing well and she was being laughed at, because I did not know where I would take her if she left that school. – Participant 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]*
>
> *We found out late about Bartimea [School for the Deaf and Blind]. She's 21 years old and in grade 10. At first, we had taken her to school X. It is a school in our town that caters for of all children with disabilities but we stopped taking her there because we felt that it was a waste of money because it was more like a day-care centre and the children did not get properly educated. We did not know where to take the child and she spent a number of years at home without attending school, until one day we heard from this one relative that there was a school available in Thaba Nchu. - Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*

Finally, the guardians had several suggestions about how they would like to receive health information about blindness. These included face-to-face communication at various locations within the community, communication over the radio, through books, and from the healthcare practitioners.

> *I think it is face-to-face, like you are talking to us right now. In that way we will be able to ask questions and better understand. - Guardian 15: Aunt, age 42 [child is a 15-year-old boy who is partially blind and has albinism]*
>
> *The best way is like you and I are doing it right now, someone should sit down with us and explain everything. Sometimes pamphlets are written in English and then we don't understand what is being said. The radio won't work because you would find that a person doesn't have a radio or that they are not listening to the radio during that particular broadcast. The best place for us to meet is at the school. They can announce that parents of blind children should meet on a particular day, at a particular time at the school. Whoever that is going to explain can visit us like you are visiting right now and explain to the parents. - Guardian 20: Grandmother, age 65 [child is a 7-year-old boy partially blind and has albinism]*
>
> *We can maybe have classes on Saturdays where there's someone who explains to us. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*
>
> *I think maybe if they go to the parents' homes, or they could call us or announce that they would like to meet with such kind of parents at a certain location. Or even if they ask to meet at the clinic, they should direct us to a certain area of the clinic. Or maybe say that we'll meet at a certain church. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *You should sit down with them, face them and talk to them. If you talk to them over the radio they might not understand because it's something that is said in passing and you'd also find that the person is not listening to the radio during that time. – Guardian 7: Grandmother, age 62 [child is an 18-year-old youngster who is partially blind]*

These should be discussed in meetings at school [for the Deaf and Blind]. There should be workshops in the community. They once had workshops at the local library and we attended. The workshops were helpful, that is where I first heard about the Social Workers. - Guardian 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]

I think the best way for us to get information is through the school [for the Deaf and Blind]. It can be announced during the meeting that they would like to meet with parents of blind children at the school on such a date in order to give them information. The school is the best location. Or maybe because some of us have to go to work, it can be announced at the school that on such a date, the parents should go to a particular clinic and then we can excuse ourselves from work. Another way to make the announcement is through the radio because posters will be put up at a certain place and some parents might not get to see them. The radio is accessible to everyone and if it happens that I miss it, someone who heard can tell me that ''hey, I heard over the radio that parents of blind children should meet at a particular clinic on such a day''. - Guardian 19: Grandmother, age 56 [child is a 13-year-old boy who is partially blind and has albinism]

I would like to get a book that has information about people who are blind. Even if they call me to go fetch it at the school, I would. But for those parents who keep their children in the house, yes I agree that the radio would be best to get the information them. There could be someone who speaks and shares the information over the radio on a regular basis. That person should also give a phone number where the parents can call if they did not understand something, or if they need more information, or if they would rather have the information shared with them on a one-on-one basis and not to a large audience. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]

They usually have experts over as guests on the radio to talk about certain illnesses and explain what the illness is, how it works and the like. So, I think that the easiest and quickest way of getting information to the parents. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]

It would be better if the information was made available by the doctors. And the radio, I would appreciate it a lot over the radio and at hospitals and churches. – Guardian 5: Mother, age 37 [child is a 9-year-old boy who is partially blind and has albinism]

Through the radio and the TV because we have them readily available. The hospitals are far and I don't always go to the clinic but I have full access to the radio and the TV. - Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]

I think it would be best if we got it on social media. I don't think data would be as big a challenge as having to travel to wherever to go and get information. With

> *social media, the information comes to you. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

Theme six - Role of schools in supporting blind and partially blind children and their guardians

The interviews highlighted the important role that both mainstream schools and schools for the Deaf and Blind play in the lives of blind and partially blind children and their guardians, particularly those who live in rural areas. Mainstream schools serve an important role in the identification and referral of blind and partially blind children to schools that are better equipped to cater for their academic and psychosocial needs, while schools for the Deaf and Blind provide a sense of belonging for the children and a sense of comfort for their guardians.

Many of the guardians initially enrolled their children in mainstream pre-primary and primary schools, where it was noticed that the children had ocular constraints and would need specialised medical attention and education.

> *While she was attending school [at a local school], they noticed that she now moves very closely to the book and she no longer writes within the margins. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *When she was in grade 1, she couldn't see the chalkboard but she didn't know that she couldn't see. She would draw circles and scribble in her school books and we assumed that it was because she's a slow learner and her writing would get better with practise. – Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*

> *He used to attend at a local crèche and the crèche has a clinic, where they have therapists and all. The people at the crèche are the ones who referred me to an occupational therapist at a hospital in Bethlehem [regional hospital]. We kept on going there for treatment and then they recommended that the child should attend school at Thiboloha [School for the Deaf and Blind] and not at any other school because by the looks of this, he won't be able to cope in a mainstream school. He needs to attend a special school. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

Some of the guardians indicated that they did not link their children's poor academic performance to their deteriorating eyesight and that some of their children's educators made the connection only after their children had repeatedly failed classes and could not be allowed to repeat the class again.

> *I took him to a local primary school. He attended the local school and then they called me and I explained to them the condition of his eyes. They made him repeat grade 1 twice. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *We noticed his eye problem when he was 9 years old when I got called to his school. He was failing and then I think that they noticed at school that he can't see properly,*

> *and then they called me and explained that it seems like he can't see well and that I should take him to the doctor. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *I told the teachers that she had eye problems and they said that they will monitor her. She passed grade R and went to grade 1. It is then that the problems started. You know that in grade 1 there are subjects and they have to write. She got stuck and failed grade 1. After repeating grade 1 and failing again, she was pushed to grade 2 because a child is not allowed to repeat a grade more than twice. She failed grade 2 and the teacher talked to the HOD and she was sent for assessment and they said she must attend a Special School. She was then sent to a Special Class at the school. A Special Class is a class for children with different disabilities. The teacher at the Special Class said that I must make arrangements for the child to be sent to the school that dealt with blind children because my child was not coping. She would do better if she attended a school where they will focus on blindness only. - Guardian 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]*

Some of the guardians indicated that they heard about the schools for the Deaf and Blind from the educators at the mainstream schools, who recommended that they take their children there and, in some cases, assisted them with the transition.

> *I ended up going to the school and I spoke to the principal and that's when we left. The principal took us to the hospital in his car, and they checked him and found that the child has to go to a school that is suitable for him. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*
>
> *I was fortunate to find teachers who told me that my child has a problem and would need to go there [Thiboloha School for the Deaf and Blind]. Had I not gotten that help, that there is somewhere where she can go, then I would have just stayed with her at home because she wasn't doing well at school because she couldn't see and would write outside of the margins. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*
>
> *I got helped by one of the teachers at the local school. We took the child to Thiboloha [School for the Deaf and Blind] and they know her [the teacher] there. It seems like she used to take children who are challenged from her school to Thiboloha. They accepted my child without any hassles. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*

The schools for the Deaf and Blind played an important role in providing the children with a sense of belonging and creating a sense of comfort for their guardians. Many of the guardians shared that the schools for the Deaf and Blind provided their children with a sense of belonging as the children were amongst others who looked like them and were no longer being victimised for looking different.

> *There was this teacher who was not treating him well [at a local school], and then I decided that I should take him there [Thiboloha School for the Deaf and Blind] where*

> *he could be with others who are like him. There you find the deaf, the mute, and those of his kind [people with albinism]. - Guardian 3: Grandmother, age 66 [child is a 13-year-old boy who is partially blind and has albinism]*

> *When he turned 6, I removed him from the local crèche and applied to Bartimea [School for the Deaf and Blind]. I told myself that I don't want him to attend local schools, I want him to go and accept himself there [Bartimea School for the Deaf and Blind] and see others who are like him there because he might get teased at local schools and refuse to attend school. – Guardian 5: Mother, age 37 [child is a 9-year-old boy who is partially blind and has albinism]*

> *When he got to Bartimea [School for the Deaf and Blind], he was there for a week and in the following week he said to one of the teachers, ''wow there are many children who are like me here. Even older guys and ladies''. H he is the only one [with albinism] in our community but when he got to Bartimea, he saw that he is not the only one [with albinism] - Guardian 19: Grandmother, age 56 [child is a 13-year-old boy who is partially blind and has albinism]*

Many of the guardians stated that they took comfort in knowing that their children's educational and psychosocial needs were well catered for at the schools for the Deaf and Blind, and that their children were not the only ones who were blind.

> *Another thing that comforted me was that when I got to her school, I just had to accept because I found that it's not only my child that's like this but there are other children. I should stop saying that my child is still young because I saw a little child who was completely blind. That comforted me and made me realise that I needed to accept because there are children who are even younger than mine, who can't see at all. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *At first I was a bit hurt because I hadn't met others that are like her but after meeting others that are like her, including white people, then I realised that there is no such [witchcraft]. I didn't even think about it. I told myself that I am just going to hurt myself over something that does not exist. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*

> *The child attended Bartimea [School for the Deaf and Blind] for the first year and in the second year I accepted it [that she was partially blind] because I saw that the child was doing well academically. – Guardian 4: Mother, age 33 [child is a 12-year-old girls who is partially blind]*

> *My child has benefited a lot from attending Bartimea [School for the Deaf and Blind]. She knows how to write in braille. I usually call the parents from my community to come and have a look at her school report and see how well she's doing at school. She can write just like any other child, the only difference is that she writes it in braille because she is blind. She uses a laptop now and I called them [parents] to come and see. Bartimea produces smart learners and our children don't get treated differently simply because they have a disability. I always encourage parents of children with*

> *disabilities to take their children to school and that they should not think that because they are unemployed, they can't afford to get their children a good education. - Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*

Culture-centred approach (CCA)

The findings of this study also suggest that the three key tenets of the CCA - culture, structure and agency - influenced the guardians' beliefs regarding the causes of their children's blindness, their eye-care seeking behaviours and their decisions to seek health information regarding their children's blindness.

Culture

Culture played a role in shaping the beliefs of the guardians, their families and their communities regarding the causes of the children's blindness and influenced the kind of help they sought, as well as their decision to seek health information.

Some of the guardians, their families and communities believed that the children's blindness was caused by the will of God, evil deeds of other people, spiritual attacks, ancestral spirits and not following the correct traditional practices.

> *To me, blindness is something that is created by God. There's no such thing as the child is bewitched or things like that. No. To me, it's simply God's doing. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*
>
> *The traditional healer said that it [child's blindness] was because of where I was employed. People did not want me to be employed and those things that they used to harm me did not affect me because I was too strong and protected by my ancestors so they got passed on to the child, because the child was not protected by the ancestors. I also ended up attending ZCC [Zion Christian Church] and they also said the same thing. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*
>
> *They [child's father's side of the family] took it that maybe the thing that made him like that is the name that they had given him, because the person who his name he takes after is there in Natal and they don't even know where his resting place is. It was during that time when there were wars and they would die wherever. They said that if he [the child] went there [to the burial site] then maybe he would be able to see […] we are yet to go there. He did not take the father's surname though because you know how things are done in Sesotho. A person first needs to pay damages [if people have a child out of wedlock, the man's family needs to make a payment to the woman's family, in money or with cattle, as appeasement for having had impregnated her before marriage or in order for the child to take on the father's surname] before the child can be his. So the name that they were referring to is one these Zulu names but I was not so keen on using the name [because damages were not paid]. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *They [community members] thought that maybe it's because the child was born at my aunt's place because according to our tradition, the first born child needs to be born at the mother's home, and have rituals performed for the child. They thought that maybe it was such a case, but then they realised that that's not really the case because we did perform rituals for the child, thinking that maybe after the rituals her eyesight would become better but it never did. – Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

Some of the guardians' lived experiences played a significant role in their beliefs and caused them to have conflicting beliefs about the causes of their children's blindness.

> *Right now I think that it's God's will. I thought it was witchcraft, that time when I couldn't accept. I tried everything. I slaughtered goats. I went to priests. I did it all, but nothing worked for me. The only thing that worked for me was telling myself that ''God, if I do not want her to be mine, who do I think she should belong to?''. That is what helped me. I told myself that I needed to let go of this whole thing, it will hurt me. Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind and has a brain tumour]*
>
> *I believe in the Bible. There was someone who was blind in the Bible. I do not believe that it is witchcraft. It became evident when she was three months old. If it [blindness] had happened when she was older I would believe that it was witchcraft. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*
>
> *I think it [child's blindness] was caused by the nurses. But initially, considering the kind of lifestyle I had around the time that my child was born, I used to think that maybe my child lost her eyesight due to the evil deeds of others, based on what people were saying and the things that were happening in the household I was staying in. […] At times when I would wake up in the morning, I'd find droplets of blood on the floor in the room I was sleeping in, and I had no other option but to jump over that blood. The things that were happening were unexplainable. It was while I was still pregnant. And then I told myself that witchcraft is something that exists, even though one may not believe it that much but I believed because I would see unusual things happening. But I later realised that although it could be that my child lost her eyesight due to the evil deeds of others, the problem also occurred when I was in labour. - Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

In addition, some of the guardians' lived experiences influenced their decision to seek traditional over allopathic eye-care interventions.

