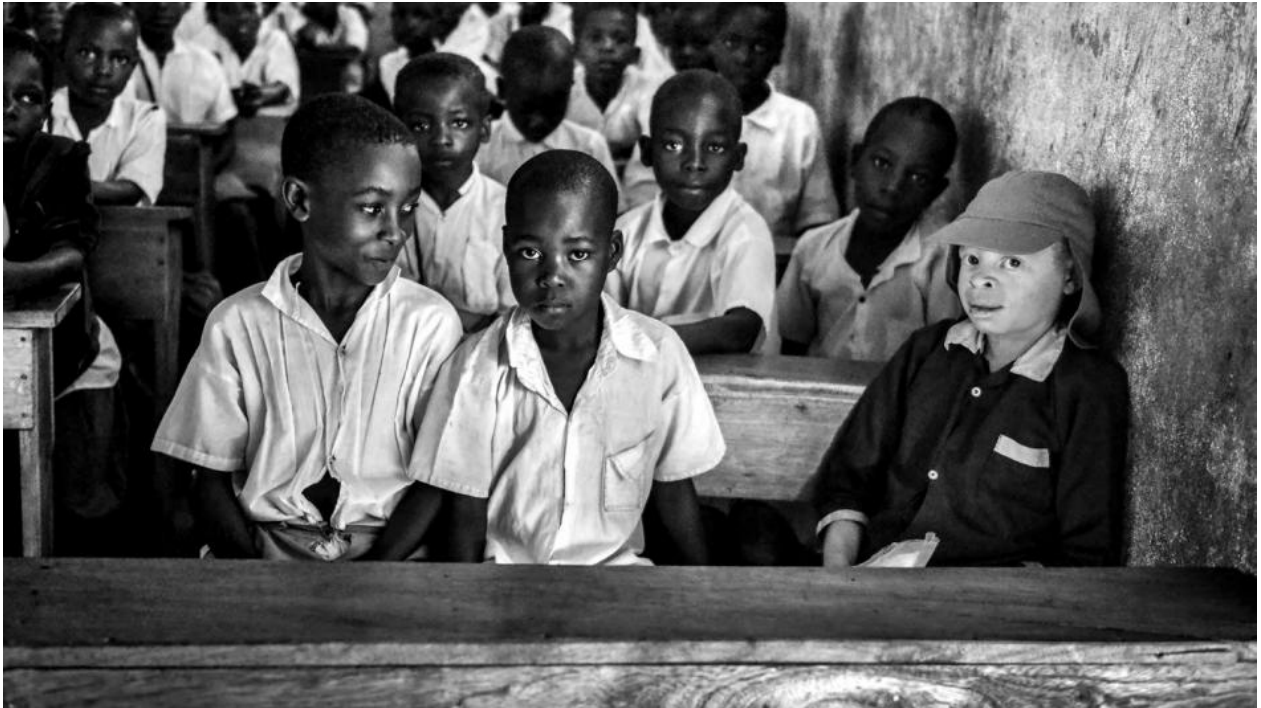


# Breaking the Stigma of Albinism

An assessment of two radio-based interventions to improve knowledge and reduce stigmatizing attitudes related to albinism in Tanzania



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'You are black, but you are white, so you belong nowhere'

(cited in: Baker et al., 2010: 6)

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*August 2019*

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**Front cover:** Picture by Sacha de Boer (Ukerewe Island, Tanzania, 2016):

‘On his first day of school, students ran away when Sabato, a ten-year-old boy with albinism, walked into the classroom; they thought he was a “ghost.” The government then sent an education officer to the school to address the issue, but some children still do not want to sit too close to him’

(Human Rights Watch (HRW), 2019).

## Preface

This thesis was written as the finalization of the Human Geography master programme at the Radboud University of Nijmegen. I have thoroughly enjoyed this last semester doing research in Kigoma, Tanzania, between March and May of 2019, followed by writing a thesis about the results. However, this amazing and interesting experience would not have been possible if it had not been for the help of some people that I would like to mention here.

First of all, I owe everything to Tjitske de Groot, without whom I would have never ended up in Kigoma; who connected me to KICORA Radio; who adjusted and validated the scales used in this study and who has helped and guided me throughout this research. Second of all, I would like to thank Deo Baribwegure, who has dedicated his life to provide chances and education to the underprivileged people of the Kigoma region. By realizing his dream to set up radio education, he will surely have a great impact on many people in the area. Deo allowed me to do my research in his name, always supported me when things got tough, helped out whenever needed, and not in the least, lent me his motorbike to reach the surrounding villages.

I would also like to thank Sifa Felix, who always came with me on my fieldwork to translate, to find participants and to explain the purpose of the study. She has shown a lot of dedication to this project and showed no fear going on the back of the motorbike to join me to the villages. Moreover, I thank Anthony, my Belgian roommate, who opened up his home to me in Kigoma, showed me around the town and joined me on our motorbike road trip. I could not have been more lucky.

Thank you to my thesis supervisor, Bert Bomert, for all the time and energy he has put into my thesis and for always being enthusiastic and supportive about my research. I have been so impressed by how fast he was able to read my pieces and provide helpful ideas and criticism. And finally, I would like to thank my parents, for always being there.



Figure 1: My translator and me in front of KICORA radio

Marjolein Veldman

Groningen, August 2019

## Abstract

In Tanzania, stigmatization of people with albinism is an everyday reality that can have dire consequences. This research examines the effects of two radio interventions targeted at spreading information concerning albinism and reducing the connected health-related stigma. Participants (N=250) were assigned to one of the two interventions: (1) an educative radio drama, or (2) a contact-based radio interview. The effectiveness of the interventions was tested through an experimental design, by making use of knowledge testing, the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS), the Social Distance Scale (SDS) and an entertainment scale. In addition, short (group) interviews were held with all participants on three occasions. The participants completed the measures and evaluations prior to, immediately after, and at least two weeks after the interventions. Both interventions showed an increase in knowledge about albinism. A significant decrease in stigmatizing attitudes on the community level was found for the radio drama and on the personal level for the radio interview. The entertainment score was high for both interventions. The qualitative data supports these measurements as respondents indicated an increase in knowledge about albinism, a better understanding of the cause of albinism and a high interest in radio education. This research shows that radio interventions about albinism can lead to an improvement of knowledge and stigmatizing attitudes concerning albinism. The outcomes of this study can be used as the basis for research addressing the relationship between a reduction in stigmatizing attitudes and stigmatizing behaviour.

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## List of Abbreviations

Edutainment	Educative entertainment
EMIC	Explanatory Model Interview Catalogue
EMIC-CSS	Explanatory Model Interview Catalogue - Community Stigma Scale
HRW	Human Rights Watch
IFRC	International Federation of Red Cross and Red Crescent Societies
KICORA	Kigoma Community College by Radio
NDP	National Development Policy
NGO(s)	Non-governmental organisation(s)
PWA(s)	Person(s) with albinism
SDS	Social Distance Scale
SRI(s)	Stigma Reduction Intervention(s)
TAS	Tanzania Albinism Society
TNBS	Tanzanian National Bureau of Statistics
UNESCO	The United Nations Educational, Scientific and Cultural Organization
UTSS	Under the Same Sun
UV	Ultraviolet

## 1. Introduction

Albinism is an inherited genetic skin condition where a faulty gene is passed on to a child when both parents are carriers of that gene. Worldwide, approximately one in 20,000 people is born with albinism (Cruz-Inigo, Ladizinski & Sethi, 2011). However, the rates are much higher in sub-Saharan Africa (Stevens, Ramsay & Jenkins, 1997). In Tanzania, for instance, the national census estimated that one out of every 2,673 people has albinism (Tanzanian National Bureau of Statistics (TNBS), 2014; Lund & Roberts, 2018). The actual number is expected to be much higher, however, as people might fear reporting those with albinism due to the perceived risk of discrimination or physical attacks (Lund & Roberts, 2018).

Besides health issues like skin cancer and impaired eye sight, persons with albinism (PWAs) have to deal with stigmatization caused by skin-colour differences (Dapi, Tambe & Monebenimp, 2018). PWAs experience stigma worldwide (Clarke & Beale, 2018), yet, the level of abuse and discrimination that they experience in Africa, is much more severe than in any other continent. They have been ridiculed, demonized, marginalized and 'disabled' by society and sometimes they are victims of extreme acts of violence (Clarke & Beale, 2018; Dapi et al., 2018). For instance, on October 21, 2009, a 10-year-old boy with albinism, Gasper Elikana, was killed by hunters. They 'fled with his leg, which they hacked off in front of his family having first beheaded him to stop him screaming. His neighbours and his black father, who was left fighting for his life in hospital, had tried bravely but unsuccessfully to protect him' (International Federation of Red Cross and Red Crescent Societies (IFRC), 2009). Unfortunately, this event is just one example of the many attacks on PWAs in sub-Saharan Africa.

With 188 registered attacks on PWAs since 2006, Tanzania is the country with the largest recorded number of attacks. The attacks can range from depriving someone of one or more of their body parts, to rape, death or desecrating a grave (Under the Same Sun (UTSS), 2019). This violence is due to superstition in combination with local mythology related to PWAs (Lynch, Lund & Massah, 2014). For example, some people believe that PWAs have special, magical powers and that their body parts will bring good fortune when used in witchcraft potions. Or they think that albinism is contagious and a curse from God or that PWAs are not human and do not die but simply disappear. Sometimes women with albinism are raped as it is believed to cure infertility or HIV/AIDS (Clarke & Beale, 2018; Cruz-Inigo et al., 2011).

Since 2008, national and international attention for the violations of PWAs has risen after documentaries showed the horrors of the slaughters of PWAs in Africa (Clarke & Beale, 2018). With that, the implementation of stigma reduction interventions (SRIs) to benefit the wellbeing of PWAs also increased (Clarke & Beale, 2018). However, the effectiveness of SRIs remains largely unexplored (Brocco, 2015; Cruz-Inigo et al., 2011). Therefore, this research focusses on the effectiveness of SRIs

related to albinism in Tanzania by ‘testing’ two different radio interventions that aim to reduce the stigmatizing attitudes towards PWAs. A comparison is made between a radio drama about a young female nurse with albinism and a contact-based radio interview in which someone with albinism talks about his life. The aim of this research is to assess the effects of educative radio interventions as a method to improving the knowledge of the Tanzanian community about albinism and reduce their stigmatizing attitudes towards PWAs.

### 1.1. Background of Albinism

The most common form of albinism is called oculocutaneous albinism. This entails a lack of pigmentation in the skin, eyes and hair. Albinism is a genetically inherited condition, passed on by both parents to their offspring (Lund, 2001). For a child to be born with albinism, both parents must possess the faulty ‘albinism gene’. This means that a child with albinism inherited two copies of that gene. When both parents are carrier of that gene, on average one out of four children will be born with albinism (Lund & Gaigher, 2002). If just one parent has the gene and the other parent has a normal pigment gene, their children will not be born with oculocutaneous albinism. However, each child will have a one in two chance of being a carrier of an albinism gene and can therefore again pass it on to their offspring. People who carry the albinism gene usually show no signs of the condition and have a skin colour typical to their ethnic group (Lund, 2001; Lund & Gaigher, 2002). In Africa, it is estimated that one in nineteen people carries the faulty albinism gene (UTSS, n.d.).

Albinism manifests itself into two conditions. The melanin deficiency can cause complex visual impairment and weakens natural defences against sun damage (Hong, Zeeb & Repacholi, 2006). As their skin is vulnerable to ultraviolet (UV) radiation, they have a high risk of developing skin cancer. Especially in Africa, where the level of UV radiation of the sun is high year-round and where access to good health care is low, PWAs are more susceptible to the harm that sunlight exposure can cause (Lund & Taylor, 2008). Usually, African children go outdoors and remain in the sunshine for the whole day and they often wear few and light clothes. Because of this, children with albinism develop solar keratosis from the age of eight and will suffer from sun damage by the age of 20 (Lund & Taylor, 2008). However, life quality can be improved by taking precautions against sun damage, such as the use of sun lotions, hats and long-sleeved clothing. When adequate care is provided for their skin, PWAs generally have the same life expectancy as the general population (UTSS, 2012). However, In Africa the life expectancy of PWAs is still between 30 and 40 years, with only 2% living beyond the age of 40 (Regional Dermatological Training Center, 2004; UTSS, 2012). This is mainly due to the majority of PWAs still working outdoors and not taking enough precautions against sun damage. A 1985 study showed that in Tanzania only 12 out of 350 adults with albinism worked indoors (Luande, Henschke & Mohammed, 1985).

Another condition that PWAs often suffer from, is vision impairment caused by the hypopigmentation of the eyes. This results in eye problems such as photophobia (sensitivity to light), nystagmus (involuntary eye movements), astigmatism (blurred vision), a problem with depth perceptions, squinting and poor eyesight (Palmer, 2007). However, constant use of sunglasses can significantly reduce the level of eye damage (Lund & Taylor, 2008; UTSS, 2012).

Besides the health issues that PWAs suffer from, they are often marginalized and excluded in their society. This happens worldwide but is especially the case in sub-Saharan Africa. Lund & Gaigher (2002) found that PWAs experienced problems with mixing at social gatherings and felt less loved by their family or were even occasionally mistreated by family members. Moreover, PWAs believed they have fewer friends than people without albinism. According to Phatoli, Bilal & Ross (2015), stereotypes, beliefs and lack of knowledge regarding albinism affect how people without albinism interact with PWAs and how PWAs viewed and presented themselves. Furthermore, social exclusion is often reinforced by PWAs themselves in order not to be judged or discriminated against (Phatoli et al., 2015). Finally, the extreme sensitivity to sunlight can also contribute to the social exclusion of PWAs as they are limited in taking part in outdoor activities, sports and work. These constraints can negatively impact the development and self-esteem of PWAs (Lund & Gaigher, 2002).

#### 1.1.1. Living with Albinism in Tanzania

Albinism is much more prevalent in sub-Saharan Africa, and particularly in all Bantu-speaking countries, than anywhere else in the world. According to Stevens et al. (1997), this prevalence is caused by a mutation of the OCA2 gene, the most prevalent gene to cause albinism in Africa. The high prevalence of albinism in Bantu-speaking countries strongly suggests that the mutation of the OCA2 gene took place before their population spread among Africa. Therefore, this mutation must have happened at least three thousand years ago (Lund & Roberts, 2018).

In Tanzania, the exact number of PWAs is unclear. The Canadian non-governmental organization (NGO) UTSS, the Tanzania Albino Society (TAS) and scholars Cruz-Inigo et al. (2011) estimate the number of PWAs in Tanzania to be about one in every 1,429 people. This would make Tanzania the country with the highest prevalence of PWAs in the world. Yet, the national census of Tanzania estimated it much lower with only one in every 2,673 people to have albinism. However, the accuracy of the latter has to be challenged as it is based on PWAs who were registered by themselves or family members. It is expected that many census respondents failed to report family members with albinism to avoid putting them at risk for possible attacks (Lund & Roberts, 2018).

In Africa, the white skin, hair and light eyes makes PWAs stand out, which makes them easy targets of taunts, discrimination and dangerous myths (UTSS, 2012). Particularly in Tanzania, PWAs frequently experience stigmatization and social inequality (Brocco, 2016). Consequently, PWAs have a

lower school attendance and drop out of school more often than other children due to bullying, harassment or mistreatment (Lynch & Lund, 2011; Kiishweko, 2017). In some cases, the mistreatment of PWAs goes beyond social exclusion and is manifested through violent (sexual) attacks and murders (Burke, Kaijage & John-Langba, 2014; UTSS, 2019).

Over the last twenty years, the attacks on and killings of PWAs in Tanzania emerged due to myths and witchcraft beliefs that the body parts of PWAs can bring luck, power and financial prosperity (Bryceson et al., 2010). The attacks include mutilations, violence, rape, (attempted) abductions, grave violations, asylum and other refuge cases. A report from UTSS (2019) showed that since 2006, 188 attacks on PWAs in Tanzania have been reported; 76 PWAs were killed and one PWA went missing. The most recent attack mentioned in the 2019 report took place on May 1, 2019. The actual numbers of attacks and killings of PWAs are likely much higher since many are never reported, documented or verified (UTSS, 2019).

In 2004, when Tanzania first developed its national development policy (NDP), the community of PWAs asked to be categorized as disabled people because of continuous oppression, stigmatization and mistreatment. Additional physical arguments to classify PWAs as disabled people in Tanzania include visual impairment and high susceptibility to skin cancer (Franklin et al., 2018; UTSS, 2012). Nowadays, albinism is one of the six registered disabilities, next to hearing, visual, intellectual, speech and mobility impairment (United Republic of Tanzania (URT), 2004). Disability in Tanzania is socially constructed and is described as 'a loss or limitation of opportunities to take part in the normal life of the community at an equal level with others due to physical, mental and social factors' (URT, 2004). Being listed as a disabled person helps PWAs to receive reasonable accommodation at school and a place of employment.

