

Tjitske de Groot

## How to break the myths surrounding albinism?

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Gaining insight into albinism-related stigma reduction interventions in local communities and formal education in Tanzania.

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Printed by:

## PROMOTORS

Prof. dr. Wolfgang Jacquet

Prof. dr. Pieter Meurs

## MEMBERS OF THE JURY

Prof. dr. Dominique Verté (Chair)

Prof. dr. Tom Vanwing

Dr. Bieke Abelshausen

Prof. dr. Geert van Hove

Prof. dr. Charlotte Baker

## LIVING IN THE SHADOW

The pictures on the cover of this thesis and at the beginning of each chapter were made by photographer Sacha de Boer in cooperation with the Liliane Foundation. The pictures were on display in the photo exhibition 'Leven in de Schaduw' (Living in the Shadow) in 2017 and 2018. I am very grateful to have the opportunity to portray these pictures in this thesis. The pictures show the strength, agency and resilience of people with albinism in Tanzania. In the pictures we can see their hope for a brighter future, in which people with albinism will have equal chances. To make their dreams come true, to get them out of the shadow, people's attitudes towards people with albinism need to change. The myths surrounding albinism should be broken.



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## FUNDING

This PhD research was funded by VLIR-UOS through a VLADOC PhD scholarship. This scholarship is offered to students to carry out research on a development oriented subject. VLIR-UOS had no involvement in the design, data collection, analysis and interpretation, in the writing of the thesis or in the decision to submit the articles for publication.

I would like to thank VLIR-UOS for giving me this opportunity.



## ACCOUNT

Chapter 4 to 10 are based on articles that are published, in press or under review in scientific journals. Chapter 1 is partly based on a published article.

### CHAPTER 1

de Groot, T., Meurs, P., & Jacquet, W. (2019). The effect of contact interventions on the stigma of people with albinism in Tanzania. *Journal of Visual Impairment & Blindness*, 113(5), 464-469.

### CHAPTER 4

de Groot, T., Peters, R., van Brakel, W., Meurs, P., & Jacquet, W. (2020). The cultural validation of two scales assessing albinism-related social stigma among high school students in Tanzania. *Disability, CBR and Inclusive Development*, 30(4), 11-38.

### CHAPTER 5

de Groot, T., Jacquet, W., Meurs, P., & Peters, R. (2020). Measuring stigma related to people with albinism in Tanzania: a cultural validation study of the EMIC-CSS and SDS among adults. *Disability, CBR and Inclusive Development*, 31(1), 7-29.

### CHAPTER 6

de Groot, T., Jacquet, W., De Backer, F., Peters, R., & Meurs, P. (2020) Using visual vignettes to explore sensitive topics: a research note on exploring attitudes towards people with albinism in Tanzania. *International Journal of Social Research Methodology*, 23(4).

### CHAPTER 7

De Groot, T., Meurs, P., Almasi, M., Peters, R., & Jacquet, W. (under review). Reducing albinism-related stigma among primary school students through a theatre intervention in Tanzania: a mixed methods study. *Journal of African Cultural Studies*.

### CHAPTER 8

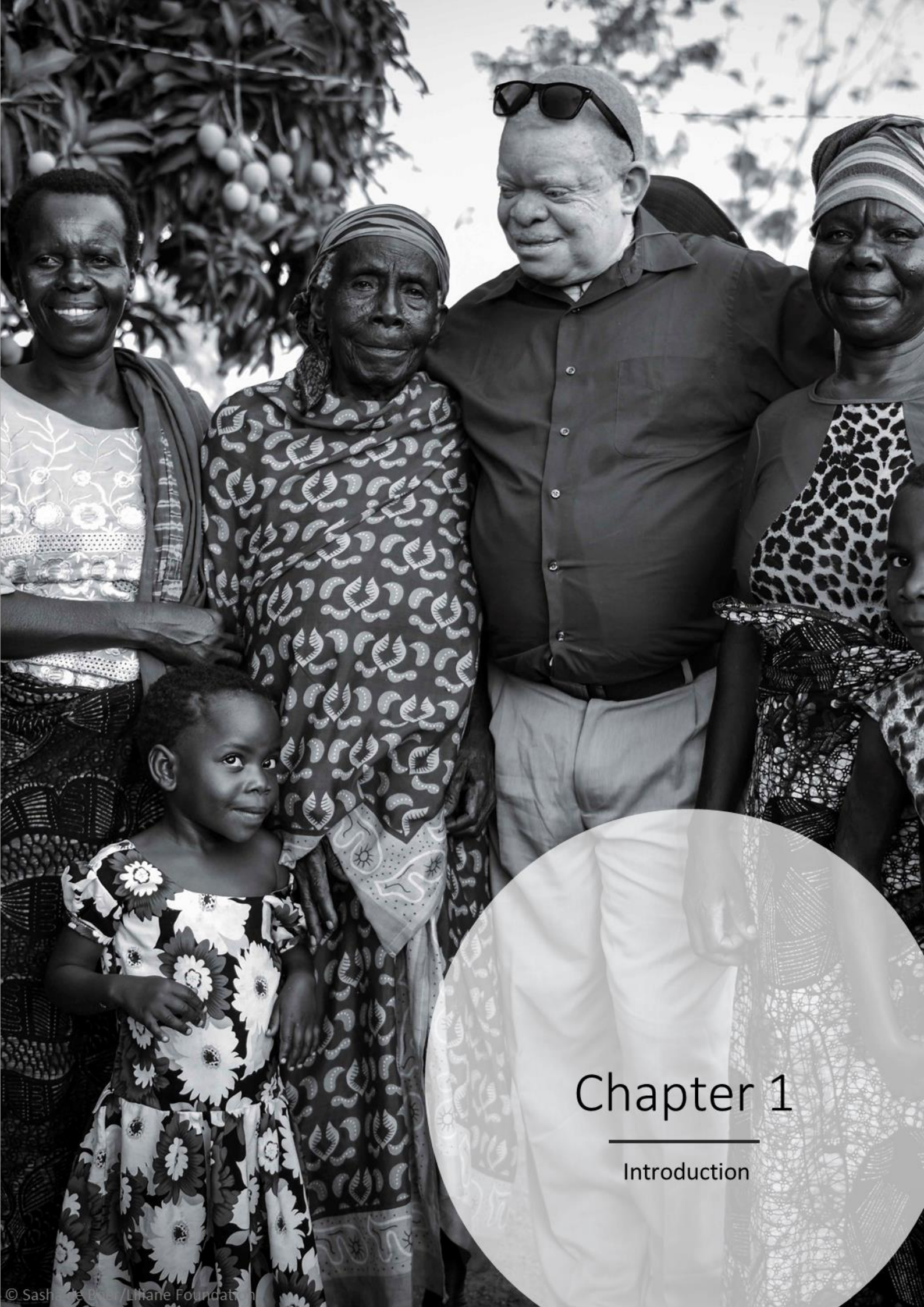
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### CHAPTER 9

de Groot, T., Meurs, P., Jacquet, W., & Peters, R. (under review). Contact vs. Education: an explorative comparison between the contact and education strategy considering albinism-related stigma in Tanzanian high schools. *Foundation of Science*.

### CHAPTER 10

de Groot, T., Peters, R., Jacquet, W., Mesaki, S., & Meurs, P. (under review). Contact strategy and albinism: an exploration of spokespersons' experiences in Tanzania. *International Journal of Disability, Development and Education*.



# Chapter 1

Introduction

## CHAPTER 1 INTRODUCTION

*When I was a child, other children did not want to play with me, and you know the stigmas they have, they don't know nothing about albinism. So, they think that it is quite strange that they are black and I'm white. (Person with albinism)*

Like the respondent in the quote above, people with albinism in Tanzania are often socially excluded. As a consequence of the stigma related to their condition they are frequently (and sometimes violently) discriminated. A variety of local mythologies, worldviews and beliefs surround albinism. For example, people with albinism are believed to be ghosts and their body parts are said to bring good fortune. As such, the health-related consequences of albinism are accompanied by discrimination and social stigma, resulting in precarious and distressing living conditions.

In recent years, various stigma reduction interventions have been implemented on a community level, by governmental and non-governmental organizations to improve the wellbeing of people with albinism in Tanzania. Whereas research on stigma reduction intervention in relation to other health-related stigma is available, little attention has been paid in research to the effectiveness of interventions related to albinism. Therefore, the aim of my doctoral dissertation is to gain insight into stigma reduction interventions in local communities and the formal education system in Tanzania.

The thesis research began with adapting and validating quantitative stigma measurement tools for adolescents and adults, to be able to measure stigmatizing attitudes towards people with albinism. The tools were based on scales that were used to measure leprosy-related stigma in Indonesia and had to be adapted to the condition of albinism and to the Tanzanian context. Additionally, I explored the possibilities of a qualitative method to do research on people's attitudes towards people with albinism: the visual vignette method. Thereafter, the effectiveness of several types of stigma reduction strategies and interventions was tested. In former research on health-related stigma the education and contact strategy had proven to be effective, and in the current thesis I wanted to gain more insight into the applicability of these strategies in albinism-related stigma reduction interventions in Tanzania. Therefore, these strategies were used in the stigma reduction interventions that were explored in this thesis: theatre, radio and filmed interventions. Additionally, I focused on the influence of entertainment in the tested interventions. At the end of the thesis it is being discussed how people with albinism feel about presenting on their own condition. With this research I want to make a contribution to the field of health-related stigma and stigma reduction interventions. Through my research I want to provide recommendations for stigma reduction interventions to governmental and non-governmental organizations.

In this introductory chapter I describe the need for this PhD research. Firstly, the situation of people with albinism in Tanzania is described. Then follows an account to situate the main aims of this thesis. At the end of the chapter an outline will be provided of the thesis' content.

## ALBINISM IN TANZANIA

In sub-Saharan Africa the prevalence of albinism in some populations is as high as 1 in 1700 (Lund & Roberts, 2018), ten-fold higher than the estimated prevalence of 1 in 17,000 people in North-America and Europe (Martinez-Garcia & Montoliu, 2013). The Tanzanian census of 2014 reported that the prevalence of people with albinism is 1 in 2,673 (The United Republic of Tanzania, 2014). For the Tanzanian population of over 44 million (2012), this number would mean that over 16,000 people have albinism (The United Republic of Tanzania, 2014). This is thought to be an underestimate, possibly due to under reporting by families hesitant to provide information about those with albinism in their household due to the fear generated by widely reported attacks on people with albinism (Lund & Roberts, 2018). Elaborating on this notion, Under The Same Sun (UTSS), a Tanzanian non-governmental organization aiming to assist people with albinism, estimates that the numbers are as high as 1 in 1400 people having albinism, which would mean over 30,000 people have albinism in Tanzania (UTSS, n.d.).

The condition of albinism has a variety of physical consequences. Oculocutaneous albinism is a recessive inherited condition, meaning that both parents must be carriers but do not necessarily have albinism themselves. When both parents are carriers they have a 25% chance of getting a child with albinism (Grønskov, Ek, & Brondum-Nielsen, 2007; Kromberg, 2018). Albinism causes a lack of melanin. This shortage does not only cause the light physical appearance of people with albinism but also causes a lack of protective pigmentation, and the skin of people with albinism is therefore highly sensitive to the ultraviolet radiation of the sun (Grønskov, et al., 2007; Hong, Zeeb, & Repacholi, 2006). This causes skin problems such as skin cancer, which can result in people with albinism to die at a young age (Kromberg, 2018; Lookingbill, Lookingbill, & Leppard, 1995; Mabula, et al., 2012; McBride, 2014). Because of the reduction of melanin in the eyes albinism generally results in low vision (Yahalom, et al., 2012), which is an extra constraint in their educational and working careers. By some it is wrongly assumed that people with albinism will become blind, causing some people with albinism to be unnecessarily schooled in schools for blind students (Lynch, Lund, & Massah, 2014). People with albinism need to protect their skin and eyes from the sun, for example through wearing a hat, long-sleeved clothing, sunglasses and sunscreen. Also, visual aids are necessary to reduce visual difficulties of people with albinism. However, these necessities are often not available or affordable for people with albinism in Africa (Kromberg, 2018; Lund & Taylor, 2008).

## STIGMA OF ALBINISM

People with albinism are discriminated worldwide, and on the African continent in specific (Brocco, 2015; Dapi, Tambe, & Monebenimp, 2018; Wan, 2003). Often people are not informed about albinism. Even people with albinism and their families have little knowledge on the condition (Braathen & Ingstad, 2006). In interviews held by Braathen and Ingstad (2006) with 25 people with albinism and their family members in Malawi, it was discovered that not one parent of a child with albinism received a biomedical explanation on the cause of albinism after the birth of the child. In some cases, people with albinism found out themselves what albinism was, during a course on genetics in secondary school (de Groot, et al., 2019).

Numerous locally constructed explanations surround albinism on the African continent. In Cameroon some believe that people with albinism are monsters and witches (Dapi, et al., 2018). In Yoruba culture in Nigeria people with albinism are seen as a special breed and are assigned mythical powers (Olagunju, 2012). In Zimbabwe it is believed people with albinism are possessed by water spirits (Machoko, 2013). In Tanzania albinism is often explained through a religious discourse, as albinism being caused by the will of God (Brocco, 2015). Many people do not believe people with albinism to be human beings (Imafidon, 2017) and in Tanzania they are thought to be ghosts (*zeruzeru* as they would call people with albinism in Swahili) (Baker, Lund, Nyathi, & Taylor, 2010; Brocco, 2015). Some other myths surrounding albinism are portrayed in Textbox 1.

Instead of dying, people with albinism are believed to just disappear (Baker, et al., 2010; Kromberg, 2018).
The body parts of people with albinism are thought to provide good fortune (Brocco, 2016; Bryceson, Jønsson, & Sherrington, 2010; Burke, Kaijage, & John-Langba, 2014; Cruz-Inigo, Ladizinski, & Sethi, 2011).
Sexual intercourse with a woman with albinism is believed to cure HIV/AIDS (Baker, et al., 2010; Cruz-Inigo, et al., 2011).
People with albinism are thought to have less mental and physical capabilities than people without albinism (Cruz-Inigo, et al., 2011; Reimer-Kirkham, Astle, Ero, Panchuk, & Dixon, 2019).
Albinism is thought to be contagious (Baker, et al., 2010; Reimer-Kirkham, et al., 2019).
Often mothers of people with albinism are blamed for causing their child to have albinism (Cruz-Indigo, et al., 2011; Reimer-Kirkham, et al., 2019).

#### Textbox 1 Myths surrounding albinism

The rise of people believing that medicine (called *muti* in many areas of the African continent) made from the body parts of people with albinism can be powerful good luck charms, has led to one of the most devastating outcomes of albinism-related stigma recently. Because of the severity of this issue, I focus on this specific myth in this section. This belief is not a traditional myth but a recent invention. In former research on traditional beliefs in Tanzania, no researcher has ever described this belief related to albinism (Bryceson, et al., 2010). Only since 2008 this myth was mentioned in an increasing amount of media reports on the killings of people with albinism (Burke, et al., 2014). However, the myths that powerful medicine can be created from human body parts originates from the past, e.g. the body parts of chiefs are known to be used to make medicine among several ethnic groups in Africa (Eiselen & Schapera, 1937; Kromberg, 2018).

Several aspects can be taken into consideration when trying to explain the sudden rise of interest in the body parts of people with albinism in Tanzania. Already in 2001, Sanders linked the liberalisation of economic policies to the rise of commodification of the occult and of body parts in Tanzania (Sanders, 2001a, 2001b). During the past decades the mainly traditional agrarian lifestyle in Tanzania has been declining, among others due to market liberalisation policies. People turned to other ways of generating an income. Some started to deal with the artisanal mining for precious materials, such as gold, diamonds and gemstones. Income generating activities such as mining, but also fishing, have high income potential, however being successful is uncertain and often encompasses personal risks (Bryceson & Jønsson, 2010). Because the belief in witchcraft in Tanzania is prominent (Mesaki, 2009), this opened up opportunities for *waganga* (witchdoctors)<sup>1</sup> to sell people some security in the shape of good luck charms.

By opening up the market, the marketing of the occult arrived, and it has been used by its players accordingly. 'Luck' has been made into a commodity that can be obtained (Bryceson, et al., 2010; Sanders, 2001a). People became in search of material wealth. There were people that sacrificed people with albinism in their search for wealth: the miners in search of precious resources, the *waganga* and their assassins by making money through selling these charms. These dynamics can be

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<sup>1</sup> It is of importance to make a distinction between the *mchawi* (a witch) and the *mganga* (witchdoctor). A *mchawi* is being accused of causing misfortune, and the *mganga* is a public figure claiming to be able to intermedate (Rasmussen & Rasmussen, 2015).

clearly observed in the areas surrounding Lake Victoria. In these areas mining and fishing became rewarding businesses and in these areas people hold strong witchcraft beliefs. Most of the people who are originally settled in this area belong to the Sukuma tribe. The Sukuma are especially known for their witchcraft beliefs (Sanders, 2001b). This combination of factors, strong witchcraft beliefs in an area where people work in an insecure field, with hopes of high income, caused the majority of the killings of people with albinism to have taken place in this region of Tanzania.