> *Her spectacles then went missing in the house and we searched for them but couldn't find them and then we consulted with a traditional healer to find out what happened to the child's spectacles. When I got there, I got help. I was told that the child's spectacles were made to go missing on purpose and when I found them, I took a decision that I wouldn't make my child wear them because I do not know where they had been. I found them after I had consulted, I came back home that day and searched*

> *again and I found them right there where we had been searching the whole time. They [traditional healer] told me who was responsible. I asked them to please describe that person for me and I was able to figure out who it was. It's someone I had considered a friend. I then told one of my neighbours that "I found the child's spectacles, but you won't believe how I found them" and after I told my neighbour that, the lady's [her friend] attitude towards me started changing. She accused me of being a witch and it's been about 5 years since she stopped talking to me. - Guardian 4: Mother, age 33 [child is a 12-year-old girl who is partially blind]*

Based on the instructions of their families and recommendations by their communities, some of the guardians consulted with various churches, traditional healers, and performed traditional rituals which were aimed at seeking counsel from and appeasing the ancestors, with the hope of curing the children's blindness or improving their eyesight.

> *We [the family] did a lot of things. We slaughtered. Took the child to traditional healers and they did all sorts of things to her. She got taken to the river by members of the Apostolic church. I ended up going to Pastor X in Johannesburg and I was told that pastors who heal people would come to the church but none of those things helped. - Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind and has a brain tumour]*

> *People [community members] said that it was caused by the evil deeds of others and I ended up going to a traditional healer to try and find out what had happened. I went to the traditional doctor after going to the allopathic doctors. People [community members] were saying things and the [allopathic] doctors had said that there was nothing they could do, my child would remain like that; she would never be able to see again. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*

> *They [child's father's side of the family] performed traditional rituals and he put on the sphandla [bracelet made of goat skin] until it broke off. He still wears the neckpiece they put on him, he still has it. We also did that thing of visiting the gravesites of our elders who have passed on. We also went to his late father's resting place thinking that there would be something different and he [late father] may be able to see from wherever he is and show us what we need to do for the child to see. But there's no solution. Truthfully, there is no solution. The people who have passed on have passed on. They are dead quiet. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

> *Her father's side of the family had said that they needed to take her to somebody's gravesite somewhere but I refused. Other family members said that I should allow them to take her to the gravesite, maybe she'll be better. I went there with her […] but there was no difference. There was no difference at all. And then they later said that they wanted to slaughter a cow and have a ritual for her and I sent her over. The dad then said that they wanted her to wear a sphandla [bracelet made of goat skin] and I refused. No, no, no. I do not believe in those things, no. I also told him that he*

> *didn’t pay damages [if people have a child out of wedlock, the man’s family needs to make a payment to the woman’s family, in money or with cattle, as appeasement for having had impregnated her before marriage or in order for the child to take on the father’s surname] for the child so there’s no need for the child to wear it. And then he told his family and the family said that it indeed is like that, they’ll put it on for a day then and remove it the following day, and they did that. They put it on, she slept with it on, and they removed it the following day and returned her home. They had bought her a new blanket and other new items. They also performed a ritual where they lit incense and communicated with our ancestors but there was no difference. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*

Structure

The majority of the guardians were unemployed and could not seek full-time employment (out of town) because they needed to take care of their children and their blindness-related needs. Their children needed to be taken to the hospital regularly for appointments and check-ups and the guardians constantly worried about their children’s safety and well-being when they were away. Many of the guardians whose children lived at home and commuted to the schools for the Deaf and Blind expressed that they worried about who would help take care of their children if they were to find employment, particularly out of town. Some of these guardians said that in addition to their eye-care related needs, their children also had other medical conditions which required strict medicine adherence and regular visits to healthcare facilities.

> *My life has changed, I cannot find a job because she has to attend monthly check ups and sometimes she gets admitted for operation if her pressure is high and I must stay with her in the hospital. I cannot leave her alone. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

> *Everything changed in my life. A lot of things got stuck. I left everything including my job and focused on my child. I had to take her to school and collect her. Many other aspects of my life also came to a standstill. – Guardian 11: Mother, age 38 [child is an 11-year-old girl who is partially blind]*

> *My child’s blindness has…how do I put this *silent* I have accepted my child’s blindness, it hasn’t stood in my way but my problem is that when I have to go find means of putting food on the table, I can’t. I am concerned about what is going to happen to the child when I leave, and I know that there are people who can take care of him and treat him the same way I treat him because that’s how they have been treating him in my presence [child’s sister and grandmother], but I just have that wish that I could get a job nearby so that I can commute to and from work. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]*

All of the guardians made use of public healthcare services and many expressed that they experienced numerous structural constraints while seeking eye-care for their children and health information regarding their blindness.

> *Ai our local clinic is not ideal because it gets full and their service is poor. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *We went to the [public] hospital and they gave us problems at the hospital. They sent us back and forth, they didn't have machines, and this and that. - Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind]*
>
> *I went to the local clinic and then they said at that there is nothing that they can do, I should take the child to a private doctor. I took the child to a private doctor and then he arranged for me to take the child to Bloemfontein. He said I should go to the clinic and the clinic would help me with transport to Bloemfontein. When I got to the clinic, they refused to help me saying that because I had taken my child to a private doctor, the private doctor should arrange transport for me to take the child to Bloemfontein. I then made a plan and got money and hired a car and took my child to National [regional hospital in Bloemfontein], and only then was I able to get help. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*
>
> *When he was about 2 to 3 months old, we realised that it seems like he can't see and then when we took him to the clinic for his post-natal check-ups and the clinic referred us to Manapo [district hospital], where we were referred to Bloemfontein [regional hospital]. When we got to Bloemfontein, the doctors told us that we were too late, the child was supposed to have received medication or had eye surgery shortly after he was born. So my concern is, how did they miss it at the clinic? How did they not see that the child had a problem? We took the child to all of his check-ups but they still missed it. - Guardian 17: Father, age 37 [child is a 9-year-old boy who is partially blind and has glaucoma]*
>
> *Let me tell you how things are at the public hospital. They made that disk that had all the information about the child's operations so that I could have it for when the child grows older and then they said that her file with her medical records went missing at the hospital. Until today, it's still missing. I was thinking the other day that I should sue the hospital because the child is growing older and she'll one day want me to explain to her what happened to her. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*
>
> *The clinic referred us to the hospital and the hospital told us that she will not be able to see properly and that she would need spectacles. We waited and waited to get the spectacles but we never did. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*

> *I had been going to National [regional hospital] trying to get spectacles, I haven't received them up until now. Up until now. They said they would call me, I am still waiting up until now. The school [for the Deaf and Blind] even took them to the hospital to get spectacles but nothing. – Guardian 5: Mother, age 37 [child is a 9-year-old girl who is partially blind and has albinism]*

> *She used to wear contact lenses but they hurt her eyes so the doctors at the hospital said that she should stop using them and that they would call her to go and get spectacles but they have a long list [of people awaiting spectacles] so they haven't called us yet. - Guardian 22: Mother, age 37 [child is a 16-year-old girl who is partially blind]*

> *Ai, I just told myself that my child will make use of public healthcare services [after husband cancelled the medical aid], he'll get the spectacles. But now his spectacles have special requirements, they need to be tinted and things like that, and they do not do such for the spectacles you get from public healthcare services. His lens also needs to be thinned, he shouldn't receive the double lens as it is, it needs to be thinned. […]. Ai and they [spectacles] are due for a renewal. He got them in 2014. Right now he doesn't wear them much because he says that they cause him to get headaches, which is why I say that they need to be renewed and we are now faced with the challenge of getting new ones. – Guardian 13: Mother, age 35 [child is a 10-year-old boy who is partially blind and has albinism]*

Some of the guardians indicated that they struggled to get information on the schools for the Deaf and Blind, while many guardians expressed that there were not enough schools for the Deaf and Blind and that were located very far from their homes. This, together with limited financial resources, made it difficult for them to efficiently attend to their children's eye-care care needs.

> *I heard from people that there were schools that are made for blind children but I did not know where to find such schools. I looked for information but I could not find it. It was difficult. – Guardian 1: Aunt, age 45 [child is a 13-year-old girl who is partially blind]*

> *Money is a problem. There is a lot of travelling that must be done. I have to collect her from school and take to check-ups. She also has needs that require money. For example she was graduating [from pre-primary to primary school] and I had to buy things for her. She also likes music and demands that I should buy her something that sings, a keyboard or something, when she comes home. –Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

Due to the rural nature of their surroundings, many guardians expressed that they had concerns about their children getting around from one place to another within their communities. These guardians explained that their children found it difficult to get around because of the shrubs and poorly maintained gravel roads and that they worried that their children would one day get hurt. Some guardians expressed that they often worried when their children had to go to the toilet alone because they are usually pit-toilets, outside of the house.

Agency

Despite numerous structural constraints, many of the guardians enacted agency and made use of multiple approaches in an attempt to aid or restore their children's eyesight. This included the use of religious, traditional and allopathic eye-care interventions.

> *I was hoping her eyes would become better. […]. We prayed a lot asking God to heal her eyes. They also prayed for her at my church and the church gave me ointment to use. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*
>
> *I decided to get help from ZCC (Zion Christian Church). Her condition had deteriorated when I went to ZCC, she couldn't see at all and there was no hope that she would be okay. The allopathic healthcare practitioners had said that her normal eyes were too damaged and that there was nothing that they could do, she'll never be able to see again. We went to Moria and other religious sites and then we got given commands and we fulfilled them. After we did that, they told us at the church that we would receive a call from the hospital and the hospital will put me in contact with an eye Professor and the eye Professor will do something that will help my child see. And then it happened, I got a call from Bloemfontein and we went to Bloemfontein and met with the eye Professor and the eye Professor placed my child on a waiting list for an eye donation. The donation took a very long time but I was patient and then I received a call and they said ''we have found a donor for your child''. I took her to Bloemfontein and then she got a donor eye. They inserted one eye first and they treated it and then called me again three months later saying that they have found another donor and she had donor eyes in both eyes, and she was able to see. She was completely blind before she received the donors' eyes. - Guardian 16: Mother, age 35 [child is a 9-year-old girl who received an eye donation and is partially blind]*
>
> *Her father's side of the family had said that they needed to take her to somebody's gravesite somewhere to appease the ancestors […]. Other family members said that I should allow them to take her to the gravesite, maybe she'll be better. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*
>
> *I took her to Umtata, they [allopathic healthcare practitioners] also said that she was blind but she will be okay but she never became okay. I then decided to take her to Cape Town, Tygerberg Hospital. There they said it was glaucoma. They operated her eye and removed the white patch and she was left with the black part. They said the right eye was totally blind and it was affecting the left eye. We went back to Eastern Cape and someone told me to come here to the Free State because they have good doctors here. Here they also told me that she has glaucoma and it cannot be cured, they will just manage it by reducing pressure in the eyes. –*

> *Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]*

After numerous failed attempts to get spectacles from the public healthcare services, the guardians enacted agency and bought their children spectacles from private eye-care practitioners, despite their financial limitations.

> *We waited and waited to get the spectacles from the public hospital but we never did until I went to a private doctor here in town. – Guardian 8: Mother, age 50 [child is a 12-year-old girl who is partially blind]*
>
> *I had taken him to National [regional hospital] on my own to get spectacles, and then the school took them as a group of albinos to go and get spectacles but they still haven't received them. So I went to a private doctor to get him spectacles. – Guardian 5: Mother, age 37 [child is a 9-year-old boy who is partially blind and has albinism]*
>
> *Ai, it took her a very long time for the hospital to give her spectacles. She got them this year [2018] from Manapo [district hospital]. The person I work for knows about my child's condition so she said that I should take her to the optometrist to get spectacles. I took her there and they checked her. The check-up cost R200, the spectacles R1 000 and the spectacle case cost R50 so everything in total cost R1 250. I told my employer and she gave me the money and I went to get them. - Guardian 6: Mother, age 39 [child is a 12-year-old girl who is partially blind and has hydrocephalous]*

Many of the guardians also actively participated in challenging the structures that constrained their lives, in a bid to assist their children and better meet their blindness related needs.