Following the attacks on PWAs, the issue received a lot of national and international attention and resulted in the implementation of many awareness campaigns from the Tanzanian government and international organizations. Recent studies showed that these campaigns did lead to an improvement in attitudes towards PWAs (Brocco, 2015; Franklin et al., 2018). Although PWAs were still seen as the result of parents' misdeeds (particularly the misdeeds of mothers), these beliefs were changing and they came to be seen as a result of God's will. According to Brocco (2015), this indicates that PWAs are beginning to be included and accepted by their families and society.

## 1.2. Relevance

### 1.2.1. Societal Relevance

Acts of violence against and discrimination of PWAs are a violation of the Universal Declaration of Human Rights. In response to the widespread disappearances and killing of PWAs in Tanzania and other

East and Central African countries, in 2008 the United Nations (UN) officially declared PWAs as 'persons with disabilities', in order to classify the violence as a human rights issue (Machoko, 2013).

Society must become aware of the effect of stigma on the quality of life of PWAs (Cruz-Inigo et al., 2011). To improve the wellbeing of PWAs, effective SRIs should be developed and implemented (Cross et al., 2011). In addition, it is important to replace the existing superstitious beliefs that affect the stigmatization of PWAs with accurate knowledge about the genetic skin disorder.

In this research the current social and cultural meaning of the stigma attached to albinism in Tanzania are analysed and the effectiveness of two different radio-based SRIs are compared. The advantage of radio-based SRIs is that they can be easily spread throughout Africa and can reach many people at the same time, including people with less or no access to other forms of education. The knowledge gathered from this research could contribute to the wellbeing of PWAs in Africa. Furthermore, the interventions could also be implemented in order to reduce stigmatizing attitudes towards other people that suffer from health-related stigmas. The research could therefore also contribute to the knowledge of SRIs for other minorities in society.

### 1.2.2. Scientific Relevance

This research fits well into the program of 'Human Geography: Conflicts, Territories and Identities' as it is about the stigmatization (conflict) of a specific minority group: people with albinism (identity) in Tanzania (territories). Furthermore, human geography is described as the discipline that studies people and their communities, culture, economies and interactions with the environment by exploring their relations and human patterns of social interaction with and across time and space (Gregory et al., 2009). This research focusses on the communities in Kigoma, Tanzania, and explores their interactions, relations and attitudes towards PWAs. In addition, it takes the differences between gender, age, religion, education and tribes into account.

Little research has been carried out on the effectiveness of health-related SRIs (Heijnders & Van der Meij, 2006). Particularly the topic of albinism-related SRIs in the area of Tanzania is largely unexplored (Cross et al., 2011), and the existing SRIs related to albinism do not seem to be effective (Brocco, 2015; Cruz-Inigo et al., 2011). Most research on SRI focusses on HIV/AIDS, mental disease or leprosy. All stigmas include a different and large complexity of factors which makes it impossible to apply the same SRIs to all health-related stigmas (Cross et al., 2011). Therefore, more evidence-based research on the effectiveness of SRIs related to albinism is needed.

This research aims to analyse the effectiveness of SRIs when used in relation to albinism, specifically in the Tanzanian context. This study differs from previous research on SRIs by focussing on educative radio-based SRIs that concentrate on the local community. This contributes to the scientific

field as it provides knowledge of the effects of radio-based education as an effective SRI in relation to albinism. Furthermore, it explores and compares two different strategies of radio-based education: the radio drama and the contact-based radio interview. If both radio strategies prove successful, scientific research can be conducted to test their effectiveness in relation to other health-related stigmas.

### 1.3. Research Objective and Research Questions

The research objective is to assess and compare two radio education strategies about albinism among community members in Kigoma, Tanzania, aiming to improve their knowledge about albinism and reduce stigmatizing attitudes towards PWAs. The knowledge and stigmatizing attitudes of the community members are measured before and after the radio interventions. Additionally, in-depth insights from the community members are gathered. In order to determine the effectiveness of radio education as a way to reduce the stigmatizing attitudes related to albinism, this research focusses on the following research question: ‘What are the effects of radio education interventions as a method to improve knowledge and reduce stigmatizing attitudes related to albinism in Tanzania, in particular in the Kigoma region?’

In this research the effects of two different radio intervention strategies were studied: an educative entertainment (edutainment) strategy in the form of a radio drama and a contact strategy in the form of a radio interview. The focus of this study was on the effects of these two SRIs as a way to improve the knowledge about albinism and decrease the personal and perceived stigmatizing attitudes of the community members in Kigoma.

To answer the main research question, the following four sub-questions are examined in this thesis: ‘What are the effects of the edutainment and contact-based strategies as a way to increase knowledge about albinism?’; ‘What are the effects of the edutainment and contact-based strategies as a way to reduce perceived stigmatizing attitudes towards people with albinism on a community-level?’; ‘What are the effects of the edutainment and contact-based strategies as a way to reduce stigmatizing attitudes towards people with albinism on a personal level?’; and ‘How do the entertainment strategy and the contact strategy compare to each other as effective stigma reduction interventions?’

### 1.4. Context of Kigoma

#### 1.4.1. Demographic Statistics of the Kigoma Region

The research was conducted in the Kigoma region, one of the 31 administrative regions in Tanzania. The Kigoma region is the most western region of Tanzania and borders to Burundi and the Democratic

Republic of the Congo (see Figure 2). The region has a population of roughly 2.4 million, of which almost 15% live in Kigoma city, the region's capital (TNBS, 2017a).



Figure 2: Kigoma highlighted on a map of Tanzania

Kigoma is one of the poorest regions of Tanzania with a high degree of illiteracy (32.3%); a large percentage of the citizens of Kigoma did not finish their primary education (34.2%) (TNBS, 2016). The majority of the population in Kigoma lives of farming; the Kigoma region has the highest number of registered farms in all of Tanzania (246,892; 16.1 percent). Furthermore, HIV-infections (2.9%) are high in the Kigoma region and the infrastructure is deficient (TNBS, 2017b). Only 18% of the married women in the Kigoma region use family planning, compared to 38% nationwide in Tanzania. The women in the region are also the youngest of the country to have children: 38% of the women has her first child between the age of 15-19 and they have seven children on average (TNBS, 2015-2016). These statistics of Kigoma show that the region is less developed compared to the rest of the country.

#### *1.4.1.1. Prevalence of people with albinism in the Kigoma region*

In 2012, in the Kigoma region 694 people were recorded to have albinism, which is one out of 17,350 people. In Kigoma city the number is much higher, with 103 recorded people having albinism, or one out of 3,433 people (TNBS, 2016). The prevalence of albinism in Kigoma was equally distributed among age groups and gender (TNBS, 2016).

Kigoma is a district in Tanzania where the killings of PWAs have been particularly prevalent (Larson, 2011). It is also the district where in 2008 the first recorded killings took place (IFRC, 2009). Following the attention these killings received in national and international media, many PWAs were left abandoned or stranded in Tanzanian schools for the disabled. In Kasulu, Kigoma district, at least 49 PWAs received refuge in the Kabanga school for the disabled (IFRC, 2009).

#### 1.4.2. Religion in Tanzania

Religion is very important in Tanzania. Survey results show that 93% of the population of Tanzania experience religion to be very important in their lives (Pew Research Center, 2010). There are three main religions in the country: Christian, Muslim and traditional African religions. The latter is often adhered to in combination with Christianity or Islam. In Tanzania about 61% is Christian and 35% percent is Muslim. In addition, an estimated 60% of the population in Tanzania practices elements of African traditional religions in their daily lives and believes that sacrifices to spirits or ancestors can protect them from harm (Pew Research Center, 2010).

#### 1.5. KICORA Community Radio

This research has been conducted in collaboration with Kigoma's radio education project: Kigoma Community College by Radio (KICORA). KICORA provides educational and communication services to the community in order to empower them and provide them with better life standards and hence, reduce poverty (KICORA, n.d.).

In 2012, 62% of the households in Tanzania owned a radio and radio access is prevalent throughout the country. In Kigoma specifically, 60.3% (65.6% in Kigoma city) of all households owned a radio (TNBS, 2012; 2016). Therefore, the radio is the most consistently available medium for Tanzanian citizens across all income levels and locations (Murthy, 2011). According to the founder of KICORA, Deo Baribwegure, radio is the best medium to reach and educate remote villages with poor infrastructure.

#### 1.6. Research Design

This research was carried out between March and May of 2019 in Kigoma, Tanzania. Two radio shows about albinism were recorded for this research in order to assess the effects. 250 participants were selected for participation in this research through purposive sampling. The data was collected through a combination of quantitative measurements and qualitative interviews, and were analysed using SSPS and ATLAS.ti. An extensive version of the research design can be found in Chapter 4.

#### 1.7. Thesis Outline

The Theoretical Framework in Chapter 2 provides a definition of the concept of stigmatization in relation to albinism. Furthermore, the reasons for stigmatizing attitudes in Tanzania are explained and different SRIs are discussed. Then, the operationalization of measuring stigmatizing attitudes is explained in Chapter 3. In Chapter 4 the Methodology is discussed and it also includes the limitations of the study. In the second part of the study the results of the research are discussed. Chapter 5

displays the results of the data analysis, followed by Chapter 6, in which the main findings are presented and evaluated, the research question is answered and recommendations for further research are given.

## 2. Theoretical Framework

In a country where most people have a dark skin, the light skin colour of PWAs makes them stand out. This has given rise to the stigmatization of PWAs. To understand the effects of a radio intervention to reduce stigmatizing attitudes related to PWAs in Tanzania, it is important to address the concept of stigmatization, and more specifically, stigmatizing attitudes towards PWAs. The term stigmatizing attitudes is commonly mentioned in this study. In Section 2.1. this term will be defined. Furthermore, the specific causes of albinism-related stigmatization in Tanzania and the state of the art on SRIs, and particularly radio education, are of importance. These topics are discussed in the Sections 2.2. and 2.3.

### 2.1. Stigmatization

Goffman (1963) first defined stigma as a physical or social attribute or sign that devalues an actor's identity and disqualifies the actor from full social acceptance. Scholars later shifted the focus of stigma from individual attributes to a more societal context (Sermitirong & Van Brakel, 2014). Stigma has its roots in 'differences', which can be related to personality, physical appearance, illness, disability, age, gender or sexuality (Mason et al., 2001). The pain and the emotional hurt that the stigmatized experience is directly connected to the pity, fear, disgust and disapproval of this difference expressed by other people (Mason et al., 2001). Hence, stigmatization is a social process, created by people out of fear for the disease, by contrasting those who are 'normal' to those who are 'different' (Parker & Aggleton, 2003).

Stigma includes three components: problems of knowledge (ignorance and misinformation), problems of attitudes (prejudice and perceptions), and problems of behaviour (discrimination and physical attacks) (Beyondblue, 2015). However, improving the knowledge about albinism will not necessarily impact the attitudes or behaviour (Thornicroft et al., 2007). Therefore, comprehensive stigma reduction strategies need to address all three components of the stigma (Beyondblue, 2015).

Stigmatized individuals or groups are often socially excluded in their society. Social exclusion is a process of change in the whole society that has negative consequences for some of the people (Byrne, 2005). Social exclusion is often characterized by unemployment, poor skills, low incomes, poor housing, experience of high crime, bad health and family breakdown. Discrimination and prejudice are behavioural methods to separate and exclude individuals from society and consequently from societal services like housing, education, health care and social support (Mason et al., 2001). Subsequently, social exclusion can lead to low self-esteem, poor social relationships, isolation, depression and self-harm.

One of the largest potentially stigmatised groups, is the group affected by illness and disability (Mason et al., 2001). Health-related stigma is characterized by exclusion, rejection, blame, or

devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health-related condition (Weiss, Ramakrishna & Somma, 2006). Stigmatizing attitudes come from many sources like the community, media, health and social services, the educational system and legislation (Van Brakel, 2006). Weiss et al. (2006) describe how stigma can further impair physical health or affect mental health of the stigmatized. The affected individuals can experience psychological stress, depression or fear, or exclude themselves (even further) from participating in society (Van Brakel, 2006).

### 2.1.1. Stigma Concerning Albinism

Albinism is an example of a health-related disorder that often causes stigma and often negatively affects social inclusion and access to education and employment for PWAs (Burke et al., 2014). In Africa, the level of stigmatization and discrimination towards PWAs is much higher than in other continents, as the difference in skin-colour is more visibly present (Brocco, 2016). Stigma is also culturally defined and particular characteristics are either accepted or rejected between culturally diverse groups (Mason et al., 2001).

Lund (2001) showed that children with albinism in Zimbabwe experienced stigmatization and discrimination both at school and at home. Stigmatizing attitudes identified by the students were name-calling, being ridiculed, beaten and avoided by peers who would not eat or play with them, and being mocked and avoided by family members, who would not share food or clothes with them. Furthermore, some children indicated that they were placed in the sun to become accustomed to UV-radiation. Being exposed to extreme forms of stigmatization from an early age on, will have permanent consequences for the self-esteem and development of PWAs for the rest of their lives (Baker et al., 2010). Particularly in Tanzania, stigmatization and discrimination of PWAs is more often manifested through violent (sexual) attacks and murders than anywhere else in the world (Burke et al., 2014; UTSS, n.d.).

That PWAs are often seen as 'incomplete humans' is also represented through language. 'In Tanzania, the terms include 'zeruzeru' (ghost), 'mzungu' (white person) and 'dili' (which literally means deal, and refers to the trade of the body parts of people with albinism on the black market)' (Brocco, 2016: 230). According to the UTSS (2012: 2), the only correct term to refer to a PWA is 'a person with albinism', because it focusses on the person rather than the disability. However, while changes in vocabulary and the passage of time can demonstrate acceptance of differences, they cannot fully eradicate stigma and alter complex cognitive behavioural aspects of stigmatizing attitudes (Mason et al., 2001).

The beliefs that PWAs are not like other human beings and that their body parts possess magical powers that can bring wealth, power and fortune, causes discrimination and social exclusion.

Moreover, it creates fear of moving around freely and being part of society. As a result, PWAs suffer from psychological stress and the social exclusion increases extreme poverty and less access to livelihood assets. This creates a vicious circle where poverty and poor living conditions intensify stigmatization, leading to further social exclusion (Bonner, 2006).

Over the last decade, the government of Tanzania and several NGOs have attempted to raise awareness about albinism. However, especially in rural areas where PWAs continue to face stigma and rejection of their community and sometimes their own family, progress remains fragile (HRW, 2019).

In summary, stigmatization of PWAs has short- and long-term negative consequences on their lives. These are manifested, lived experiences of social isolation, extreme poverty, fear, lack of education and unemployment, among other indicators of social exclusion. In the case of stigmatization towards PWAs in Tanzania, the stigmatization often comes from cultural beliefs, superstition and local mythology that attribute magical powers and sub-human characteristics to PWAs (Burke et al., 2014).

### 2.1.2. Stigmatizing Attitudes

An attitude is 'a mindset or a tendency to act in a particular way due to both an individual's experience and temperament' (Pickens, 2005: 44). Attitudes are general evaluations that people have regarding people, objects, and issues. An attitude is often expressed through words or behavior. Therefore, behavior is the embodiment or action following a certain attitude.

Although closely related, attitudes differ from perceptions. Perceptions are a recognition and interpretation of sensory information (Qiong, 2017). People select, organize and interpret this sensory information differently and therefore people can have different perceptions. Attitudes can change because of a learned tendency to evaluate things in a certain way and a difference in perceptions also leads to a difference in attitudes (Cherry, 2019).

An attitude can have a powerful influence on behavior (Cherry, 2019). However, behavior not always corresponds to an attitude (Ajzen & Fishbein, 2000). For example, a parent might think that his child with albinism is not as smart as other children, however, that does not necessarily mean that the parent will therefore not send the child to school. Furthermore, behavior is more reliant on the situation and is ruled by social norms, while attitudes are formed during a lifetime of experiences and observations and depend on perception (Surbhi, 2017).

Beyondblue (2015) distinguishes four different types of stigma: personal stigma: a person's own stigmatizing attitudes about other people; perceived stigma: a person's perceptions about the stigmatizing attitudes that other people hold; self-stigma: the stigmatizing views that individuals hold about themselves; and structural stigma: the policies of private and governmental institutions and cultural norms that restrict the opportunities of the stigmatized. This research focusses on the personal and perceived stigma, where personal stigma refers to an individual's personal thoughts and beliefs

about albinism, while perceived stigma represents an individual's perception of what other people think and feel about albinism (Griffiths et al., 2006).

According to Latalova, Kamaradova & Prasko (2014) perceptions held by the public that the stigmatized individual is socially undesirable, can lead to stigmatizing attitudes by family members and community members and even by the stigmatized themselves. In previous studies, participants rated other people's stigma as being higher than their own personal stigma (Calear, Griffiths & Christensen, 2011). These differences in perceived and personal stigma could be influenced by the social desirability bias in which people tend to answer more socially desirable and hold back negative attitudes. Another reason for differences between both types of stigma could be that people overestimate the levels of stigma in the community. Therefore, it is important to investigate and address both types of stigma (Calear et al., 2011).