Imafidon (2017) provides us with further explanation on why people with albinism in African society are targeted by fierce stigmatization:

*The deep-seated causes [of the challenges faced by people with albinism in Africa] that I have emphasized as foundational to the challenges, are the perception of the person with albinism as an unusual (nonhuman) being, an ontological other who does not fit within (and is thus excluded from) the structure of beings, and the ethical points of view that justify the ill-treatment of persons with albinism. (Imafidon, 2017, p. 175)*

According to Imafidon (2017), the appearance of people with albinism makes them to be seen as something different from the ordinary. He states that in African tradition, communal harmony among beings is emphasised a necessity for survival. To sustain this communal harmony, something different from the ordinary is seen as a threat for the continuation of society. In order to protect societies, ideologies and structures are promoted that sustain the status quo. Since people with albinism are seen as a danger to the status quo, and they are not seen as belonging to the society of human beings, they are thus considered a threat and therefore people in society believe that people with albinism deserve maltreatment.

## VIOLATION OF HUMAN RIGHTS OF PEOPLE WITH ALBINISM IN TANZANIA

The myths surrounding albinism lay the foundation for a large number of violations of human rights in Tanzania. As described by Franklin, Lund, Bradbury-Jones and Taylor (2018) people with albinism are heavily affected by the stigmatizing and discriminative processes and practices against them: 'they face significant 'barriers to being' and 'barriers to doing'. Firstly, the rights of people with albinism to life and protection and the right to freedom from discrimination are heavily threatened: 'barriers to being'. Recently the myth that the body parts of those with albinism can cause good fortune, caused the killing of many people with albinism. Also, it is said that children with albinism are often murdered after birth because they are thought to be incapable to provide for their family (Bryceson, et al., 2010). Between 2000 and 2019 in Tanzania, 76 people with albinism were killed and 182 people survived a physical attack, 1 person with albinism has been abducted and 2 graves of people with albinism have been violated (UTSS, 2020). There are also other mistreatments of people with albinism, who are not recorded officially, such as cutting the hair of children with albinism in order to sell it as good luck charms (Taylor, Bradbury-Jones, & Lund, 2019). Secondly, people with albinism face "many 'barriers to doing', structural and physical barriers that prevent them from being included fully in society or having the same opportunities their non-disabled peers" (Franklin, et al., 2018, p. 4). People with albinism are mostly discriminated by people from outside the closer social circle (Braathen & Ingstad, 2006). Discriminative acts experienced by people with albinism on a day-to-day basis can be: name-calling, being laughed at, avoidance and exclusion (de Groot, et al., 2019; Taylor, et al., 2019). People with albinism have difficulties to obtain a good education (Lynch, et al., 2014) and to find a job (Braathen & Ingstad, 2006; Kiprono, Joseph, Naafs, & Chaula, 2012), which has many unfavourable consequences. Not only people with albinism themselves experience discrimination, but also their families can be affected and influenced. It happens for example that fathers leave the mother of their child after she gave birth to a child with albinism (Braathen & Ingstad, 2006; Taylor, et al., 2019).

Families of people with albinism can be stigmatized because they have someone with albinism in the family (Brocco, 2016).

The discrimination of people with albinism is also expressed by the use of many derogative terms to label people with albinism. As already mentioned in Tanzania they are often referred to as *zeruzeru* (ghost), most likely derived from the English word zero (Brocco, 2015; Bryceson, et al., 2010). They are also frequently called *mzungu* ('European', a word used to refer to people with a white skin colour) (Brocco, 2015). A new term has also been put into use: *dili* (deal), this term relates to the myth that albinism body part are able to provide riches, either by selling them or gaining luck through them (Brocco, 2015). Inside Tanzania no differences have been found in the use of certain terms, however, throughout the African continent terms to label people with albinism can vary. In Malawi for example, people with albinism are sometimes called 'yellow man', 'Jeffrey Zigoma' (famous Malawian gospel singer with albinism) and *napwere* (wrinkled type of pea) (Braathen & Ingstad, 2006). The Bamana and Maninke of Mali use the term *gomblé* (red monkey) (Imperato & Imperato, 2006). As can already be read, in this thesis the term 'people with albinism' will be used. The often-used term 'albino' will not be used as the Tanzanian Albinism Society and other albinism-related non-governmental organizations prefer the term 'people with albinism'. 'People with albinism' puts emphasis on the person, instead of the condition (National Organization for Albinism and Hypopigmentation, 2019; UTSS, 2019).

The Universal Declaration of Human Rights states that everyone has the right to be treated equally and with dignity. Discrimination and social exclusion, based on any condition is a violation of human rights (UN, 1948). Since 2013, four resolutions that specifically concerned the situation of people with albinism have been adopted by the United Nations' Human Rights Commission and the African Commission on Human and Peoples' Rights (ACHPR, 2013; UN, 2013a; UN, 2013b; UN, 2014). In June 2015 the UN designated Ikponwosa Ero as the UN Independent Expert on the enjoyment of human rights by persons with albinism, through whom more attention has been given to the situation of people with albinism worldwide.

## STIGMA REDUCTION

Stigmatization has a large effect on negative stereotyping of the affected. Stigmatization can, among others, lead to avoidance and rejection of the person with a stigmatizing condition (Dovidio, Major, & Crocker, 2000; Herek, 1999). Health-related stigma causes problems worldwide and in relation to a large variety of conditions, e.g. HIV/AIDS and leprosy. The negative outcomes of stigma make research on stigma an important topic for social and health policy and for clinical practice (Weiss, et al., 2008). The topic of health-related stigma has been studied to a great extent and has a long history in scientific literature. As will be discussed in further detail in Chapter 2.

Recently, there has been a rise of albinism-related studies in the scientific literature. Most of these studies focussed on the experienced stigmatization by people with albinism (e.g. Affram, Teye-Kwadjo, & Gyasi-Gyamerah, 2019; Brocco, 2015; Brocco, 2016; Franklin, et al., 2018; Reimer-Kirkham, et al., 2019; Taylor, et al., 2019) and the myths about albinism (e.g. Baker, et al., 2010; Braathen & Ingstad, 2006; Bradbury-Jones, Ogik, Betts, Taylor, & Lund, 2018; Bryceson, et al., 2010; Dapi, et al., 2018; Reimer-Kirkham, et al., 2019). Several research articles provide suggestions for educating people about albinism (Baker & Lund, 2017; Hong, et al., 2006; Lund, Massah, & Dart, 2014). In other articles, authors emphasize the importance of attitudinal change (e. g. Franklin, et al., 2018). However, there is little scientific research focussing on the effectiveness of interventions that set out to generate attitudinal change towards people with albinism. Nor has there been much research focussing on how to increase people's knowledge about albinism. In general, the evaluation of interventions has been carried out by the implementing organizations themselves (e.g. Clarke & Beal, 2018; Welcome Trust & Standing Voice, 2018). Additionally, albinism has not often been studied in the context of health-



related stigma, even though the study of the health-related stigma of albinism can add to the insights into the study field of health-related stigma.

Action is being taken to reduce the health-related stigma towards people with albinism and to improve their well-being. The Tanzanian government has tried to counter the discrimination of people with albinism by condemning the killings and by trying to improve the inclusion in the local community (Brocco, 2015). With government support the Kilimanjaro Christian Medical Centre in Moshi has been conducting programs to take care of the skin of people with albinism, by providing them with information, sunscreen and surgical treatment for skin cancer. The government does this in collaboration with two of the major NGOs that support people with albinism in Tanzania: Standing Voice and Under the Same Sun. Besides these organizations there are other organizations trying to support people with albinism, varying from small voluntary organizations that help people with albinism by providing necessities such as sunscreen and sunglasses, to large organizations focussing on advocacy and education. The Tanzanian Albinism Society (TAS) is a national NGO established by people with albinism themselves, who among others involve themselves with the registration of people with albinism. Many organizations that aim to improve the lives of people with albinism focus on awareness raising campaigns on the community level.

Stigma reduction interventions cannot be thought of as optional but should be included as part of the treatment of a disease or condition. This because health-related stigma often has far reaching negative outcomes for the stigmatized, as is the case for people with albinism in Tanzania. Through stigma reduction interventions the incidence and burden of stigma can be reduced (Hartog, et al., 2020). However, more research on the effectiveness of stigma reduction interventions is necessary (Bos, Pryor, Reeder, & Stutterheim, 2013; Cross, Heijnders, Dalal, Sermittiron, & Mak, 2011; Hofstraat & van Brakel, 2016; Rao, et al., 2019). Additionally, there is a lack of research focussing on stigma reduction interventions in relation to albinism in specific. To develop effective stigma reduction interventions, these interventions should be based on theory and their effectiveness should be tested (Bos, Schaalma, & Pryor, 2008; Bos, et al., 2013; Parker & Aggleton, 2003): which is what I set out to do in this research. In this research I made use of the existing literature on health-related stigma and explored the possibilities for stigma reduction strategies and intervention that had proven to be effective in relation to other health-related stigmas. Through this research I want to contribute to the field of health-related stigma.

The above arguments all led to the formation of the current research, titled: "How to break the myths surrounding albinism?". This study aimed to gain insights into albinism-related stigma reduction interventions in the local community and formal education system in Tanzania. Improved understanding will enable us to provide recommendations to policy makers and researchers about valid stigma measurement tools, effective elements of stigma-reduction interventions and add to the literature on health-related stigma and stigma reduction interventions.

## OUTLINE OF THESIS

The chapters of this thesis are organized in four parts. **Part 1** forms an introduction to the thesis research. In Chapter 2 further explanation will be provided on the theoretical concepts used in this thesis. The basic concepts of stigma reduction will be discussed in further detail. An overview of the research design used for this study will be provided in **Chapter 3**.

**Part 2** of this thesis focusses on methods to evaluate people's attitudes towards people with albinism. **Chapter 4** focusses on a scale validation to measure the attitudes towards people with albinism among high school students. In **Chapter 5** scales were validated to measure these attitudes among an adult

population. In **Chapter 6** a qualitative method using visual vignettes is explored to do research on a sensitive topic such as albinism.

In **Part 3** several stigma reduction interventions and strategies are examined. In **Chapter 7** the effect of a theatre intervention in primary schools is explored. **Chapter 8** focusses on the outcomes of community radio on albinism, in which two shows about albinism were broadcasted: a radio drama and a radio interview. In **Chapter 9** the contact strategy is compared with the education strategy among high school youth. The experience of people with albinism performing as spokespersons in a contact intervention is explored in **Chapter 10**.

To conclude in **Part 4**, a discussion of the findings and its implications will be provided in **Chapter 11**. Other initiatives that were taken during this PhD research which did not result in academic articles are discussed in **Chapter 12**.

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## Chapter 2

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Theoretical background



## CHAPTER 2 THEORETICAL CONCEPTS

Chapter 2 provides a theoretical background of the main concepts that are used in this thesis. The chapter will start by discussing the concept of stigma. Then follows an explanation of aspects of stigma reduction and stigma reduction interventions.

### DEFINING STIGMA

The description of 'stigma' begins with the early ideas about the concept by Erving Goffman (1963). According to Goffman, a stigmatized person, 'the stigmatized', possesses a discrediting attribute, causing that individual to be different from 'normal' people. Consequently these 'normal' people discriminate or react negatively towards people with this discrediting attribute. The word 'stigma' itself, derives from the ancient Greek practice of tattooing slaves with a 'stigma', which indicated the owner of the slave. Later in history the word stigma was used by Christians referring to the crucifixion marks of Jesus Christ.

Large variations exist in the definition of the stigma concept. This disparity is caused by the use of the stigma concept across disciplines, theoretical backgrounds and circumstances (Link & Phelan, 2001). For the current study two commonly used definitions of stigma will be introduced that provide a workable description of the concept in relation to the topic of research.

The first definition of stigma is based on the work of Link and Phelan (2001), according to them stigmatization exists out of the following four components:

- (1) the distinguishing and labeling of human differences,
- (2) the association of undesirable characteristics to negative stereotypes,
- (3) the marking of the stigmatized group as 'the other' (us vs. them),
- (4) the experiencing of status loss and discrimination.

Stigmatization can only arise when the beforementioned elements co-occur in a power structure enabling stigmatization to happen. According to this conceptualization, stigmatization occurs through social relations and are therefore only experienced in social interaction. Stigmatization is therefore bound to its cultural and social context. All components of stigma are a continuum, the outcomes of stigma therefore vary largely. Stigmatization can target small or large groups in society, even individuals (Link & Phelan, 2001; Pescosolido & Martin, 2015). The definition of stigma by Link and Phelan (2001) is especially useful when conceptualizing stigma on the level of the community.

The second definition of stigma of interest to this research comes from Weiss, Ramakrishna and Somma (2006). This definition is often used when focusing on stigma related to a health condition. Weiss et al. (2006) describe stigma as follows:

*Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g., race, ethnicity, sexual preferences), may also affect health; these are*

*also matters of interest that concern questions of health-related stigma. (Weiss, et al., 2006, p. 280)*

The above definition is proposed as a working definition when analyzing health-related problems. Weiss et al. (2006) point out the importance of including social, cultural and economic settings when analyzing stigma. They point out that these settings can vary across countries and cultures. This definition can form a solid base for the development of interventions to reduce stigmatization.

There is a variety of concepts that are often used when discussing stigma. Stigma goes accompanied by labels. These labels often lead to stereotypes. These stereotypes can cause negative outcomes for the stigmatized, such as prejudice and discrimination (Pescosolido & Martin, 2015). This is summarized by Pescosolido and Martin (2015) as follows: “in other words, stigma represents the intersection of cultural differentiation, identity formation through social interaction, and social inequality” (Pescosolido & Martin, 2015, p. 22.7). In Textbox 1 below the above-named concepts accompany the stigma concept are further explained.

**Labels:** Officially sanctioned terms applied to conditions, individual, groups, places, organization, institutions, or other social entities.  
**Stereotypes:** Negative beliefs and attitudes assigned to labelled social entities  
**Prejudice:** Endorsement of negative beliefs and attitudes in stereotypes  
**Discrimination:** Behaviours that act to endorse reinforce stereotypes, and disadvantage those labelled.

Textbox 1 Concepts accompanying the stigma concept (Pescosolido & Martin, 2015, p. 22.6)

Over the years, a large variety of definitions of stigma arose and many of them have been criticized. The conceptualization of stigma as used in this thesis took into account these critics. To situate the used conceptualization further I will discuss two common critiques here. Firstly, critics point out that stigmatization is a dynamic process and one has to be careful not to define it as a static phenomenon, as is often done in conceptualizing stigma (Livingston & Boyd, 2010; Weiss, 2008). Secondly, others have argued that many stigma definitions based on Goffman’s work are lacking the focus on the context in which stigmatization takes place (Farrugia, 2009; Parker & Aggleton, 2003; Scambler, 2009). Investigating this context is important (Link & Phelan, 2001) because one should take account of the power structures, and with that the local knowledge systems, that enable stigmatization. These social structures, legitimizing social inequality, are culturally and historically specific (Bos, Pryor, Reeder, & Stutterheim, 2013; Foucault, 1977). By ignoring these power structures, the stigmatized is denied agency to counteract the structure and analysis of stigmatization is limited. Using a limited definition of stigma can therefore lead to an incomplete apolitical conclusion from which it is hard to develop proper stigma reduction interventions (Farrugia, 2009; Scambler, 2009). Therefore, Parker and Aggleton (2003) suggest having a closer look at Foucault’s work when discussing stigma. Foucault underlines the cultural production of difference in order to endorse and strengthen the power system in place, however he never mentions stigma. By putting Goffman’s and Foucault’s work together, a more complete view and possibilities for analysis and construction of stigma reduction interventions can arise. As stated by Parker and Aggleton (2003) when emphasizing the importance of combining these works:

*It is only by exploring the relationships between these different categories (culture, power and difference) that it becomes possible to understand stigma and stigmatization not merely as an isolated phenomenon, or expressions of individual*

*attitudes or of cultural values, but as central to the constitution of the social order.*  
(Parker & Aggleton, 2003, p. 17)

## MANIFESTATIONS OF STIGMA

To get a better understanding of stigmatization this section will discuss two different distinctions of the manifestations of stigma. These theories enable the positioning of this research within the broader field of stigma research and they assist in further defining the focus of this research. Firstly, the four types of stigma as described by Pryor and Reeder (2011) will be illustrated. Secondly, the extended Hidden Distress Model of Stigma by Weiss (2008) will be explained.