> *Her father and I had bought her a car type of thing when she was still young and we would push her around everywhere we went. […]. I taught my child from a very young age how to identify objects using her hands. She knows everything that is in the house and where to find it. She correctly identified all of the objects during the selection interview at her school [School for the Deaf and Blind]. She even knew things that I didn't think she would know, like a surgical injection for instance. My child knew how to use the outside toilet on her own when she was 5 years old. I taught her that this is the route you take when going to the toilet. - Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*
>
> *I just told myself that I am going to do the best that I can for my child with the little money that we have. I even hire private transportation every time we have to take her to or fetch her from school. We pay R800. We used to hitchhike but this one time we struggled to get a hike from Bloemfontein to here [her town which is 2 hours away] up until 7 pm in winter and then I realised that I am just putting my child's life in danger. I just told myself that all her [disability] grant money will go towards her needs and we'll see how we make ends meet. - Guardian 18: Mother, age 50 [child is a 21-year-old youngster who is blind]*

I have already found someone to teach him braille so that he can already be prepared, should anything happen in the future. I also explain to him as often as I can that he is not like the other children and he seems to be understanding because he said to us the other day that when he grows up, he's going to buy a particular car and his cousin will drive it for him. Guardian 17: Father, age 37 [child is a 9-year-old boy who is partially blind and has glaucoma]

What I really want is for me to get a braille machine. My child is active and talks a lot and I am unable to read what she has written. I want her to practise using the braille machine when she is at home and also teach us, so that I can help her with her homework. – Guardian 10: Mother, age 29 [child is a 7-year-old girl who is partially blind and has glaucoma]

Our roads here are terrible so when we walk with this child, there are parts in the road that have shrubs and because he can't see, I want him to have these sticks that they use when walking. His aunt had said that I should meet up with that lady and ask her how much he would make the stick for. We need to get him the stick […]. I need to know that he'll be able to find his way while walking. – Guardian 2: Mother, age 47 [child is a 13-year-old boy who is partially blind]

My child struggled to get admitted at Bartimea [School for the Deaf and Blind] because her one arm doesn't work properly. I fought with the school for a very long time in order to have my child admitted. At some point they said to me that they do not have a problem if I want my child to attend there, I should just know that I would have to relocate and go stay closer to the school so that my child can stay at home with me and commute to school. I told them that I stay far and that I can't get divorced because of my child. My child will get an education. They have caretakers at the school, those caretakers should guide my child on how to do things, up until her arm gets used to it. I went back and forth to Bartimea for two years struggling to get her admitted because their concern was that she wouldn't be able to bathe herself. She's 9 years old but she's only starting grade 1. She was supposed to receive an adapted braille machine because the braille machines that they use require them to use both hands and they sent her to the section for critical learners for 2 years. Critical learners are those who can't do much. I fought that my child is smart, she knows everything that she is taught and they said yes, they agree but they don't have any other option because she can't write in braille [because of her arm]. They only got her an adapted braille machine last year after I went to the Free State Department of Education. There seems to be some discrimination amongst our children depending on their disability. - Guardian 14: Mother, age 42 [child is a 9-year-old girl who is blind and has a brain tumour]

Summary

The interviews with the guardians yielded six distinct themes. They were (1) reaction to blindness diagnosis, (2) guardians' coping strategies (3) beliefs about the causes of blindness, (4) eye-care seeking behaviour, (5) health information seeking behaviour and the (6) role of schools in supporting blind and partially blind children and their guardians.

This study found that the guardians were overall in a state of disbelief and expressed emotional reactions to their children's diagnosis of blindness which included hurt, shock, feeling suicidal, uncertainty, anxiety and acceptance. The guardians' families and communities expressed varying reactions to the children's blindness which in turn had either a positive or a negative emotional impact on the guardians. Many of the guardians, their families and their communities had firmly held beliefs regarding the causes of blindness, which had an influence on the guardians' eye-care seeking behaviours and their decisions to seek health information. Due to close familial ties and the need for support, a majority of the guardians first sought advice from their families before they sought medical assistance regarding their children's eye condition. The guardians then sought religious, traditional and/or allopathic eye-care interventions in an attempt to determine what could be wrong with, or to restore, their children's eyesight. Although a majority of the guardians demonstrated a deeply rooted fear of eye-related surgical interventions, some showed a willingness to consider them due to the fact that they knew (of) people who had positive surgical outcomes.

None of the guardians actively sought medical information regarding their children's blindness. Their reasons for not seeking information were driven by acceptance, fear and a lack of awareness. On the other hand, many of the guardians actively sought information about the schools that would be able to cater for their children's visual needs. All of the guardians expressed a desperate need to know what the actual cause of their children's blindness was, what they could do as guardians to help their children as they grew older and transition into various life stages, and what they should expect regarding the progression of their children's eye condition.

The guardians suggested that the best way of getting information about blindness to guardians of blind and partially blind children who live in rural areas was through face-to-face at local schools, churches and clinics as these places were easily accessible. The guardians also stated that the information could also be communicated over the radio, through books, and by the healthcare practitioners.

The findings also highlighted the pivotal role that both mainstream schools and schools for the Deaf and Blind play in the lives of blind children and their guardians who live in rural areas. Mainstream schools are instrumental in identifying and referring blind and partially blind children to schools that are better equipped to cater for their academic and psychosocial needs, while schools for the Deaf and Blind provide a sense of belonging for the children and a sense of comfort for their guardians.

Additionally, the responses of the guardians pointed to the influence of the three key tenets of the CCA —culture, structure and agency. The researcher found that these tenets both constrain and enable the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas of the Free State province.

The findings mentioned above will be analised and discussed in relation the literature in the in the next chapter.

CHAPTER SIX

DISCUSSION

Introduction

The culture-centred approach (CCA) to health communication examines the ways in which the voices of members of subaltern communities have been erased from the dominant discourses of health communication and suggests alternatives to these dominant discourses by engaging with the members of these communities (Dutta, 2008). The CCA considers members of disadvantaged communities as experts on what they need, thus this study engaged with guardians of blind and partially blind children who live in rural areas of the Free State province in order to learn from them how to best meet their health information needs regarding their children's blindness.

Health information, in the context of this study, refers to blindness-related medical information and information about specialised support that the children may need. The children whose guardians were interviewed were either completely blind, had sight in only one eye, or had very little sight in both eyes. The objectives of this study were to (1) identify the role that cultural beliefs play in the guardians' perception of the causes of their children's blindness, (2) identify the source(s) of health information that the guardians commonly used and (3) determine the health information source(s) that the guardians preferred and whether the reasons for those preferences were culturally bound.

This study found that the guardians' cultural beliefs shaped how they perceived the causes of their children's blindness, which in turn influenced their eye-care seeking behaviours and decisions to seek health information. The source of health information that the guardians commonly used was face-to-face communication between themselves and members of their families and communities, religious leaders, traditional healers, allopathic healthcare practitioners and educators from the mainstream schools that their children formerly attended. The source of health information that the guardians preferred the most was face-to-face communication in their native language at central locations within their communities such as at the local clinics, churches, schools, libraries and community halls. This study found that this preference was not culturally bound but rather influenced by the guardians' literacy levels, socio-economic status and the accessibility of resources available to them.

The findings of this study also highlight the importance of understanding the influence of the three key tenets of the CCA - culture, structure and agency - on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas. This study argues that this understanding may help increase the guardians' access to and use of health information by allowing for the creation of culturally relevant health information material and the provision thereof through platforms that are commonly used by and easily accessible to the guardians. This study found that the three key tenets of the CCA intersect and both enable and constrain the guardians' health information seeking behaviour. None of the guardians of this study actively sought blindness-related medical information. In fact, in most cases they received very little health information from their children's healthcare practitioners. Despite this, many of the guardians actively sought information about schools that would be able to cater for their children’s visual needs, often after learning about the existence of such schools from their families, members of their communities, the radio or upon recommendation by allopathic healthcare practitioners and educators at the mainstream schools that their children formerly attended. Even after enrolling their children in the schools for the Deaf and Blind, the guardians received very little blindness related health information from the teachers, social workers or school officials at the School of the Deaf and Blind their children attended. Given that this is the reality guardians of blind and partially blind children experience, this study suggests that health information be provided through mainstream schools and schools for the Deaf and Blind as they are easily accessible to the guardians and are regarded as trustworthy sources; as well as through face-to-face interactions in the guardians’ native language at central locations within their communities as this was their preferred means of receiving health information.

The themes that emerged from this study, along with the three key tenets of the CCA, are analised and discussed in relation the literature in the section below.

Reaction to blindness diagnosis

Numerous scholars affirm that the disclosure of a child’s diagnosis of disability is an overwhelming experience for guardians, which often results in new responsibilities (e.g. Perryman, 2005; Kandel & Merrick, 2007). All of the guardians of this study were in a state of disbelief and many expressed feeling shocked and hurt by their children’s diagnosis of blindness. Bambara et al. (2009) asserted that family caregivers of blind persons tend to experience a great deal of emotional distress, while Fathizadeh et al. (2012) found guardians of blind children to often be in denial upon diagnosis.

In addition to normal parenting tasks, guardians of children living with disabilities are faced with the need to manage uncertainties about their children’s medical, motor, intellectual and social prognosis (Barnett et al., 2003, Gona et al., 2011). The guardians of this study expressed uncertainties about their children’s future. Many of these guardians had concerns about the kind of lives that their children would lead and worried about how their children would manage living with blindness. These guardians also expressed feeling anxious about having their children reside at the schools for the Deaf and Blind and wondered if their children would be able to take care of themselves, especially those who were still young. Khan et al. (2017) found that caregivers of blind persons often suffered from the burden of care and depression induced by their loved ones’ blindness. Jenaabadi (2014) asserted that parents of children who are blind experienced stress which emanated from feeling guilty, their inability to accept their children’s diagnosis of blindness and a lack of social support. This study similarly found that some of the guardians - as well as some members of their families – had physical ailments resulting from stress, felt isolated and lacked social support.

Families of guardians of blind and partially blind children play a pivotal role in helping the guardians accept their children’s diagnosis of blindness. This study found that positive reactions from the families made the guardians feel supported while negative reactions caused them to feel more hurt, and worsened the feeling of despair. Many of the negative reactions were from the children's paternal families and were motivated by the suspicion that the mothers were the cause of the children's blindness as there were no other blind persons in their families. This resulted in strained relations among the family members. Fathizadeh et al. (2012) asserted that communities play a significant role in helping families of blind persons to adapt to their new situation. These scholars found that communities can play either a supportive or an unsupportive role (ibid). Those who played a supportive role reacted positively to the blindness and those who were unsupportive reacted negatively (ibid). The findings of this study highlight the impact of these responses on the guardians' sense of belonging within their communities. Positive reactions from the communities caused the guardians and their children to feel accepted, while negative reactions caused them to feel hurt and isolated.

Guardians' coping strategies

All of the guardians of this study struggled to cope with their children's diagnosis and the challenges that came with raising children that are blind. These guardians employed various strategies as a means of coping. Many prayed to God for strength and guidance, others took comfort in believing that at least God showed His favour upon them and made their children partially and not completely blind, while some guardians took solace in the belief that God would one day hear their prayers and restore their children's eyesight. The guardians also sought counsel from their family members, medical advice from allopathic healthcare practitioners and spiritual guidance from their religious leaders and traditional healers.

Numerous scholars have reported that guardians of blind children find it difficult to accept their children's diagnosis of blindness or that they never come to terms with it (Fathizadeh et al., 2012; Jenaabadi, 2014; Khan et al., 2017). Consistent with this finding, many of the guardians of this study stated that they struggled to accept their children's diagnosis and some expressed that they still have not come to terms with the fact that their children are blind. Only a few guardians received counselling upon diagnosis, and none received on-going counselling since many were not aware of the counselling services that were available to them at the allopathic healthcare facilities. It is worth noting that the guardians whose children had other medical conditions which were thought to be the cause of the children's blindness seemed to be more accepting of their children's diagnosis of blindness. These medical conditions included albinism, glaucoma, tumours, pre-existing eye/ear medical problems, Human Immunodeficiency Virus (HIV) and hydrocephalous.

The guardians of this study found it difficult to cope with rejection and scorn from their communities. As a coping mechanism, many of the guardians withdrew from social activities and refrained from building and nurturing relations with their neighbours. The guardians also encouraged their children to stay indoors or to swear at the children who mocked them.

Many of the guardians also struggled to cope with the fear of having more children. They feared that their newly-born children could be born with the same medical conditions as their blind children, that they would not love their blind children in the same way as they currently did, and that they might not be able to fully attend to the needs of either their blind or newly-born children. As a means of coping with these fears, the guardians decided to either not have more children or trust that God would not give them any more children who were blind. Those guardians who had more children used prayer, traditional rituals and regular eye examinations as mechanisms to cope with their fears.

Beliefs about the causes of blindness

Although most of the guardians of this study expressed having limited knowledge about blindness, many had deeply rooted beliefs regarding the causes of their children's blindness. There were marked differences between the guardians' responses regarding what they thought caused their children's blindness and their personal beliefs about the causes of the blindness. The guardians' thoughts about what had caused their children's blindness were based on what the allopathic healthcare practitioners told them or the assumptions they made based on other medical conditions that their children had. Their beliefs, however, mostly stemmed from their lived experiences, families, communities or their religious and traditional beliefs.

Numerous scholars have reported differing beliefs regarding the causes of blindness in rural areas (Nwosu, 2002; Ashaye, Ajuwon & Adeoti, 2006; Olatunji, Adepoju & Owoeye, 2015; Ofosu et al., 2018). These scholars found that the rural dwellers believed that blindness was hereditary or caused by germs, smallpox, measles, long-term spectacle wear, eye injuries and eye diseases such as onchocerciasis, conjunctivitis, and filariasis. Other rural dwellers attributed blindness to spiritual causes such as evil spirits, violation of pregnancy taboos and witchcraft (ibid).