## 2.2. Reasons for Stigmatizing Attitudes

### 2.2.1. Witchcraft

In Africa, witchcraft provides answers to many of nature's mysteries and oftentimes explains social and political misfortunes (Tebbe, 2007). In practice, witchcraft is often used in order to harm others or to help oneself at the expense of others. This is done by the secret use of the supernatural power for evil (Tebbe, 2007). In Tanzania, belief in witchcraft is widespread and it is part of daily life in all social settings and in all locations, though, the beliefs and practices can vary greatly between places and even within a community (Mesaki, 2009; Tebbe, 2007). The Pew Research Center (2010) conducted a study of 25,000 people in nineteen sub-Saharan African countries, including Tanzania, and found that 62% of the Tanzanian population believes in witchcraft. Moreover, 80% of the population believes that certain people can cast spells and curses while 49% of the population believes that sacred objects can protect them from harm. And finally, 43% believes in the effect of traditional healers.

Attacks on PWAs are often driven by traditional 'witchdoctors', and carried out by contract killers. The witchdoctors claim to use supernatural power to cause or prevent death, sickness, loss of cattle or loss of property (Tebbe, 2007). Albino body parts, blood and hair are believed to bring wealth and fortune and are used in witchcraft potions (Burke et al., 2014) – 'In Tanzania, they believe that albinos have magical powers. If you kill an albino and you have a bone you can get rich. The private part of an albino, the blood, hair and flesh will make you rich and help you get a promotion at work' (cited in: Phatoli et al., 2015: 7). The body parts are often taken from live victims. This is because it is believed that the screams of victims being hacked, enhances the potency of the medicine (UTSS, 2012).

It is believed that the market for albino body parts exists mainly, if not solely in Tanzania (IFRC, 2009). A single potion or talisman will sell for roughly \$2,000, while an entire body of a PWA could

raise the equivalent of up to \$75,000 (Alum, Gomez & Ruiz, 2009; IFRC, 2009). As these potions and talismans are so expensive, it is often the 'wealthy businessmen and women in the mining and fishing industries that are fuelling the growing market for albino body parts' (Alum et al., 2009: 12). Also, politicians provide a high demand of magical potions. Attacks on PWAs peak especially during political elections, when politicians are seeking power (Uromi, 2014).

People who believe in witchcraft often do not question the authenticity of witchdoctors, even though schools often teach them that natural occurrences instead of evil spirits can cause epidemics, disorders and natural disasters. The vast majority of the killings of PWAs occurred in remote areas where other religious faiths were lacking and the villagers were uneducated. Consequently, witchdoctors in these villages enjoy great power and respect (Alum et al., 2009).

### 2.2.2. Myths and Superstitions

Myths and superstitions refer to the belief in extreme fantasies in an attempt to explain occurrences that are not well understood, out of the ordinary or uncontrollable. These explanations fulfill a fundamental human need to make sense of the world (Baker et al., 2010). They have no immediate empirical foundation and are often attributed to some supernatural force or power (Mulemi & Ndolo, 2014). In Africa, superstitious beliefs and myths are more prevalent among the less educated population.

Besides witchcraft, there are other superstitions and myths that affect the stigma attached to albinism. For example, some people believe that albinism is contagious and that touching someone with albinism can cause albinism to them as well. Other people believe that albinism is a curse from God or the devil. One of the most powerful myths is that PWAs are ghosts or not human and that they thus cannot die but simply disappear (Clarke & Beale, 2018; Cruz-Inigo et al., 2011; UTSS, 2012): 'Albinos don't die, they just go missing and they disappear. Last year when I was pregnant, I was told that I must not look at the albinos because if I do I will get a child with albinism or if I do look at them by mistake I should spit at them to avoid a child with albinism' (cited in: Phatoli et al., 2015: 6).

Sometimes it is believed that sex with women with albinism can cure infertility or HIV/AIDS (Clarke & Beale, 2018; Cruz-Inigo et al., 2011). Furthermore, some people believe that albinism is brought by a mother's infidelity with a Caucasian man (Alum et al., 2009): 'Honestly, I think albinism is a curse because people always stare at me, talk about me behind my back and also make very nasty remarks when I pass, saying that I do not know that my father is not black but is a white person and that is why I look the way I do' (cited in: Phatoli et al., 2015: 5).

Another incorrect assumption about PWAs is that they will go blind. Consequently, PWAs are often sent to schools for the blind (Lynch et al., 2014). However, most students with albinism are capable of attending regular schools. Another problem fueling the assumption that PWAs are unable

to learn or are less smart than others is the lack of visual aid in schools. This increases the likelihood of dropping out and consequently unemployment (UTSS, 2012).

All these myths and superstitions towards PWAs tend to dehumanize them. This has far-reaching consequences for the self-esteem of PWAs (Mulemi & Ndolo, 2014). Furthermore, they make it difficult for PWAs to feel included, find a job and marriage prospect and to fully participate in society (Hong et al., 2006).

### 2.2.3. Lack of Knowledge

The above sections indicate a lack of knowledge about albinism among peers and family members of PWAs. The beliefs surrounding albinism in sub-Saharan Africa are often found to compensate for such a lack of knowledge (Baker et al., 2010). However, also the parents of PWAs, teachers and even PWAs themselves often do not fully understand what albinism means and how PWAs can be protected or assisted (Cruz-Inigo et al., 2011).

For example, in a study by Lund (2001), half (50.7%) the surveyed children with albinism in Zimbabwe indicated that they have no idea why their skin was pale. In another study, by McBride et al. (2002), 10% of the participants indicated that they also applied sunscreen at night.

A study about albinism in Malawi shows that the parents of PWAs do not have an adequate explanation about albinism either: 'They were [...] asked what they had been told by medical personnel after the birth of a child with albinism. Not one person had received a good explanation for why a child is born with albinism. Some had been told to keep children with albinism out of the sun, while others had not been told anything' (cited in: Braathen & Ingstad, 2006: 603).

The public educational system often remains unaware of the health implications of PWAs. A 15-year old student relates to this: 'This school is not good. They force us to do activities in the sun. Teachers can also punish you if you say you can't do activities in the sun. They caned me three times and it was very painful' (as cited in: HRW, 2019: 16). Moreover, teachers often think that albinism is associated with abnormal intelligence because of poor vision and the consequential setbacks at school. They are unaware that children with albinism are as capable as other students, but have difficulties with vision and therefore reading, and thus requiring books with enlarged text and seating closer to the blackboard is important (Cruz-Inigo et al., 2011).

Educating the population in sub-Sahara Africa would be a first step in increasing the awareness and knowledge about albinism and the protection of PWAs. According to Lund (2005), radio broadcasts and schools' curricula are helpful ways to raise awareness.

### 2.3. Stigma Reduction Interventions

Superstition, myths and witchcraft in Tanzania are not easily fought. Nonetheless, many interventions have been implemented throughout Africa in order to reduce the stigmatizing attitudes that these beliefs can cause. Escalating violence against PWAs in Tanzania has become prominent in local and international media over the recent years (Burke et al., 2014). Since 2008, numerous awareness campaigns were conducted by organizations as the TAS and the NGO UTSS. Furthermore, public debates were organized by the Tanzanian government (Brocco, 2015). However, according to Brocco (2015), most of the attacks and superstitious beliefs surrounding albinism come from impoverished areas where people are less educated. These people were often not reached by the campaigns and remain unaware of the (bio-)medical explanations of albinism. They therefore complicate the process of inclusion and acceptance of PWAs in their communities.

To reach the people in the more isolated and less educated areas of Tanzania, many interventions have been implemented to reduce albinism-related stigma. Although the issue of stigmatization has substantially been researched, little attention is paid to the effectiveness of SRIs (Cross et al., 2011; Heijnders & Van der Meij, 2006). Most research focusses on describing attitudes towards the affected (Thornicroft et al., 2008), while more evidence-based SRIs are needed to identify effective stigma reduction strategies that can be applied in the field (Bos, Schaalma & Pryor, 2008; Parker & Aggleton, 2003).

The effectiveness of SRIs is largely unexplored because validated tools to measure the effectiveness are often not available, especially in developing countries (Van Brakel, 2006). Most of the scales that have been developed to measure stigma reduction, have been validated in relation to one specific stigmatizing condition and can therefore not be applied to SRIs in relation to other conditions. Link et al. (2004) emphasize the importance of our capacity to observe and measure stigma reduction in order to scientifically understand it. There is a need for more research on stigma assessment tools and they should be adapted to the context of different health-related stigmas (Van Brakel, 2006). All health-related stigmas have different and complex features that make it impossible to apply the same SRI to all stigmas (Cross et al., 2011). However, most research on SRIs focusses on HIV/AIDS, mental disease or leprosy. Hence, special attention to the particular characteristics of albinism is needed in order to implement a successful albinism-related SRI.

Existing SRIs related to albinism do not seem to be effective and do not seem to reach all areas of Tanzania. This is because people, especially in rural areas, continue to understand and explain albinism in a religious or superstitious discourse (Brocco, 2015; Cruz-Inigo et al., 2011). Research on the lived experiences of PWAs usually focusses on the stigmatization of PWAs (Baker et al., 2010; Brocco, 2015; Hong et al., 2006). Scholars give examples of existing SRIs (Brocco, 2015; Bryceson,

Jønsson & Sherrington, 2010; Cruz-Inigo et al., 2011) and recommendations for inclusion in education of children and young PWAs in Malawi (Lynch & Lund, 2011). However, none of the research focusses on the effectiveness of SRIs and current SRIs are not evidence-based.

### 2.3.1. Radio Education

Radio can be used as a tool for development and education worldwide. It can reach its listeners, even in the most remote places and also includes the illiterate population. In addition, the broadcasting of radio is relatively cheap compared to other types of media. The radio is therefore the most universal and versatile medium of communication (De Fossard, 2005). In addition, in Tanzania the radio is the most consistently available medium for citizens across all income levels and locations (Murthy, 2011).

Radio shows have been used both as SRI as well as an educational method on many occasions – for example, Kuhlmann et al. (2008) used radio role models in a radio drama to prevent mother to child transmission of HIV and promote HIV testing among pregnant women in Botswana; Sallar and Somda (2011) discussed the use of radio in reducing stigma related to homosexuality and HIV in the continent of Africa; Valente et al. (1994) provide evidence for the effectiveness of a radio drama to promote family planning in The Gambia; and a radio phone-in was researched by Laughrane et al. (2013) in relation to mental health education in order to reduce stigma by influencing behaviour.

Radio interventions have also been used in relation to albinism (Lund, Massah & Dart, 2014; United Nations Educational, Scientific and Cultural Organization (UNESCO), 2016). However, the effectiveness and impact of these strategies and interventions are rarely evaluated. Only one study, conducted by UNESCO (2016), in which a radio program was used to sensitize people against discrimination of PWAs, indicated that, although some misconceptions about albinism remained, people's perceptions were changing for the better. However, the study was only based on the evaluation of 28 participants and recommendations were made for more evidence-based research on the effectiveness of radio interventions in relation to albinism.

#### 2.3.1.1. *Dramatized edutainment*

One possibility for a radio intervention is an albinism-themed educative and entertaining drama. According to De Fossard (1993; 2005), edutainment is the key to bring about successful social change. Dramatized radio can be used to engage listeners' emotions while informing them or modelling them to adapt new behaviour (De Fossard, 2005). Audience of a dramatized radio intervention indicated that they could more easily identify with the characters and understand the relevance of the storyline (Bilali & Vollhardt, 2015). The format of a drama has also proven to increase critical reflection on listeners' own behaviour (Bilali & Vollhardt, 2015).

#### *2.3.1.1. Contact-based education*

Brown, Macintyre and Trujillo (2003) argue that contact as a strategy in combination with an educational intervention is one of the most promising approaches to reduce health-related stigma. According to Heijnders and Van der Meij (2006), contact strategy does refer to an interaction between the affected person and the public, with the aim to reduce stigmatizing attitudes. The contact strategy as a way of SRI can be direct (face-to-face) or indirect (through the media or recorded testimonial). With the contact strategy, the stigmatized is able to clarify and dispel misinformation and generate empathy. In turn, this can reduce stigma and prejudice towards the affected (Brown et al., 2003).

In previous research on SRIs related to the stigma attached to mental illness, contact-based strategies have proven to be effective (Nguyen, Chen & O'Reill, 2012; Patten et al., 2012; Papish et al., 2013; Wong et al., 2018). However, more research is needed to prove the effectiveness of the contact-based strategy for other health-related stigma's, like albinism.

### 3. Measuring Stigmatizing Attitudes

As mentioned in the previous chapter, in this study two different types of stigma are measured: the perceived stigma and the personal stigma. The perceived stigma involves the perceived stigmatizing attitudes of the community in general, and the personal stigma refers to stigmatizing attitudes of community members themselves (i.e. the participants in this study). A combined measurement of both types of stigma provides a more reliable score of social stigma, as explained in Section 2.1.2.

Research findings suggest that there are two effective approaches to reduce stigma: educational approaches which challenge inaccurate stereotypes and replace them with factual information; and contact approaches, which includes interpersonal contact with a person with albinism (Beyondblue, 2015). This study uses two different stigma reduction strategies. Both strategies are educational radio interventions that inform the audience with factual information. The radio drama challenges inaccurate myths more extensively, while the radio interview focusses more on the similarities between PWAs and other people. More information on both radio interventions can be found in Appendix A.

To measure attitudes, surveys are usually designed using 5-point response formats, e.g. Likert-type ('strongly agree-strongly disagree') or frequency ('always happens-never happens') (Pickens, 2005). A popular method to measure personal stigma is the Social Distance Scale (SDS) (Beyondblue, 2015; Yang & Link, 2015). This scale was first developed by Bogardus (1925) to 'assess the attitude of individuals to others free from the influence of other personality attributes' (Yap et al., 2014: 50). This scale measures the intended avoidance behavior (social distance), by asking people how willing they would be to move next door to; befriend; work with; or have their child marry a person with albinism as depicted in a vignette (Beyondblue, 2015).

To measure the perceived stigma of the community, another method is used: the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS). This scale is based on the Explanatory Model Interview Catalogue (EMIC) developed by Weiss (1997). The EMIC is a framework which can be used to investigate stigma. Rensen et al. (2010) and Van Brakel et al. (2012) developed and (partially) validated a stigma scale based on the EMIC specifically for assessing people's perceptions of stigma from the community (Peters et al., 2015). The EMIC-CSS includes items that can be conceptualized to assess perceived attitudes and perceived behavior towards PWAs.

Both scales assess elements of 'social stigma', but take a different approach; the EMIC-CSS measures how albinism is perceived in the community of the respondents, while the SDS assesses the personal attitudes of the respondent towards PWAs. Peters et al. (2015) studied and validated the combination of the EMIC-CSS and the SDS as a way to assess levels of social stigma in the field of leprosy in Indonesia. The combined score of both scales was used as the overall score and higher scores

reflect greater levels of social stigma (Peters et al., 2015). This study uses the same approach as Peters et al. (2015). De Groot (submitted) adjusted and validated these scales in order to measure albinism-related stigmatization in the Tanzanian context.

Both the EMIC-CSS and the SDS do not focus on individual knowledge about the stigmatized. Nevertheless, knowledge is an important component to measure stigma (Beyondblue, 2015). Therefore, besides the two scales, the pre- and post-measurements also include knowledge questions about albinism. The knowledge questions are of importance in order to understand where stigmatizing attitudes come from and whether or not an increase of knowledge results in a decrease of stigmatizing attitudes.

Additionally, the surveys include demographic questions in order to measure or eliminate external demographic characteristics as factors of stigmatizing attitudes. And, finally, the level of interest of both interventions is measured by using an entertainment scale. A more detailed outline of the quantitative research follows in Sections 4.3.2. and 4.3.3.

## 4. Methodology

This research focusses on the effects of two different radio education interventions aiming to improve the knowledge about albinism and reduce the stigmatizing attitudes related to albinism in the selected communities in Tanzania. This chapter describes the methods used to conduct the study. The area of study, the sampling method and study population are explained in Section 4.2. Moreover, the materials used to collect the data, the participant characteristics and the data analysis are discussed.

### 4.1. Approach

In order to assess a change of knowledge and attitudes related to albinism in Tanzania, quantitative and qualitative methods have been used. Surveys with questions and scales were used to pre- and post-measure the knowledge about albinism and levels of albinism-related stigma of the community in Kigoma, Tanzania. In addition to the quantitative measurements, short (group) interviews were held before and after the intervention in order to evaluate the effects of the radio interventions in larger detail. Table 1 provides an overview of the procedure. A more detailed explanation of this overview follows in the next sections.

*Table 1: Overview of procedure*

<b>Phase</b>	<b>When</b>	<b>Method</b>
Baseline	Directly before radio intervention	Short (group) interviews Pre-measurement survey - Demographic questions - Knowledge questions - EMIC-CSS questions - SDS questions
Radio intervention		Radio Strategy (drama or interview)
Evaluation	Directly after radio intervention	Short (group) interviews Evaluation survey - Entertainment questions
Long-term effect	Two to five weeks after radio intervention	Short (group) interviews Post-measurement survey - Knowledge questions - EMIC-CSS questions - SDS questions

The radio interventions were implemented directly after the pre-measurements and the first short (group) interviews. Two different radio interventions were used: the edutainment-based radio drama and the contact-based radio interview. The contents of these radio interventions are explained in larger detail in Section 4.3.1.