Pryor and Reeder (2011), inspired by theories of Corrigan, Kerr and Knudsen (2005) and Herek (2007), suggest the subdivision of stigmatization into four manifestations: (1) public stigma, (2) self-stigma, (3) stigma by association and (4) structural stigma. (1) Public stigma is about larger social groups who endorse stereotypes and act on them. It includes the cognitive, affective and behavioural reactions of the stigmatizer (Bos, et al., 2013; Corrigan & Watson, 2002; Corrigan, et al., 2005; Herek, 2007). As can be seen in the figure below, public stigma is the only manifestation linked to all the other manifestations of stigma (Figure 1). (2) Self-stigma is the effect of stigma on the stigmatized him or herself. By becoming aware of the stigmatizing attitudes in the community one can internalize the stigma which can result in a loss of self-esteem and self-efficacy. However, it is important to be aware that not everyone with a stigmatizing condition suffers from self-stigma (Corrigan & Watson, 2002; Corrigan, et al., 2005). (3) There is stigma by association, which is the stigma people endure because of their social relation to a stigmatized person, for example friends or family can experience stigma by association (Bos, et al., 2013). (4) There is structural stigma referring to the endorsement of stigmatization through social institutions and ideological systems (Pryor & Reeder, 2011). As portrayed in Figure 1, manifestations of stigma are not isolated from each other. Public stigma plays a central role in stigmatization. Because the public stigma manifests itself at a community level this research focusses mostly on stigmatization at a community level.

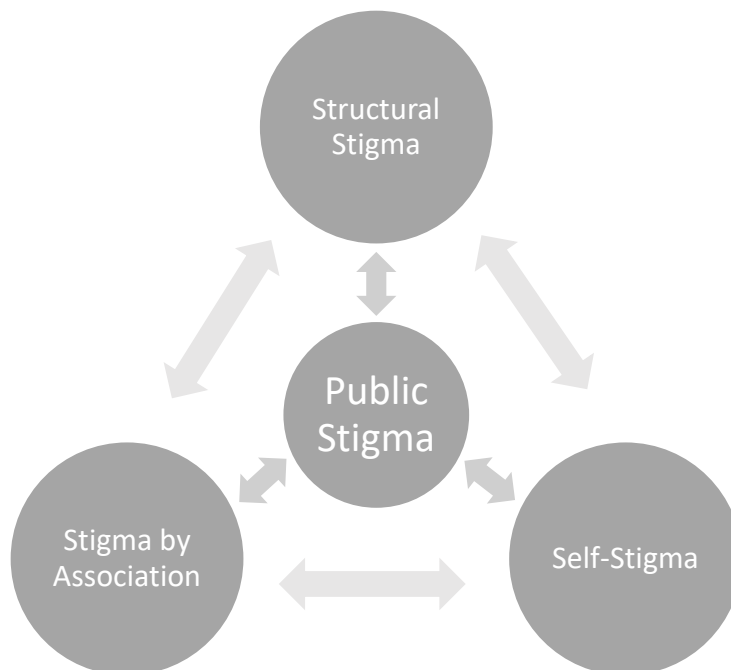


Figure 1 Four manifestations of stigma (Based on Pryor & Reeder, 2011)

The theory of Weiss (2008) elaborates on public stigma. Weiss extended the Hidden-Distress Model of Scambler (1998) by indicating six levels of stigma. Firstly, a distinction was made between enacted stigma and felt stigma. Enacted stigma refers to the actual experience of discrimination, so the actual stigmatizing acts towards the stigmatized. Felt stigma refers to feelings about (possible) stigmatization. Secondly, from the perspective of the stigmatized, stigmatization is further distinguished into (1) enacted stigma: the actual experience of actions of discrimination, (2) internalized stigma: the acceptance by the stigmatized of the stigmatizing attitudes of the society through which he or she will self-stigmatize (Livingston & Boyd, 2010) and (3) anticipated stigma: the expectation that others will stigmatize him or her. Thirdly, from the perspective of the stigmatizer Weiss (2008) distinguished: (4) enacted stigma: the action of discrimination, (5) accepted stigma: not performing nor supporting stigmatizing acts but also not protesting against it and (6) endorsed stigma: supporting stigmatization but not participating (see Figure 2). My research, focussing on stigmatization on a community level, mainly concerns enacted, accepted and endorsed stigma. However, the distinction by Weiss (2008) as the subdivision by Pryor and Reeder (2011) show us the interconnectedness of different manifestations of stigma.

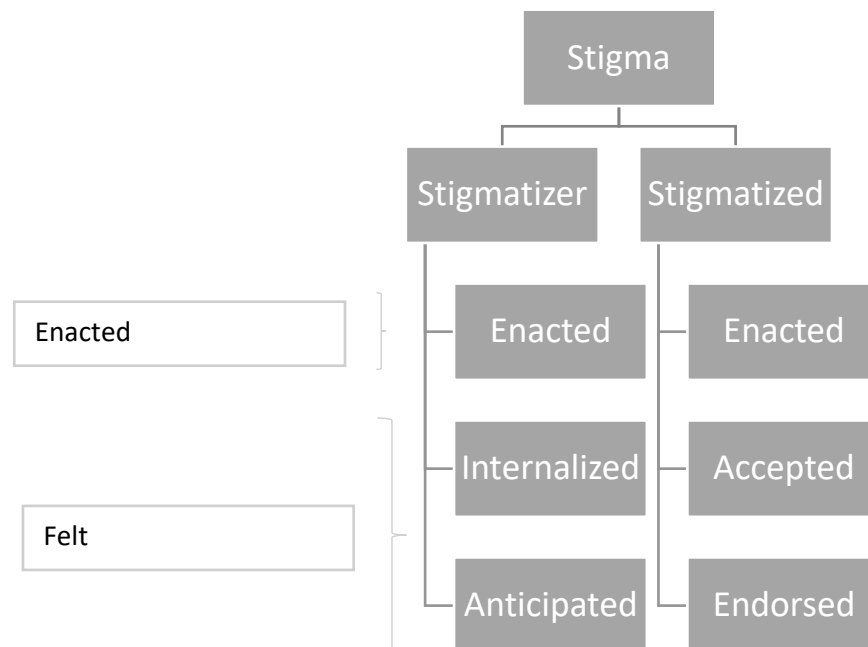


Figure 2 Distinction of stigma manifestations (Weiss, 2008)

### DRIVERS AND OUTCOMES OF STIGMATIZATION

In the existing literature on health-related stigma several aspects of stigmatizing conditions were distinguished that can mediate the strength of stigmatization. Stangl et al (2019) term these aspects as stigma drivers. Some of these drivers are explained below. Firstly, *fear of contagion* can increase stigmatizing feelings, for example people can fear to receive HIV/AIDS by touching someone with the condition (Bos, et al., 2013; van Brakel, et al., 2019). Secondly, the *perceived dangerousness* influences the level of stigma, for example people with a mental illness are often feared for possible unpredictable actions (Mak, Chong, & Wong, 2014; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). Thirdly, the *perceived severity* of the condition has an influence, very severe conditions cause both fear and sympathy (Alphen, Dijker, Bos, Borne, & Curfs, 2011; Bos, et al., 2013). Fourthly, when there is a *lack of knowledge* about certain conditions this can also worsen stigmatizing attitudes (Link & Phelan,

2001). Fifthly, *cultural beliefs* about the cause of the condition play a role. When a condition is thought to be caused by deviant behaviour and the stigmatized is therefore ascribed *personal responsibility* for the condition this can worsen stigmatizing attitudes (Bos, et al., 2013; Dijker & Koomen, 2003; Mak, et al., 2006). Sixthly, another factor that can play a role in the level of stigmatization is the *possibility for concealment* (Bos, et al., 2013), whereas HIV/AIDS might be easily concealed in most cases, the visible impairments of people affected by leprosy cannot. The applicability of these drivers to albinism-related stigma is yet unknown. Through the current study I hope to gain more insight in the applicability of these aspects on albinism-related stigma and this will be reflected upon in Chapter 11 (Discussion and Conclusion).

Outcomes of stigma are multiple and involve a large dynamic process, in which one outcome can influence another outcome. Van Brakel (2006) has compared the effects of stigma for a variety of stigmatizing conditions, excluding albinism. He concludes that, regardless of the specific condition, people with a stigmatizing condition often experience emotional stress and anxiety, and problems in friendships and social relationships. Many people with a stigmatizing condition face problems in marriage or in getting married and problems with employment or getting a job. Van Brakel (2006) provided an overview of the effects experience by people with different conditions based on literature review (Table 1). It is in the interest of my study to observe how this existing literature can be linked to albinism-related stigma. As will be reflected upon in Chapter 11 (Discussion and Conclusion).

<b>Effect on the individual and/or community</b>	<b>Leprosy</b>	<b>HIV/AIDS</b>	<b>TB</b>	<b>Mental Illness</b>	<b>Epilepsy</b>	<b>Disability</b>	<b>Buruli ulcer</b>	<b>Onchocerciasis</b>
1. <i>Emotional stress and anxiety</i>	X	X	X	X	X	X	X	X
2. <i>Problems in marriage or in getting married</i>	X	X		X	X	X	X	X
3. <i>Problems in friendships and social relationships</i>	X	X	X	X	X	X	X	X
4. <i>Problem with employment or in getting a job</i>	X	X		X	X	X		X
5. <i>Reduced educational opportunities</i>	X	X		X	X	X		
6. <i>Increased inequities between those affected and those who are not</i>	X	X		X	X	X		
7. <i>Concealment of the disease after diagnosis</i>	X	X	X	X	X			
8. <i>Poor(er) prognosis</i>	X	X	X	X				
9. <i>Other participation restrictions (e.g. economic dependency, denied access to loans and credit etc)</i>	X	X		X	X	X	X	
10. <i>Isolation</i>	X	X	X	X	X	X		X
11. <i>(Increased) psychological and psychiatric morbidity</i>	X	X	X	X	X	X		X
12. <i>Lack of motivation to continue treatment</i>	X	X	X					
13. <i>Motivation to continue treatment</i>	X		X	X	X			
14. <i>Increased disability</i>	X	X	X	X				
15. <i>Increased gender differences</i>	X	X	X					
16. <i>Empowerment (e.g., positive self image and confidence developed in resistance to discrimination)</i>	X	X		X	X	X		

Table 1 Overview of effects of stigmatization (van Brakel, 2006)

Link and Phelan (2001) emphasize the importance of understanding the influence of stigma on the distribution of life chances, such as job opportunity, educational opportunities, housing, criminal involvement and health. They distinguish three areas in which stigma influences life chances: Firstly,

status loss, because of a stigmatizing label the stigmatized are being downgraded on the societal ladder, consequently this leads to other difficulties, such as finding a proper marriage partner (van Brakel, 2006). Secondly, structural discrimination can go beyond the originally stereotypical beliefs surrounding a condition (Link & Phelan, 2001). As an example, because people with albinism are discriminated in school, they do not receive proper education, and this gave rise to the belief that people with albinism do not have the same mental ability as people without albinism (Cruz-Inigo, et al., 2011). Thirdly, people with a stigmatizing condition can suffer from stress of trying to disprove their own stereotype (Link & Phelan, 2001).

## EDUCATIONAL SCIENCES AND STIGMA REDUCTION

Stigma reduction interventions are implemented to improve people's attitudes towards people with a stigmatizing condition. As such, it harbours an educational quality: people can learn (from) it, and people can teach (about) it. The question is, however, in what way should we understand this educational quality. How does stigma reduction fit within the field of educational sciences, the focus of the faculty where this research was conducted? To answer this question, it is important to examine the meaning of education itself. Education can be split in three different formats: (1) formal, (2) informal and (3) non-formal education. (1) Formal education is the more traditional approach of education: students go through an organized structural school system leading up to a diploma. Formal education sets out with a goal, such as preparing people for a job and/or to be part of society. (2) Informal education refers to all other forms of education that cause a learning process. However, this learning process is not formally organized, e.g. knowledge can be generated from everyday experiences. Informal education is not imposed upon the student by a teacher. Besides informal education there is (3) non-formal education, referring to educational activities that have been organized but not by the official institutions, they are organized for example by organizations and groups. For non-formal education there is an educational context, but there is no curriculum or clearly set result. Stigma reduction interventions fall under this last category. Non-formal education, even if it is offered within a structured curriculum, does not lead to a certain completely defined learning goal such to be captured in a diploma or a future job, it does however lead to personal development and, hopefully attitudinal, change. It is an often externally driven type of education leading to societal change, by training people to behave a certain way within the society (Meurs, 2019). Which leads to building a society in which everyone will be able to participate.

## STIGMA REDUCTION INTERVENTIONS

There is no existing literature on albinism-related stigma reduction interventions. In this study I make use of existing literature on health-related stigma and I hope to gain more insight into how it is applicable to albinism-related stigma. Heijnders and Van der Meij (2006) distinguished levels on which stigma reduction interventions can be implemented: the intrapersonal, interpersonal, organizational/institutional, community, and governmental/structural level (Heijnders & van der Meij, 2006; McLeroy, Bibeau, Steckler, & Glanz, 1988). To effectively reduce all aspects of stigmatization, stigma reduction interventions should be implemented at all levels. However, as a scope for this research it was decided to focus at analysing possible stigma reduction interventions at the community level, since many interventions that are currently being implemented by the government of Tanzania and albinism focused NGOs, as described in Chapter 1, take place on this level. Community level interventions target specific groups within a community in order to increase knowledge and improve attitudes within these groups. Stigma reduction interventions consist of stigma reduction strategies. Frequently used strategies at the community level are: (1) education, (2) contact, (3) advocacy and (4) protest. All four of them will be discussed briefly.

(1) The education strategy entails the provision of information about a certain condition (Heijnders & Van der Meij, 2006). The education strategy is the most commonly used stigma reduction

strategy (Hartog, et al., 2020; Kemp, et al., 2019). A classroom presentation by an expert would be a typical example. Among other things, an education strategy can focus on disproving myths about a condition. As an example, in the case of albinism, an education-based intervention can provide information on the cause of albinism or explanation on how to take care of the skin of someone with albinism. An education strategy can take a variety of forms, for example: flyers, tv commercials, radio shows and internet websites. It is frequently assumed that providing information on the cause of a condition will cause attitudinal change. This starting point is based on the 'attribution theory'. This model states that human motivation and emotion is based on the search for the causal understanding of things (Corrigan, 2006; Weiner, Perry, & Magnusson, 1988). However, some researchers question if an explanation of the cause of conditions, such as a genetic explanation, truly reduces stigma (Kvaale, Haslam, & Gottdiener, 2013; Read, Haslam, Sayce, & Davies, 2006). The education strategy has proven to be successful in relation to the stigma of a variety of health-related conditions such as HIV/AIDS and mental illness related stigma (Cook, Purdie-Vaughns, Meyer, & Busch, 2013; Griffiths, Carron-Arthur, & Parsons, 2014; Hartog, et al., 2020; Mehta, et al., 2015). Other studies showed a smaller impact of this strategy (Morgan, Reavley, Ross, Too & Jorm, 2018; Rao, et al., 2019). For a more effective intervention, the education strategy is recommended in combination with another strategy (Stangl, Lloyd, Brady, Holland, & Baral, 2012; Thornicroft, et al., 2009; Rao, et al., 2019), particularly the combination of the education and contact strategy has proven to be successful (Chan, Mak, & Law, 2009; Dadun, et al., 2017; Peters, et al., 2015; Stuart, et al., 2014).

(2) The contact strategy is based on the assumption that intergroup contact decreases prejudice. This theory finds its roots in the contact hypothesis of Gordon Allport (1954). Contact itself refers to the interaction of someone with someone with a stigmatizing condition (Heijnders & van der Meij, 2006). A contact intervention can for example exist out of a person with albinism giving a presentation about his or her life. Studies suggest that there are multiple formats for contact interventions: the stigmatized can be present during the intervention resulting in direct/face-to-face contact. Para-social contact is the interaction between an audience and the representative of a medium, such as actors and presentors in a radio show. Instead of direct contact, para-social contact can also reduce prejudice (Giles, 2002; Schiappa, Gregg, & Hewes, 2005). Research showed that indirect contact, for example through video, does not influence the outcome of an intervention in comparison to an intervention based on direct contact (Morgan, et al., 2018). Turner, Crisp and Lambert (2007) even showed that when a contact person is not available, imagined group contact can also improve attitudes. Additionally, Hackler, Vogel and Cornish (2016) provided evidence for video contact with family and friends of people with a stigmatizing condition to be effective in reducing stigma. Through personal contact, people engage in a personal relationship with the stigmatized, which often disconfirms stereotypes through correcting misinformation, and generating empathy (Allport, 1954; Brown, et al., 2003; Corrigan & Penn, 1999; Corrigan, et al., 2012; Pettigrew, 1998). In case of invisible stigmatizing conditions, such as HIV/AIDS, a contact intervention requires the disclosure of the condition of the contact person (Gronholm, Henderson, Deb, & Thornicroft, 2017; Stutterheim, et al., 2011). The necessity of disclosure might be a hurdle for potential contact persons or spokespersons and carries potential harm for the conditioned (Gronholm, et al., 2017; Muula & Mfutso-Bengo, 2005). Contrary, research by Paxton (2002) on public HIV disclosure showed that through proper support disclosure of one's condition can even be beneficial for the contact persons themselves. It was found that by coming out openly that one has HIV/AIDS, a burden was lifted from the discloser. However, since albinism is a very visible condition this cannot be concealed, and therefore it cannot be disclosed. The contact strategy proved to be effective in reducing stigma (Dadun, et al., 2017; Mehta, et al., 2015; Paluck, Green, & Green, 2018; Peters, et al., 2015; Yamaguchi, et al., 2013). However, others temper the findings considering this strategy (Brown, et al., 2003; Couture & Penn, 2003; Jorm, 2020; Mak, Mo, Ma, & Lam, 2017). Some studies show contact to be more effective than education (Corrigan, et al., 2012; Griffiths, et al., 2014), other research shows no difference between education and contact strategy and even states that combining education and contact has

the same effect as separate interventions (Morgan, et al., 2018). An additional advantage of including people with a stigmatizing condition in stigma reduction interventions is the opportunity to show that people with a stigmatizing condition are not passive victims, but they can play an active role in stigma reduction (Howarth, 2006). Also, their real-life experience can improve the quality of the intervention (Cook, et al., 2013; Rai, et al., 2018; Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008).