This study similarly found that guardians of blind and partially blind children who live in rural areas of the Free State province believed that their children's blindness was caused by either medical, religious or traditional factors. The medical factors the guardians believed caused their children's blindness were albinism, glaucoma, tumours, pre-existing eye/ear medical problems, hydrocephalous, the drinking of alcohol during pregnancy and difficulties experienced during labour. Although it was not explicitly discussed, a few guardians hinted that Human Immunodeficiency Virus (HIV) may have been the cause of their children's blindness. These guardians stated that their child was blind because he or she 'is ill', 'is positive' or has 'the virus'. Those who attributed their children's blindness to religious factors believed that it was due to spiritual attacks, evil deeds of others, God's will or that the children's blindness was merely a test of faith. The traditional factors that were believed to have caused the children's blindness were ancestral spirits, evil deeds of other people and a lack of adherence to traditional practices. These traditional practices include performing traditional rituals for the child upon birth. A ritual that is common amongst many South African cultures is known as the ''spilling of blood''. When a child is born, a cattle is slaughtered and its blood gets spilled onto the ground. The blood is spilled as a means of appeasing the ancestors, letting them know that there is a new member in the family, and asking them for their protection and guidance over the child. If a child is born out of wedlock, the child's paternal family needs to perform this ritual, even if the child does not carry the father's surname.

The guardians' families and communities all shared beliefs similar to those of the guardians regarding the causes of the children's blindness. This could be attributed to the collectivistic nature of South African cultures and how cultural knowledge is generated and passed on from one generation to the next in rural settings.

Eye-care seeking behaviour

Children with ocular ailments often rely on their guardians to provide for their eye-care needs (Gilbert, 2007). This study found that the guardians' decision to seek eye-care was motivated by the children's ocular complaints or the noticeable signs that the children presented such as itchiness, redness of the eyes and difficulties seeing. The majority of the guardians first consulted with their families when they realised that something was wrong with their children's eyes/eyesight. These guardians stated that they first consulted with their families because they needed emotional support and advice from their elders before they made a decision regarding the children's eye-care.

After consulting with their families, the guardians then sought religious, traditional and/or allopathic eye-care interventions. Many of the guardians made use of religious interventions by praying for their children at their homes, taking their children to various churches for prayer and/or applying holy oil and holy water in and/or around their children's eyes. These holy substances were used with the hope of restoring the children's eyesight, casting out evil spirits and/or protecting the children from further spiritual attacks. It is important to note that not all churches prescribed the use of holy oil and holy water.

Some of the guardians of this study made use of traditional interventions by consulting with traditional healers and performing traditional rituals. The traditional healers prescribed traditional eye medicine, which was aimed at healing the children's ocular ailments, restoring their eyesight, casting away the evil spells and/or protecting the children from harm. The traditional medicine could be consumed orally or mixed with the children's bath water and/or body lotion and applied topically. All of the guardians either started with or ultimately resorted to the use of allopathic eye-care interventions. These guardians consulted with allopathic healthcare practitioners who prescribed eye ointment and/or eye drops to help manage the symptoms, spectacles to help improve the children's eyesight, and recommended eye-related surgical interventions in an attempt to restore the children's eyesight.

The majority of the guardians in this study consulted with multiple sources when seeking eye-care for their children. These guardians either consulted with different sources within the same eye-care system or moved from one eye-care system to the other. When one eye-care system failed to produce the desired outcomes, the guardians often made use of another. The World Health Organisation (2013) stresses the need to develop a cohesive and integrative approach to the provision of healthcare. Nxumalo et al. (2011) similarly assert that given the common use of the two parallel healthcare systems—traditional and allopathic—strategies should be developed to protect poor South Africans from out-of-pocket payments for healthcare. They found that almost three-quarters of their poorest respondents spent more than 10% of their household expenditure in the previous month on traditional healers.

The World Health Organisation (2007) posits that there are a number of factors that can influence the eye-care seeking behaviour of guardians of blind children. These factors include competing demands for scarce resources within the family; a shortage of paediatric eye-care professionals; barriers to accessing services such as distance, cost and fear; as well as their lack of awareness about childhood blindness-related preventive measures or the fact that the vision of blind and partially blind children can often be improved. This study revealed similar findings. In addition, this study found that the guardians' beliefs regarding the causes of their children's blindness also influenced their eye-care seeking behaviour. The guardians who believed that their children's blindness was caused by religious factors sought eye-care from churches and religious leaders; those who attributed it to traditional causes consulted with traditional healers; and those who believed that their children's blindness was due to medical problems sought eye-care from allopathic healthcare practitioners. Despite this, as mentioned earlier, most of the guardians ended up using a combination of methods to address their children's eye problems.

Numerous studies have found that people seek assistance from various sources of care in times of ill-health and that their care seeking behaviour is often influenced by their beliefs (Dutta-Bergman., 2004, Masasa, Irwin-Carruthers and Faure., 2005; Otomoye et al., 2013; Olatunji, Adepoju & Owoeye, 2015; Maregesi et al., 2016; Ofosu et al., 2018.) Dutta-Bergman (2004), for instance, found that although the guardians of their study believed in the healing powers of allopathic and homeopathic treatment, they strongly believed that these forms of treatment did not address the actual causes of illnesses and stressed the need to supplement modern medical treatment with religious rituals that appeased the spirits and the Gods. Masasa, Irwin-Carruthers and Faure (2005) similarly found that caregivers of children living with disabilities sought assistance from traditional healers as they believed that traditional healers were able to identify the source of the problem. These beliefs were common amongst the guardians of this study. Many of the guardians sought religious and/or traditional eye-care interventions because they perceived an underlying spiritual cause to their children's blindness and believed that these sources of eye-care would be able to identify the cause and heal the blindness.

Many of the guardians of this study experienced multiple challenges when seeking eye-care for their children, which in turn had an impact on their eye-care seeking behaviour. Peters et al. (2008) assert that an individual's utilisation of healthcare services is influenced by four dimensions of access to healthcare services which are geographic accessibility, availability, financial accessibility and acceptability. The findings of this study support this assertion. Although public allopathic healthcare services are provided free of charge in South Africa, many of the guardians struggled to access these services as they lived in remote areas with poor infrastructure and often needed to travel for long distances to get to these allopathic healthcare facilities. Those guardians who lived in close proximity to public clinics initially sought allopathic eye-care interventions but later got discouraged by having to travel from one allopathic healthcare facility to another, each further away from their homes. This in turn motivated the guardians to seek religious and/or traditional eye-care interventions because the providers of these services mostly lived amongst them or close to their homes and were more easily accessible. A lack of financial resources posed a great challenge for most of the guardians and impacted their eye-care seeking behaviour. Although most of the guardians were dissatisfied with the provision of services at public allopathic healthcare facilities, many made use of these services because the services were free and they did not have the financial means to use private healthcare services. Other guardians had to discontinue the use of traditional eye-care interventions and resort to religious and/or allopathic means also because of limited financial resources. Acceptability of the providers of eye-care also had an impact on the guardians' eye-care seeking behaviour. Many of the guardians who sought religious and traditional eye-care interventions did so because they regarded the providers as trusted sources who were not only members of their communities but were also responsive to the social and cultural values/beliefs of the guardians and the communities they lived in.

Studies conducted in Tanzania, Nigeria, Ghana, Pakistan and India (Ashaye, Ajuwon & Adeoti, 2006; Ukponmwan & Momoh, 2010; Iqbal et al., 2012; Olatunji, Adepoju & Owoeye, 2015; Maregesi et al., 2016; Ofosu et al., 2018) found the use of traditional eye medicine to be a common practise in rural areas. Contrary to these findings, this study revealed that although the guardians sought religious and traditional eye-care interventions, many of them did not use the prescribed medicine for their children's eyes because they feared that it might cause further damage. Those who made use of the eye medicine did so for a short duration and discontinued it out of the same fear.

Many of the guardians of this study also demonstrated a deeply rooted fear for eye-related surgical interventions and stressed that they would never agree to submit their children to surgery. These guardians feared that surgery would further damage their children's eyesight or cause them to lose it completely. A few guardians stated that they would agree to surgical interventions, only as a last resort and only if they were reassured that it would definitely restore their children's eyesight. These findings are in alignment with the literature (Rotchford et al., 2002; Nwosu, 2002; Olatunji, Adepoju & Owoeye., 2015; Ebeigbe, 2018). Contrary to the findings of Olatunji, Adepoju and Owoeye (2015). In addition, this study found that the guardians who had positive attitudes toward eye-related surgical interventions were not influenced by their educational level but rather by their acquaintance with people who had positive surgical outcomes.

Health information seeking behaviour

Guardians of children living with blindness can manage uncertainties about their children's medical, motor, intellectual and social prognosis by seeking health information. This information can include blindness specific information and information about specialised support that the children may require to ensure optimum development (Barnett et al., 2003; Eleweke et al., 2008). This study found that allopathic healthcare practitioners seldom offered health information to the guardians. In the rare instances when the information was provided, it was in English, which is not a language that many of the guardians understood well.

Bates (2002) suggests that information can be sought by searching, browsing, monitoring and being aware. Searching refers to when an individual actively seeks out information in order to address an already identified information need (ibid). Browsing occurs when an individual actively collects information but with a purpose that is unclear or not yet known (ibid). Monitoring is when an individual is on the lookout for information, but has not yet identified a particular information source (ibid). Being aware involves an individual passively receiving information they did not know they needed (ibid). This study found that none of the guardians actively sought blindness-related medical information. However, many actively sought information about schools that would be able to cater for their children's visual needs after being alerted to the existence of such schools. None of the guardians engaged in browsing and monitoring, but a few indicated that they passively received blindness-related medical information from allopathic healthcare practitioners upon diagnosis.

It is well documented in the literature that guardians of children living with disabilities have unmet health information needs and that these needs are worsened in rural areas by factors including poverty, lack of education, cultural beliefs and limited access to healthcare resources (Sloper, 1999; Rahi, Manaras, Tuomainen & Hundt, 2004; Jackson, Baird, Davis-Reynolds, Smith, Blackburn & Allsebrook, 2007; Skinner & Skilfkin, 2007; Lorenzo, van Pletzen & Booyens, 2015). The findings of this study concur with the literature.

Numerous scholars affirm that guardians of children living with disabilities have varying health information needs, which change as the children grow older (Jackson et al., 2007; Lwoga & Mosha, 2013; Al-Daihani & Al-Ateeqi, 2015; Alsem et al., 2017, Baba et al., 2017). These include medical information about the children's disability, information on how to communicate with the children and how to develop their resilience, information on available support services and government benefits, as well as care guidelines the guardians can share with members of their families and communities (ibid). Similar information needs were communicated by the guardians of this study. In fact, all of the guardians expressed a desperate desire to know what the actual cause of their children's blindness was, what the general causes of blindness were, and if blindness was curable. The guardians also expressed a need for information on their likelihood of having other blind children, whether anything could be done to help fully restore their children's eyesight, if their children's eyesight would worsen as they grew older, as well as information on how to best live with and support their blind children.

Boyd (2004) identified a number of factors that influence an individual's decision to act in a particular way while seeking information. These factors include the information that the individual has access to, the information that they receive, their trust in the information source, perceived quality, and the manner in which they make sense of the information (ibid). In addition to these factors, this study found that the guardians' beliefs about the causes of their children's blindness also influenced their decision to seek blindness-related medical information. Those who believed that their children's blindness was due to the will of God did not seek blindness-related medical information because they believed that God had done His will and that He would provide the necessary guidance. Those who believed that their children's blindness was caused by the evil deeds of other people, ancestral spirits or a lack of adherence to traditional practices did not seek any blindness-related medical information because they believed that the children's eyesight would be restored after addressing the cause of the blindness through traditional rituals. Those who believed that their children's blindness was caused by medical factors also did not seek any blindness-related medical information as they believed that blindness was in the genetic makeup of the children.

Research indicates that guardians of children living with disabilities make use of various communication platforms in order to obtain health information (Jackson et al., 2007; Lwoga & Mosha, 2013; Al-Daihani & Al-Ateeqi, 2015; Alsem et al., 2017, Baba et al., 2017; Sukati, Moodley & Mashige, 2018). Findings from various studies reveal that these guardians sought health information from the internet and social media platforms, radio and television, printed books, magazines, newspapers and leaflets, disability specific organisations, as well as from verbal discussions with medical healthcare practitioners, members of their families and communities, and other guardians of children living with the same or similar disabilities (ibid). However, the guardians of this study did not seek any blindness-related medical information. Their reasons were driven by fear, acceptance and a lack of knowledge. Many of the guardians feared that actively seeking such information would make them feel worse about their children's blindness or that they would find information that would stress the need for eye-related surgical interventions. Other guardians had accepted their children's blindness as God's will or accepted the diagnosis and explanation from the allopathic healthcare practitioners that their children would not be able to see. Some guardians expressed that they had no prior knowledge of or experience with blindness and that they did not know what to do when it came to matters concerning blindness.

The internet is generally believed to be the ideal communication platform for providing health information as it cuts across geographic barriers. However, rural dwellers - such as those who participated in this study - have access related challenges, which are further worsened by their low socio-economic status and literacy levels. Given this reality, the guardians of this study identified various ways they believed were best suited to provide them with the health information they needed. A majority of these guardians expressed a strong preference for face-to-face communication in their native language. Many of these guardians suggested that they could congregate in a central location within their communities (local clinics, churches, schools, libraries and community halls) and have face-to-face discussions with health communication practitioners. The guardians explained that this was their preferred form of receiving health information as it would enable the guardians to interact with the health communication practitioners and get clarity on issues that concerned them. Some guardians suggested home-visits and expressed that such visits would allow for one-on-one communication between the guardians and health communication practitioners. Other guardians suggested workshops where practical demonstrations could be offered. The guardians suggested that details about these discussion sessions and workshops could be announced at the schools for the Deaf and Blind during the parent-teacher meetings or over the radio.