Because of technical delays at KICORA radio, it has been impossible to broadcast the recordings through the KICORA community radio network during the time of the research. Therefore, this study is based on radio recordings that were played directly at the selected households of the participants. In five cases the place of research was not an actual household but a place of work, a shelter for the rain or a coffee house. For convenience, these locations are also labelled as 'household'. Besides the households, one church group of eleven participants was also selected for participation in this research: the Pentecostal FPCT church, located in Mwanga, Kigoma city. The church was connected to the networks of KICORA Radio and it was decided to include the church group in the research as all respondents could guarantee their availability to participate in the post-measurement. Despite the church group being of the same religion, they provided a varied demographic sample for this study.

For the interest of the study, participants living in the rural regions were preferred over participants living in the urban regions of the Kigoma districts, as it was expected that this would include a generally less educated group of people, and that therefore their knowledge about albinism would be lower and their stigmatizing attitudes about PWAs would be higher. Therefore, SRIs in the villages around Kigoma city were expected to be more effective.

The data was collected with the help of a research assistant who spoke both English and Swahili. This research assistant explained the purpose of the study to potential participants, she helped the participants with filling out the surveys and she functioned as a translator between the researcher and the participants during qualitative data collection.

## 4.2. Data Collection

### 4.2.1. Area of Study

The study was conducted in the Kigoma region in Tanzania between March and May of 2019. Kigoma is divided into eight districts. The area of study is the two districts in closest proximity to Kigoma city: Kigoma Rural and Kigoma Urban. As of 2017, the total population of these districts were 211,566 and 215,458, respectively (TNBS, 2017a). The two districts are divided into 31 wards; each ward includes a number of villages. In total there are 71 villages in Kigoma Rural and Kigoma Urban (TNBS, 1998).

The research took place in fourteen villages and in one church group. Nine villages were located in Kigoma Rural, five in Kigoma Urban. The selected church was also located in Kigoma Urban.

Figure 3 provides an overview of the districts Kigoma Rural and Kigoma Urban. Figure 4 shows the selected villages in which this study was conducted.

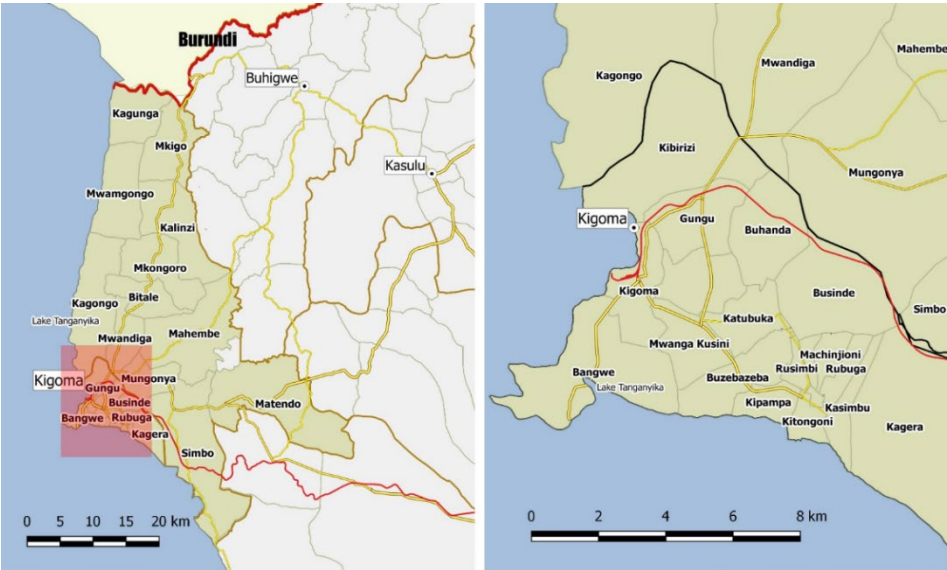


Figure 3: The districts Kigoma Rural (Left) and Kigoma Urban zoomed in (right)

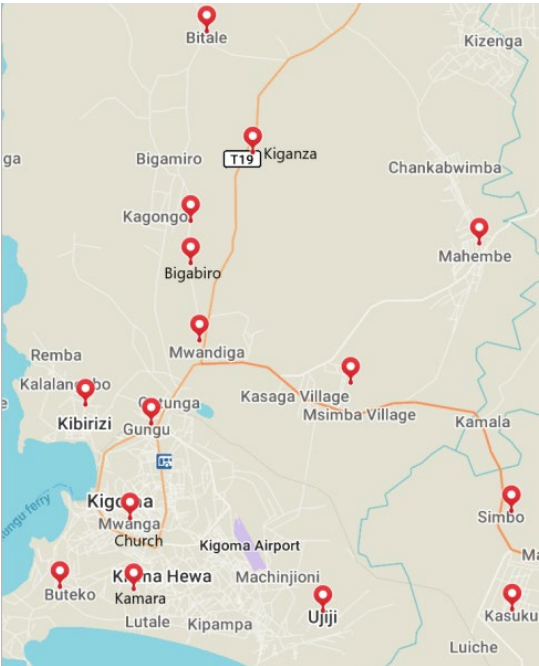


Figure 4: The area of study with selected villages

#### 4.2.2. Sampling

A minimum sample size of 120 adult participants was determined to be sufficient for statistical analysis for each radio intervention strategy. For the post-measurement it was determined that a minimum of 80 participants would be sufficient. It was expected that around 33% of the participants would not be willing to participate in or be available for the re-test. Therefore, a minimum of 240 participants were needed to participate in this study in order to adequately measure stigmatizing attitudes towards albinism before and after the radio interventions.

As the qualitative data collection took place at the same time as the quantitative data collection, it was decided that the same number of respondents would be selected to participate in the short (group) interviews. However, in practice the respondents from the qualitative data were not always participating in the surveys and the participants from the surveys were not always participating in the interviews. Nevertheless, each household participated in both types of data collection. The data collection from the qualitative data is only recorded per household and not per participant.

The sampling method used for this research was purposive sampling. Due to time and budget limitations, 20 out of the 71 villages in the districts were selected as a possible place of research based on their proximity to Kigoma city. Ultimately, the research took place in 14 of these 20 villages. There were only two restrictions for the selection of participants in this research. The participants had to be at least 18 years of age at the time of research and because of the post-measurement the participants had to live at, or in close proximity to the place of research. Moreover, in most cases, households with only one potential participant present during pre-measurement were excluded due to time restrictions.

The aim of the purposive sampling method was to get a varied and representative sample of the community in each village and select respondents that balanced on categories as gender, age and religion. This sampling method was chosen over random sampling as it turned out to be difficult to find sufficient people both at home and willing to participate.

#### 4.2.3. Procedure

The data was collected as follows: one of the 20 selected villages was chosen by the researcher to visit, after being dropped in the centre of the village, one of the streets was chosen by the researcher to enter. Once the researcher expected to have found a household where at least two adults were present and available, the household was selected for possible participation. Then, the research assistant would explain the purpose of the study and ask for their permission to participate. The research assistant would also inform the participants that a second round of this study would take place at least two weeks later. Once the possible participants would agree to participate, the short

(group) interviews would take place. After the interviews, the participants were asked to fill out the surveys. If they were not able to read and/or write, the research assistant would help out. After the surveys were filled out, the radio intervention was played on a speaker. Next, a second round of short (group) interviews was held. And finally, the participants were asked to fill out another short survey about their experience of the radio intervention.

Following, the next household would be selected for participation. Depending on the presence and availability of sufficient participants, this could be in the same street or in another street. Other factors that influenced the selection of a household were rainfall, a shortage of either men or women on the sample and unavailability of households of more than one person. Each day, on average four households were selected. The data collection would usually take between one and two hours per household.

For the re-test each household was revisited up to seven times, depending on the presence and availability of the participants. The participants that were present, were asked to participate again for the post-measurement. If they accepted, a third round of short (group) interviews was held, followed by the post-measurement surveys. Finally, the participants were shown three pictures illustrating different forms of interaction between an African person and someone with albinism. The data collection of the re-test would usually take between half an hour and an hour and a half.

## 4.3. Materials

### 4.3.1. Radio Interventions

In this study the effectiveness of a radio intervention targeted at improving knowledge about albinism and reducing albinism-related stigmatizing attitudes was analysed. To assess the data, two different radio strategies were used and compared. In this section a short summary of each intervention is given. A complete (translated) transcript of both radio interventions can be found in Appendix A.

The first intervention was a radio drama. Two episodes of seven minutes each were recorded especially for this study by a radio-DJ in Mbeya, in the south of Tanzania. For this study, both episodes were combined into one for the purpose of feasibility. This drama strategy focusses on the story of Sarah, a young nursing student with albinism. In the first episode she is talking to her classmate about her childhood and the challenges she faced growing up because of albinism. The second episode takes place in the hospital. Sarah has to treat a patient who does not want to be touched by her because he thinks albinism is contagious. A doctor then explains that albinism is not contagious, that it is caused by albinism genes from the family and that it has nothing to do with witchcraft. Furthermore, he explains albinism occurs in humans, animals and plants all around the world. The patient feels bad and

apologizes. Then the voice-over takes over and says that the patient changed his idea about PWAs and that Sarah and her classmate are getting married.

The second intervention is a nine-minute radio interview in which Sijajali, a person with albinism, explains about his life. An interviewer from KICORA radio was present to guide the intervention. They discuss superstitions and misinformation about albinism. For example, Sijajali explains the cause of albinism and how albinism affects his skin and eyes. He also undermines the myths that PWAs can see better in the dark or from far away and that they disappear instead of die. Furthermore, this contact strategy emphasizes that PWAs are no different from other people in their community: Sijajali explains that he has a wife and five children, all without albinism, and that he studied to become a teacher. He states that he can do the same things as other people, apart from staying in the sun too much. He ends with telling the audience that he likes to sing and mentions a religious song that he and his family love to listen to.

Both interventions explained some but not all knowledge items that were included in the survey. Nevertheless, both interventions emphasized how PWAs are psychologically no different from people without albinism. Table 2 shows a comparison of information covered in each of the interventions. Section 4.3.2.2 explains more about which knowledge items from the surveys were covered in both interventions. Even though some items were not covered in the interventions, they could nevertheless lead to a correct answer indirectly by listening and understanding the other information in the radio intervention.

*Table 2: Items covered in the radio interventions*

<b>Items covered</b>	<b>Drama</b>	<b>Interview</b>
Albinism is prevalent in other countries	Yes	Yes
The cause of albinism	Yes	Yes
PWAs can study	Yes	Yes
PWAs can marry someone without albinism	Yes	Yes
PWAs can have children without albinism	No	Yes
PWAs have problems with the skin	No	Yes
PWAs have problems with the eyes	No	Yes
PWAs can get cancer	No	Yes
PWAs need long clothes / hat / sunglasses	Yes	Yes
PWAs have problems being part of the society	Yes	Yes
PWAs don't die but disappear	No	Yes
'Zeruzeru' is not the correct reference	Yes	No
PWAs are like other people	Yes	Yes

Albinism is not contagious	Yes	No
PWAs can do the same as other people	Yes	Yes
Albinism is prevalent in animals and plants	Yes	No
PWAs cannot see better at night or from far away	No	Yes
PWAs are being mistreated	Yes	No

#### 4.3.2. Quantitative Data: Pre- and Post-Measurements

Three surveys were included in this study. One survey to pre-measure knowledge and stigmatizing attitudes related to albinism, one to post-measure these factors and a final survey directly after the radio intervention to assess how entertaining the radio intervention was for the participants.

The pre-measurement survey included participant-related demographic questions, albinism-related knowledge questions, and the two scales EMIC-CSS and SDS. The post-measurement is based on the same albinism-related knowledge questions, EMIC-CSS questions and SDS questions. The post-measurement was carried out between two and five weeks after the radio interventions, in order to measure the ‘longer’-term (hereafter: long-term) effects of the radio intervention.

##### 4.3.2.1. Demographic questions

In the pre-measurement survey the participants were asked to fill out nine demographic questions. These questions can be found in Table 3.

Table 3: Demographic questions

D-01. What is your date of birth?*
D-02. What is your level of education?
D-03. Where were your born?*
D-04. Where do you live now?*
D-05. To what tribe do you belong?*
D-06. What religion do you adhere to?*
D-07. What is your profession?
D-08. Do you know someone with albinism?
D-09. Do you have a person with albinism in your family?

\* Open-ended questions

##### 4.3.2.2. Knowledge questions

To assess the knowledge of the participants regarding albinism, 11 knowledge questions were included in the survey. Knowledge questions are missing in the pre-test in 50 surveys (38%) of the radio drama

as they were removed due to time limitations. It was only decided to include the knowledge items again in the surveys after four days of field research, because of their scientific value for this research. For the post-test the knowledge questions were always included in both interventions. These questions can be found in Table 4 and shows which items were covered in each of the interventions. The three answering possibilities of the questions were: ‘yes’, ‘no’, and ‘I don’t know’.

Table 4: Knowledge questions

Do you think:	Covered in drama	Covered in Interview
K-01. albinism is contagious?	Yes	No
K-02. a person with albinism will turn blind?	No	No
K-03. a person with albinism can get a child without albinism?	No	Yes
K-04. a person with albinism can learn how to read and write?	Yes	Yes
K-05. a person with albinism need to eat special food?	No	No
K-06. a person with albinism can go to a normal school?	Yes	Yes
K-07. a person with albinism is bewitched?	No	No
K-08. a person with albinism can get skin cancer from being in the sun?	No	Yes
K-09. a person with albinism does not die but just disappears?	No	Yes
K-10. the body part of someone with albinism can bring good fortune?	No	No
K-11. it is the fault of the mother to get a child with albinism?	No	No

4.3.2.3. EMIC-CSS

The EMIC-CSS includes 16 questions that measure the perceptions the respondents have about the stigmatizing attitudes of people in their society towards PWAs. It covers areas of life that are often affected by stigma, such as marriage (prospects) and work and aspects such as avoidance, perceptions of self-worthy and shame (see Table 5). The answer possibilities were divided into five categories: ‘it never happens’, ‘it rarely happens’, ‘it happens sometimes’, ‘it happens often’, ‘it happens always’.

Table 5: EMIC-CSS questions

E-01. Would the family of someone with albinism keep this person hidden out of shame?
E-02. Would the family of someone with albinism feel less worth?
E-03. In your community, does albinism cause shame or embarrassment?
E-04. Would people in your community think less of a person with albinism?
E-05. Would people in your community exclude a person with albinism?
E-06. Would people in your community refuse to visit the home of a person with albinism?

E-07. Would people in your community think less about the family of a person with albinism?
E-08. Would albinism cause any problems for the family in the community?
E-09. Is albinism a problem for a person to get married?
E-10. Would getting a child with albinism cause problems in a marriage?
E-11. Would having a relative with albinism cause problems for someone to get married?
E-12. Would people buy goods or services from a person with albinism?*
E-13. To have albinism can cause problems in finding work?
E-14. Would people call people with albinism bad names?
E-15. Would people in your community gossip/talk bad about a person with albinism?
E-16. Do people in general fear people living with albinism?

\* Positive item rescored to fit list of negative items

#### 4.3.2.4. SDS

The SDS measures participants' personal attitudes towards PWAs by asking ten questions about their feelings towards PWAs in certain social relationships, ranging from a small to a larger 'social distance' (see Table 6). The answer possibilities for the SDS questions were the following: 'I do not have a big problem', 'I do not have a problem', 'I do have a problem' and 'I do have a big problem'. The questions follow after a vignette about the life of a person with albinism. For the purpose of relatability, the name of this PWA is either John or Joyce, depending on the gender of the participant. The vignette reads as follows:

*John is a 23-year-old man living with albinism. John's white skin looks injured and his eyes move uncontrollably from side to side. John has a job in a telecom prepaid shop that belongs to his uncle. He earns 100,000 TZS per month and is doing well in his job. He cannot do work outside because the sunrays hurt his skin. At his job, John gets along well with his colleagues. John would like to get married. He is considering joining activities, so he can meet people of the same age. He also hopes to get a better job to be able to earn more than in his present job.*

Table 6: SDS questions

S-01. How would you feel to visit a house of someone like John/Joyce?
S-02. How would you feel working together with someone like John/Joyce?
S-03. How would you feel having someone like John/Joyce as a neighbour?
S-04. How about having someone like John/Joyce taking care of your children for a couple of hours?
S-05. Would you permit your child to marry someone like John/Joyce?

S-06. How would you feel about introducing John/Joyce to a young woman you are friendly with?
S-07. How would you feel about recommending John/Joyce for a job working for a friend of yours?
S-08. How would you feel to sit next to someone like John/Joyce in the bus?
S-09. How would you feel to have someone like John/Joyce as a friend?
S-10. How would you feel shaking hands with someone like John/Joyce?

#### 4.3.3. Quantitative Data: Evaluation Survey

Directly after the radio intervention, the participants were asked to fill out another short survey in order to measure the level of entertainment of the radio intervention. This survey consisted of six questions (see Table 7). The answer possibilities of these questions were the following: ‘completely disagree’, ‘disagree’, ‘neither disagree nor agree’, ‘agree’, ‘completely agree’.