(3) Advocacy campaigns aim at prioritizing the rights of people with stigmatizing conditions, so that they can enjoy their rights as recorded in legislation. Advocacy campaigns strive for equal rights for people with a certain condition. Advocacy endeavours target politicians and decision makers (Arboleda-Flórez & Stuart, 2012; Heijnders & van der Meij, 2006). An example of an advocacy campaign would be the lobby of the Tanzanian Albinism Society (TAS), trying to put the importance of the rights of people with albinism on the national agenda. The advocacy strategy is implemented by many NGOs working with people with a stigmatizing condition. However, evidence for the effectiveness or ineffectiveness of this strategy is lacking (Heijnders & van der Meij, 2006).

(4) Protest attempts to reduce stigmatizing attitudes by addressing the negative stereotypes of people directly (Couture & Penn, 2003). An example of a protest intervention related to albinism would be the National Organization for Albinism and Hypopigmentation (NOAH), objecting to the portrayal of people with albinism as villains in movies (Croley, Reese, & Wagner, 2017). The protest strategy is often implemented through a formal, mostly written, objection that targets opinion leaders or people with stigmatizing attitudes (Arboleda-Flórez & Stuart, 2012). There is no research available that proved this strategy to be effective and it has even been shown that this strategy can have a negative effect, therefore it is questionable if protest actually has an effect on stigmatization (Corrigan, et al., 2001; Corrigan & Penn, 1999).

In addition to the above-mentioned strategies, interventions often contain an entertainment element. An example of an entertainment strategy in relation to albinism is an educational theatre play about albinism. The entertainment within interventions can take multiple forms, such as: nice music, images and jokes. The entertainment strategy is coined Entertainment Education (EE) by Sallar and Somda (2011). EE is defined as follows: “the process of purposely designing and implementing a media message to both entertain and educate, in order to increase audience members’ knowledge about an educational issue, create favourable attitudes, shift social norms, and change overt behaviour” (Singhal & Rogers, 1999, p. 9). EE is based on the social learning theory by Bandura (1971) that states that people are likely to learn by observing and imitating a ‘good’ example/role model. Especially if people see someone like themselves or someone they like displaying certain behaviour, it is likely to influence their behaviour. As explained by Slater (2002): “According to social cognitive theory, vicarious experience may alter behaviour by changing beliefs about our competencies in successfully performing a behaviour (i.e., “self-efficacy beliefs”), and by providing vicarious practice in carrying out a desired behaviour” (Slater, 2002, p. 166). Slater (2002) also points out that EE builds on more than the social learning theory alone, also persuasion theory plays a role, such as the theory of reasoned action. This theory states that the communication of behavioural change causes people to change expectations and beliefs about possible (positive or negative) outcomes of certain behaviour. Additionally, the reasoned action theory entails that communicating about behavioural change can cause the change of perceptions considering the social norms of a certain behaviour (Ajzen & Fishbein, 1980 ; Fishbein & Ajzen, 2010; Yzer, 2017).

Ritterfeld and Jin (2006) summarized the following functions of EE: (a) it motivates people to process the provided information (Ritterfeld, Klimmt, Vorderer, & Steinhilper, 2005), (b) causes cognitive and emotional participation of the participants (Murphy, Frank, Moran, & Patnoe-Woodley, 2011; Vorderer, Klimmt, & Ritterfeld, 2006), (c) reduces counter arguing (Slater & Rouner, 2002), (d) because of the good experience respondents are more likely to process the information (Ritterfeld & Weber, 2006). Story telling is often used in entertainment education and has been applied in Westers



and non-Western cultures. It is, and has been, part of oral culture but is also used in books and later on in radio and tv (Slater & Rouner, 2002).

Because little research has yet been carried out in the field of albinism-related stigma reduction. The applicability and effectiveness of the stigma reduction strategies as discussed above to a variety of health-related stigma and the similarities between health-related stigma in relation to a variety of health-conditions (Hofstraat & van Brakel, 2016; van Brakel, et al., 2019) encourage us to explore the possibilities of these strategies when applied to albinism-related stigma. The education and contact strategy have proven to be effective stigma reduction strategies in relation to other health-related stigma, as is the entertainment strategy. Therefore, this thesis will explore the use of these strategies in a variety of pilot interventions focussing on reducing albinism-related stigma in Tanzania.

### FOCUSSING ON WORLDVIEWS FOR STIGMA REDUCTION

In their study of HIV/AIDS related stigma, Parker and Aggleton (2003), concluded that stigma cannot be fully understood without understanding the cultural context that allows stigmatization to occur. This is acknowledged by many (e.g. Airhihenbuwa & DeWitt Webster, 2004, Scambler, 2009, Weiss, 2006) such as Bos et al. (2008) who stated that stigma-reduction interventions can only be effective when they come forth out of a context-specific needs assessment. What can be valued in one cultural context can be less important in another. Weiss (2006) names the example of the large concerns about one's chances to get married as an aspect of stigma in south-Africa, whereas in other cultures this might be of less importance. Weiss (2001) emphasizes the importance of analysing the social context in the following citation:

*The analysis of the social context in the narrative accounts of stigma-related illness experience in response to focused queries provides complementary information that indicates the nature of the issues that contribute to a coherent concept of stigma, what they mean, and how they affect people's lives. It is only through an appreciation of this complex relationship between stigma and context that efforts to reduce stigma can address the core issues that have made it a high priority in public health policy for mental illness and other health problems for which the impact of stigma is a critical issue. (Weiss, 2001, p. 86)*

Baker (2010) argues that in order to reduce albinism-related stigma it is of major importance that people receive contextualized information about albinism, otherwise myth will keep on circulating. Bradbury-Jones, Ogik, Betts, Taylor and Lund (2018) also point out the cultural embeddedness of the myth related to albinism and the importance of investigating this further to be able to change such beliefs:

*Underpinning this (myths related to albinism) are deep rooted, culturally embedded beliefs about people with albinism that simultaneously hold them as enigmatic and frightening. To date however, such beliefs have been understood largely through anecdote, rather than empirical investigation. (Bradbury-Jones, et al., 2018, p. 2)*

The importance of the study of worldviews underlying the stigmatization of people with albinism is also described by Imafidon (2017):

*... the African ethical point of view, the ethics of solidarity, also forms the basis for the justification within the African worldview for the established alterity and, by implication, stigmatization of persons with albinism. By this view, actions that promote harmony and prevent discord and disequilibrium among accepted beings in the African community are permissible. To this extent, I argue that treating or isolating an other*

*(such as a person with albinism or leprosy, a morally bankrupt or evil person, or a contagiously ill person) from the community of beings is permissible, insofar as it protects the status quo. (Imafidon, 2017, p. 164)*

As can be concluded, when studying albinism-related stigma and stigma reduction interventions, the understanding of the context in which stigmatization can occur and the worldviews underlying the stigmatization of people with albinism is of uppermost importance.

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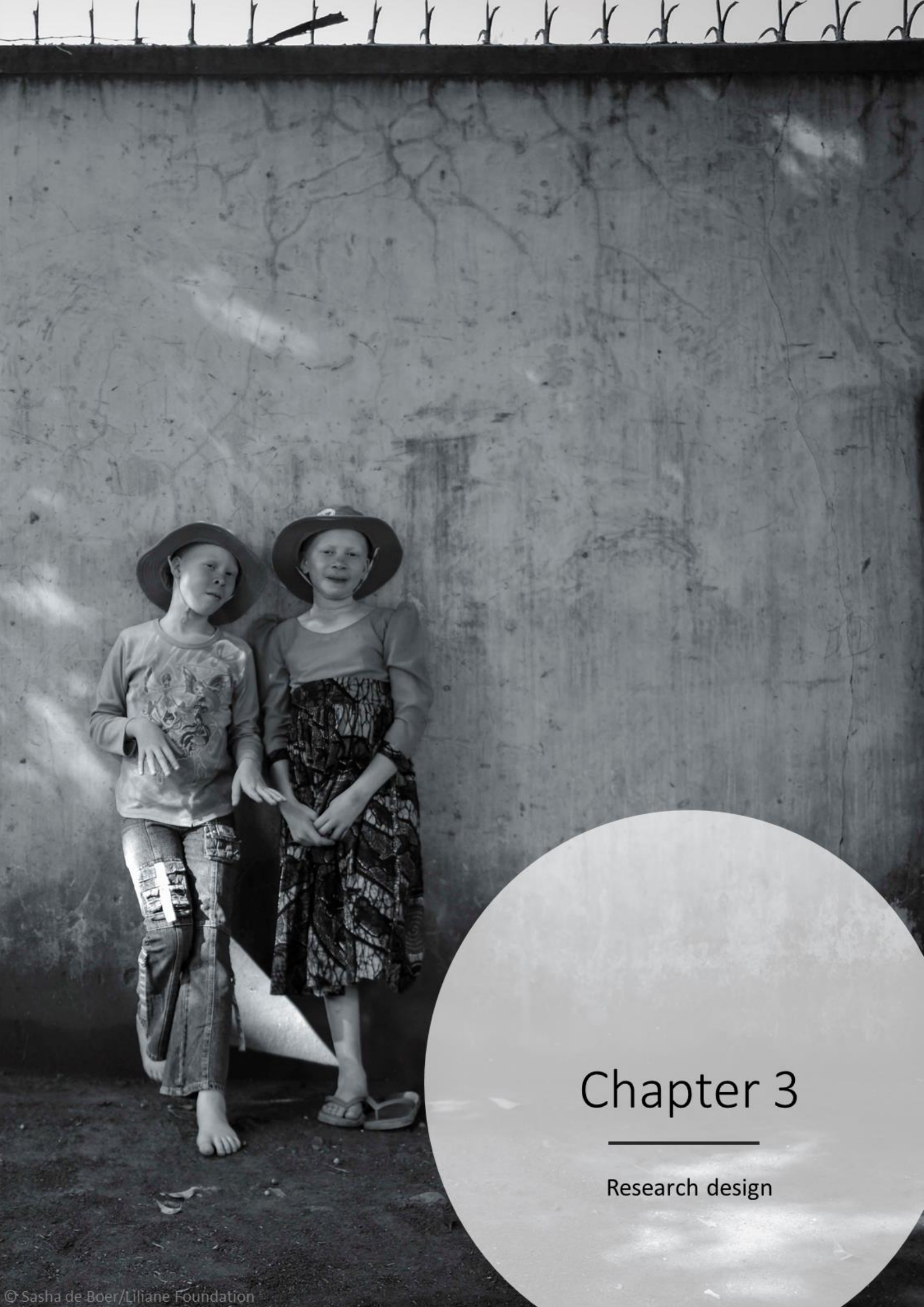
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# Chapter 3

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Research design

## CHAPTER 3 – RESEARCH DESIGN

In Chapter 1 (Introduction) the need for further research on albinism-related stigma has been described. People with albinism suffer from fierce stigmatization. Research on stigma reduction interventions exists, however it is not yet been applied to albinism in Tanzania. Chapter 2 (Theoretical Concepts) provides an introduction to the current state of research on health-related stigma and stigma reduction interventions. These chapters lay the base for the following chapter. Chapter 3 will provide an overview of the specific questions that were asked in this thesis and provides an outline of the methods used to answer them.

### MAIN RESEARCH QUESTION AND SUB-RESEARCH QUESTIONS

This study set out to answer the following main research question:

**How to reduce stigma related to albinism in Tanzania on a community level using the education and contact strategy?**

The main question can be divided into several sub-research questions.

Firstly, when aiming to gain more insight into the effects of stigma reduction interventions, it is important to gain more insight into the attitudes, ideas and understandings people have. More in-depth knowledge should be gained about people's worldviews and the cultural and social contexts surrounding the stigmatization of people with albinism. These insights provide a basis for the development of fitting stigma reduction intervention and a reference for the assessment of the effect of stigma reduction interventions. This line of thought resulted in the subdivision in the following sub-research questions:

- 1. What are people's attitudes towards people with albinism in Tanzania?**
- 2. How can attitudes towards people with albinism be measured?**

Secondly, to gain further insight into albinism-related stigma reduction on a community level, it is of interest to take a closer look at often used stigma reduction strategies, interventions and their outcomes. As described before, the education and contact strategy have often proven to be effective in stigma reduction in relation to other health-related stigma. However, little to nothing is known about the effects of these strategies in relation to albinism. Therefore, it is of interest to explore the use of these strategies for albinism-related stigma in Tanzania. During the study I had the opportunity to test three types of interventions (1. a theatre intervention, 2. a radio intervention, 3. a filmed contact and education based intervention, for more information on the tested interventions see Textbox 1). Furthermore, interventions used for stigma reduction often contain some elements to entertain the audience, therefore a sub-research question about the role of entertainment was added:

- 3. What are the effects of an education strategy on albinism-related stigma and knowledge in Tanzania?**
- 4. What are the effects of a contact strategy on albinism-related stigma and knowledge in Tanzania?**

## 5. What role does entertainment play in stigma reduction interventions related to albinism in Tanzania?

As described in Chapter 2 not much is known about the effectiveness of stigma reduction interventions in relation to albinism in Tanzania. In research about other health-related stigma reduction interventions the education and contact strategy have proven to be effective in reducing stigma on a community level. Therefore, it is of interest to explore the applicability of these strategies in the Tanzanian setting in relation to albinism. Since this research is at the beginning of testing stigma reduction intervention in relation to albinism it was decided to explore the outcomes of a couple of interventions to gain more insight in the possibilities of the strategies and different types of interventions. In consultation with local albinism focused NGOs three intervention types were tested. The first two intervention types (theatre and radio) have often be implemented as stigma reduction interventions in an African context and have proven to be promising in relation to other health-related stigmas. The thirds type of intervention (a filmed contact and education-based interventions) was tested to enable me to compare the two intervention strategies. Below I will set out shortly the development of the used interventions.

1. **Theatre intervention** (Chapter 7): This already existing theatre intervention was part of the *Haki Yetu* (Our Rights) theatre tour that aimed at raising awareness on albinism in Tanzanian primary schools and communities. The show was developed by the Tanzanian theatre production group Dar Creators and was initiated by several NGOs (Under the Same Sun (UTSS), the European Committee for Training and Agriculture (CEFA) and the Global Network of Religions for Children (GNRC). These theatre interventions were observed in three primary schools surrounding Sengerema.
2. **Radio interventions** (Chapter 8): Two types of radio interventions were developed in cooperation with the participating local NGOs. A radio drama about albinism was developed in cooperation with Child Support Tanzania (CST), Tanzanian Albinism Society (TAS) branch Mbeya and Baraka FM. A radio interview was held with a person with albinism with the assistance of Kigoma Community College by Radio (KICORA) and the TAS branch Kigoma. These radio shows were tested in local communities surrounding Kigoma.
3. **Filmed education and contact-based intervention** (Chapter 9): The filmed interventions existed about two movies of about 10 minutes in which one movie focussed on personal contact with someone with albinism and another movie focussed on educating people about the condition of albinism. The movies were edited in consultation with staff members from cooperating NGOs. Both movies were based on a Tanzanian movie about people with albinism "Watu Kama Sisi" (People Like Us), which was created by Albino Peacemakers, an organization that supports people with albinism in Tanzania. The movies were tested among high school students in Mbeya.

Textbox 1 Tested stigma reduction interventions

Thirdly, in relation to albinism in Tanzania a contact-based intervention often exists out of face-to-face interaction with a person with albinism. In many cases a person with albinism presents on his/her condition and life experiences. In this thesis these presenters with albinism are called 'spokespersons'. Because people with albinism experience a lot of discrimination in daily life, there might be complications for spokespersons to present themselves to an audience. The question arose how spokespersons themselves feel about presenting on their condition. This led to the following sub-research question:

## 6. What are the effects of a contact strategy on spokespersons with albinism in Tanzania?

To answer these questions several studies were done.