Radio was also identified as an effective communication platform for sharing health information because of its potential to reach the guardians who keep their children out of school. Another reason for this preference was that many rural dwellers have access to radios, which would allow for greater reach and those who miss the broadcast could find out information from others who were listening. However, not all of the guardians agreed on the value of radio. Some argued that not everyone had radio or that some guardians might miss the broadcast if they were not listening to the radio or to a particular radio station.

Some of the guardians disapproved of written communication because such material is often written in English, which is not the guardians' native language. Other guardians argued that posters tended to be useless since they were often showcased in places where the guardians might not see them. Only one guardian indicated a preference for written communication because it would afford an opportunity to take the information home and read it at their leisure. Another guardian suggested the use of social media as it would allow the guardians to access the information as and when they needed it. This guardian acknowledged that data costs would be a problem, but stated that data would not be as costly as having to travel to workshops or other locations where information might be provided.

In contrast to the findings of numerous studies (Jackson et al., 2007; Al-Daihani & Al-Ateeqi., 2015; Alsem et al., 2017), the guardians of this study identified allopathic healthcare practitioners as their least preferred source of health information. This could be attributed to language barriers between the guardians and the allopathic healthcare practitioners as they, in most cases, did not speak the same native language; the structure of the provision of public allopathic healthcare in South Africa and its referral system that required the guardians to travel from one healthcare facility to the next – with each healthcare facility being further away from their homes; monetary and physical expenses incurred while traveling to and from the various public allopathic healthcare facilities; having to queue for long hours in order to consult with the public allopathic healthcare practitioners; as well as the fact that the public allopathic healthcare practitioners are burdened by a large number of patients and are thus unable to counsel and guide the guardians in the way that they need/want.

The role of schools in supporting blind and partially blind children and their guardians

Mainstream schools and schools for the Deaf and Blind can play a significant role in supporting blind and partially blind children and their guardians who live in rural areas. For example, teachers in mainstream schools can be instrumental in identifying and referring these children to schools that are better equipped to cater for their psychosocial needs. Mainstream schools can also provide support with the transition to a specialised school and educate guardians and children about how schools for the Deaf and Blind can provide a sense of belonging for the children and a sense of comfort for their guardians.

Many of the guardians of this study indicated that they first enrolled their children at their local crèches and mainstream schools. Some of these guardians expressed that although they were aware of the children's visual limitations, they did not know about the availability of schools that would be able to cater for their children's visual needs. Due to their visual limitations, these children were often victimised by other children at the mainstream schools and performed poorly academically. Many of the visually-impaired children struggled to see what their teachers wrote on the chalkboards, had terrible handwriting, would write outside of the margins and were not able to complete their class assessments within the given timeframe. As a result, many of these children failed and had to repeat classes the following year. Some of the guardians indicated that they did not link their children's poor academic performance to their deteriorating eyesight and that some of their children's teachers made the connection only after their children had repeatedly failed classes. Many of the guardians said that they got called to their children's schools to discuss their children's poor academic performance on numerous occasions, and that the poor performance was often attributed to the children's poor cognitive abilities and not to their failing eyesight. Ebeigbe (2018) similarly reported that parents of children with ocular ailments were not likely to associate their children's poor academic performance with visual problems.

Many of the guardians shared that the schools for the Deaf and Blind provided them with a sense of comfort because their children's educational needs were finally well taken care of. The guardians also took comfort in knowing that their children were not the only ones who were blind. One guardian particularly stated that she was battling to accept that her child was blind but things got better after her child got admitted to the school for the Deaf and Blind. The guardians were also pleased that their children were no longer in an environment where they got teased and laughed at because they were different. Many of the guardians expressed that their children's academic performance improved significantly when they began to attend the schools for the Deaf and Blind.

Culture-centred approach (CCA)

The culture-centred approach (CCA) to health communication has three key tenets which are culture, structure and agency. This study focused on the intersections between these key tenets and found that they both enable and constrain the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas of the Free State province.

Culture

A person's culture often dictates the language that they speak. South Africa is dubbed the 'Rainbow Nation' because of its multiplicity of cultural groups. There are 12 official languages in South Africa: Afrikaans, English, Sepedi, Setswana, Sesotho, siSwati, isiNdebele, isiXhosa, isiZulu, Tshivenda, Xitsonga and South African Sign Language. South Africans also speak Shangaan and Khoisan. Each cultural group uses a different language and has its own cultural norms and practices that govern the members' beliefs and behaviour.

This study was conducted in the Free State province, where the Sotho people are the largest cultural group and Sesotho is the most commonly spoken language. A majority of the guardians of this study were Sotho, although there were other cultural groups such as Tswana, Xhosa and Zulu.

A culture and its approaches to ill-health, healing and curing are understood through the lived experiences of its members, and these lived experiences are shaped by what the culture sanctions as knowledge, the values attached to it, and how culture is used as a resource in the daily lives of its members (Dutta, 2008). Many of the guardians of this study held conflicting beliefs about the causes of their children's blindness, which stemmed from their lived experiences and what their culture sanctioned as knowledge. These guardians maintained that despite what they were told by allopathic healthcare practitioners, they still believed that their children's blindness had religious and/or traditional causes. Olatuji, Adepoju and Owoeye (2015) and Ofosu et al. (2018) reported similar findings. This study, for instance, found that although some of the guardians did not believe in the existence of witchcraft, a lot of unexplainable things happened that caused them to believe that their children's blindness was caused by the evil deeds of other people. One guardian particularly expressed that although the allopathic healthcare practitioners said that her child's blindness was caused by an infection, she believed that she may have 'walked over' something while she was pregnant. A common belief in many South African cultures is that when a woman is pregnant, she should limit walking outside of her home because she puts herself at risk of 'walking over' things and exposing both her and her unborn child to harm. It is believed that those who wish to cause harm, to either the child or both the child and the woman, strategically place objects or pour substances at places where the woman is most likely to walk. The woman then exposes both herself and her unborn child to harm by 'walking over' these things. If exposed, the woman stands the risk of losing her child before birth, having the child die either during or shortly after birth, or experiencing complications during labour - which may result in her death or cause the child to be born with defects.

Masasa, Irwin-Carruthers and Faure (2005) reported that caregivers who held mixed beliefs regarding the causes of their children's disability prayed to God, visited traditional healers and consulted with allopathic healthcare practitioners. These scholars suggested that the caregivers' behaviour was reflective of their need for a meaningful explanation for their children's disability. Similarly, this study found that in search of a meaningful explanation for their children's blindness, the guardians concurrently made use of religious, traditional and allopathic eye-care systems.

Religion is an important aspect of culture and Rumun (2014) describes it as a communal social phenomenon. Many of the guardians of this study were Christian. Rumun (2014) asserts that Christianity teaches reliance on God for healing, and that treatment is often sought through prayer. This was the case with the participants of this study. Some of the guardians held religious beliefs regarding the causes of their children's blindness and many found solace in prayer. Given that the doctrines of Christian churches vary, the guardians of this study consulted with various churches for spiritual guidance and for help with identifying the cause of, and a cure for, their children's blindness. The various denominations that the guardians consulted with included Apostolic, Catholic, Charismatic, Pentecostal, Revival and Zion churches. Masasa, Irwin-Carruthers and Faure (2005) reported that caregivers who professed a Christian faith also attributed their children's disability to witchcraft. Their finding was consistent with the findings of this study. Some of the guardians of this study expressed that although they believe that their children's blindness was due to the will of God, they also believed that it was caused by the evil deeds of other people.

This study also found that cultural beliefs have an influence on the guardians' decision to seek health information as many indicated that they did not seek any because they had accepted their children's blindness. This acceptance was driven by the belief that the children's blindness was ordained by God, which may have discouraged them from seeking blindness-related medical information. Masasa, Irwin-Carruthers and Faure (2005) similarly reported that the belief that a child is ordained to be disabled might demotivate caregivers from seeking rehabilitation services that may help minimise the effects of the disability. The traditional beliefs that the children's blindness was caused by ancestral spirits, the evil deeds of other people, or a lack of adherence to traditional practices may have discouraged the guardians from seeking blindness-related medical information as they believed that the children's eyesight would be restored after addressing the culture-based cause of the blindness. Beliefs regarding the medical causes of the children's blindness may have also discouraged the guardians from seeking blindness-related medical information as they believed that blindness was in the genetic makeup of the children. Some of the guardians accepted what they were told by allopathic healthcare practitioners upon diagnosis and did not look for further information or second opinions. This deference to allopathic healthcare practitioners may have been influenced by culture and the general belief that allopathic healthcare practitioners are knowledgeable and their opinions ought to be respected and accepted. However, it is worth noting that these beliefs, which are influenced by culture, were not the primary motivation for the guardians' health information seeking behaviour. Often, the guardians simply did not have the financial resources to seek additional care or second opinions.

Additionally, the collectivistic nature of Black South African families also plays an important role in the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas. Many of the guardians of this study first spoke to their families before they sought eye-care for their children's blindness because making decisions without counsel from the elderly or input from other members for the family is culturally frowned upon. Ebeigbe (2018) affirms that the opinion of extended family members is often sought in communal settings. Ukponmwan and Momoh (2010) additionally found that many people who live in rural areas in Africa often consult their elders in an event of an ocular ailment and that their decision is driven by the belief that diseases are caused by breaking taboos or not conforming to traditional societal rules.

The findings of this study, thus, revealed that culture can both enable and constrain the health information and eye-care seeking behaviour of guardians of blind and partially blind children who live in rural areas, as well as their ability to cope with their children's blindness. Culture enabled the guardians' health information seeking behaviour as it encouraged them to seek alternatives to the dominant approaches of receiving health information. Culture also helped provide a sense of hope and solace for the guardians, as well as possible answers to the perceived underlying spiritual causes of their children's blindness. Culture, however, constrained the guardians' health information seeking behaviour as it influenced their beliefs and these beliefs discouraged them from seeking blindness-related medical information regarding their children's blindness on a timely basis. Additionally, some of the cultural beliefs regarding the causes of the children's blindness constrained and further marginalised the guardians and their children as the children were stigmatised for not fitting into what the culture considered as a 'normal child'.

Structure

The South African allopathic healthcare system is divided into public and private healthcare sectors. The public healthcare sector is government-run and caters for the medical needs of the majority of the South African population, while the private healthcare sector serves the minority that are able to pay for privatised healthcare services. Most of the guardians of this study were unemployed and made use of public allopathic healthcare services.

Structure refers to the aspects of social organisations which enable and/or constrain an individual's capacity to engage in health-related behaviours (Dutta, 2008). Various scholars have reported that rural dwellers experience numerous structural challenges which include poor infrastructure, limited financial resources, a lack of emotional and social support, a lack of transportation and high traveling costs (Jenaabadi, 2014; Shrestha et al., 2014; Ofosu et al., 2018). This study similarly found that the guardians of blind and partially blind children who live in rural areas had numerous structural constraints, which influenced their eye-care and health information seeking behaviour regarding their children's blindness. These structural constraints were physical, financial, social and emotional.

Structure is deeply connected with the availability of material resources and influences the daily healthcare choices of cultural members living in marginalised communities (Dutta, 2008). Structure also limits these members' healthcare resources and other critical resources that are available to members of privileged communities (Dutta, 2008). Dutta (2008) asserts that the biomedical model denies members of resource-deprived communities access to the basic infrastructures of biomedicine. The findings of this study concur with Dutta's (2008) assertion. This study found that although public allopathic healthcare services were provided free of charge, these services were often inaccessible and thus did not optimally serve the needs of the guardians in this study. This study also found that, although initially driven by their beliefs, the guardians' preference for one eye-care provider over the other was also influenced by the material resources available to them. Dutta (2014) affirms that individuals make use of cultural resources to navigate the structures that they find themselves in. Many of the guardians of this study sought religious and/or traditional eye-care interventions in the absence of adequate access to allopathic healthcare services. Ofosu et al. (2018) reported that in the absence of eye-care expertise, rural dwellers often consulted with traditional healers or chemists because they were readily available and close to the community. This study similarly found that the guardians who first sought religious and/or traditional eye-care interventions did so because the religious leaders and the traditional healers were easily accessible and were trusted members of their communities.

The findings of this study also concur with Dutta's (2008) assertion that the options sought out by members of marginalised communities are often informed by their structural condition of being deprived of resources. This study found that although some of the guardians preferred the use of traditional eye-care interventions, they had to discontinue and opt for religious and/or allopathic eye-care interventions because they could no longer afford to pay for the services of the traditional healers. Many of the guardians who sought allopathic eye-care interventions first did so because the services were provided free of charge at public allopathic healthcare facilities and because they lived close to the local public clinics. However, many of these guardians expressed dissatisfaction about the provision of eye-care services in the public allopathic healthcare sector. These guardians expressed that customer service was often poor, particularly at the clinics and district hospitals; the queues were very long and they at times either did not get to consult with the doctors and had to return the following day; and that the doctors would be tired and would not optimally attend to their medical needs. Other guardians stated that they noticed that something could be wrong with their children's eyes/eyesight timeously but they were told by public allopathic healthcare practitioners that the children were still young and that they would outgrow it, they did not have the necessary equipment to conduct the required eye examinations or that and that they should come back when the children were older because the children were small and could not sit still enough during eye examinations. Additionally, many of the children who needed to use spectacles did not do so because their guardians had given up after waiting for a very long time and enquiring countless of times with the hospitals. Many of these guardians expressed that although they would have preferred to make use of privately owned allopathic healthcare services, they could not do so because they could not afford to pay for them.