*Table 7: Entertainment questions*

ENT-01. The show was very entertaining
ENT-02. I had the sense of being pulled right into the show
ENT-03. The show did not interest me*
ENT-04. I wasn't involved in the show*
ENT-05. I very much enjoyed the show
ENT-06. The show was very important

\* Negative items rescored to fit the list of positive items

#### 4.3.4. Qualitative Data: Short (Group) Interviews

To get a more in-depth understanding of the participants’ knowledge and stigmatizing attitudes towards PWAs, the participants were also briefly interviewed before and after the radio intervention, and again during the post-measurement. This qualitative data provides insight into the direct effects of the radio interventions and how they can influence the attitudes of the community towards PWAs. The data is useful to encourage a variety of responses which provide a greater understanding of the behaviour, opinions or perceptions of the participants on the issues that are discussed (Hennink, 2007). Furthermore, the qualitative approach gives the participants an opportunity to define what lessons they learned from the interventions, which aspects were most relevant and have made the greatest impact (Liamputtong, 2011).

The interviews were usually conducted with all participants of each household at the same time. Only one participant spoke sufficient English to be interviewed by the researcher, the rest of the interviews were conducted in Swahili with the help of a translator. The interviews were directly translated and documented in a notebook at each household. Because of this, and to give the

participants the chance to speak freely, the interviews were not recorded on a voice recorder and transcribed. All interviews were semi-structured.

Before the radio intervention, participants were asked if they ever saw a PWA and how they reacted the first time they did. Furthermore, they were asked about the cause of albinism and how they think albinism affects a PWA.

Directly after the radio intervention the participants were asked what they learned from the radio show and what they thought was the most important message of the radio show. If they indicated to not know the cause of albinism before the intervention, they were asked if they could explain the cause after having heard the radio.

For the post-measurement, not all participants were found back at the same time. Therefore, more often the interviews took place individually. During these interviews the participants were asked what they still remembered about the radio program and what they had learned from it. Furthermore, they were asked whether or not they recently talked to anyone about the radio show. Finally, they were shown three pictures (see Appendix B). One picture showed a person shaking hands with a PWA; the second a mother holding a baby with albinism; the last picture showed a female nurse or doctor with albinism treating a young patient. The participants were asked about their opinion about the interactions presented in the pictures, and if they felt different about it after hearing the radio.

The data gathered from the interviews provided a more in-depth understanding of the participants' knowledge and stigmatizing attitudes towards PWAs before and after hearing the radio intervention. By extension, this contributed to a deeper understanding of the effects of the two radio interventions. Therefore, the qualitative data offers an interesting and important addition to the quantitative data.

#### 4.4. Data Analysis

The quantitative data from the surveys has been analysed using IBS SPSS statistics 25. In this study, only the data is included of participants who filled out both the pre-test as well as the post-test. The reason for this is that a more reliable comparison can be made about the effects of the radio intervention as the data before and after the radio can be linked. When the data would also include the people who only filled out the pre-test, the results turned out differently but no significant differences were found. Appendix C can be consulted for a complete overview of results from all the participants as opposed to only the participants who filled out the pre-test and post-test.

Statistical tests were run as follows: demographic and knowledge items were analysed item-wise. To compare the total knowledge scores, a dichotomised knowledge variable (1=correct answer, 2=wrong answer or 'I don't know') was computed. For each intervention the difference between pre-

and post-test was analysed through the non-parametric McNemar test. Since the knowledge items do not form a scale, a pragmatic sum scale was computed comprising the dichotomised items K-01 up to K-11, to test for significant changes in knowledge before and after the intervention through Wilcoxon Signed-Rank Test.

The EMIC-CSS items were analysed per item and as a sum scale. Item E-12 has been rescored due to its negative formulation. Due to some skewed items, all differences in items before and after intervention were analysed through Wilcoxon signed rank. Scale reliability was analysed through Cronbach's alpha. SDS items were analysed in their original form and at sum scale level through the Wilcoxon Signed-Rank Test, because of the skewed distribution.

To compare interventions pre-test scores and post-test scores were compared for the pragmatic knowledge scale, the EMIC-CSS and the SDS. A difference variable was computed (post-test score minus the pre-test score) to be able to compare the effect of the interventions. The entertainment score was compared through pragmatic sum scale.

The qualitative data is thematically coded according to the interview. Interviews were documented in a notebook per household. Statements mentioned multiple times within one household were counted once. When different answers were given within one household regarding one topic, all different answers were counted. Because of this, the number of statements that were counted per topic and per intervention can vary. The data was categorized and analysed using ATLAS.ti 8 and Excel 2016.

#### 4.5. Limitations

The chosen method comes with some limitations. First of all, to fully assess the effectivity of radio-based SRIs in relation to albinism in Tanzania, the effects should be tested over a longer time period. The research would also provide a more complete overview if it would be conducted in other areas in Tanzania. However, due to time restrictions this was not possible.

Furthermore, Van Brakel (2006) argues that stigma should be assessed from the community perspective as well as from the perspective of the affected persons and their family. Therefore, the success of the interventions should not only be tested from the (perceived) changes in attitude of the community, but also from the perspective of the affected PWAs to assess a possible change in behaviour. This is however difficult to measure, as it remains uncertain if the changes in stigmatization were the result of the interventions or if other factors contributed to these changes. Furthermore, the direct effects of the interventions used in this research will most probably not be noticeable to PWAs within the first few months after the implementation of the radio interventions.

In addition, there are some limitations regarding the measurement of stigma. Stigma is a complex issue which does not mean the same for everyone and does not necessarily align with behavior (Thornicroft et al., 2007). Moreover, this study is based on hypothetical situations and therefore answers will not necessarily correspond with attitudes in real situations (Yap et al., 2014). And finally, the topic of albinism is sensitive in Tanzania and has received a lot of attention over the last decade. The participants might therefore be tempted to provide the researcher with socially desirable answers. Therefore, measuring stigma does not always reflect reality (Calear et al., 2011).

Other limitations in relation to the researcher could include the lack of understanding of the local language, Swahili, or valuable information being misinterpreted by the translator. The fact that the researcher is European, white and female could also consciously or unconsciously affect the results of the research.

## 5. Results

### 5.1. Participant Characteristics

In total 66 households and one church group participated in this research for the pre-measurement, comprising 250 adults: 35 households and a church group (36 sessions, 127 adults) for the radio drama, 31 households (31 sessions, 123 adults) for the contact-based interview. The participants included neighbours, friends and family of the members of the selected households. Out of the 250 participants, 179 were living in rural regions.

For the post-measurement, not all participants were found back. Each household was contacted up to seven times to try and find as many participants back as possible. Some participants were unwilling or unable to participate again. Reasons for not participating a second time included travel, work, illness, weddings, mourning, moving away and not getting permission from the head of the household. For the radio drama 80 participants (63%) participated in the post-measurement; for the radio interview also 80 participants (65%) participated in the post-measurement. For the analysis just the results of the 80 participants who filled out both the pre-test and the post-test have been used. For the qualitative data, the participants that only attended the pre-test were also included. However, for the qualitative research, the data is recorded per household instead of per participant.

On average 48.4% of all the participants was male, 51.6% was female. Their age varied between 18 and 94, with an average age of 42.1. The level of education among the participants was low: 25.1% of the participants were not able to read or write and just 59.6% finished their primary school; only 15.5% finished more than primary education. Regarding their religion, 64.2% is Muslim and 35.8% is Christian. 88.2% of the participants belonged to the most prevalent tribe of the region: the Waha tribe (Olson, 1996). The rest of the participants belonged to 14 other ethnic tribes. The majority of the participants (90%) was self-employed, which usually implies they were farmers. Only 6.8% stated that they had a paid job. Finally, 79.9% of the participants indicated that they knew someone with albinism and 14.1% declared that one of their family members has albinism. Table 8 displays an overview of the participants' characteristics.

Table 8: Demographic statistics of participants

		Drama (%)	Interview (%)
Gender	Men	48.8	48
	Women	51.2	52
Level of education	I cannot read or write	30.7	19.4
	I can read and write	12.9	15.7
	I finished primary school	39.6	50.9

	I finished ordinary level (high school)	12.9	10.2
	I finished advanced level (high school)	2	1.9
	I finished higher education/university	2	1.9
Religion	Christian	42.3	29.3
	Muslim	57.7	70.7
Profession	Paid Job	5.1	8.7
	Own business/farmer	91.5	88.3
	Student	3.4	2.9
Know a PWA	No	26.4	13.6
	Yes	73.6	86.4
Family with albinism	No	88.8	82.9
	Yes	11.2	17.1

## 5.2. Quantitative Research

### 5.2.2. Knowledge questions

For the radio drama intervention there is an improvement on all items and a significant improvement on three items (K-01, K-08 and K-11), whereas with the interview intervention there is an improvement on all items, apart from K-03, where the amount of correct answers remained the same. A significant improvement was found on six items (K-01, K-02, K-06, K-08, K-09, K-11). After the drama intervention the mean in the pre-test is 14.36 (N=39), in post-test 13.22 (N=74), which is a significant improvement in correct knowledge ( $Z=-3.93$ ;  $p=0$ ). For the interview intervention the mean in the pre-test is 13.61 (N=72), in the post-test 12.38 (N=69), which again showed that the intervention caused a significant improvement in correct knowledge ( $Z=-4.91$ ;  $p=0$ ). See Table 9 for an overview of the results of the knowledge questions.

Table 9: Results of knowledge questions

	Drama		Interview	
	Pre-test	Post-test	Pre-test	Post-test
Do you think:	Correct (%)	Correct (%)	Correct (%)	Correct (%)
K-01. albinism is contagious?	75.6	94.8*	80.5	94.7
K-02. a person with albinism will turn blind?	20.5	39.7	31.6	50
K-03. a person with albinism can get a child without albinism?	84.4	92.3	93.5	93.5*
K-04. a person with albinism can learn how to read and	95.6	100*	92.2	98.7*

write?				
K-05. a person with albinism needs to eat special food?	47.7	56.4	67.1	80.5
K-06. a person with albinism can go to a normal school?	97.8	100*	89.6	98.7*
K-07. a person with albinism is bewitched?	86	94.9	90.9	94.8
K-08. a person with albinism can get skin cancer from being in the sun?	70.5	77.9	63.2	79.2*
K-09. a person with albinism does not die but just disappears?	64.4	75	66.2	86.7*
K-10. the body part of someone with albinism can bring good fortune?	52.3	53.2	66.7	76.3
K-11. it is the fault of the mother to get a child with albinism?	84.4	98.7	89.3	98.7
Items highlighted in green showed a significant difference	* Items were directly covered in intervention			

### 5.2.2. EMIC-CSS

For the drama a significant difference can be seen with four items (E-02, E-05, E-06, E-07). The interview intervention showed no significant difference. When we compute the EMIC-CSS sum scale for the drama intervention, the mean in the pre-test is 1.92 (N=68), and in the post-test 1.73 (N=78), which is a significant reduction in the perceived stigmatizing attitudes in the community ( $Z=-3.25$ ;  $p=0$ ). For the interview intervention sum scale the mean in the pre-test is 1.93 (N=71), and in the post-test 1.92 (N=74), which shows that the intervention did not cause a significant reduction in the perceived stigmatizing attitudes in the community ( $Z=-0.74$ ;  $p=0.46$ ). Table 10 provides an overview of the results of the EMIC-CSS.

Table 10: Results of EMIC-CSS

	Drama		Interview	
	Pre-test	Post-test	Pre-test	Post-test
	Mean	Mean	Mean	Mean
E-01. Would the family of someone with albinism keep this person hidden out of shame?	1.79	1,59	1,79	1,86
E-02. Would the family of someone with albinism feel less worth?	2.04	1,62	2,04	1,7
E-03. In your community, does albinism cause shame or embarrassment?	1.45	1.37	1.45	1.57

E-04. Would people in your community think less of a person with albinism?	2.13	1.99	2.13	2.04
E-05. Would people in your community exclude a person with albinism?	1.82	1.56	1.82	1.9
E-06. Would people in your community refuse to visit the home of a person with albinism?	1.82	1.58	1.82	1.74
E-07. Would people in your community think less about the family of a person with albinism?	1.8	1.47	1.8	1.88
E-08. Would albinism cause any problems for the family in the community?	1.48	1.53	1.48	1.64
E-09. Is albinism a problem for a person to get married?	1.75	1.68	1.75	1.61
E-10. Would getting a child with albinism cause problems in a marriage?	2.04	1.81	2.04	1.95
E-11. Would having a relative with albinism cause problems for someone to get married?	1.7	1.53	1.7	1.75
E-12. Would people buy goods or services from a person with albinism?*	2.74	2.71	2.55	2.36
E-13. To have albinism can cause problems in finding work?	1.88	1.62	1.99	2.15
E-14. Would people call people with albinism bad names?	1.86	1.99	2.22	2.03
E-15. Would people in your community gossip/talk bad about a person with albinism?	2.27	1.97	2.37	2.48
E-16. Do people in general fear people living with albinism?	1.93	1.69	1.96	1.81
* Positive item rescored to fit list of negative items Items highlighted in green showed a significant difference				

### 5.2.3. SDS

The drama intervention caused a significant difference on three items (S-01, S-03, S-10). When we compute the SDS, the mean in the pre-test is 1.49 (N=72), and in the post-test 1.29 (N=78), which means the intervention did not cause a significant reduction in personal stigmatizing attitude ( $Z=-1.50$ ;  $p=0.13$ )

The interview intervention caused a significant difference on four items (S-02, S-07, S-08, S-10). When we compute the SDS the mean in the pre-test is 1.3 (N=74), and in the post-test 1.16 (N=74), the Wilcoxon signed-rank test shows that the intervention did cause a significant reduction in personal stigmatizing attitude ( $Z=-2.24$ ;  $p=0.03$ ). See Table 11 for a summary of the results of the SDS.

Table 11: Results of SDS

	Drama		Interview	
	Pre-test	Post-test	Pre-test	Post-test
	Mean	Mean	Mean	Mean
S-01. How would you feel to visit a house of someone like John/Joyce?	1.53	1.24	1.31	1.17
S-02. How would you feel working together with someone like John/Joyce?	1.47	1.31	1.27	1.17
S-03. How would you feel having someone like John/Joyce as a neighbour?	1.49	1.26	1.32	1.17
S-04 How about having someone like John/Joyce taking care of your children for a couple of hours?	1.51	1.27	1.31	1.26
S-05. Would you permit your child to marry someone like John/Joyce?	1.68	1.42	1.45	1.33
S-06. How would you feel about introducing someone like John/Joyce to a young woman you are friendly with?	1.48	1.29	1.29	1.16
S-07. How would you feel about recommending someone like John/Joyce for a job working for a friend of yours?	1.43	1.32	1.35	1.16
S-08. How would you feel to sit next to someone like John/Joyce in the bus?	1.44	1.27	1.26	1.1
S-09. How would you feel to have someone like John/Joyce as a friend?	1.47	1.29	1.24	1.14
S-10. How would you feel shaking hands with someone like John/Joyce?	1.46	1.27	1.26	1.09
Items highlighted in green showed a significant difference				

#### 5.2.4. Entertainment scale

Both SRIs score quite high in terms of entertainment. The drama scores 4.26 (N=102) and the interview scores 4.11 (N=76). For an overview of these results, see Table 12.

Table 12: Results of entertainment scale

	Drama	Interview
	Mean	Mean
ENT-01. The show was very entertaining	4.63	4.56
ENT-02. I had the sense of being pulled right into the show	4.47	4.62
ENT-03. The show did not interest me	3.62	2.78
ENT-04. I wasn't involved in the show	3.46	3.23

ENT-05. I very much enjoyed the show	4.64	4.73
ENT-06. The show was very important	4.68	4.63

### 5.2.5. Comparison between the radio interventions

In terms of knowledge, the sample that underwent the drama intervention had significantly less correct knowledge on albinism in the pre-test ( $Z=-2.05$ ,  $p=0.04$ ). Therefore, a comparison between the interventions might be influenced by this and should be kept in mind while interpreting the results. However, no difference was found on the difference variable between the interventions ( $Z=-.40$ ,  $p=0.69$ ), therefore it might not be surprising that the knowledge level after the interview intervention is significantly higher than after the drama intervention ( $Z=-3.49$ ,  $p=0$ ).

No significant difference was found between the samples on the EMIC-CSS before ( $p=0.9$ ) the intervention and on the difference variable ( $p=0.18$ ). However, the interview sample has a significantly higher score after the interview intervention ( $p=0.05$ ). There is no significant difference between the samples on the SDS before the intervention ( $Z=-0.48$ ,  $p=0.63$ ), nor on the change variable ( $Z=-0.33$ ,  $p=0.74$ ). However, the drama sample scored significantly higher after the intervention ( $-2.09$ ,  $p=0.04$ ). No significant difference in entertainment level was found between the interventions. The entertainment level mean score of the drama was 4.26 ( $N=102$ ), of the interview 4.11 ( $N=76$ ).

## 5.3. Qualitative Research

In the next sections the analysed data from the short (group) interviews can be found. All the quotes used in this section were directly translated during the interviews from Swahili into English by the research assistant. The respondents remain anonymous.