### STUDY SITES, COOPERATION, SAMPLE SELECTION AND STUDY POPULATION

This research was carried out in Tanzania, situated in eastern Africa. Tanzania has a population size of 44,928,923 (The United Republic of Tanzania, 2012), of which a large majority (70.9%) lives in the rural areas. The population of Tanzania exists out of a large young population (50.1% aged between 0 and 17 years). The adult literacy rate (15 years and above) is 78.1%, with higher levels of literacy in urban areas (92%) as in rural areas (71%). Of the people involved in economic activity (which is 63% of the population older than 10 years) a majority is working in agriculture (62.8%). Kiswahili is the national language of Tanzania and is spoken by the majority of people. People originating from certain ethnic groups speak their mother- and sometimes also their father tongues within their communities but are mostly able to communicate to others through Kiswahili. In some institutions English is used, e.g. in secondary and higher education is the language of instruction. Most people in Tanzania affiliate to either a Christian (61%) or Islamic religious institution (35%) (Bureau of Democracy, Human Rights, and Labor, 2017). Tanzania exists out of approximately 120 different ethnic groups, making it the most ethnic diverse country of sub-Saharan Africa (Fearon, 2003).

This research has been carried out in cooperation with a variety of local NGOs that were aiming to improve the lives of people with albinism. For an overview of cooperating NGOs see Textbox 2. In the beginning of the research, the exploratory phase, a variety of NGOs throughout Tanzania were approached as possible partners for this research. With the inclusion of these NGOs in the research I aimed to position the research and the interventions in the local context, and I wanted to create the opportunity for these NGOs to use the outcomes of this research in practice. In cooperation with the NGOs data was gathered and discussed. Stigma reduction interventions were discussed, developed and implemented with these NGOs. Also, the connections of the NGOs with schools, teacher training colleges and the local community largely benefitted the research. The NGOs introduced me to schools, teacher training colleges and community members, which made them willing to assist in the research. The connection of the researcher with the local NGOs helped the respondents in schools, teacher training colleges and in the community to understand and position the research. It could have been confusing for the respondents if a foreign researcher asked them to participate in a research out of the blue.

#### **Child Support Tanzania (CST)**

CST is a Tanzanian NGO based in Mbeya in the south of Tanzania. CST focuses on inclusive education to cater for the learning needs of children with disabilities, this includes the learning needs of children with albinism.

#### **Kigoma Community College by Radio (KICORA)**

Through community radio and education by radio in Kigoma, in the west of Tanzania, the organization of KICORA wants to assist those with little access to education. Among others, KICORA sets out to raise awareness through radio on a variety of pressing problems in Tanzanian society.

#### **New Light Children Centre Organization (NELICO)**

NELICO seeks to promote human rights through a variety of projects. Among others their projects involve psychosocial support, legal aid, child protection and the assistance of people with albinism. The organisation is based in Geita in the north west of Tanzania.

### **The Tanzanian Albinism Society (TAS)**

TAS is a national non-profit organisation with local branches all over Tanzania. TAS is established by people with albinism. TAS is involved in the protection and empowerment of people with albinism and among others they are involved with the registration of people with albinism. About 13.000 people with albinism are registered with TAS.

### **Under The Same Sun (UTSS)**

The organization UTSS aims to promote the wellbeing of people with albinism throughout Tanzania. Their activities include education and support projects for people with albinism and they run projects that focus on advocacy and awareness raising in the community.

## Textbox 2 Cooperating NGOs

The choice of research sites was depending on the location of the participating NGOs. I tried to contact organizations throughout Tanzania, hoping to be able to gain insight into the attitude toward people with albinism country wide. An overview of study sites is presented in Figure 1. The sites indicated in Figure 1 are the urban centres around which the research took place. Research took place within the urban area as well as in the rural area surrounding the urban centres, more information on the exact study sites is provided in the relevant chapters.

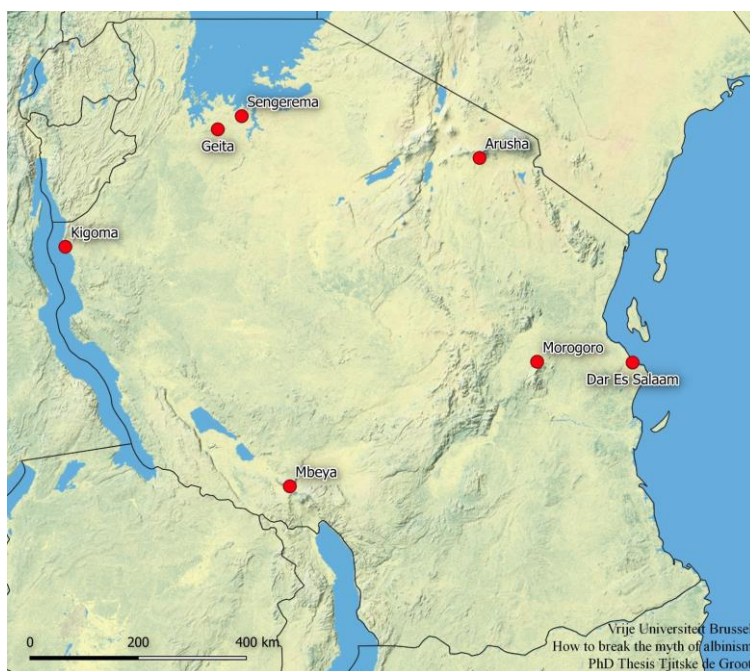


Figure 1 Locations of the research

Several study populations have participated in this research. In this study stigma measurement scales have been validated among high school students and among adult from urban and rural areas. Stigma reduction strategies have been tested among primary school students, high school students and adult community members. More information on sample selection and the study population is provided in the relevant chapters. An overview is made of the study population that participated in each study and their geographic location (Table 1).

Chapter	Study population	Study site
<i>Chapter 4</i>	Master Students from the University of Dar es Salaam	Dar es Salaam
	People with albinism	Dar es Salaam, Mbeya, Kilimanjaro, Kigoma, Mwanza
	Experts in language and albinism	Dar es Salaam
	NGO staff	Dar es Salaam, Geita Kigoma
	High school teachers and leaders	Arusha
	High school students	Arusha
<i>Chapter 5</i>	Adult community members	Morogoro
<i>Chapter 6</i>	High school students	Geita, Arusha
<i>Chapter 7</i>	Primary school students	Sengerema
<i>Chapter 8</i>	Adult community members	Kigoma
<i>Chapter 9</i>	High school students	Mbeya
<i>Chapter 10</i>	People with albinism	Dar es Salaam, Mbeya, Kilimanjaro, Kigoma, Mwanza

Table 1 Study population and site per chapter

## ARTICLES AND METHODOLOGY

Several studies have been carried out. A short overview of the studies and their methodology will be provided. In general, mixed methods have been applied to gain an in-depth understanding albinism-related stigma and stigma reduction. More specific information and motivation for using certain methods can be found in the relevant chapters in this thesis.

Sub-research question **1 (What are people’s attitude towards people with albinism in Tanzania?)** was partly answered in Chapter 1 which was partly based on the article ‘The effect of contact interventions on the stigma of people with albinism in Tanzania’ (de Groot, Meurs, & Jacquet, 2019) and throughout the thesis. To answer sub-research question **2 (How can attitudes towards people with albinism be measured?)**, I set out to explore, adapt, and validate scales to measure stigma related to albinism. Scales measuring attitudes towards people with albinism in Tanzania were not yet existing. Two existing scales measuring the health-related stigma of another condition in another context have been used as a base. Chapter 4 and 5 describe the validation studies of the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) and the Social Distance Scale (SDS). See for more information on the quantitative instruments Textbox 3 below. Both scales ask respondents about their attitude towards people with albinism in certain social interactions. The scales were adapted to the local social context. Chapter 4 focuses on measurement tools to use among high school students and Chapter 5 focuses on the use of the measurement tools among adults. For this cultural validation a variety of methods was used; workshops with master students from the University of Dar es Salaam, in-depth interviews with people with albinism, focus group discussions using visual vignettes, translation and re-translation, a pilot test and re-test and focus group discussions. In Chapter 6 the possibilities for using visual vignettes for doing research on a sensitive topic such as albinism are being explored. Respondents are shown visual vignettes about a certain social interaction between a person with and a person without albinism and they are being asked how people would feel in these situations.

### **Explanatory Model Interview Catalogue Community Stigma Scale**

The Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) asks respondent about how people in their community feel about people with a certain stigmatizing condition. The EMIC-CSS is based on the work of Weiss (1997). The EMIC-CSS has been implemented in a variety of cultures and in relation to different health conditions (Brieger, Oshiname & Ososanya, 1998; Peters, et al., 2014; Stienstra, van der Graaf, Asamoah & van der Werf, 2002). Like the ASDS the EMIC-CSS has been validated to a Tanzanian context in relation to albinism in Chapter 4 and 5, and the name was adapted into the Albinism Explanatory Model Interview Catalogue Community Stigma Scale (A-EMIC-CSS). An example item of the A-EMIC-CSS is: A-E5 Would people in your community avoid a person with albinism?.

### **Social Distance Scale**

The social distance scale (SDS) asks respondents about their personal attitude towards various social relationships with someone with certain characteristics (Link, Cullen, Frank, & Wozniak, 1987). The SDS is based on the work of Bogardus (1925), and has been adapted for use in a variety of countries and researching attitudes towards people with various characteristics (Crandall & Moriarty, 1995; Leiker, Taub & Gast, 1995; Peters, et al., 2014). In Chapter 4 and 5 the SDS has been validated for use in Tanzania in relation to albinism. The scale was renamed the Albinism Social Distance Scale for Adolescents, for use with adolescents, and the Albinism Social Distance Scale, for use with adults. In this research the scales are preceded by a vignette with a description of a person with albinism (John or Joyce, depending on the gender of the respondent). An example question of the ASDS is: A-S1 How would you feel to visit a house of someone like John/Joyce?.

### **Knowledge items**

For this research Knowledge items were developed to test the knowledge of the respondents about albinism. These items were based on what experts in the field selected as the most important information about albinism, the items also reflect aspects of knowledge about albinism that are often lacking in the society. Knowledge items exist out of 'knowledge explanation items', closed-ended question that require written explanation in case the respondent answers the question positively, an example of a knowledge explanation item is: K-01 Do you know the reason for albinism?, in case respondents answer 'Yes', they were required to write down more explanation. Other Knowledge items did not require further explanation, an example of such an item is: K-04 Do you think albinism is contagious? (Chapter 7 and 9).

### **Entertainment items**

The Entertainment items asked after the level of entertainment of an intervention. These items were based on items by Ritterfeld & Jin (2006). An example of an Entertainment item is: "1. The show was very entertaining", to which the responded can choose an answer ranging from I completely disagree to I completely agree (Chapter 8 and 9).

## Textbox 3 Quantitative methods

Chapter 7, 8 and 9 were written to answer sub-research question **3 (What are the effects of an education strategy on albinism-related stigma and knowledge in Tanzania?)**, **4 (What are the effects of a contact strategy on albinism-related stigma and knowledge in Tanzania?)** and **5 (What role does entertainment play in stigma reduction interventions related to albinism in Tanzania?)**. Because not much is known on stigma reduction in relation to albinism, this study set out to explore

the possibilities for stigma reduction through the education and contact strategy that have proven effective in relation to other health-related stigma.

Chapter 7 explores the possibilities for stigma reduction through an interactive theatre intervention among primary school students. For this exploration, a theatre play on albinism, that was being implemented in primary schools in Tanzania by several albinism focused NGOs such as UTSS (see Textbox 2), was observed. The aim of the observation was to gain more understanding on possible aspects of a theatre intervention that would influence the attitude towards people with albinism of the audience. Pre- and post-measurement (directly after the intervention) was carried out by using the Albinism Social Distance Scale for Adolescents (ASDS-A) and Knowledge items.

Chapter 8 addresses the potential of radio shows for stigma reduction. A radio drama about someone with albinism and a radio interview with someone with albinism were tested among community members. The radio shows were developed in cooperation with albinism focused NGOs, such as KICORA (see Textbox 2). Pre- and post measurement (after two or three weeks) was carried out through the Albinism Explanatory Model Interview Catalogue Community Stigma Scale (A-EMIC-CSS), Albinism Social Distance Scale (A-SDS) and Entertainment items. Directly after the intervention feedback was requested from the participants through informal (group) interviews. After two to three weeks respondents participated in a short informal (group) interview about the radio shows.

In Chapter 9 the outcomes of a filmed contact based interventions and a filmed education based intervention are being compared among high school students. The filmed interventions were based on an existing awareness raising film. The following methods were used: pre- and post-measurement existing out of the ASDS-A, Knowledge items and Entertainment items. After the intervention a focus group discussion was conducted with the participants.

Chapter 10 addresses sub-research question 6 (**What are the effects of a contact strategy on spokespersons with albinism in Tanzania?**). This sub-research question was answered through in-depth interviews that were held with spokespersons with albinism.

An overview of the used methods and the samples for each sub-research question and chapter is provided below (Table 2).

Chapter	Methods	Sample	Sub-research questions
1. Theoretical background. (Part of this chapter was based on the article: The effect of contact interventions on the stigma of people with albinism in Tanzania.)	Literature review		1
	In-depth interviews	11 spokespersons with albinism	
4. The cultural validation of two scales assessing albinism-related social stigma among high school students in Tanzania.  &  5. Measuring stigma related to people with albinism in Tanzania: a cultural validation study of the EMIC-CSS and SDS among adults.	Workshops	83 master students	1 & 2
	In-depth interviews	13 people with albinism	
	Translation into Swahili	5 experts in language	
	Translation into English	1 expert in albinism	
	Final check	3 master students	
	Test of new scales	10 NGO staff members & 3 master students	
	Test for target population	4 high school teachers, 3 high school leaders, 4 high school students	
Pilot Adolescents: Test	337 high school students		



	Re-test	142 high school students	
	Focus group discussion	25 high school students	
	Pilot Adults: Test	101 adults	
	Re-test	79 adults	
6. Using visual vignettes to explore sensitive topics: a research note on exploring attitudes towards people with albinism in Tanzania.	Focus group discussions using visual vignettes	52 high school students	2
7. Reducing albinism-related stigma among primary school students through a theatre intervention in Tanzania: a mixed methods study	Observation of play		3, 4 & 5
	Pre- & Post measurement: ASDS-A & Knowledge items	Pre 210 primary school students Post 175 primary school students	
8. Reducing albinism-related stigma in Tanzania through community radio: exploring drama and interview	Pre- & Post measurement: A-EMIC-CSS, A-SDS & Entertainment items	Pre 234 respondents Post 142 respondents	3, 4 & 5
	Informal (group) interview 1 (directly following the radio shows)		
	Informal (group) interview 2 (two to three weeks after the radio show)		
9. Contact vs. Education: an explorative comparison between the contact and education strategy considering albinism-related stigma in Tanzanian high schools	Pre- & Post measurement: ASDS-A, Knowledge items, Entertainment items	192 high school students	3, 4 & 5
	Focus group discussions	80 high school students	
10. Contact strategy and albinism: an exploration of spokespersons' experiences in Tanzania	In-depth interviews	13 spokespersons with albinism	6

Table 2 Overview of methods and samples

All quantitative measures have been conducted in Swahili, which is the national language of Tanzania. Qualitative data gathering has been conducted in either English or Kiswahili, depending on which language the respondents felt most comfortable with during a study. In terms of data management and data analyses the following software packages have been used. Recordings of qualitative data have been recorded and were analysed using NVivo 12 or Atlas.ti 8. Quantitative data has been analysed using IBM SPSS Statistics 24 and IBM SPSS Statistics 25. More specific information on the analysis can be found in the relevant chapters.

## FIELDWORK

The data for the above described studies has been gathered in five field visits, the purpose for each visit is described below. A short overview of the field visits in relation to the chapters in this thesis is provided in Table 3. For clarity, only the field work activities that have led to studies that are described in this thesis are described. However, more studies and observations have been done, and other studies were initiated that have not (yet) led to a full-grown analysis or academic articles. These observations are discussed in Chapter 12.

Field visits	Period of Time	Chapter 4	Chapter 5	Chapter 6	Chapter 7	Chapter 8	Chapter 9	Chapter 10
1	March - May 2017							
2	October - November 2017							
3	March - May 2018							
4	October - November 2018							
5	March - April 2019							

Table 3 Field visits

#### FIELD VISIT 1: MARCH - MAY 2017

The first field visit had an explorative character. Firstly, it was used to meet possible stakeholders and parties that would be willing to cooperate in this research. In Dar es Salaam, Mbeya, Kigoma, Mwanza, Bunda, Geita and Arusha meetings were held to discuss cooperation. The research was introduced to a large number of organizations, as presented in Textbox 2 earlier. Additionally, meetings to explore collaboration were held with primary and secondary schools that were familiar with the cooperating organizations. Secondly, this field visit set out to make a start with the validation of the scales to measure people's attitude towards people with albinism. Qualitative data was gathered for scale validation (Chapter 4 and 5) and the scales were adapted and piloted among high school students (Chapter 4). Thirdly, in-depth interviews were conducted with people with albinism to gain more understanding about the experience of people with albinism with stigmatization (Chapter 1) and the experience of people with albinism as spokespersons (Chapter 10).