Many of the guardians of this study expressed that transportation was a major challenge and that they incurred a lot a financial strain because they had to catch taxis to and from the public clinics and district hospitals for their children's repeated eye-care visits. The term 'taxi' in South Africa refers to a cab that seats 4 passengers or a van/minibus that seats 12 to 22 passengers. A single taxi ride in many South African communities costs 12 Rands on average, although the cost is dependent on the distance that a person needs to travel. In some cases, the guardians would be required to use four taxis per return trip—e.g. they would need to take a taxi from their homes to town and from town to the clinics or district hospitals, and then pay for a similar trip back to their homes. Children who are too grown to sit on top of their guardians' laps in the taxi pay the full price, regardless of their age. Thus, a single visit to the clinic or district hospital could easily cost roughly 50 Rands per person. Although many of the guardians made use of transportation provided by the state to get to and from the regional and academic hospitals in Bloemfontein (the closest large city), in addition to the taxi fare to and from the pick-up and drop-off points (clinics and district hospital) the guardians incurred other costs such as food related expenses and possible loss of income for that day. Some guardians had to travel for about 400 kilometres to and from Bloemfontein and they, in some cases, arrived in their hometowns late at night, which posed other risks and possible additional costs as they needed to travel from the drop-off points (clinics or hospitals) to their homes.

The findings of this study revealed that structure can both enable and constrain the guardians' eye-care seeking behaviour. Structure enabled their eye-care seeking behaviour as it prompted them to explore the various sources of eye-care that were available to them and encouraged them to make optimal use of these resources. Dutta-Bergman (2004) affirms that communities that have access to multiple health-related resources are able to better sustain the health of their members. On the other hand, structure greatly constrained the guardians' eye-care seeking behaviour as it limited their ability to make use of the sources of eye-care that they preferred and resonated the most with.

Structure also refers to the communicative resources that enable and/or constrain access to resources (Dutta, 2014). These include communicative rules, processes, roles, and rituals that create the realms of participation and representation (ibid). Members of marginalised communities have limited access to mainstream communication platforms that share health information and allow them to express their questions and concerns (Dutta, 2008). In this study, structure mostly constrained the health information seeking behaviour of these guardians as it limited their knowledge about and access to available health information regarding their children's blindness. None of these guardians actively sought blindness-related medical information and their reasons mainly stemmed from acceptance and a lack of awareness. Some of the guardians accepted what they were told by allopathic healthcare practitioners upon diagnosis and did not look for further information. This deference to allopathic healthcare practitioners may have been influenced by structure as the guardians did not have enough financial and other resources to look for further information or seek second opinions. Many of the guardians were not aware that they needed to look for such information while others did not know where to look.

Agency

Agency refers to an individual's ability to make choices that are in their best interest and to participate actively in working with and/or challenging the structures that constrain their lives (Dutta, 2008; Sheik, 2013). All of the guardians of this study found ways of working with the numerous structures that constrained their lives. For instance, many of the guardians often borrowed money (even from loan sharks) to ensure that their children's eye-care related and educational needs were efficiently cared for, despite being unemployed and having limited financial resources. Many of the guardians also actively participated in challenging the structures that constrained their lives by seeking religious and/or traditional eye-care interventions when allopathic healthcare practitioners told them that nothing could be done to restore their children's eyesight. This act gave the guardians a sense of agency as they took action and attempted to seek a solution for their children's ocular ailments.

The structures within which resources are organised not only constrain an individual's ability to act, but also offer a framework for challenging and transforming those structures (Dutta, 2014). For instance, schools for the Deaf and Blind do not admit children who have multiple disabilities due to a lack of adequate support equipment. However, one guardian whose child is blind and has a disability in her left arm enacted agency and fought with the Free State Department of Education and the school for the Deaf and Blind to get her child admitted to the school and have the school receive a modified braille machine that would be able to accommodate her child's physical disability. This guardian's action initiated social change as she created an opportunity for more children with multiple disabilities to be admitted at the schools for the Deaf and Blind and have their needs adequately catered for. The guardians also enacted agency in their willingness to engage with an inadequate public health structure and did not allow themselves to be deterred. Despite getting limited results from various sources, the guardians persisted and endured multiple visits and long trips in a bid to get eye-care for their children.

Some guardians also used agency to promote the independence of their children. They enrolled their children for private braille lessons, taught their children how to walk independently and how to locate and identify objects with their hands. Other guardians sought to get their children walking canes so that they could be able to function optimally on their own. Dutta and Basu (2008) reported that the participants of their study enacted agency in familial networks, where health decisions were made. This study consistently found that all of the guardians consulted with their families before seeking eye-care for their children, and relied on religious and/or traditional eye-care interventions because their families trusted the providers. Dutta and Basu (2008) affirm that having trust in the provider is important as relationships of trust enact agency and help provide ways of coping in resource-deprived communities.

This study found that agency can both enable and constrain the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas. Agency enabled the guardians' health information seeking behaviour as it drove them to seek and ultimately find information about the schools that would be able to cater for their children's visual needs, despite the numerous challenges that they faced. A perceived lack of agency constrained the guardians' health information seeking behaviour and caused them to not seek blindness-related medical information. Some of the guardians did not deem it necessary to seek blindness-related medical information as they had already accepted that their children were blind. Many of these guardians accepted what they were told by allopathic healthcare practitioners upon diagnosis and did not look for further information. This deference to allopathic healthcare practitioners may have been influenced by a perceived lack of agency as the guardians understood that nothing could be done to restore their children's eyesight. Other guardians perceived their low levels of education as a barrier and thus did not seek any blindness-related medical information.

Recommendations

This study recommends that health communication strategies be tailored to the situational environments of the guardians of blind and partially blind children living in rural areas in order to maximise the relevance and reach of health information. This could be achieved through customising the message, channel and source of health communication to the needs and preferences of these guardians; and formulating messages that take into consideration the guardians' cultural beliefs, practices and norms as these factors influence their decision making and govern their behaviour. However, given the structural constraints that these guardians face, this study recommends that health information be provided through mainstream schools and schools for the Deaf and Blind as they are easily accessible to the guardians and are regarded as trustworthy sources. In addition, this study recommends that health information be communicated through face-to-face interactions in the guardians' native language via discussion sessions and workshops held at central locations within their communities such as local clinics, churches, libraries and community halls.

Based on the themes that emerged, this study also recommends that health information be shared with the guardians' families and communities as they have a significant influence on the guardians' decision making regarding their children's blindness. Free eye-screening and early detection initiatives could be implemented for all children and conducted at central places within the communities, such as at mainstream schools. The information about these initiatives could be communicated through the radio. These initiatives could help identify children with ocular ailments early and afford the guardians an opportunity to engage in face-to-face communication in their native language about where and how to seek eye-care and related health information. In addition, traditional folk media could be used in awareness and educational campaigns aimed at sensitising community members about blindness and the negative impact that their rejection and scorn have on the guardians and their children.

Religious leaders, traditional healers and allopathic healthcare practitioners should be sensitised about the role that each eye-care system plays in the general eye-care of the children. Teachers in mainstream schools could also be trained on how to identify ocular and visual problems in children and give appropriate advice to the guardians. Finally, schools for the Deaf and Blind could organise support groups to provide ongoing emotional and social support for the guardians and their children. Through these groups, guardians of older children could serve as a source of guidance and support to guardians of younger ones.

Limitations

This study is not representative of the entire population of guardians of blind and partially blind children who live in rural areas of the Free State province because it was limited to the guardians whose children attended Bartimea and Thiboloha, which are the only two schools for the Deaf and Blind in the Free State province. There may be more blind children who are not attending schools for the Deaf and Blind, nor any other school, who live in rural areas and were therefore not represented in this study.

This study had only one child who had more than one form of disability (blindness and a physical disability). Children with multiple disabilities are seldom accepted at schools for the Deaf and Blind. This suggests that there may be more children with multiple disabilities who do not attend these schools and are thus not represented in this study.

Suggestions for future research

This study suggests that a study be conducted that explores the health information seeking behaviour of guardians of blind and partially blind children who live in urban areas. Such a study would assist in our understanding of how the three key tenets of the culture-centred approach (CCA) to health communication – culture, structure and agency - enable and/or constrain the health information seeking behaviour of these urban guardians. In addition, a study of guardians of children who do not have access (or attend) schools of the Deaf and Blind may help inform health officials about additional structural limitations that keep rural guardians of blind children from accessing educational services that can change the children's lives for the better.

Value of the study to the community studied

The findings of this study could help provide a greater understanding of how guardians of blind and partially blind children who live in rural areas seek health information about their children's blindness. This understanding could improve the provision of health information to this population.

To assist in this goal, the researcher has made arrangements with the guardians who participated in this study and the principals of Bartimea and Thiboloha schools for the Deaf and Blind for a presentation on the findings and the various ways in which the schools can take a more active role in acting as a source of health information and support to both the guardians and their children. The researcher will also do a presentation for the Free State Departments of Health and Education on the findings of this study and highlight the important role that mainstream schools and schools for the Deaf and Blind can play in the dissemination of health information to the guardians of blind and partially blind children who live in rural areas and the community at large.

CONCLUSION

Dutta (2008) posits that the biomedical model of health communication marks local or cultural choices as ʺprimitiveʺ on the basis of its own scientific rational standards, and stresses the need to disrupt the universalistic and exclusive logic of the biomedical model in order to create meaningful discursive spaces that will allow for health communicators to understand the health choices of cultural members who survive within very limited structural resources.

This study found that listening to the voices of guardians of blind and partially blind children who live in rural areas can help challenge the frameworks within which health is constructed and help create opportunities for change. The guardians of this study expressed a need for face-to-face communication in their native language, which was Sesotho, and explained that face-to-face communication would enable them to interact with the health communication practitioners and get clarity on issues that concerned them. These guardians indicated that they would prefer health information to be conveyed through home-visits, publicly-held discussion sessions and workshops. These discussion sessions and workshops should be held at central places within the guardians' communities such as at the local clinics, churches, schools, libraries and community halls. Announcements about these discussion sessions and workshops should be communicated to the guardians through the schools for the Deaf and Blind and over the radio. These guardians also stressed the need for health information to be communicated over the radio, in their native language, and highlighted that the radio would serve as an effective medium of communication as it is accessible to many rural dwellers.

The dominant approach to health communication takes culture for granted in its assumptions about the central role of the biomedical model in problematising health and in proposing solutions to health problems (Dutta, 2008). Kreuter and McClure (2004) stress the need for recognising culture as an important factor in health communication and affirm that this recognition can potentially contribute to the development of new and more effective communication strategies. Health communication scholars have posited that health communication is more effective in capturing the attention of the intended audience and stimulating their information processing when it is culturally appropriate (Kreuter et al., 2003; Kreuter and Haughton, 2006). This study found that in order to provide health information that is culturally appropriate, health communicators must first identify the cultural beliefs of their intended audience and how these beliefs might influence their perceptions about health and solutions to health problems.

Dutta (2008) argues that the conditions in marginalised communities are sustained through the unavailability of communication channels. The findings of this study concurred with Dutta's (2008) argument and reiterated the need for alternatives to the dominant discourses regarding the provision of health information in rural areas. This study highlighted the importance of understanding the influence of the three key tenets of the CCA - culture, structure and agency - on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas, and argues that this understanding may help increase their access to and use of health information by creating relevant health information material and the provision thereof through platforms that are easily accessible to the guardians.

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Appendix A – Interview schedule in English

INTERVIEW SCHEDULE FOR GUARDIANS OF BLIND AND PARTIALLY BLIND CHILDREN LIVING IN RURAL AREAS OF THE FREE STATE PROVINCE.