### 5.3.1. Before the Radio Interventions

#### 5.3.1.1. First reaction to seeing someone with albinism

Responses varied when asked how the participants reacted the first time they saw a PWA. The majority of the participants stated that they did not feel anything in particular when they saw a PWA for the first time. They often indicated to have felt indifferent to seeing a PWA because they already knew someone with albinism from a very young age.

However, a large number of the participants was very surprised or confused the first time they saw a PWA. They often wondered what was going on: 'We had so many questions: what is wrong? Why is he born like this? What happened to him? But we had no answers' (interview, session 28); 'I was also surprised. How do you get white children from black parents? I still wonder about this now (drama, session 32)' and 'first you ask questions: are the parents white? Is he from somewhere else?

Is it inherited? If all the answers are no, then it can only be God’s willing, so there is no need to be surprised or scared anymore’ (interview, session 24).

Furthermore, it was mentioned 18 times that participants felt scared the first time they saw a PWA. For example, one respondent said when she was younger her neighbour was a child with albinism but she was still scared of her. Other participants indicated to be scared of PWAs because of their skin or eyes: ‘I never wanted to be close to them. Especially when I saw their eyes. I thought maybe they were ghosts’ (drama, session 23) and ‘I felt scared because of their skin. But there are differences among albinos. Some have good skin, some have bad skin; some have wounds that spray blood. They often have wounds on their mouth and hands’ (interview, session 2).

Participants indicated seven times that they thought it was maybe a mzungu (white foreigner): ‘I used to call an albino a mzungu, but then an albino explained that albinism is different’ (drama, session 36). And three times people felt pity because they either heard of the attacks on PWAs or because their skin was full of wounds. Table 13 provides an overview of the reactions of the participants when they first saw a PWA.

*Table 13: Reaction the first time participants saw a PWA*

<b>Reaction the first time participants saw a PWA</b>	<b>Mentioned (#) times</b>
Nothing happened	32
Were scared	18
Were surprised / confused	28
Felt pity	3
Thought it was a mzungu (white foreigner)	7
Something else happened*	4
<b>TOTAL</b>	<b>92</b>

*5.3.1.2. Explaining the cause of albinism*

When asked what participants think is the cause of albinism, the majority explained that albinism can only be caused by God:

‘When I first saw an albino, I asked my parents what it was, and they told me that the parents did something wrong and this was the punishment of God. It is God’s will to give the parents a child with albinism when they have done something wrong in the society. It’s the payback. This is what we were told by our parents as kids’ (interview, session 2)

'It is Gods will, he created everyone as they should be. I know that science says it is something that the mother is missing in the body but I do not focus on science but only on God's creation' (drama, session 2).

Participants indicated 20 times to know albinism is caused by genetics, and eight times people knew that it has something to do with science, they only did not know what exactly. Often they thought albinism is caused by the lack of something, like protein, vitamins or hormones: '[...] I think that maybe they lack some vitamins. They might not be getting the right food and get an albino because of that' (interview, session 21).

Other explanations for albinism were given eight times. For example, one person explained that albinism is caused by polluted air and water:

'In Africa they cut many trees and then the factories use a lot of smoke which goes into the Ozon layer. In combination with the lack of trees, the smoke brings bad air and when it rains also the rainwater goes bad. Some women were breathing that bad air and drinking the bad water and because of that they could give birth to an albino. [...] Also, science says there are some reproductive problems, and because of that humans can have a disease and carry that disease for a long time. And then because of that they could give birth to an albino' (interview, session 18).

Another person thought that albinism was caused by ghosts: 'It's all about the power of ghosts. They are born like a normal person but will turn into an albino because of the work of ghosts' (drama, session 35). Someone else disagreed and said it is all about the genetics of the parents. Finally, 31 times, people said not to know the cause of albinism. Table 14 displays a summary of these results.

*Table 14: What participants think is the cause of albinism*

<b>What participants think is the cause of albinism</b>	<b>Mentioned (#) times</b>
God's will	33
Genetics	20
Don't know	31
Something to do with science	8
Other answers	8
<b>TOTAL</b>	<b>100</b>

### *5.3.1.3. How albinism affects someone with albinism*

The participants were asked how they think albinism affects a PWA (see Table 15). The majority of the participants stated that sunshine affects a PWA and that it can be damaging for their skin and eyes (mentioned 51 times). Another thing they often mentioned is that PWAs suffer from wounds and moles (mentioned respectively 19 and eight times), that they have low vision or unstable eyes (mentioned 16 times) and they should wear long clothes, caps and/or sunglasses (mentioned ten times):

‘They are affected by the sun and they can’t see well. Also the skin, which brings them to have serious wounds and moles and can change them into animals. If you see them, you can’t even see them as human beings. Especially the wounds around the mouth’ (interview, session 7)

‘The sun affects them. PWAs are suffering from the sun with their skin and their eyes. [...] Where the shirt stops you can see the skin is full of wounds and moles but under the shirt the skin is nice’ (interview, session 1).

It was also mentioned 16 times that flies are affecting PWAs: ‘The flies go into the insides of the eyes of PWAs and eat the insides’ (drama, session 9). Often the flies are indicated as the reason that PWAs have wounds and moles. Sometimes participants connected this to their soft skin and flies can cause instant wounds when they land on their skin: ‘When they [flies] come to the skin and you try to remove it, even when they don’t bite you, you will still see wounds and moles. Especially when they wear short clothes’ (interview, session 3) and ‘Flies can bring wounds to the skin even without biting them. It just happens instantly as soon as the flies come to the skin’ (interview, session 11).

Some people said the heat affects PWAs (mentioned eight times). In most cases they mentioned hot temperature, but also the heat coming from fire or hot pans is mentioned. Again, this is often linked to their sensitive skin: ‘They are mostly affected by the light of the sun and the fire. But electricity is no problem’ (interview, session 32) and ‘The fire affects them because of the soft skin of PWAs. They cannot carry hot things like hot pans and pots without a cloth because they will give them burns on their skin’ (drama, session 21).

The sensitive skin was mentioned also in combination with the wounds, one person stated that they can even get wounds from the grass that cuts into their skin and therefore they cannot do outside work. Another person was not sure if the wounds are from sunshine or that maybe they are cutting themselves. It was mentioned five times that PWAs are unable to do the same as other people because they are weaker and cannot do hard tasks: ‘They are weak and do not have the power like black people’ (interview, session 17).

In seven households, participants mentioned that PWAs are insecure about their lives or about who they are and what they look like and that they are affected by that. Another seven times, people mentioned that bad living conditions and poverty affects PWAs. One person said that PWAs only suffer from wounds and bad skin when they are poor, if they are rich they have no problems: ‘It is all about money. When an albino is born in a poor family he suffers a lot; having wounds and moles and being dirty. But in a rich family the albino will not suffer’ (drama, session 21).

Participants mentioned three times that PWAs talk or smell different from other people: ‘They are talking different. You can hear when an albino is speaking that it is someone with albinism’ (drama, session 21) and ‘When the sun shines they have a different body odor than other Africans’ (drama, session 27).

Table 15: How albinism affects a PWA according to the participants

How albinism affects persons with albinism	Mentioned (#) times
Sunshine affects them (or their skin and / or eyes)	51
Flies affect them	16
They suffer from low vision / unstable eyes	16
They need to wear long clothes / caps / sunglasses	10
The heat affects them (high temperature or fire)	8
They speak or smell different	3
They are insecure / ashamed for who they are / afraid for attacks	7
They cannot do the same as other people	5
They have a sensitive skin	9
They have a hard time finding work	2
They suffer from wounds	19
They suffer from moles	8
They suffer from mistreatment	2
They suffer from bad living conditions / poverty	7
Don't know	6
<b>TOTAL</b>	<b>169</b>

### 5.3.2. Short-term Effects

#### 5.3.2.1. Lessons learned from the radio

The lessons that the participants indicated to have learned from the radio interventions were often different in the drama intervention than in the interview intervention (see Table 16). After hearing the drama intervention, most participants stated that they learned that PWAs are just human beings like

others and they should not be mistreated. Instead, people should love PWAs and collaborate with them.

Furthermore, some items were only covered in the drama and the participants indicate to have learned only then that 'wazungu' (white foreigners), plants and animals can also have albinism (mentioned six times) and that albinism is not contagious (mentioned six times): '[...] I also learned that you cannot get albinism through blood, so it is not contagious' (drama, session 31). In two households, participants learned that 'zeruzeru' is not the correct reference for a PWA.

After hearing the interview intervention, the participants often stated to have learned that people with albinism can have a baby without albinism and that albinism is inherited by their parents. See for example the quotes of two participants:

'I didn't know it was all about genes from the mother and the father. I used to know someone with albinism who gave birth to a black child and I never understood how that was possible but now I understand' (interview, session 4).

'I used to believe they were miracle people with special powers, and when you have a child with albinism you can ask for miracles. But the radio said that an albino can give birth to kids without albinism so that shows that they are not miracle people but just normal human beings and have no special powers' (interview, session 12).

Some myths that were only covered in the interview also show to be important items that the participants learned from. Four times people stated that they learned that PWAs die and not just disappear: 'I didn't know albinos were dying and thought they were disappearing, so that was very new information' (interview, session 5), and 'I was also told that they disappear and you will not find the grave after a while but now I know that this is not true they are just normal human beings that die' (interview, session 12). Six times, people learned that PWAs do not see better in the dark or from far away: 'I always thought they see like cats and now I know this is not true and their sight is not better during the night' (interview, session 3). And five times participants learned that PWAs can marry someone without albinism.

In both interventions the respondents indicated that they learned about the skin sensitivity to the sun that PWAs suffer from: 'I never knew that the sun can destroy their skin' (interview, session 5). Also, participants who heard the drama indicated seven times to have learned that PWAs have the same abilities as other people 'I was surprised to hear PWAs can be a nurse and treat people' (drama, session 31); '[...] I learned that PWAs could work and even become nurses' (drama, session 34) and 'I learned that someone with albinism can be a doctor and that albinism is not contagious. So if you get

a child with albinism you let him play with others and go to school and they could one day become important to others’ (drama, session 25). Participants who heard the interview indicated four times to have learned this.

Table 16: Learned from the radio (short-term)

Learned from the radio (short-term)	Drama	Interview
People with albinism are human beings like others	12	7
People with albinism should not be mistreated and/or people should work together with them/love them	16	4
People with albinism have the same abilities as others	7	4
Albinism is not contagious	6	0
Wazungu (white foreigners) can also have albinism	4	0
Participant is no longer afraid of people with albinism	4	1
People with albinism have skin problems/are sensitive to the sun	5	8
'Zeruzeru' is not the correct name for people with albinism	2	0
People with albinism have low vision/problems with too much light	2	5
Animals and plants can also have albinism	2	0
The myth that people with albinism disappear instead of die is not true	0	4
People with albinism can get a baby without albinism	0	17
People with albinism can marry someone without albinism	0	5
Albinism is inherited/caused by genetics	9	11
People are misinformed about albinism/mistreating people with albinism	3	2
People with albinism can't see better in the dark or from far away	0	6
Everything was new information	0	2
Nothing new was learned	12	6
<b>TOTAL</b>	<b>84</b>	<b>81</b>

### 5.3.2.2. Most important message of the radio

The majority of the participants stated that the most important thing they heard in the drama as well as the interview was that PWAs are like other human beings and that PWAs should not be mistreated but instead should be loved: ‘Most important is that we need to be close to them. They need long clothes for the sun and the flies. And we should not mistreat them but collaborate with them’ (drama, session 15), and ‘Society needs education and more information. It must be removed from their minds that they might not be human beings’ (interview, session 29).

For the participants who listened to the interview, two other messages were also found of importance: the explanation of the cause of albinism and the message that people with albinism can

have a baby without albinism. For example: ‘I thought the most important thing was when I heard that a pure albino gives birth to five kids without albinism. My in-law is also an albino and he even has two wives and he also has black kids’ (interview, session 14). Table 17 displays an overview of these results.

Table 17: Most important part of the radio

Most important part of the radio	Drama	Interview
To learn the cause of albinism	0	8
People with albinism are like others/are normal human beings	9	12
People with albinism should not be mistreated and/or people should work together with them/love them	15	16
People with albinism have the same abilities as others	3	2
Albinism is not contagious	2	0
Education/information about albinism is important	4	1
Participant is no longer afraid of people with albinism	1	0
Protection of people with albinism from the sun/information about skin problems	3	1
There is no shame in getting a child with albinism	1	1
People with albinism can get a baby without albinism	0	7
People with albinism (can) marry someone without albinism	1	2
People are misinformed about albinism/mistreating people with albinism	1	0
Everything was important	1	1
Nothing was really important	0	1
<b>TOTAL</b>	<b>41</b>	<b>52</b>

5.3.2.3. Understanding the cause of albinism

When asked if the participants learned more about the cause of albinism, the majority of the participants who heard the radio drama indicated that they learned that albinism is inherited or that it has something to do with genetics. However, as the drama does not explain the cause of albinism in larger detail, the participants also did not expand on the explanation of the cause. Furthermore, four times people explained it incorrectly and twice people insisted it was only God’s will if someone would be born with albinism.

For the interview the majority of the people explained the cause correctly, indicating that albinism is inherited by the parents when both parents carry a specific gene, and the genes of both parents meet. When the genes do not meet, they will not get a child with albinism: ‘It’s all about genes from the man and the woman. When they have albinism genes and those genes meet, they can get a child with albinism’ (interview, session 18). Seven times, people gave an incomplete explanation that

albinism is inherited or that it has something to do with genetics. Six times people indicated that they were still unable to explain the cause of albinism. A summary of these results can be found in Table 18.

Table 18: An explanation for the cause of albinism

An explanation for the cause of albinism	Drama	Interview
Both parents carry an albinism gene and those genes from both parents have to meet in order to get a child with albinism (or in any other way explained correctly)	0	16
It is inherited from the family/it has something to do with genetics (or in any other way explained incomplete/partly correct)	12	7
It is because of the genes from the mother or the father/if someone else in the family has albinism (or in any other way incorrect)	4	0
It is only God’s will	2	1
Unable to explain	1	6
<b>TOTAL</b>	<b>19</b>	<b>30</b>

5.3.3. Long-term Effects

5.3.3.1. What participants remember of the radio intervention

When asked two to five weeks after hearing the drama what the participants remembered of the radio intervention, the majority indicated to remember that the radio was about how PWAs should not be mistreated or dismissed. Also, participants often remembered specific details from the radio and repeated those:

‘It was about an albino named Sarah. She was mistreated and couldn’t go to school. But her uncle then made sure she could. And her teacher also gave her a chance to go study and she turned out to be really smart and became a nurse that started treating patients’ (drama, session 7).

Furthermore, they remembered that PWAs are like other human beings and that the radio explained how you should live with PWAs and love them. Six times people stated not to remember anything of the radio, or only that it was about albinism.

For the radio interview the majority of the participants remembered that PWAs are like other human beings: ‘Sijajali was on the radio to tell people there is no difference between people with albinism and other people. They die just like others and are the same like others’ (interview, session 12). Also, participants remembered that PWAs are affected by sunshine and that the radio explained

how you should live with PWAs and love them, the cause of albinism, to not mistreat PWAs and that a PWA can give birth to someone without albinism. In some households participants stated not to remember anything of the radio, or only that it was about albinism.

Table 19: What participants remember of the radio intervention

What participants remember of the radio intervention	Drama	Interview
The cause of albinism/explanation of genetics	1	7
People with albinism are like others/are normal human beings	9	10
To not mistreat or dismiss people with albinism	13	6
People with albinism have the same abilities as others	1	2
How to live with/share with/collaborate with/love people with albinism	7	8
Albinism is not contagious	1	0
People with albinism are affected by the sun/have problems with their skin	1	9
People with albinism can marry someone without albinism	1	3
People with albinism can give birth to someone without albinism	0	6
The myth that people with albinism disappear instead of die is not true	0	3
People with albinism cannot see far/are not ghosts/have no magical powers	1	2
Detailed repetition of the intervention	11	2
Remembers only that is was about albinism/nothing at all	6	5
<b>TOTAL</b>	<b>53</b>	<b>62</b>

5.3.3.2. What participants learned from the radio

To understand the effects of the radio interventions on a long-term, the participants were asked again what they learned from the radio intervention (see Table 20 for an overview). Similar to the short-term effects, the participants from the drama intervention stated again that they learned that PWAs are like other human beings and that they should not be mistreated or dismissed but people should love them and collaborate with them:

‘Before I was afraid but through the drama I found that the patient understood that an albino is just a human being and through that patient I also understood that myself. Now I will not be afraid of albinos anymore’ (drama, session 12).

Four times people indicated to have learned that PWAs have the same abilities as others:

‘Albinos are human beings like we are, they can do the same as we can do. It’s not because that they have a different color that they are unable to do something like

others. They can carry luggage like us. Because they are the same' (interview, session 10).

For the radio interview, the majority of the participants stated that PWAs are like other human beings as the main aspect they learned from the radio. Furthermore, respondents said to have learned that PWAs should be loved and that there is no reason to be afraid of them:

'If I meet an albino now I would greet him and give him a hand. And I would share food with an albino now. Because it is a human being and the only difference is the skin color. So, there is no reason to fear him. And it can happen that an albino wants to marry someone black and then there is no reason to say no because they are human beings like us' (interview, session 22).