#### FIELD VISIT 2: OCTOBER - NOVEMBER 2017

The second field visit had multiple goals. Firstly, the validation study of the scales to measure attitudes towards people with albinism among adults was continued (Chapter 5). Secondly, more possibilities for cooperation were explored through introduction to teacher training colleges: St. Aggrey Teacher Training College in Mbeya, and Patandi Teacher Training college in Arusha. Thirdly, to explore possibilities for stigma reduction interventions, focus group discussions were conducted with high school students, high school teachers, student teachers and student teachers' mentors. By making use of visual vignettes the situation of people with albinism in Tanzania was discussed. The use of this visual vignettes among high school students is discussed in Chapter 6. During these focus group discussions, the respondents were also asked what they, or others, would like to learn about albinism and in what kind of format they would like to receive this information. Fourthly, a follow-up study for the youth scale validation was carried out, focus group discussions were held with high school students who had participated in the pilot of the scale before (Chapter 4).

### FIELD VISIT 3 MARCH - MAY 2018

In March 2018, a stigma reduction intervention in the format of a theatre intervention was observed. The theatre intervention was developed and implemented by UTSS, the European Committee for Training and Agriculture (CEFA) and the Global Network of Religions for Children (GNRC) in co-operation with Dar Creators. The *Haki Yetu* (Our Rights) theatre tour aimed at raising awareness on albinism in Tanzanian primary schools and communities (Chapter 7). Also, during this field visit the integration phase of the research was initiated. The findings of the research conducted in the last two field visits were presented to staff members of the cooperating NGOs and the students and mentors of a teacher training college. These presented findings discussed the attitudes of people towards people with albinism and presented stigma reduction interventions that were suggested by the respondents and by literature.

### FIELD VISIT 4 OCTOBER - NOVEMBER 2018

The fourth field visit consisted of three activities. Firstly, the possibilities for a radio intervention were explored (Chapter 8). Two members of the Tanzanian Albinism Society in Mbeya were interviewed by a local radio station, Baraka FM. Through this radio interview test more insight could be gained into people's attitude towards raising awareness through radio. Secondly, I provided 3 weeks of training about albinism and research methods at Patandi Teachers Training college. Thirdly, a few visits to organizations were conducted to strengthen my network.

### FIELD VISIT 5 MARCH - APRIL 2019

The fifth field visit started in Mbeya, where the filmed contact intervention was compared with the education intervention in high schools (Chapter 9). Thereafter, preparations were made for the exploration of the radio intervention. With the help of Nico Makasy, a radio dj at Baraka FM, and Child Support Tanzania, a radio drama about albinism was developed. Later, in cooperation with KICORA a radio interview with someone with albinism was recorded. The radio drama and the radio interview were tested in communities surrounding Kigoma in cooperation with KICORA (Chapter 8).

### ILAA: CHALLENGES FACED

The original proposal planned to use the Interactive Learning and Action Approach (ILAA) during this research. Through this approach respondents and researcher continue in knowledge co-creation by continuous reflection on the learning process. This transdisciplinary approach has been tested successfully in a variety of contexts (Betten, et al., 2013; Bunders, et al., 2010; Caron-Flinterman, 2006; Swaans, Broerse, Meincke, Mudhara, & Bunders, 2009). The ILAA process contains five phases:

1. Exploratory phase: in this introductory phase of ILAA the research team is established, a literature research and exploratory interviews are conducted to gain an insight into the state of the art, the views of stakeholders, and the problem context.
2. In-depth phase: in this phase problem perceptions, opinions and ideas of the stakeholders are being identified and analysed.
3. Integration phase: the perspectives gathered in the in-depth phase are being compared and combined for a discussion between the various stakeholders.
4. Prioritization and action planning phase: priority issues and common goals are singled out by the stakeholders, actions are being planned as are the follow up meetings.
5. Implementation phase: plans are being implemented. Learning action spirals are used for reflection on the implementation, leading to new plans for action.

Difficulties in implementing ILAA were faced in phase 3, the integration phase, during field visit 3. During phase 3 the findings of the orientation phase and the in-depth phase were presented to

respondents/stakeholders through a workshop. Participants consisted of respondents who had already participated in phase 1 or phase 2 of the ILAA, but also respondents who were new to the research joint. The workshop took place nine times, in total 11 high school student participated (5 men, 6 women) and 23 adults (12 men, 11 women). The adult participants were either working with an NGO, student teachers or teachers at a teacher training college. A power-point presentation was used to present the findings of phase 1 and 2 (see Appendix A). The presentations consisted of the following components:

1. A short (re-) introduction of the research goals: developing and assessing albinism-related stigma reduction interventions.
2. Presenting findings considering people's attitudes towards people with albinism. The goal of this part of the presentation was to get everyone in the workshop on the same page. A secondary goal was to counter respondents' tendency to keep repeating beliefs about albinism when asked to participate in a workshop about albinism.
3. Discussing possible ways of improving people's attitudes towards people with albinism with the respondents.
4. Presenting frequently asked questions about albinism.
5. Presenting aspects of stigma reduction strategies that have been proven to be successful in the past, the contact and education strategy, and the discussion of the importance of entertainment in an intervention.
6. Discussion of the ideas of the participants in the workshops about their ideas on effective stigma reduction interventions.

The problems faced in this phase of the research consisted of difficulties for the respondents to brainstorm about the possibilities for stigma reduction interventions. Respondents mostly refrained from suggestions or suggested people should be taught about albinism, for example by "telling people that people with albinism are normal persons like you and me, it is just a different skin". Respondents did emphasize that people should get education about albinism, but respondents did not elaborate on this.

For the research it was important to think of strategies other than the existing ones because the proof of their effectiveness was lacking. However, thinking 'out of the box' proved hard for the respondents. Because the brainstorming strategy was not working well, it was decided to present a list of possible interventions to open up the discussion: story telling/story finishing, serious games, picture book/book, cartoon/photo novella, presentation by someone with albinism, video, religious intervention, 'normal education' and theatre. However, it was not effective to continue brainstorming about interventions that the respondents were not familiar with. Respondents had a hard time imagining how some interventions work, e.g. story finishing and educative games. Therefore, it became very hard to work together, to think of new and unknown types of stigma reduction interventions.

Another problem with the ILAA was that organizations were willing to discuss their work but were not interested in cooperation on setting up an intervention together. For many organizations a longer-term commitment was not fitting with their plan of action or was hard to imagine. This might also be caused by the unfamiliarity of organization with this method of testing interventions. Unfortunately, organizations were not interested in further cooperation to go through all the steps of ILAA together.

Because of the above arguments it became impossible to complete phase 3 successfully. Phase 3 requested all stakeholders to agree and continue with the action planning. Unfortunately, the recommendations of the stakeholders did not point in the direction of one or two types of interventions. Therefore, it was hard to continue with the planning of interventions based on their recommendations. Additionally, the lack of far-reaching cooperation with organizations made it

impossible to continue action planning together with organizations. Therefore, further cooperation and knowledge co-creation became limited and made the full use of the ILAA impossible.

The interventions that were eventually analyzed in this thesis were still developed in cooperation with stakeholders however I had to take a lead in deciding which interventions were tested. The interventions that were evaluated were therefore based on availability of existing stigma reduction interventions, the theatre intervention in Chapter 7, and possibilities for creating interventions that came up through my network, such as the radio intervention in Chapter 8 and the comparison of a contact and education strategy in Chapter 9.

## VALIDITY

To guarantee richness and accuracy in the data, a variety of qualitative and quantitative methods were used throughout the research: interviews, focus group discussions, workshops, attitude scales, Knowledge items and Entertainment items. To guarantee validity of the used quantitative attitude measures, a large part of my study was dedicated to the cultural validation of these measures (Chapter 4 and 5). Scales were conducted in Swahili to guarantee respondents' understanding of the items. When gathering qualitative and quantitative data it was tried to obtain a varied sample, among others through focusing on gender and age categories. Sometimes other characteristics were emphasised in gathering respondents, such as religion or place of residence.

Close cooperation with local NGOs that were focusing on improving the lives of people with albinism has been of major importance in this research. All the data obtained for this research has been done in cooperation with these NGOs or with schools that were familiar with these NGOs. Through the assistance of the NGOs and the schools the research and the tested interventions were adapted to the local context. For example, the organizations Child Support Tanzania and KICORA (and a local radio station) were involved in the development of the radio interventions that were tested in Chapter 8. The cooperating NGOs and schools also assisted in implementing the research and they often helped to introduce the research to the respondents. For example, when research was carried out in schools the school leaders or teachers always provided assistance in introducing the work to the students after which they left the room. Another example, when testing the radio interventions in the local community (Chapter 8) a staff member of a local NGO assisted in explaining the community member the research and emphasised that it was part of the work of the local NGO, this made it easier for the respondents to understand the project because they were familiar with the NGO.

Several experiences added to my understanding of the Tanzanian context. I have been to Tanzania five times for fieldwork visits, each visit was 2 to 3 months, so in total more than a year of fieldwork has been conducted. Two years before the start of the research I have conducted an internship in Tanzania with the local organization NELICO for six months. During this internship I have worked on projects that were aiming to empower people with albinism. I learned Kiswahili, which helped greatly in research and communicating with the respondents. The fact that I am a foreign researcher will have influenced the research and this will be reflected upon in Chapter 11.

## ETHICAL CONSIDERATION

Information about the aim, methods and implications of the research and the voluntary nature of participation was discussed with all participants before respondents' participation in research. Respondents were informed that they could withdraw from the study at any time. When fitting with the contribution of the respondents and understanding of the respondents written consent forms were signed, e.g. by spokespersons with albinism and high school leaders. These forms were written in Kiswahili. However, for respondents with a smaller contribution oral consent was requested. Anonymity was guaranteed to the participants but nevertheless respondents sometimes preferred to provide oral consent because they did not want their name on the informed consent form. All data has

been anonymised and was saved on the computer of the researcher and on two extra external hard disks which were all secured by a password. Only the researcher, research assistants and the promoters of this study had access to the anonymised data. This was also communicated to the respondents.

Documents for ethical approval were submitted to the Tanzanian Commission for Science and Technology (COSTECH) and to the Ethical Committee for Human Sciences (ECHS) of the Vrije Universiteit Brussel. COSTECH approved the study and ECHS decided that the research was exempt from ethical approval. The research was done in accordance with the ethical code of scientific research in Belgium, the European charter for researchers, and the Framework for Research Ethics (FRE) of the European and Social Research Council of the European Commission. The ethical consideration will be further discussed in Chapter 11 (Discussion and conclusion).

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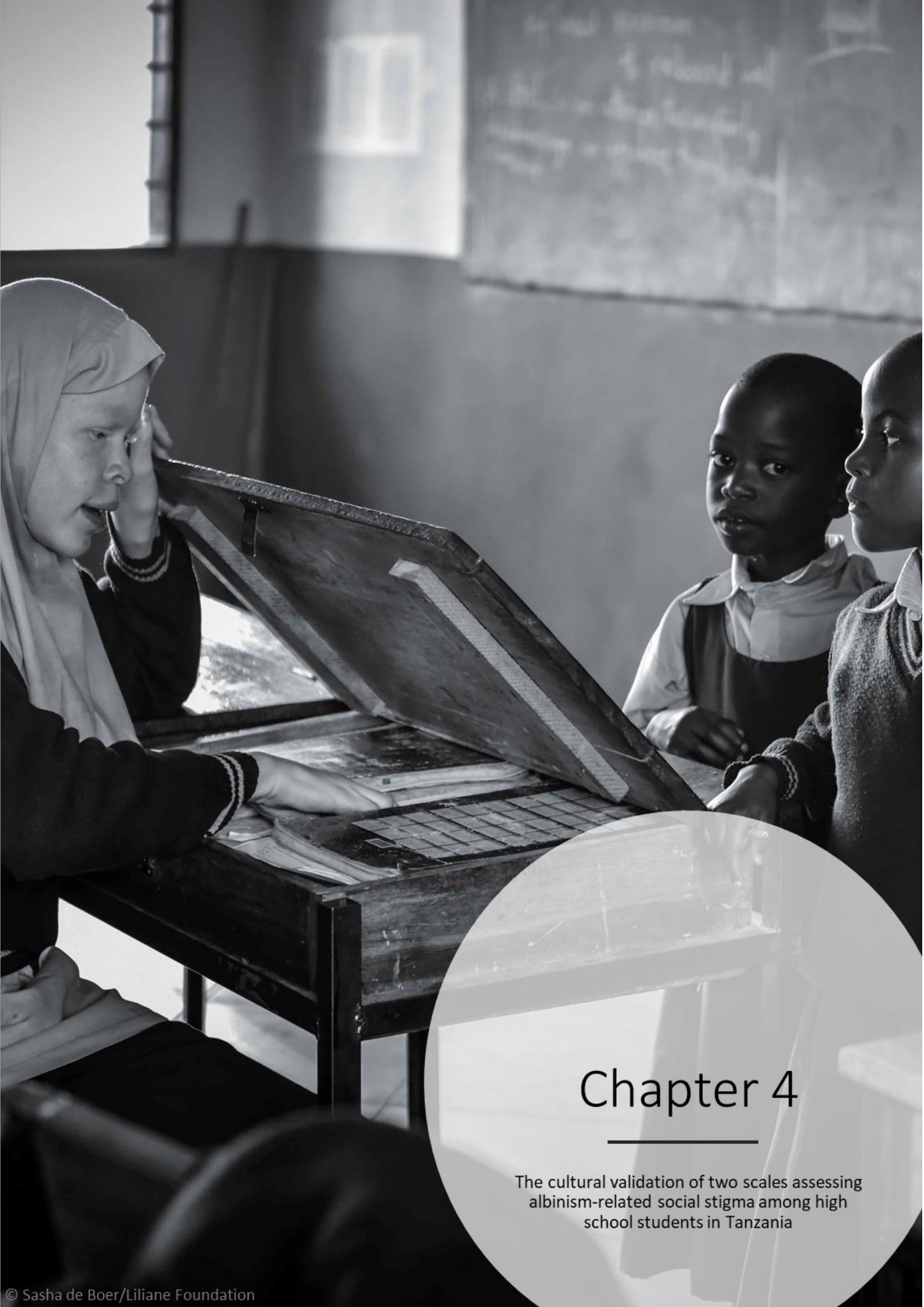
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## Chapter 4

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The cultural validation of two scales assessing albinism-related social stigma among high school students in Tanzania

## CHAPTER 4: THE CULTURAL VALIDATION OF TWO SCALES ASSESSING ALBINISM-RELATED SOCIAL STIGMA AMONG HIGH SCHOOL STUDENTS IN TANZANIA

*Published as: de Groot, T., Peters, R., van Brakel, W., Meurs, P., & Jacquet, W. (2020). The cultural validation of two scales assessing albinism-related social stigma among high school students in Tanzania. Disability, CBR and Inclusive Development, 30(4), 11-38.*

**Purpose:** Albinism in Tanzania causes fierce stigmatisation. Although various stigma reduction interventions (SRI) are employed, research on their effectiveness is lacking. This research aimed to develop a tool to measure albinism-related social stigma among high school students in Tanzania. Cultural equivalence was tested for the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) and Albinism Social Distance Scale for Adolescents (ASDS-A) assessing conceptual, item, semantic, operational and measurement equivalence.

**Methods:** The methods used were workshops, in-depth interviews, translation and re-translation, discussions, a test (n=337) re-test (n=142) of the survey, and follow-up focus group discussions (n=25).

**Results:** The scales have proven to be adequate on all equivalences other than measurement equivalence. The reproducibility statistics raise questions that can be explained by characteristics of the sample.

**Conclusion and Implications:** The analysis provides insights for further validation of the scales, contributes to the discussion about a universal stigma measurement tool and demonstrates the importance of validation studies of existing and proven tools used in a different context.

**Key words:** health-related stigma, EMIC-CSS, ASDS-A

## INTRODUCTION

Oculocutaneous albinism is a genetic condition causing a lack of melanin pigment. Consequently, people with albinism have low vision and are very sensitive to ultraviolet radiation (Hong, Zeeb, & Repacholi, 2006; Lund, 2001). They have white skin, sand coloured hair and light brown or blue eyes, which makes them stand out in a country where most people have dark skin.

Like other health-related conditions (van Brakel, 2006), albinism can cause stigmatisation (Wan, 2003). In Tanzania, albinism is surrounded by dehumanising myths (Baker, 2010; Braathen & Ingstad, 2006; Brocco, 2015; Bryceson, Jønsson, & Sherrington, 2010; Uromi, 2014). It is believed for example, that body parts of people with albinism bring good fortune and sexual intercourse with them cures HIV/AIDS (Bryceson, et al., 2010; Cruz-Inigo, Ladizinski & Sethi, 2011).