Participant:

SECTION ONE

1. What is your relationship to your child that is blind?
    - ☐ Parent(s)
    - ☐ Guardian(s)

2. How old are you?

3. Gender
    - ☐ Male
    - ☐ Female

4. What is your highest level of education?
    - ☐ No formal schooling
    - ☐ Primary school
    - ☐ High school
    - ☐ Vocational school
    - ☐ Tertiary education

5. What is your employment status?
    - ☐ Employed (full-time/part-time/self-employed)
    - ☐ Unemployed

6. What is your monthly income?
    - ☐ I have no monthly income
    - ☐ Under R500
    - ☐ R501 – R1 000
    - ☐ R1 001 – R2 000
    - ☐ R2 001 – R3 000
    - ☐ R3 001 – R4 000
    - ☐ R4 001 – R5 000
    - ☐ R5 0001 – R10 000
    - ☐ More than R10 000

7. What is the source of your income?
    - ☐ Salary
    - ☐ Social grant
    - ☐ Disability grant
    - ☐ Pension grant
    - ☐ Other

Appendix B – Interview schedule in Sesotho

KEMISO EA DIPUISANO HO BAHLOKOMEDI BA BANA BA FOUFETSENG/BONELANG HAUFI BA DULANG DIBAKENG TSA MAHAENG POROFENSING EA FREE STATE

Morupeuloa :

KAROLO EA PELE

1. Kamano ya hao le ngwana a foufetseng ke eng?
   - ☐ Motsoadi
   - ☐ Mohlokomedi

2. O dilemo di kae?

   ____

3. Tekano?
   - ☐ Monna
   - ☐ Mosadi

4. Sepheo sa hao se phahameng ka ho fetisa sa thuto ke sefe?
   - ☐ Ha ke a kena sekolo
   - ☐ Poraemari/ Sekolo sa mathomo
   - ☐ Sekolo se phahameng
   - ☐ Sekolo sa thuto ea matsoho
   - ☐ Kholetshe kapa Unibesiti

5. Sebaka sa hao sa mosebetsi ke sefe?
   - ☐ O hiriloe (nako e tletseng/nakwana/oa e tshebetsa)
   - ☐ Ha o sebetse

6. Moputso o kenang khoedi le khoedi?
   - ☐ Ha kena moputso o kenang
   - ☐ Tlasa R500
   - ☐ R501 – R1 000
   - ☐ R1 001 – R2 000
   - ☐ R2 001 – R3 000
   - ☐ R3 001 – R4 000
   - ☐ R4 001 – R5 000
   - ☐ R5 0001 – R10 000
   - ☐ Ho feta R10 000

7. Mohlodi wa chelete lapeng ke ofe?
   - ☐ Moputso
   - ☐ Thuso ea sechaba (social grant)
   - ☐ Phenshene
   - ☐ Tse ding____

Appendix C – Ethical clearance from the University of the Free State

UNIVERSITY OF THE
FREE STATE
UNIVERSITEIT VAN DIE
VRYSTAAT
YUNIVESITHI YA
FREISTATA
UFS·UV
THE HUMANITIES
GEESTESWETENSKAPPE

Faculty of the Humanites

28-Aug-2018

Dear Miss Motseke

Ethics Clearance: **Perceptions of rural parents on their health-information seeking behaviour concerning their blind children: A health communication perspective**

Principal Investigator: **Miss Molebogeng Motseke**

Department: **Communication Science Department (Bloemfontein Campus)**

APPLICATION APPROVED

With reference to your application for ethical clearance with the Faculty of the Humanities. I am pleased to inform you on behalf of the Research Ethics Committee of the faculty that you have been granted ethical clearance for your research.

Your ethical clearance number, to be used in all correspondence is: **UFS-HSD2018/0541**

This ethical clearance number is valid for research conducted from 27-Aug-2018 to 27-Aug-2019. Should you require more time to complete this research, please apply for an extension.

We request that any changes that may take place during the course of your research project be submitted to the ethics office to ensure we are kept up to date with your progress and any ethical implications that may arise.

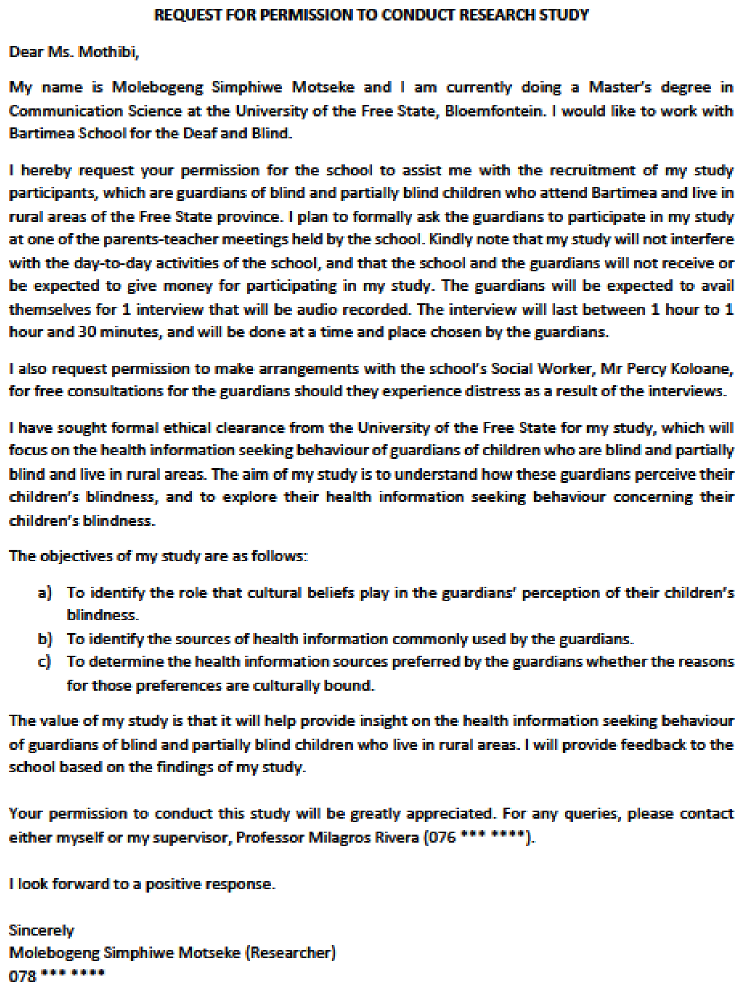
Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours Sincerely

Dr. Asta Rau
Chair: Research Ethics Committee
Faculty of the Humanities

Dekaanskantoor: Fakulteit Geesteswetenskappe
Office of the Dean: Faculty of the Humanities
T: +27(0)51 401 2240, E: humanities@ufs.ac.za
Flippiegroenewoud Building / Gebou, FGG106
205 Nelson Mandela Drive/Rylaan | Park West/Parkwes, Bloemfontein 9301 | South Africa/Suid-Afrika
P.O. Box/Posbus 339 | Bloemfontein 9300 | South Africa/Suid-Afrika | www.ufs.ac.za

Appendix D – Request for permission from Bartimea School for the Deaf and Blind



REQUEST FOR PERMISSION TO CONDUCT RESEARCH STUDY

Dear Ms. Mothibi,

My name is Molebogeng Simphiwe Motseke and I am currently doing a Master's degree in Communication Science at the University of the Free State, Bloemfontein. I would like to work with Bartimea School for the Deaf and Blind.

I hereby request your permission for the school to assist me with the recruitment of my study participants, which are guardians of blind and partially blind children who attend Bartimea and live in rural areas of the Free State province. I plan to formally ask the guardians to participate in my study at one of the parents-teacher meetings held by the school. Kindly note that my study will not interfere with the day-to-day activities of the school, and that the school and the guardians will not receive or be expected to give money for participating in my study. The guardians will be expected to avail themselves for 1 interview that will be audio recorded. The interview will last between 1 hour to 1 hour and 30 minutes, and will be done at a time and place chosen by the guardians.

I also request permission to make arrangements with the school's Social Worker, Mr Percy Koloane, for free consultations for the guardians should they experience distress as a result of the interviews.

I have sought formal ethical clearance from the University of the Free State for my study, which will focus on the health information seeking behaviour of guardians of children who are blind and partially blind and live in rural areas. The aim of my study is to understand how these guardians perceive their children's blindness, and to explore their health information seeking behaviour concerning their children's blindness.

The objectives of my study are as follows:

a) To identify the role that cultural beliefs play in the guardians' perception of their children's blindness.
b) To identify the sources of health information commonly used by the guardians.
c) To determine the health information sources preferred by the guardians whether the reasons for those preferences are culturally bound.

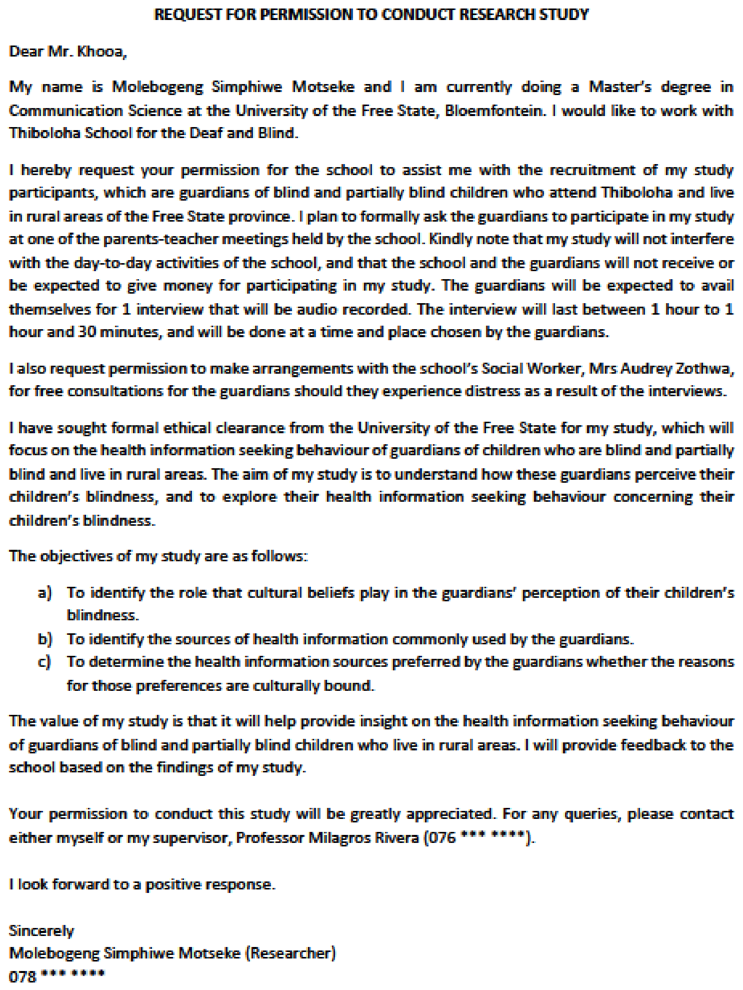
The value of my study is that it will help provide insight on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas. I will provide feedback to the school based on the findings of my study.

Your permission to conduct this study will be greatly appreciated. For any queries, please contact either myself or my supervisor, Professor Milagros Rivera (076 *** ****).

I look forward to a positive response.

Sincerely
Molebogeng Simphiwe Motseke (Researcher)
078 *** ****

Appendix E – Request for permission from Thiboloha School for the Deaf and Blind



REQUEST FOR PERMISSION TO CONDUCT RESEARCH STUDY

Dear Mr. Khooa,

My name is Molebogeng Simphiwe Motseke and I am currently doing a Master's degree in Communication Science at the University of the Free State, Bloemfontein. I would like to work with Thiboloha School for the Deaf and Blind.

I hereby request your permission for the school to assist me with the recruitment of my study participants, which are guardians of blind and partially blind children who attend Thiboloha and live in rural areas of the Free State province. I plan to formally ask the guardians to participate in my study at one of the parents-teacher meetings held by the school. Kindly note that my study will not interfere with the day-to-day activities of the school, and that the school and the guardians will not receive or be expected to give money for participating in my study. The guardians will be expected to avail themselves for 1 interview that will be audio recorded. The interview will last between 1 hour to 1 hour and 30 minutes, and will be done at a time and place chosen by the guardians.

I also request permission to make arrangements with the school's Social Worker, Mrs Audrey Zothwa, for free consultations for the guardians should they experience distress as a result of the interviews.

I have sought formal ethical clearance from the University of the Free State for my study, which will focus on the health information seeking behaviour of guardians of children who are blind and partially blind and live in rural areas. The aim of my study is to understand how these guardians perceive their children's blindness, and to explore their health information seeking behaviour concerning their children's blindness.

The objectives of my study are as follows:

a) To identify the role that cultural beliefs play in the guardians' perception of their children's blindness.
b) To identify the sources of health information commonly used by the guardians.
c) To determine the health information sources preferred by the guardians whether the reasons for those preferences are culturally bound.