Moreover, some people indicated that they learned that PWAs suffer from the sun (mentioned five times), and that albinism is caused by genetics and a PWA can give birth to someone without albinism (mentioned six times): 'I never understood where albinos are coming from, but now I know they are human beings like us. They die and they can marry so no reason to mistreat them. We have to be close to them' (interview, session 8).

Table 20: Learned from the radio (long-term)

<b>Learned from the radio (long-term)</b>	<b>Drama</b>	<b>Interview</b>
People with albinism are like anyone else/human beings	10	12
To not mistreat/dismiss people with albinism	10	4
People with albinism have the same abilities as others	4	2
We should love people with albinism/treat them like relatives	8	7
Albinism is not contagious	1	0
People said they were no longer afraid of people with albinism	2	6
Learned about the sensitivity to the sun towards skin or eyes	1	5
Learned that the myth that people with albinism disappear instead of die is not true	0	3
Learned about the cause of albinism/that albinism is genetically inherited	3	6
People with albinism are suffering/things they are going through	0	3
People with albinism can't see better in the dark or from far	0	1
People learned something that was incorrect	2	0
People learned nothing new/cannot remember anything	2	5
<b>TOTAL</b>	<b>43</b>	<b>56</b>

### 5.3.3.3. *The influence of the radio intervention*

To understand how the radio intervention influenced the participants on a long-term, they were asked if they had talked to other people about the radio. Furthermore, they were shown pictures of PWAs and were asked how they would respond to it and how they would have responded before hearing the radio (see Table 21 and Table 22 for an overview of the results).

The majority of the participants of both interventions stated to have talked about the radio intervention after hearing it. They usually indicated to have talked to family members or neighbors. Often, they explained that they found the message of the radio intervention of importance and they learned a lot from it and therefore they wanted to share it with others.

After showing the pictures, the majority of the people of both interventions indicated that it is normal or not a problem to shake hands with a PWA, see a black woman with a baby with albinism and to have a nurse with albinism treat patients: ‘This is normal and no problem for me, it is not an illness because you can’t turn into an albino by shaking hands’ (drama, session 29). For some people it was only normal or not a problem after hearing the radio: ‘Seeing an albino as a nurse treating a black patient is very nice because I have never seen that before and I learned from the radio that an albino could be a nurse. I am very happy to have learned that’ (drama, session 33).

For both interventions only one person found that having a baby with albinism is not normal or a problem:

‘Even though you can educate about it that it is normal, it is not easy to believe it. Maybe when it happened to myself I will slowly believe it but I would not be happy on the spot. The woman in the picture also does not look happy. Maybe now she is happy, after a while when she got used to it. But in the first moment she was unhappy’ (interview, session 2).

Many participants also expressed their opinion about the radio intervention. In general, responses were very positive and the message of the intervention was often found educative, interesting and important. Two times, the respondents suggested that the drama should be played on tv instead of on the radio, even though they did not own a tv.

*Table 21: Talked to people after the radio intervention*

<b>Talked to people after the radio intervention</b>	<b>Drama</b>	<b>Interview</b>
Yes	26	22

No	8	7
<b>TOTAL</b>	<b>34</b>	<b>29</b>

Table 22: Pictures portraying a person with albinism interacting with a black African

<b>Picture: Shaking hands with a person with albinism</b>	<b>Drama</b>	<b>Interview</b>
It was normal/no problem already before hearing the radio	22	16
It is normal/no problem now but only after hearing the radio	1	4
It was already normal/no problem but the radio emphasized this idea	1	1
<b>TOTAL</b>	<b>24</b>	<b>21</b>
<b>Picture: Mother holding baby with albinism</b>		
It was normal/no problem already before hearing the radio	21	14
It is normal/no problem now but only after hearing the radio	2	2
It is not normal/a problem even after hearing the radio	1	1
It was already normal/no problem but the radio emphasized this idea	0	4
<b>TOTAL</b>	<b>24</b>	<b>21</b>
<b>Picture: Nurse with albinism</b>		
It was normal/no problem already before hearing the radio	20	15
It is normal/no problem now but only after hearing the radio	3	4
It was already normal/no problem but the radio emphasized this idea	1	2
<b>TOTAL</b>	<b>24</b>	<b>21</b>

## 6. Discussion and Conclusion

In this chapter, the findings of this research are discussed and the main research question is answered. The chapter will conclude with a reflection on the limitations of this study and with recommendations for further research.

This research aimed to measure and understand the effects of educative radio interventions as successful strategies to increase the knowledge about albinism and reduce the (perceived) stigmatizing attitudes towards PWAs in Kigoma, Tanzania. Two radio interventions were tested: an edutainment radio drama about albinism and a contact-based radio interview. Both interventions took a different approach to connect to their listeners. The radio drama focussed on a young, educated woman with albinism who is mistreated and faces difficulties in her daily life because of her condition. The radio interview is about a man with albinism who grew up and lives in the same area as the participants. He is also educated and has a wife and children without albinism. This strategy focusses more on the cause of albinism and that it does not obstructs a PWA from living a normal life.

This study used quantitative and qualitative data to assess the effects of the radio interventions as successful methods to reduce stigmatizing attitudes related to albinism in Kigoma, Tanzania. The combination of quantitative measurements (knowledge questions, EMIC-CSS, SDS and an entertainment scale) and qualitative data (short group interviews) provided an in-depth understanding of the effects of both SRIs.

### 6.1. Discussion

In terms of knowledge, both interventions showed an improvement of correct knowledge about albinism. Although not always significant, an increase in correct knowledge was seen on all items for both interventions, with the exception of question K-03 for the interview intervention: Do you think a person with albinism can get a child without albinism? The amount of correct answers on this question stayed the same with 93,5%. This is interesting because Sijajali, the PWA being interviewed, explicitly mentioned he had five children, all without albinism. Even though an improvement on this item did not show in the quantitative measurements, the participants did mention this aspect often during the interviews. In fact, a PWA able to have children without albinism is the main item that the participants mentioned to have learned from the radio intervention, and they often found this to be the most important message of the radio interview. In the radio drama it is not mentioned that PWAs can have children without albinism, and no participant of the drama mentioned to have learned this. Nevertheless, their knowledge about this increased with 7.9%.

The qualitative data supports the argument that both interventions led to an increase in correct knowledge about albinism. Before listening to the radio intervention, only 20% of the

participants knew that albinism is caused by genetics, whereas 34% indicated not to know the cause or believed it was only God's will. After hearing the radio interventions, 71% of the participants knew albinism is caused by genetics. Furthermore, before the interventions some participants mentioned that PWAs do not have the same abilities as other people, but after hearing the radio interventions, in particular the radio drama, they learned that is not true.

The participants who listened to the radio drama more often indicated to have learned that PWAs are just like other human beings and people should not mistreat them but collaborate with them. It is also only the participants from the drama who indicated to have learned that albinism is not contagious. The mistreatment of PWAs was the main focus of the radio drama, and it is explicitly covered that albinism is not contagious. In the interview intervention these aspects are not covered directly. However, quantitatively the participants from the interview did significantly improve on this question (K-01 'Do you think albinism is contagious?'). A possible explanation for this is the difference in sample. The participants from the interview intervention had a generally higher level of education than the participants from the drama intervention. This could mean that the participants from the interview intervention are better in deriving correct answers indirectly by learning other facts related to the same topic (e.g. Sijajali mentioned he had a wife and five children without albinism and he used to be a teacher so albinism is then probably not contagious).

The participants who listened to the radio interview indicated more often that they learned that albinism is caused by genetics and that PWAs suffer from skin and vision problems. The interview intervention focusses more extensively on the explanation of the cause of albinism than the radio drama. And while the skin sensitivity and low vision are mentioned in both interventions, more attention is paid to this in the radio interview. Moreover, only the participants from the interview intervention stated to have learned that PWAs cannot see better in the dark or from very far away and that they die instead of just disappear. These items were only covered in the interview intervention. It is only the participants from the drama intervention who indicated to have learned that albinism is also prevalent among white foreigners, plants and animals; a fact that was only covered in the interview.

For some items, even after the intervention, the correct knowledge is still quite low. Particularly for the participants who listened to the radio drama, the items K-02 ('Do you think a person with albinism will turn blind?'), K-05 ('Do you think people with albinism need to eat special food?') and K-10 (Do you think that the body parts of someone with albinism can bring good fortune?') scored relatively low. None of these three items were covered in either intervention, yet the participants from the radio drama show a higher improvement in answering these questions correctly. Again, this could be supported by the argument that these participants had a higher level of education and could have derived the correct answers indirectly.

As both interventions failed to address all beliefs and superstitions, it is expected that some will carry on even after hearing the interventions. For example, the participants often mentioned that flies and heat are factors that affect PWAs, or that they speak or smell different. As the surveys measured a low improvement on the questions if the body parts of PWAs bring luck, if PWAs will turn blind or if they need to eat special food, it is likely that those false beliefs and superstitions that are not undermined in the interventions, will carry on. This seems to be especially the case for the participants with a lower level of education.

In conclusion, both radio-based SRIs that were studied turned out to be effective in improving knowledge about albinism, although the radio interview showed a more significant and varied improvement than the radio drama. However, three things should be noted: the interview intervention covered more knowledge items, the demographic sample of the interview showed a higher level of education and on two items the knowledge of the participants in the drama improved to a 100%. While this was not a significant improvement, it obviously could not have improved further. The qualitative findings support the measurements and showed that many respondents let go of their myths and superstitions about albinism. For example, changes were seen in beliefs that PWAs are not human, that they do not die but disappear, that they do not have the same abilities, that they see better in nighttime (like cat's eyes), that albinism is contagious, that albinism is the fault of the mother or that it is a punishment from God.

In terms of stigmatizing attitudes, an improvement was seen on a community level for the radio drama and on a personal level for the radio interview. On a community level, the perceived stigmatizing attitudes from the participants of the radio drama decreased on 14 out of 16 items, and significantly decreased on four items. The interview intervention did not significantly influence the participants' perceptions regarding stigmatizing attitudes from the community. A decrease of perceived stigmatizing attitudes from the community regarding PWAs was found on eight items. However, on the other eight items an increase of perceived stigmatizing attitudes was measured.

On a personal level, opposite results were measured for a reduction of stigmatizing attitudes. While the SDS measured an improvement in the reduction of stigmatizing attitudes on all items for both interventions, an overall decrease on the personal stigma level from the drama intervention was not measured. However, for the participants who heard the interview intervention, the SDS did measure an overall improvement on the personal stigma level. Significant reductions for the radio drama were found on three out of ten items and for the radio intervention on four out of ten. For both interventions, the participants indicated that the biggest problem for them is to permit their child to marry a PWA. In the interviews they often expanded the reason for this to be the fear that they would then also have children with albinism.

Qualitative results generally confirm the measurements of stigmatizing attitudes. In comparison to the people who listened to the interview intervention, the participants who heard the drama intervention more often indicated that they learned that PWAs are human beings like others and should not be mistreated. Furthermore, participants from the drama more often talked to other people in their community about the radio drama than the participants who heard the radio interview. This could possibly spread information from the intervention to a wider audience and reduce stigmatizing attitudes on a community level more broadly.

The participants from the radio interview more often indicated that they learned that PWAs are being mistreated or suffering which could influence their perceptions of the stigmatizing attitudes from the community. The participants from the radio interview more often indicated that they found interactions with a PWA (shaking hands, PWA being a nurse) normal or not a problem only after hearing the interview than the people who heard the radio drama. They also more often indicated that they were no longer afraid of PWAs on the long-term and that they learned that they die instead of disappear, something that was not covered in the radio drama.

Participants from both interventions (generally short-term for the drama and long-term for the interview) mentioned a reduction of fear towards PWAs which could be the result of the correction of myths and superstitions about PWAs.

To sum up, the drama interventions proved to be more effective in decreasing perceived stigmatizing attitudes by the community. This is supported qualitatively, as those participants more often shared information about the intervention with family members and neighbours, and that the participants from the interview intervention more often became aware of mistreatment of PWAs after hearing the radio interview. The interview intervention proved to be more effective in decreasing personal stigmatizing attitudes. While both interventions showed a decrease of personal stigma, only an overall significant decrease for the radio interview was measured. The qualitative data supports these measurements, as the participants from the radio interview more often indicated to find interacting with PWAs not a problem after hearing the radio and that they more often learned about the cause of albinism and can thus marry and have children without albinism.

In terms of entertainment, both interventions scored high. The drama measured a slightly higher level of entertainment, though this difference is not significant. This showed that both interventions were found interesting, entertaining and important. Qualitative data supports this as many participants expressed they found the intervention interesting, educative and important. In addition, the participants often spoke to other people in their community about the radio intervention.

The qualitative outcomes of the radio drama did not change too much over time. However, for the radio interview they did. On the short-term the participants indicated a wider variety of important lesson from the radio than the participants from the drama. On the long-term these lessons became

almost the same as for the group that heard the drama. Only the cause of albinism remained important on the long-term after the radio interview, whereas it was not of importance for the participants from the radio drama.

The overall sample was well divided, though participants had a relatively low level of education. However, the demographic sample used for the drama turned out to be significantly different than the sample used for the interview for the factors of education and religion. The reason for this difference in sample is unclear. Before the radio interventions, the sample of the drama had less knowledge on albinism in comparison to the group of the interview. The difference between the samples in terms of knowledge might have influenced the outcomes and comparison between the interventions. Nevertheless, no difference in knowledge acquisition was found, even though the pre-test and post-test do point out that the people in the drama group have significant less knowledge before and after the intervention.

## 6.2. Reflection and Recommendations

In the course of this research some circumstances might have affected the outcomes or interpretations of this research. For example, during the drama intervention, the knowledge questions were only included after four days, therefore the knowledge-items in the pre-test were missing in 50 surveys. This could have influenced the results of the effect of the drama on increasing knowledge about albinism as the post-test could not be connected to the pre-test. For the interview intervention, the knowledge questions were included from the start.

In some surveys the same answers were filled out for all the questions. The test was very tiring and long for the participants. Especially for the participants who had trouble reading and writing but were still able to fill out the surveys themselves. It often took half an hour or more to fill out one survey. This survey, in combination with the radio intervention, the entertainment survey and two short interviews in one day could have affected the results of the survey as participants might have lost interest or focus. While the validated scales are valuable for this type of research, it is recommended to divide the data collection over multiple days.

Discussions and disagreements between participants within one household were rare. Most often one person would take charge and give the answers in the interviews and the others would agree. Furthermore, women and young participants often tried to fill out surveys together or indicated to be afraid to fill out the wrong answer. Because of time restrictions, it was decided to find multiple participants from one household at the same time. However, to collect the most objective and varied results, it is recommended to find participants separate from each other.

The two different strategies used in this study not only took a different approach to connect to their listeners, they also covered different knowledge-items and stigma-items related to albinism. It is unclear to what extent it is the difference in coverage that influenced the results or the difference in approach. Therefore, it is recommended for future research that focus on different strategies, to cover the same information to more objectively measure the effects of the strategy instead of the type of information that was given.

Furthermore, it would be interesting to measure actual changes in stigmatizing behavior following the radio interventions. To make that possible, it is recommended to include PWAs in the research for the long-term and have a large group of participants within one community to listen to the radio intervention.

And finally, due to time limitations it was not possible to include popular opinion strategy in this research. This third radio-based strategy would have entailed a respected person of the community like a doctor or a head of the village or region to talk about albinism. This comparison to a third strategy could be of interest for further research.

### 6.3. Conclusion

In Tanzania PWAs frequently experience stigmatization due to a combination of a lack of knowledge about albinism and the beliefs in witchcraft, myths and superstition. Over the last decade, many interventions have been implemented all over Tanzania in order to reduce stigmatizing attitudes. However, the effectiveness of these SRIs is often unknown. In this research two different radio-based SRIs were studied: a drama and an interview. This study aimed to answer the following research question: 'What are the effects of radio education interventions as a method to reduce stigmatizing attitudes related to people with albinism in Tanzania, in particular in the Kigoma region?'

In short, radio education interventions seem to be effective as a method to reduce stigmatizing attitudes regarding albinism in Kigoma, Tanzania. Although the interview covered more knowledge-items than the drama, both radio interventions have shown to be effective in improving the knowledge regarding albinism. However, a higher improvement on correct knowledge was found on items that were addressed directly in the radio intervention. The interventions also seem to be effective in reducing (perceived) stigmatizing attitudes related to PWAs. However, there were differences between both interventions in the reduction of perceived stigmatizing attitudes from the community and personal stigmatizing attitudes. The drama intervention seems to be more effective in improving perceived stigma measured through EMIC-CSS. The interview intervention is slightly more effective in decreasing peoples stigmatizing attitudes measured through the SDS. In addition, participants often indicated to have learned that PWAs are human beings like others and should be treated as such.

The two different strategies used in this study not only took a different approach to connect to their listeners, they also covered different knowledge-items and stigma-items related to albinism. There are different strategies to choose from for a radio education intervention and each strategy can provide different results in reducing stigmatizing attitudes. Nevertheless, an overall improvement in reducing stigmatizing attitudes was found for both the edutainment strategy and the contact-based strategy. It is recommended for future research to focus on multiple strategies that cover the same information and to include PWAs in the research for the long-term to also measure actual changes in stigmatizing behavior.