A substantial number of instruments and measurement tools exist to measure health-related stigma (van Brakel, 2006). However, no measurement tool has been validated to measure albinism-related stigma. This research aims to develop one such tool, relying on earlier developed measurement tools with respect to other health-related stigma and adapting these existing tools to albinism and the cultural context of Tanzania. This study is part of a larger research on the effectiveness of albinism-related stigma reduction interventions that are implemented in secondary education in Tanzania. Therefore, this article will specifically focus on the Scale validation for adolescents in secondary school.

Two scales to assess social stigma were chosen as they have proven to be appropriate and adaptable to several cultures: the Explanatory Model Interview Catalogue Community Stigma Scale or EMIC-CSS (Brieger, Oshiname, & Ososanya, 1998; Peters, et al., 2014, Stevelink & van Brakel, 2013; Stienstra, Asamoah, & van der Werf, 2002; van Brakel, et al., 2012, Weiss, 1997), and the Social Distance Scale or SDS (Bogardus, 1925; Corrigan, et al., 2002; Crandall & Moriarty, 1995; Leiker, Taub, & Gast, 1995; Link, Cullen, Frank, & Wozniak, 1987; Mak, Chong & Wong, 2014; Penn, et al., 1994; Peters, et al., 2014). The EMIC-CSS asks respondents about stigmatisation in their community. In the version by van Brakel et al. (2012) and in the article of Peters et al. (2014), seven aspects of stigmatisation were treated in the EMIC-CSS: (1) concealment, (2) process of discrediting, (3) shame and embarrassment, (4) avoidance/taking distance/isolation, (5) problems with getting married or ongoing marriage, (6) problems for family or other people, and (7) problems with work. The SDS measures personal attitudes about different social relationships with someone with a stigmatising condition (Link, et al., 1987). The two scales can complement each other since EMIC-CSS measures stigmatising attitudes in the community and the SDS investigates personal stigma.

## CROSS-CULTURAL VALIDATION

The cross-cultural validation in this study uses the method as described by Peters et al. (2014) in an article on the cultural validation of the EMIC-CSS and SDS to assess stigma in leprosy at Cirebon District, Indonesia. Their method was based on articles by Herdman, Fox-Rushby and Badia (1998), Stevelink and van Brakel (2013) and Terwee et al. (2007). Cultural equivalence was tested for the scales by assessing five equivalences (Herdman, Fox-Rushby, & Badia, 1997; Herdman, et al., 1998; Peters, et al., 2014; Stevelink & van Brakel, 2013; Terwee, et al., 2007) (see Table 1).

<b>Equivalences</b>	<b>Explanation</b>
<i>Conceptual</i>	The correspondence of the concept(s) measured between the cultures, in this case in relation to stigmatizing attitudes and (perceived) practices.
<i>Item</i>	The equivalence of items between cultures in terms of usefulness, relevancy and acceptability.
<i>Semantic</i>	The correspondence in linguistic meaning.
<i>Operational</i>	The suitability of the format of the instrument for practical implementation in the specific culture.
<i>Measurement</i>	The psychometric properties: internal consistency, reproducibility, construct validity, floor and ceiling aspects and interpretability.

Table 1 Equivalences

## METHOD

### STUDY SETTING

This validation study took place in five regions of Tanzania (Dar es Salaam, Mbeya, Kigoma, Geita and Arusha).

### PROCEDURE

A mixed methods approach was used, alternating qualitative and quantitative stages. The English versions of the items and scales as used by Peters et al. (2014) will be referred to as the “original items” and “original scales” (indicated with O), while the “new items” are adapted to Tanzania and albinism (indicated with N).

The following steps were undertaken to validate the scales (Table 2).

<b>Steps</b>	<b>Methods</b>	<b>Sample</b>	<b>Proceedings</b>
<i>Step 1 – conceptual and item equivalence</i>	Workshops	83 master students	The original scales and vignette were used as a directory for discussion in four workshops to explore the aspects of the stigmatization of people with albinism in Tanzania.
	In-depth interviews	13 people with albinism	12 In depth interviews were conducted to gain more insight in the experienced stigma of people with albinism after which new items were formulated.
<i>Step 2 – Semantic equivalence</i>	Translation into Swahili	5 experts in language	The items were translated and discussed with five experts in language.
	Translation into English	1 expert in albinism	After re-translation into English, differences in meaning were discussed and adjustments were made.
	Final check	3 master students	Controlling translation on clearness of meaning of the items.
<i>Step 3 – conceptual, item, semantic and operational equivalence</i>	Test of new scales	10 staff members of 3 Tanzanian NGOs and 3 master students	The scales were filled out and discussed.
	Test for the target population	4 high school teachers, 3 school leaders, 4 high school students	The scales were filled out and discussed.

<i>Step 4 – Measurement equivalence</i>	Pilot: Test	337 high school students	The scales were tested at three high schools. Besides the scale items, questions were asked about demographic characteristics, relationship to people with albinism (yes/no?) and knowledge concerning albinism.
	Re-test	142 high school students	After two to three weeks the students retook the survey to assess test-retest reliability and scale consistency. To gain better understanding of the EMIC-CSS, an item was entered about which community respondents had in mind while filling out the survey (home, tribe, school or different).
<i>Step 5 – Conceptual and item equivalence</i>	Focus group discussion	25 high school students	The lowest and highest scoring items were discussed in five focus group discussions at two schools that participated in the pilot study four months after the pilot, to analyse whether the outcomes of the scales really represent the viewpoints of the respondents. To develop a natural conversation, drawn visual vignettes were used.

Table 2 Steps of scale validation

## DATA ANALYSIS

The data was analysed using IBM SPSS Statistics 24. The tested psychometric properties and corresponding statistical methods are described below (Table 3).

<b>Psychometric properties</b>	<b>Statistical methods</b>
<i>Internal consistency</i>	Exploratory Factor Analysis or Confirmatory Factor Analysis as recommended when a factor structure is known in advance (Terwee, et al., 2007; de Vet, Adèr, Terwee, & Pouwer, 2005)
	Cronbach's alpha: scores between 0.70 and 0.95 are classified as good (Terwee, et al., 2007)
<i>Reproducibility</i>	On scale level: Gwet's AC1 <sup>2</sup>
	On item level: Kendall's Tau and Wilcoxon Signed Rank
<i>Construct validity</i>	Correlation between the scales
<i>Floor and ceiling aspects</i>	These effects are present if 15% of the responses have the highest or lowest score (Terwee, et al., 2007)
<i>Interpretability</i>	Through calculating the scale means for four subgroups (gender, school, know a person with albinism) the qualitative meaning of the results can be analysed

Table 3 Psychometric properties and corresponding statistical methods

Qualitative data was analysed through an iterative triangulation process with the respondents. All notes were analysed and, when reasonable, used for the adaption in the validation process of the scales, followed by other discussions in which the adaptations were discussed with the respondents.

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<sup>2</sup> Due to the sensitivity of Cohens kappa for skewed distribution, the measure cannot be used in the analyses for making decisions on the agreement between the test and re-test. Gwet's AC1 provides a stabler inter-rater reliability coefficient: it is less affected by prevalence and marginal probability (Gwet, 2008; Wongpakaran, et al., 2013).

## ETHICS

This study was approved by the Tanzania Commission for Science and Technology (COSTECH) and the Ethical Review Board of the Vrije Universiteit Brussel decided that the research was exempt from ethical approval. Oral informed consent was obtained from individual participants of the exploratory focus groups/workshops and written consent was given by participants of in-depth interviews. The head teachers of the participating high schools, who were responsible for their students, provided written informed consent.

## RESULTS

### CONCEPTUAL EQUIVALENCE

#### EMIC-CSS

Following the first three steps of the Scale validation, 6 of the 7 aspects of stigmatisation seem equally fit to measure stigma related to albinism among adolescents in Tanzania. The quotes below illustrate the correspondence of the aspects.

<b>Aspects of stigmatization</b>	<b>Illustrating quotes</b>
<i>Process of discrediting</i>	They think like we are maybe ghosts, or we are not human. (interview with woman with albinism, adult)
<i>Shame and embarrassment</i>	My condition bothered me, it used to bother me a lot and I used to be ashamed of it. (interview with woman with albinism, adult)
<i>Avoidance/taking distance/isolation</i>	It reached even a time, that when you were going to take lunch, the plate that was used by an albino somebody could not use it. (discussion with high school student, female, youth)
<i>Problems with getting married or on-going marriage</i>	Despite of that even for an albino it is difficult to marry a family with another person that is maybe black like other people. You can find that for an albino to get a woman who is not a fellow albino is very difficult because the society discriminates them and sees that they are no body. (discussion with high school student, female, youth)
<i>Problems for family or other people</i>	Family with a baby or a person with albinism is alienated, is discriminated. So, if I have a baby with albinism, if I have a husband with albinism, if I have a friend with albinism you may be alienated from the mainstream of society, so, so it is dangerous items. (interview with man with albinism, adult)
<i>Problems with work</i>	When I was starting with working as a nurse people, people didn't accept me as quite well because they are afraid that I will not take care of them. (interview with woman with albinism, adult)

Table 4 Aspects of stigmatization and supporting quotes

The aspect 'concealment' is not applicable, since it is difficult to conceal albinism as compared to covering up leprosy. Nonetheless, those who live with people with albinism often try to hide them because they are afraid of the community's response. Item O-E1 was adapted accordingly to N-E1: "Would family of someone with albinism keep this person hidden?". Other concealment-related items (O-E5 and O-E10) were removed (see Appendix B).

As opposed to some health-related conditions that one can get in one's lifetime, an individual is born with albinism. Consequently, the aspect of 'problems in an ongoing marriage' because of albinism might be less relevant. However, marital problems caused by getting a child with albinism

occur frequently (Bryceson, et al., 2010). Item O-E12 was adapted to N-E12: “Would getting a child with albinism cause problems in a marriage?”.

Since people often fear individuals with albinism because of the beliefs surrounding the condition, the concept of “fear” was added to the Scale through item N-E18: “Do people in general fear people with albinism?”.

SDS

When discussing the concepts of SDS in the workshops, interviews and discussions, all the items seemed relevant. An overview of the original and new items and their adaptations can be found in Appendix B.

## ITEM EQUIVALENCE

EMIC-CSS

Two items were irrelevant to everyday adolescent life in Tanzania:

1. Since most Tanzanians grow and cook their own food, item O-E15 was adjusted to N-E15: “Would people buy goods or services from a person with albinism?” and
2. High school students said they were not familiar with the labour market, therefore item O-E14: “Would having leprosy cause difficulty for a person to find work?” was deleted.

The items suggested by Peters et al. (2014) were added: “Would other people in your community mock a person affected by leprosy?” (translated as N-E16: “Would people call people with albinism bad names?” and N-E17: “Would other people in your community gossip about a person affected by leprosy?”). These items seem to fit in with the real situation for people with albinism:

*“I don’t remember a day going by without someone telling me something that is uncomfortable just because of our look” (Interview with woman with albinism, adult).*

SDS

Since the original SDS was developed for adults (Link, et al., 1987) the items were adapted to situations in which a high school student could easily imagine him/ herself, such as a school setting (see Appendix B). The written vignette accompanying the SDS was modified to one in which the respondents are introduced to John (for boys) or Joyce (for girls), a peer with albinism. The vignette portrays a person “like you and me” through her/his aspirations - performing well in school and getting married.

In the discussions and interviews, many new items fit for the SDS came up. Some were added because they were situations in which people with albinism could frequently experience stigmatisation in everyday life: shaking hands (N-S9), being friends (N-S8), people knowing there is someone with albinism in the family (N-S10), playing sports (N-S11) and going to the same school (N-S12) (see SDS new items, Appendix B).

The extent of changes in the SDS are such that it will be renamed the Albinism Social Distance Scale for adolescents (ASDS-A). The EMIC-CSS name remains because there were not as many changes.

## SEMANTIC EQUIVALENCE

The scales were translated into Swahili, the respondents’ mother tongue, for their better understanding, convenience and ease of use, and to create the possibility of using it among other Swahili speaking populations. As direct translation into Swahili is often troublesome, minor changes have been made so that the items can be better understood.

The response options of the original SDS (“definitely willing”, “probably willing”, “probably not willing”, “definitely not willing”) caused problems since a direct translation does not exist. “Easily willing” tends to be translated with “*Ninaomba/Ninataka*” meaning “*I want*”, or “*Ninapenda*” meaning “*I like*”, which mistakenly portrays a value judgment. One could understand “*I want*” as “*I would like*”

to be sitting next to a person with albinism more than sitting next to a person without albinism". Since some people also assign good fortune to albinism, it is important to be careful with this translation. Therefore, the following response options are used: "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".

Items O-E2 and O-E9 were reformulated. O-E2 asked: "If a member of your family had leprosy, would you think less of yourself?". However, an item measuring community stigma should not be formulated through a personal perspective, hence N-E2: "Would the family of someone with albinism feel less worth?". O-E9 was reformulated in terms of clarity.

#### OPERATIONAL EQUIVALENCE

Following discussions with experts and the target population, the operationalisation was adapted to self-administered scales. This provides the respondents with more anonymity and decreases the risk of socially desirable answers. Since high school students are familiar with reading and answering questions on paper in a school setting, it was assumed as a fitting operationalisation of the scales: more efficient, less pressure on the respondents and less time-consuming than an interviewer-administered Scale.

The first author and a schoolteacher provided the respondents with oral instructions, and short instructions were written in the survey ("Pick the correct answer"). Students were unfamiliar with filling out surveys, and most questions by the respondents pertained to marking the right answer (crossing, colouring or checking the box?). Probably due to its novelty, students considered the survey interesting. They took their time and made an effort to answer the survey seriously.

During step 3, respondents tended to choose the answer option "do not know" quite easily, with the rationale that they were not the expert in the field. They often thought that only researchers, social workers, community leaders, etc., would be able to answer the questions. Therefore, the "do not know" answer option was removed.

#### MEASUREMENT EQUIVALENCE

##### PARTICIPANTS' CHARACTERISTICS

The survey was filled out by 337 students, of whom 149 were male and 188 were female (Table 5). Three high schools participated, among which one school had no students with albinism (school 1) and two schools had students with albinism (schools 2 and 3). A limited number of students with albinism participated (n=5). The average age of the students was 17 years, ranging from 10 – 34 years old (age data was missing for 14 respondents). Almost all the participants had seen a person with albinism (97.9%), most of them knew someone with albinism (83.1%) because of the schools that they attended, and a few had relatives with albinism (5.9%).

	School			Total
	1	2	3	
<b>Respondents</b>	109 (32.3%)	101 (30%)	127 (37.7%)	337
<b>Male</b>	46 (30.9%)	52 (34.9%)	51 (34.2%)	149
<b>Female</b>	63 (33.5%)	49 (26.1%)	76 (40.4%)	188
<b>Average age (in years)</b>	16.3	17.2	16.1	

Table 5 Socio-demographic characteristics participants



## ITEM CHARACTERISTICS

Most people scored low on the EMIC-CSS and ASDS-A. An extensive overview of item characteristics is presented in Appendix C - EMIC-CSS, and Appendix D - ASDS-A. A summary of the item characteristics is presented in Table 6. Standard deviations are included merely for descriptive purposes to indicate possible absence of variability and cannot be used in an absolute normative way since they have an ordinal character.

Nr.	Code	Item	Mean	SD
<b>EMIC-CSS</b>				
1	N-E3	In your community, does albinism cause shame or embarrassment?	0.16	0.49
2	N-E15	Would people buy goods or services from a person with albinism?	0.17	0.47
3	N-E11	Is albinism a problem for a person to get married?	0.56	0.82
4	N-E6	Would people in your community avoid a person with albinism?	0.62	0.86
5	N-E8	Would people in your community think less about the family of a person with albinism?	0.69	0.84
6	N-E1	Would family of someone with albinism keep this person hidden?	0.7	0.80
7	N-E2	Would the family of someone with albinism feel less worth?	0.73	0.79
8	N-E9	Would albinism cause any problems for the family in the community?	0.78	0.92
9	N-E18	Do people in general fear people with albinism?	0.81	0.85
10	N-E13	Would having a relative with albinism cause problems for someone to get married?	0.94	0.86
11	N-E16	Would people call people with albinism bad names?	0.98	0.90
12	N-E7	Would others refuse to visit the home of a person with albinism?	1.05	0.85
13	N-E17	Would people in your community gossip/talk bad about a person with albinism?	1.07	0.86
14	N-E12	Would getting a child with albinism cause problems in a marriage?	1.38	0.78
15	N-E4	Would people think less of a person with albinism?	1.43	0.82
<b>ASDS-A</b>				
1	N-S12	How would you feel being in the same school with someone like John/Joyce?	0.19	0.45
2	N-S7	How would you feel helping someone like John/Joyce with a question about school work?	0.22	0.48
3	N-S2	How would you feel to be in the same class with someone like John/Joyce?	0.23	0.45
4	N-S4	How would you feel having someone like John/Joyce, who is older, as a teacher?	0.24	0.49
5	N-S8	How would you feel to have John/Joyce as a friend?	0.24	0.53
6	N-S9	How would you feel shaking hands with someone like John/Joyce?	0.24	0.52
7	N-S3	How would you feel to sit next to someone like John/Joyce in class?	0.26	0.47
8	N-S11	How would you feel if someone like John/Joyce was your teammate when playing games/sports?	0.26	0.51
9	N-S1	How would you feel to visit a house of someone like John/Joyce?	0.28	0.51
10	N-S6	How would you feel to introduce John/Joyce to your friends?	0.34	0.58
11	N-S10	How would you feel if your friend knew that you had someone like John/Joyce in your family?	0.43	0.69
12	N-S5	How would you feel to have someone like John/Joyce as a family member?	0.44	0.67

Table 6 Descriptive statistics EMIC-CSS and ASDS-A

## INTERNAL CONSISTENCY

Exploratory factor analysis did not confirm the one-dimensionality of the scales. For the EMIC-CSS the three first factors had Eigen values above one and only covered 43.5% of variability. To account for above 70.0% of variability, eight factors were needed. For the ASDS-A the first two factors had Eigen values above one and only covered about 67.4% of variability. To account for above 70.0% of variability, three factors were needed. However, the skewness of the item distribution did not endorse exploratory factor analysis.