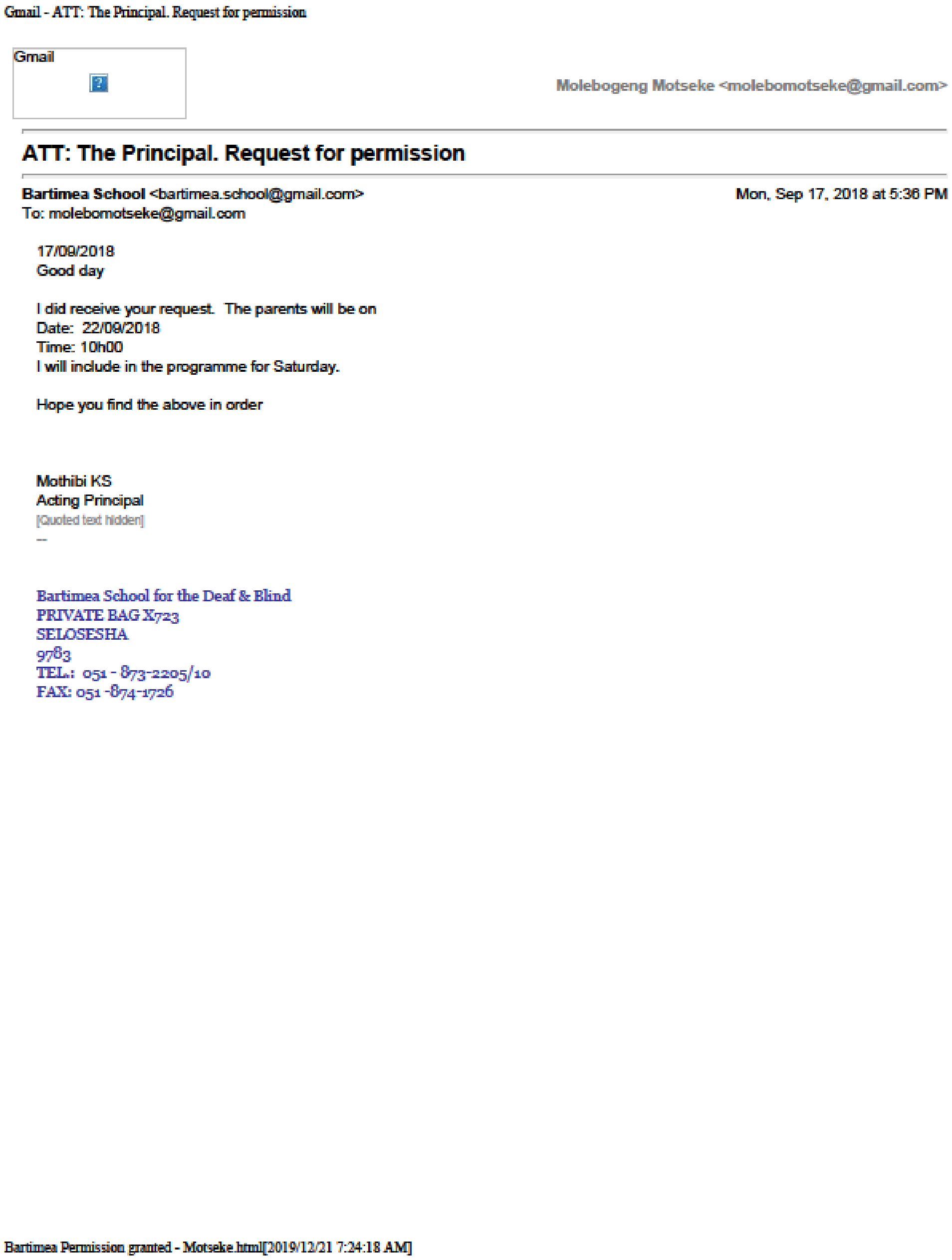
The value of my study is that it will help provide insight on the health information seeking behaviour of guardians of blind and partially blind children who live in rural areas. I will provide feedback to the school based on the findings of my study.

Your permission to conduct this study will be greatly appreciated. For any queries, please contact either myself or my supervisor, Professor Milagros Rivera (076 *** ****).

I look forward to a positive response.

Sincerely
Molebogeng Simphiwe Motseke (Researcher)
078 *** ****

Appendix F – Permission from Bartimea School for the Deaf and Blind



Gmail - ATT: The Principal. Request for permission

Molebogeng Motseke <molebomotseke@gmail.com>

ATT: The Principal. Request for permission

Bartimea School <bartimea.school@gmail.com> Mon, Sep 17, 2018 at 5:36 PM
To: molebomotseke@gmail.com

17/09/2018
Good day

I did receive your request. The parents will be on
Date: 22/09/2018
Time: 10h00
I will include in the programme for Saturday.

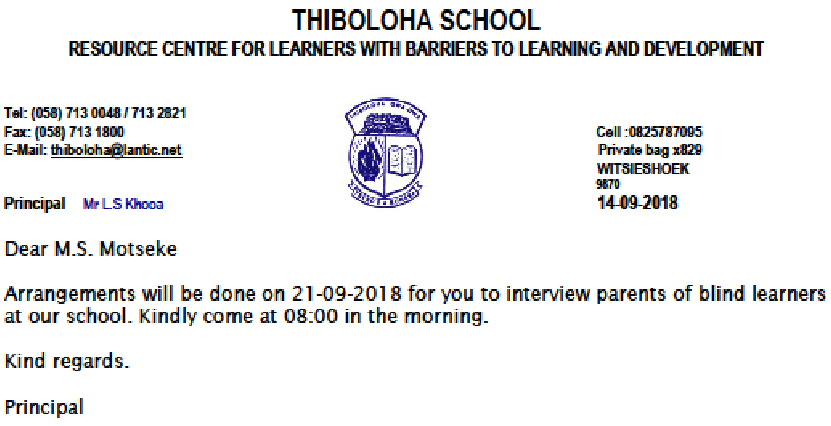
Hope you find the above in order

Mothibi KS
Acting Principal
[Quoted text hidden]
--

Bartimea School for the Deaf & Blind
PRIVATE BAG X723
SELOSESHA
9783
TEL.: 051 - 873-2205/10
FAX: 051 -874-1726

Bartimea Permission granted - Motseke.html[2019/12/21 7:24:18 AM]

Appendix G – Permission from Thiboloha School for the Deaf and Blind



THIBOLOHA SCHOOL
RESOURCE CENTRE FOR LEARNERS WITH BARRIERS TO LEARNING AND DEVELOPMENT

Tel: (058) 713 0048 / 713 2821
Fax: (058) 713 1800
E-Mail: thiboloha@lantic.net

Principal Mr L.S Khooa

Cell :0825787095
Private bag x829
WITSIESHOEK
9870

14-09-2018

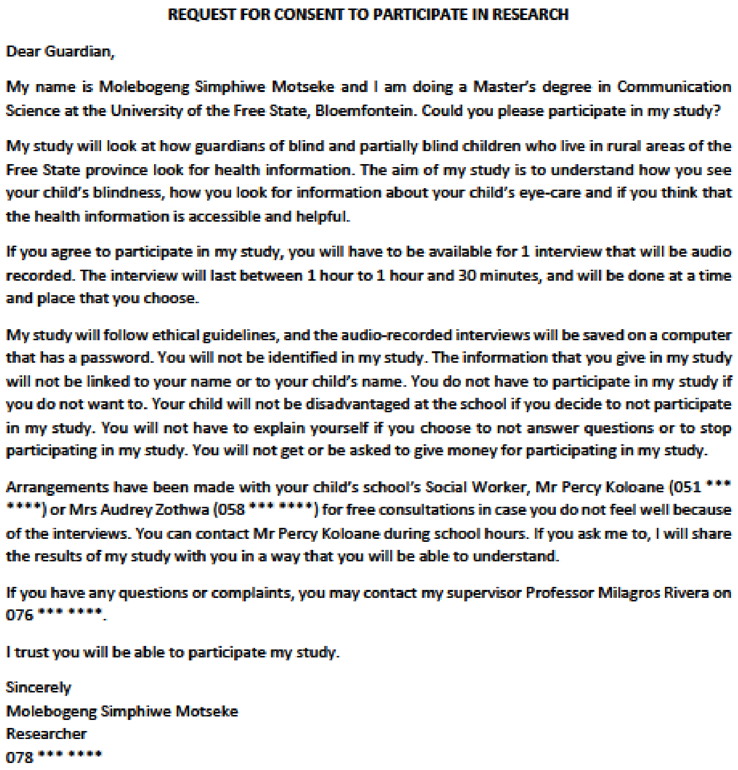
Dear M.S. Motseke

Arrangements will be done on 21-09-2018 for you to interview parents of blind learners at our school. Kindly come at 08:00 in the morning.

Kind regards.

Principal

Appendix F – Parental consent form in English



REQUEST FOR CONSENT TO PARTICIPATE IN RESEARCH

Dear Guardian,

My name is Molebogeng Simphiwe Motseke and I am doing a Master's degree in Communication Science at the University of the Free State, Bloemfontein. Could you please participate in my study?

My study will look at how guardians of blind and partially blind children who live in rural areas of the Free State province look for health information. The aim of my study is to understand how you see your child's blindness, how you look for information about your child's eye-care and if you think that the health information is accessible and helpful.

If you agree to participate in my study, you will have to be available for 1 interview that will be audio recorded. The interview will last between 1 hour to 1 hour and 30 minutes, and will be done at a time and place that you choose.

My study will follow ethical guidelines, and the audio-recorded interviews will be saved on a computer that has a password. You will not be identified in my study. The information that you give in my study will not be linked to your name or to your child's name. You do not have to participate in my study if you do not want to. Your child will not be disadvantaged at the school if you decide to not participate in my study. You will not have to explain yourself if you choose to not answer questions or to stop participating in my study. You will not get or be asked to give money for participating in my study.

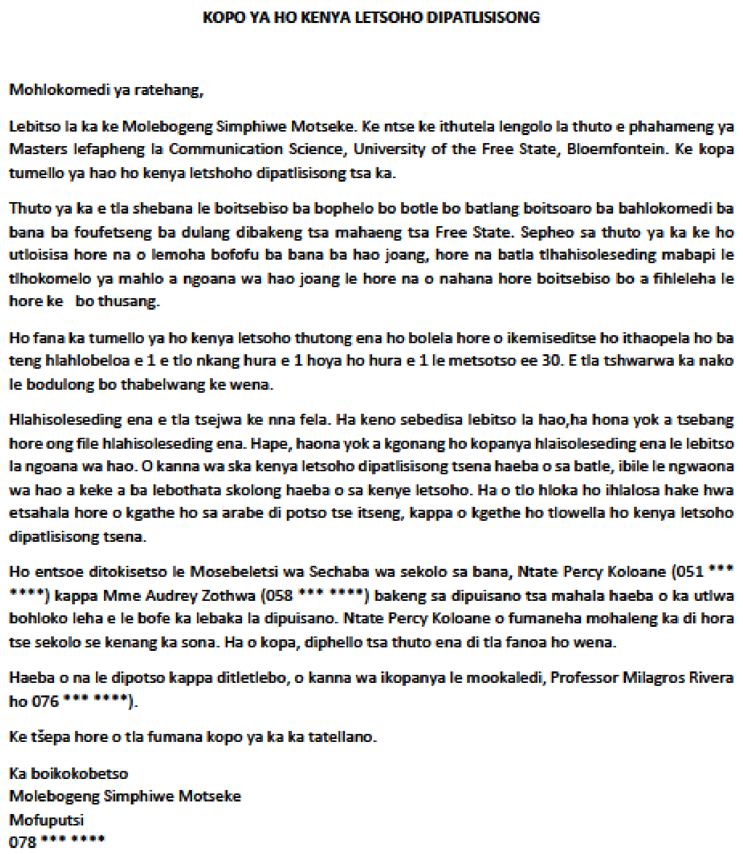
Arrangements have been made with your child's school's Social Worker, Mr Percy Koloane (051 *** ****) or Mrs Audrey Zothwa (058 *** ****) for free consultations in case you do not feel well because of the interviews. You can contact Mr Percy Koloane during school hours. If you ask me to, I will share the results of my study with you in a way that you will be able to understand.

If you have any questions or complaints, you may contact my supervisor Professor Milagros Rivera on 076 *** ****.

I trust you will be able to participate my study.

Sincerely
Molebogeng Simphiwe Motseke
Researcher
078 *** ****

Appendix I – Parental consent form in Sesotho



KOPO YA HO KENYA LETSOHO DIPATLISISONG

Mohlokomedi ya ratehang,

Lebitso la ka ke Molebogeng Simphiwe Motseke. Ke ntse ke ithutela lengolo la thuto e phahameng ya Masters lefapheng la Communication Science, University of the Free State, Bloemfontein. Ke kopa tumello ya hao ho kenya letshoho dipatlisisong tsa ka.

Thuto ya ka e tla shebana le boitsebiso ba bophelo bo botle bo batlang boitsoaro ba bahlokomedi ba bana ba foufetseng ba dulang dibakeng tsa mahaeng tsa Free State. Sepheo sa thuto ya ka ke ho utloisisa hore na o lemoha bofofu ba bana ba hao joang, hore na batla tlhahisoleseding mabapi le tlhokomelo ya mahlo a ngoana wa hao joang le hore na o nahana hore boitsebiso bo a fihleleha le hore ke bo thusang.

Ho fana ka tumello ya ho kenya letsoho thutong ena ho bolela hore o ikemiseditse ho ithaopela ho ba teng hlahlobeloa e 1 e tlo nkang hura e 1 hoya ho hura e 1 le metsotso ee 30. E tla tshwarwa ka nako le bodulong bo thabelwang ke wena.

Hlahisoleseding ena e tla tsejwa ke nna fela. Ha keno sebedisa lebitso la hao,ha hona yok a tsebang hore ong file hlahisoleseding ena. Hape, haona yok a kgonang ho kopanya hlaisoleseding ena le lebitso la ngoana wa hao. O kanna wa ska kenya letsoho dipatlisisong tsena haeba o sa batle, ibile le ngwaona wa hao a keke a ba lebothata skolong haeba o sa kenye letsoho. Ha o tlo hloka ho ihlalosa hake hwa etsahala hore o kgathe ho sa arabe di potso tse itseng, kappa o kgethe ho tlowella ho kenya letsoho dipatlisisong tsena.

Ho entsoe ditokisetso le Mosebeletsi wa Sechaba wa sekolo sa bana, Ntate Percy Koloane (051 *** ****) kappa Mme Audrey Zothwa (058 *** ****) bakeng sa dipuisano tsa mahala haeba o ka utlwa bohloko leha e le bofe ka lebaka la dipuisano. Ntate Percy Koloane o fumaneha mohaleng ka di hora tse sekolo se kenang ka sona. Ha o kopa, diphello tsa thuto ena di tla fanoa ho wena.

Haeba o na le dipotso kappa ditletlebo, o kanna wa ikopanya le mookaledi, Professor Milagros Rivera ho 076 *** ****).

Ke tšepa hore o tla fumana kopo ya ka ka tatellano.

Ka boikokobetso
Molebogeng Simphiwe Motseke
Mofuputsi
078 *** ****