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## Appendix A - Overview of both radio interventions

### **Description radio drama**

The first intervention was a radio drama. Two episodes of seven minutes each were recorded especially for this study by a radio-DJ in Mbeya, in the south of Tanzania. This drama strategy focusses on the story of Sarah, a young nursing student with albinism. The episode starts and ends with a song 'Nafasi', which was written and recorded by PWAs from Mbeya.

In the first episode Sarah is talking to her classmate about her childhood and the challenges that she faced growing up because of albinism. For example, she only got to go to school at a later age after an educated uncle explained to her parents that Sarah is as smart as anyone else and that albinism does not affect her ability to attend school. Sarah also talks about her vision impairment when she sits too far from the blackboard. After she finished her secondary school, being the best in her class, her uncle supported Sarah to enter nursing school. Finally, Sarah explains about her skin sensitivity to the sun. She explains she needs to wear long-sleeved clothes and a wide-brimmed head. Then the bell rings and a voice-over takes over by stating that the nurse students went to do a practical course in the hospital.

The second episode, and second part of the radio drama, takes place in the hospital. Sarah and John, a classmate of hers, are assigned to a patient; a young boy that hurt his arm playing soccer. The patient is crying. John tries to console the patient and tells him that his classmate Sarah will put some bandages on his wounds. When Sarah introduces herself and tells the patient that she will put some bandages on his wounds, the patient starts screaming. John and Sarah assume that the patient is in too much pain. When a doctor comes in to ask what is going on, the patient says he does not want the 'zeruzeru' to touch him. The doctor asks if the boy is afraid he might also get albinism if Sarah touches him or that maybe something bad will happen to him. The patient confirms this. Then, the doctor explains that albinism is not contagious and that it is caused by albinism genes from the family. Those genes must have found each other when Sarah's parents had Sarah. He says that albinism is only about genes and has nothing to do with witchcraft. Furthermore, he explains albinism happens in humans, animals and plants all around the world. The patient feels bad and apologizes. Then the voice-over takes over and says that the patient changed his idea about people with albinism. Also, John felt bad about the whole situation and he liked Sarah very much. He decides to propose to her and he and Sarah get married.

### **Description radio interview**

The radio interview was recorded in Kigoma. The person being interviewed is a PWA from the area. The interviewer is a woman working for KICORA.

*Starts with 'Nafasi' song (written and recorded by PWAs from Mbeya)*

**Interviewer:** Welcome, community radio Kigoma. The subject of today is albinism, we have a guest with albinism: Sijajali, welcome Sijajali, can you introduce yourself shortly.

**PWA:** Thank you, my name is Sijajali [...]. I am from Mole, Kigoma.

**Interviewer:** welcome, can you explain shortly what albinism is?

**PWA:** Albinism is a lack of original colour, in the skin, eyes and hair or a lack of melanin. It means people born with albinism are different from Tanzanians, as in America, people with albinism are different from Americans, because of the colour of hair, eyes and skin.

**Interviewer:** Can you tell our listeners how you get albinism?

**PWA:** That is because the parents have 'genes' our 'vinasabaa' in Kiswahili, if the father has the genes and the mother has the genes, and they meet, you can get a child with albinism, but if they don't meet you will get a normal child. So it is in the mother and father, they can get a child with albinism or without albinism.

**Interviewer:** So if only one parent has these albinism genes, you cannot get a child with albinism?

**PWA:** If father has albinism genes, and the mother doesn't the child will not have albinism, but if the mother has albinism genes, and the father, they can get a child with albinism.

**Interviewer:** Perhaps, another short question: can people with albinism study?

**PWA:** Yes, very much. For example, I have studied from form 1 till form 4, (ordinary level) and after that I went to teacher training college, so I am now a teacher, teacher at primary school.

**Interviewer:** Thank you. Do you have a wife?

**PWA:** Yes, I have a wife but luckily it is not a person with albinism and I have children, I have a family, five children and a wife, but luckily the kids do not have albinism they are normal children, they look like their mother.

**Interviewer:** So listeners we hear that people with albinism can marry a wife that doesn't have albinism, but also they can get children without albinism. What problems do you face?

**PWA:** We people with albinism, not only me, we have problems, not one, problems with being in the sun with the skin and with the eyes, it is a problem of people with albinism all over the world, everywhere in the world. Thank you.

**Interviewer:** So problems with the skin, and with eyes. Perhaps explain about the skin, and if you can see far? What are the problems with the eyes for functioning in the society, please explain a bit more.

**PWA:** We people with albinism lack melanin, the sun can get to the skin and we can get cancer because we get blisters and after that if you don't get treatment early if you don't go to a clinic, a clinic for people with albinism, cancer can happen. But you can protect yourself by wearing long sleeves, and long pants for men or a long skirt for ladies, a dress with long sleeves, or a very large protecting hat. Also the eyes, many people say people with albinism see well in the night, it is not true. We, because

of the lack of melanin, we cannot see far, we cannot focus far, that is a problem. Biologically in the veins, they lack melanin in the eye, the original colour of the eye, the veins don't function well like a normal person that doesn't have albinism.

**Interviewer:** Ok thank you, maybe another short question, in the community that you live, there are perhaps people that don't have albinism, how do they 'interact' with people with albinism like you?

**PWA:** You know, in the community, in Tanzania, we are with many people. The education about albinism is very little, but luckily people begin to understand what albinism is. There are many problems in the community. People say 'zeruzeru', and that we don't die, but disappear. And there are many other things. But very clearly, people with albinism are people like others. There are only problems, like the lack of melanin. People with albinism can marry, they can study, and things like that, they can do the things that normal people can, just not stay in the area with the sun. But they can marry, they can love, like normal people.

**Interviewer:** Perhaps, another question, just the last one. In your everyday life, what do you like?

**PWA:** I like to sing

**Interviewer:** Singing, songs of gospel?

**PWA:** I like very much religious songs.

**Interviewer:** What songs do you like to listen to? Do you listen to songs with your children and wife?

**PWA:** Thank you presenter for this question, for example at this moment we have recording of a group from Dar es Salaam, they have a song 'God is love, bwana Jesus'. We like it very much to listen to that song. It is a good song.

**Interviewer:** Thank you. God is love. Thank you, welcome again next Sunday with the radio, thank you to our guest.

**PWA:** Thank you very much.

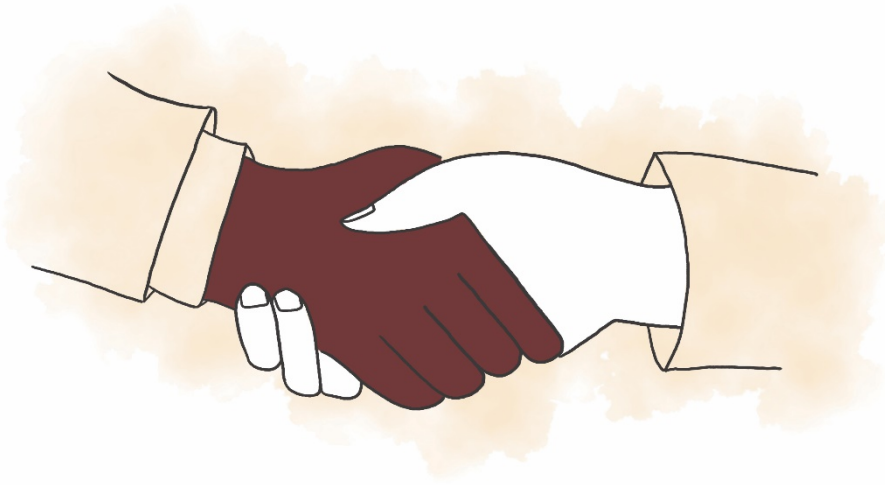
*Closing song 'Nafasi'*

## Appendix B - Three pictures of people with albinism

The next three pictures were used during the interviews to test the long-term effects of the radio intervention. All three pictures were made by 'Happy made by' (see: <http://www.happymadeby.com/>)

Questions asked with these pictures were the following:

- What do you see in this picture?;
- What do you think of this interaction?;
- How does it make you feel now that you heard the radio?;
- Do you feel different about this interaction now than before you heard the radio?



*Figure B.1: Shaking hands with a person with albinism*



*Figure B.2: A mother holding a baby with albinism*



*Figure B.3: A nurse / doctor with albinism treating a young patient*

## Appendix C - Results including all participants

The next tables show all results of the quantitative data including the participants (Ps) who did not participate in the post-test.

Table C.1: Results of knowledge questions including all participants

	Before radio drama	Before radio drama	After radio drama	Before radio interview	Before radio interview	After radio interview
	All Ps	Only Ps who did post-test	Only Ps who did post-test	All Ps	Only Ps who did post-test	Only Ps who did post-test
Do you think:	<b>Correct</b>	<b>Correct</b>	<b>Correct</b>	<b>Correct</b>	<b>Correct</b>	<b>Correct</b>
K-01 albinism is contagious?	72	75,6	94,8*	80,2	80,5	94,7*
K-02 a person with albinism will turn blind?	21,6	20,5	39,7	32,5	31,6	50*
K-03 a person with albinism can get a child without albinism?	89,3	84,4	92,3	88,5	93,5	93,5
K-04 a person with albinism can learn how to read and write?	97,3	95,6	100	94,3	92,2	98,7
K-05 a person with albinism need to eat special food?	47,3	47,7	56,4	68,6	67,1	80,5
K-06 a person with albinism can go to a normal school?	96	97,8	100	91,7	89,6	98,7*
K-07 a person with albinism is bewitched?	89	86	94,9	92,6	90,9	94,8
K-08 a person with albinism can get skin	74,3	70,5	77,9*	58,3	63,2	79,2*

cancer from being in the sun?						
K-09 a person with albinism does not die but just disappears?	68	64,4	75	65,5	66,2	86,7*
K-10 the body part of someone with albinism can bring good fortune?	51,4	52,3	53,2	60,8	66,7	76,3
K-11 it is the fault of the mother to get a child with albinism?	88	84,4	98,7*	91,7	89,3	98,7*
	* Items showed a significant difference					

Table C.2: Results of EMIC-CSS for the radio drama including all participants

	Before radio drama	Before radio drama	After radio drama		
	All Ps	Only Ps who did post-test	Only Ps who did post-test		
	Mean	Mean	Mean	Z	p
E-01. Would the family of someone with albinism keep this person hidden out of shame?	1,84	1,79	1,59	-1,805b	0,071
E-02. Would the family of someone with albinism feel less worth?	1,94	2,04	1,62*	-3,121b	0,002
E-03. In your community, does albinism cause shame or embarrassment?	1,56	1,45	1,37	-1,105b	0,269
E-04. Would people in your community think less of a person with albinism?	2,08	2,13	1,99	-1,838b	0,066
E-05. Would people in your community exclude a person with albinism?	1,79	1,82	1,56*	-2,002b	0,045
E-06. Would people in your community refuse to visit the home of a person with albinism?	1,87	1,82	1,58*	-1,987b	0,047
E-07. Would people in your community think less about the family of a person with albinism?	1,83	1,8	1,47*	-2,807b	0,005

E-08. Would albinism cause any problems for the family in the community?	1,5	1,48	1,53	-,853b	0,394
E-09. Is albinism a problem for a person to get married?	1,76	1,75	1,68	-,280b	0,779
E-10. Would getting a child with albinism cause problems in a marriage?	2,04	2,04	1,81	-1,770b	0,077
E-11. Would having a relative with albinism cause problems for someone to get married?	1,65	1,7	1,53	-,988b	0,323
E-12. Would people buy goods or services from a person with albinism? (rescored)	2,67	2,74	2,71	-,132b	0,895
E-13. To have albinism can cause problems in finding work?	1,93	1,88	1,62	-1,845b	0,065
E-14. Would people call people with albinism bad names?	2,01	1,86	1,99	-1,010b	0,313
E-15. Would people in your community gossip/talk bad about a person with albinism?	2,28	2,27	1,97	-1,670b	0,095
E-16. Do people in general fear people living with albinism?	1,98	1,93	1,69	-1,420b	0,156
* Items showed a significant difference					

Table C.3: Results of EMIC-CSS for the radio interview including all participants

	Before radio interview	Before radio interview	After radio interview		
	All Ps	Only Ps who did post-test	Only Ps who did post-test		
	Mean	Mean	Mean	Z	p
E-01. Would the family of someone with albinism keep this person hidden out of shame?	1,85	1,8	1,86	-,483b	0,629
E-02. Would the family of someone with albinism feel less worth?	1,92	1,93	1,7	-1,944b	0,052
E-03. In your community, does albinism cause shame or embarrassment?	1,68	1,68	1,57	-,953b	0,341

E-04. Would people in your community think less of a person with albinism?	2,01	2,12	2,04	-,472b	0,637
E-05. Would people in your community exclude a person with albinism?	1,87	1,96	1,9	-,128b	0,898
E-06. Would people in your community refuse to visit the home of a person with albinism?	1,73	1,66	1,74	-,655b	0,513
E-07. Would people in your community think less about the family of a person with albinism?	1,78	1,76	1,88	-1,258b	0,208
E-08. Would albinism cause any problems for the family in the community?	1,49	1,52	1,64	-1,170b	0,242
E-09. Is albinism a problem for a person to get married?	1,85	1,91	1,61	-1,712b	0,087
E-10. Would getting a child with albinism cause problems in a marriage?	1,88	2,04	1,95	-,953b	0,341
E-11. Would having a relative with albinism cause problems for someone to get married?	1,71	1,65	1,75	-,455b	0,649
E-12. Would people buy goods or services from a person with albinism? (rescored)	2,53	2,55	2,36	-,962b	0,336
E-13. To have albinism can cause problems in finding work?	1,9	1,99	2,15	-,743b	0,457
E-14. Would people call people with albinism bad names?	2,21	2,22	2,03	-1,377b	0,169
E-15. Would people in your community gossip/talk bad about a person with albinism?	2,27	2,37	2,48	-,575b	0,565
E-16. Do people in general fear people living with albinism?	1,98	1,96	1,81	-,988b	0,323

Table C.4: Results of SDS for the radio drama including all participants

	Before radio drama	Before radio drama	After radio drama		
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	All Ps	Only Ps who did post-test	Only Ps who did post-test		
	Mean	Mean	Mean	Z	p
S-01. How would you feel to visit a house of someone like John/Joyce?	1,57	1,53	1,24*	-2,422b	0,015
S-02. How would you feel working together with someone like John/Joyce?	1,57	1,47	1,31	-1,593b	0,111
S-03. How would you feel having someone like John/Joyce as a neighbour?	1,58	1,49	1,26*	-2,107b	0,035
S-04 How about having someone like John/Joyce taking care of your children for a couple of hours?	1,61	1,51	1,27	-1,944b	0,052
S-05. Would you permit your child to marry someone like John/Joyce?	1,77	1,68	1,42	-1,804b	0,071
S-06. How would you feel about introducing John/Joyce to a young woman you are friendly with?	1,56	1,48	1,29	-1,890b	0,059
S-07. How would you feel about recommending someone like John/Joyce for a job working for a friend of yours?	1,51	1,43	1,32	-,870b	0,384
S-08. How would you feel to sit next to John/Joyce in the bus?	1,53	1,44	1,27	-1,503b	0,133
S-09. How would you feel to have John/Joyce as a friend?	1,5	1,47	1,29	-1,567b	0,117
S-10. How would you feel shaking hands with someone like John/Joyce?	1,54	1,46	1,27*	-1,986b	0,047
* Items showed a significant difference					

Table C.5: Results of SDS for the radio interview including all participants

	Before radio interview	Before radio interview	After radio interview		
	All Ps	Only Ps who did post-test	Only Ps who did post-test		
	Mean	Mean	Mean	Z	p

S-01. How would you feel to visit a house of someone like John/Joyce?	1,35	1,31	1,17	-1,895b	0,058
S-02. How would you feel working together with someone like John/Joyce?	1,38	1,27	1,17*	-2,138b	0,033
S-03. How would you feel having someone like John/Joyce as a neighbour?	1,31	1,32	1,17	-1,875b	0,061
S-04 How about having someone like John/Joyce taking care of your children for a couple of hours?	1,38	1,31	1,26	-,812b	0,417
S-05. Would you permit your child to marry someone like John/Joyce?	1,55	1,45	1,33	-1,047b	0,295
S-06. How would you feel about introducing John/Joyce to a young woman you are friendly with?	1,32	1,29	1,16	-1,708b	0,088
S-07. How would you feel about recommending someone like John/Joyce for a job working for a friend of yours?	1,36	1,35	1,16*	-2,884b	0,004
S-08. How would you feel to sit next to John/Joyce in the bus?	1,27	1,26	1,1*	-2,202b	0,028
S-09. How would you feel to have John/Joyce as a friend?	1,28	1,24	1,14	-1,882b	0,06
S-10. How would you feel shaking hands with someone like John/Joyce?	1,3	1,26	1,09*	-2,555b	0,011
	* Items showed a significant difference				