Cronbach's alpha (0.78) showed an acceptable internal consistency of the EMIC-CSS and an excellent internal consistency for the ASDS-A (0.93). However, for both scales, Cronbach's alpha could be influenced by the high number of items (EMIC-CSS: 15 items, ASDS-A: 12 items) and the skewness of the distribution. The following items did not add to the internal consistency, according to Cronbach's alpha if Item Deleted: N-E15, N-E9, N-E11 ( $\alpha$ : 0.79) and item N-E3 could also be removed ( $\alpha$ : 0.79, 11 items). Removing items of the ASDS-A would lower the alpha substantially.

To improve working with the skewed data, a log transformation was performed; however it did not improve the distribution for analysis. A log transformation of a variable with a discrete distribution with an extreme low amount of possible values boiled down to a re-scaling, making the position of the saturated extreme value the sole representative of most of the distribution. The normal approximation of the transformed distribution remained inadequate, though the SD will be less through this transformation.

## REPRODUCIBILITY

Reproducibility statistics can be found in Table 7. For both scales, Gwet's AC1 gave a nuanced picture of test-re-test reliability ranging from reasonable, to weak, to good correspondence (EMIC-CSS: 0.45 to 0.79; ASDS-A: 0.63 to 0.81). Kendall's Tau showed a weak correspondence (EMIC-CSS: 0.24 to 0.55, ASDS-A: 0.30 to 0.51), which showed an average to low correlation between test and re-test. Without exception, all differences between test and re-test were negative (EMIC-CSS:  $Z=-3.043$  to  $Z=-0.032$ ; ASDS-A:  $Z=-2.430$  to  $-0.016$ ), which in itself made the results significant. The test-retest correlation of the global EMIC-CSS and ASDS-A were a moderate  $t=0.58$  and  $t=0.53$ , respectively. After Bonferroni correction for multiple testing the significance at item level disappeared.

	Scale		Items			
	Cronbach's alpha	Kendalls Tau	Gwet AC1	Kendalls Tau	Answers unequal	Z values
<b>EMIC-CSS</b>	0.78	0.58	0.45-0.79	0.24-0.55	19.1%-46.5%	-0.032- -3.043
<b>ASDS-A</b>	0.93	0.53	0.63-0.81	0.30-0.51	18.3%-33.1%	-0.016- -2.430

Table 7 Main statistical findings for the total EMIC-CSS and ASDS-A and individual items

## CONSTRUCT VALIDITY

The correlations between the EMIC-CSS and the ASDS-A were extremely low (Kendall's correlation 0.11 ( $p<0.05$ ) (2-tailed .015) ( $n=290$ )).

## FLOOR AND CEILING ASPECTS

No floor or ceiling effects were identified for the EMIC-CSS, five of the respondents (1.5%) had the lowest possible score and no one had the maximum score. A large floor effect was identified for the ASDS-A, 150 (44.5%) of the respondents had the lowest score and again no one had the maximum score.

## INTERPRETABILITY

Scores differ between subgroups (Table 8). Total scores are only used for the comparison of the means and the validation.

Variables		EMIC-CSS Total score means (SD)	ASDS-A total score means (SD)
<b>Sex</b>	Male	11.96 (6.18)	3.67 (5.25)
	Female	11.98 (5.82)	2.96 (4.37)
<b>School</b>	School 1	11.14 (5.38)	2.7 (4.95)
	School 2	14.02 (6.11)	3.08 (3.93)
	School 3	11.01 (6.00)	3.93 (5.21)
<b>Know PLWA</b>	No	10.46 (6.23)	3.53 (5.7)
	Yes	12.24 (5.9)	3.23 (4.59)

Table 8 Interpretability table

## FOLLOW-UP FOCUS GROUPS

In the follow-up focus groups, the highest and lowest scoring items were discussed. Many attitudes presented by the items were confirmed by the respondents. However, the respondents contradicted the low score on item N-E15 considering people's attitude towards buying something from someone with albinism ( $\mu$ : 0.17).

The ASDS-A showed that respondents felt uncomfortable about having a family member with albinism but were less uncomfortable having someone with albinism as a friend (Appendix D). Respondents had difficulty in explaining differences in feelings in different relationships. One respondent explained the attitude towards these different relationships as follows:

*“Having a friend who has albinism, because he or she is not part of your family, it is not that shaming than having a relative (with albinism) ... is like having a curse in some community” (High school student, female).*

## OTHER FINDINGS

People had these “communities” in mind while filling out the EMIC-CSS.

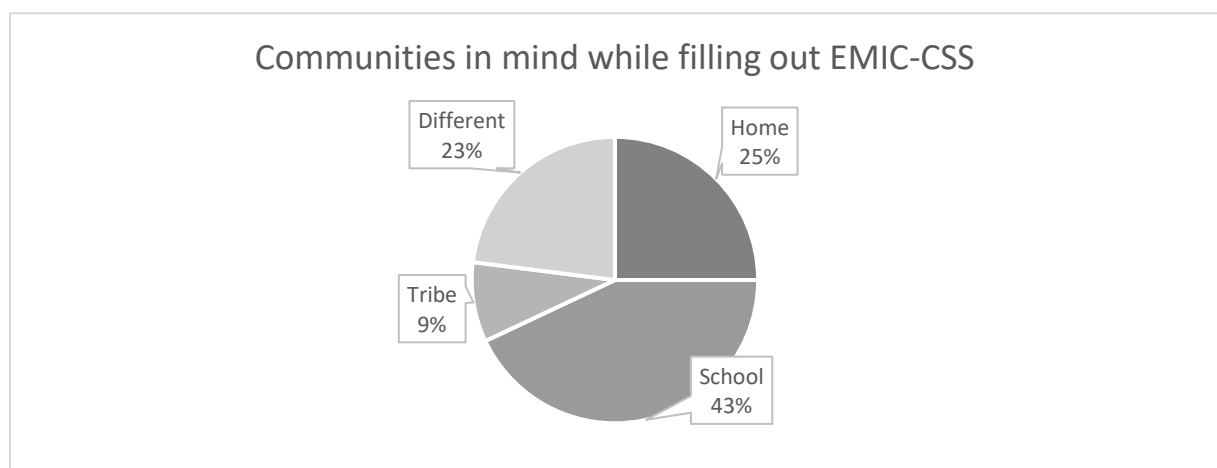


Figure 1 EMIC-CSS communities (n=117)

## DISCUSSION

Valid instruments are necessary to assess the prevalence and severity of albinism-related stigma and the effectiveness of implemented stigma reduction interventions. This research adapted and validated existing stigma-measurement tools to measure health-related stigma in a cross-cultural setting: the EMIC-CSS measuring community stigma by asking people about the views of their community towards the stigmatised (Brieger, et al., 1998; Peters, et al., 2014; Stevelink & van Brakel, 2013; Stienstra, et al., 2002), and the ASDS-A measuring personal stigma by asking people about their personal views of the stigmatised (Link, et al., 1987; Peters, et al., 2014).

Conceptual equivalence of the EMIC-CSS was sufficient, as six of the seven aspects of stigmatisation measured stigma related to albinism in Tanzania. The aspect of concealment is not applicable in a Scale measuring albinism-related stigma due to the different nature of the condition. As for the aspect: 'Problems with getting married or ongoing marriage', it must be noted that since one is born with albinism it will not cause trouble during marriage, but it can be a problem for someone to get a marriage alliance. The concept of fear was added, because fear for someone with albinism seems relevant in Tanzanian society as is confirmed by the item characteristics, and the concept is also often used in research on attitude towards people living with HIV/AIDS (Bos, Schaalma, & Pryor, 2008; Creel, Rimal, Mkandawire, Böse, & Brown, 2011; Nyblade, 2006). Item characteristics showed that the aspect of discrediting measured high levels of stigma and the aspect of shame and embarrassment measured relatively low levels of stigma.

In terms of item equivalence, respondents scored extremely low on item N-E15: "Would people buy goods or services from a person with albinism?" in the EMIC-CSS ( $\mu$ : 0.17). This item is formulated positively, as opposed to all other negatively formulated items, which could have influenced the respondents' answering behaviour, as was also found with a positively scored item in Peters, et al. (2014). Additionally, the respondents in the follow-up focus groups doubted the accuracy of the answering behaviour of the sample, since they supposed people would have stigmatising feelings about the matter. For future use it is suggested that it be reformulated to: "Would people dislike buying goods or services from a person with albinism?". The two items suggested by Peters et al. (2014), namely N-E16: "Would people call people with albinism bad names?" and N-E17: "Would other people in your community gossip about a person affected by leprosy?" turned out to be relevant, supported by relatively high item means of 0.98 for N-E16 (fifth highest) and 1.07 for N-E17 (third highest). The recommended EMIC-CSS and ASDS-A can be found in Appendix E, in English and in Swahili.

To obtain item equivalence for the ASDS-A, new items were suggested because of the new context and applicability in a high school setting. The ranking of the items based on the total item score corresponds with the level of social distance. For example, people feel less comfortable having someone with albinism in the family (small social distance) as compared to having someone with albinism in the same school (large social distance). Through qualitative analyses, the new items of the ASDS-A seem to be relevant. After adjustment, the item equivalence of both scales was adequate.

The statistics regarding measurement equivalence should be interpreted correctly. From the acceptable to excellent internal consistency of the EMIC-CSS ( $\alpha$ : 0.78) and ASDS-A ( $\alpha$ : 0.93), it can be deduced that both scales are valid to measure stigma, as both alphas are comparable with the finding of Peters et al. (2014). However, both Cronbach's alphas can be influenced by the skewness of the distribution and the high number of items (EMIC-CSS: 15 items, ASDS-A: 12 items). The skewness of the distribution and the floor effect in the case of the ASDS-A, can be caused by the population in which the scales were conducted. In two of the three high schools, people with albinism were present and the students were familiar with albinism through their educational background, therefore the distribution can be explained by a low stigmatising attitude and is not necessarily reason for an invalid Scale. For further validation, the scales should be tested in a different population. For the EMIC-CSS

the following items could be removed for a smaller Scale and higher Cronbach's alpha ( $\alpha$ : 0.79 with 11 items): N-E3, N-E9, N-E11 and N-E15.

Reproducibility statistics show an average to low correlation between test and re-test: people have not been consistent in answering questions. However, in the re-test, people's answers to the questions were more positive and less stigmatised towards people with albinism. A plausible cause for this disparity is that the survey itself can be an intervention in populations living closely together. The survey, the subject of research and the researcher could have stimulated the debate on the topic and the evolution of opinions.

The low construct validity, extremely low Kendall correlation of .11, differs from results found in Peters et al. (2014) and can be explained by the different nature of the EMIC-CSS and ASDS-A. The students do not portray stigmatising attitudes in the ASDS-A, whereas they do believe that the community in general has a stigmatising attitude as expressed in the EMIC-CSS. As such, this points at a difference between community and personal attitudes caused by differences in age, culture and education. Respondents indicated that older people hold more traditional beliefs about albinism and in general have a lower level of education. Testing the scales among adults who live in the community the EMIC-CSS asks about, might give more insight into the validity of the scales. This study also showed that the respondents in school had different communities of reference (Figure 1). It might be interesting to research the reference community of people in the EMIC-CSS. For a more consequent interpretation of the EMIC-CSS a possible improvement could be to specify 'a community', e.g., a school.

#### RECOMMENDATIONS AND LIMITATIONS

The social desirability bias is problematic in stigma measurement; this could have caused the skewed distribution and the floor effect of the ASDS-A. People in Tanzania are aware of the stigmatisation of people with albinism and the bad name this has given the nation. Consequently, a foreigner researching this topic might cause respondents to hesitate to portray stigmatising feelings. The school as a place of inquiry could also have caused socially desirable answering as respondents might view the survey as an exam. The lack of floor effects for the EMIC-CSS could demonstrate that people find it easier to talk about someone else's attitude and therefore the EMIC-CSS might be less sensitive for socially desirable answering. Adapting the ASDS-A to cope with social desirability might be done through the introduction of items with a less distinct meaning, a balanced Scale of positive and negative items or the addition of a social desirability Scale to at least measure the level of social desirability (Beretvas, Meyers, & Leite, 2002).

This validation focussed on high school students, which limits the generalisability of the findings to the general Tanzanian population. For further validation, one should keep in mind that many people in Tanzania are not able to read or are unused to reading. Careful translation of items and answer possibilities to Swahili is important, especially with a self-administered survey since one cannot give direct feedback to the interpretation. Additionally, one can doubt whether the chosen translation of the ASDS-A answer possibilities ("I do not have a big problem", etc.) are as value-free as intended, since they might be interpreted as more negative because they are referring to a problem.

The researchers wish to underline the importance of using mixed methods to assess stigma (Yang, et al., 2007). Scales like the EMIC-CSS and ASDS-A are more valuable when qualitative methods are used to interpret quantitative data.

#### CONCLUSION

This validation study shows the potential of the EMIC-CSS and ASDS-A as scales for measuring stigma towards people with albinism in Tanzania. On many aspects the scales have been proven adequate: conceptual, item, semantic and operational equivalence is achieved. In terms of measurement equivalence, the reproducibility statistics raise questions that can be explained by the characteristics

of the sample. However, research among a different population is necessary to exclude the doubts that are caused through the skewness of the item distribution and the possible effect of the test itself as an intervention to control the reproducibility of the Scale. Recommendations for further Scale development are presented in the article. Moreover, this article shows the importance of validating existing measurement tools to specific settings and respondents.

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## Chapter 5

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Measuring stigma related to people with albinism in Tanzania: a cultural validation study of the EMIC-CSS and SDS among adults

## CHAPTER 5: MEASURING STIGMA RELATED TO PEOPLE WITH ALBINISM IN TANZANIA: A CULTURAL VALIDATION STUDY OF THE EMIC-CSS AND SDS AMONG ADULTS.

*Accepted for publication as: de Groot, T., Jacquet, W., Meurs, P., & Peters, R. (accepted). Measuring stigma related to people with albinism in Tanzania: a cultural validation study of the EMIC-CSS and SDS among adults. Disability, CBR and Inclusive Development.*

**Purpose:** People with albinism in Tanzania are severely stigmatised. A measurement tool to assess this stigmatisation among adults is lacking. This research aimed at the cultural validation of two Scales to measure stigma related to albinism: the Albinism Social Distance Scale (A-SDS) and the Albinism Explanatory Model Interview Catalogue Community Stigma Scale (A-EMIC-CSS).

**Method:** Conceptual, item, semantic and operational equivalences were evaluated through focus groups and interviews. A pilot study among adults attending religious institutes, as a representation of Tanzanian society, was conducted to assess the measurement equivalence. There were 101 respondents for the test and 79 respondents for the re-test.

**Results:** Conceptual, item, semantic and operational equivalences of the Scales are sufficient. In terms of measurement equivalence, the internal consistency of the A-SDS and A-EMIC-CSS are adequate. However, social desirability should be taken into account when interpreting the findings.

**Conclusion and Implications:** The insights provided by this article can aid in the development of tools to measure stigma cross-culturally and across stigmatising conditions. The combination of the two Scales for short and long-term effect measurement is recommended.

**Key words:** health-related stigma, EMIC-CSS, SDS, albinism, Tanzania

## INTRODUCTION

People with albinism are often, sometimes violently, discriminated against in Tanzania. The exclusion of people with albinism is caused by their conspicuous physical appearance and the meaning that society attaches to this appearance (Brocco, 2016; Bryceson, Jønsson, & Sherrington, 2010). A genetic mutation causes a reduction of melanin in the hair, skin and eyes, which therefore are light in colour. As a result, people with albinism look 'different' from most people in Tanzanian society who have darker skin. The condition not only causes a 'different' appearance but also affects their skin and eyes, so that people with albinism have skin that is very sensitive to UV rays and have poorer vision as well (Grønsvov, Ek, & Brøndum-Nielsen; Hong, Zeeb, & Repacholi, 2006)

A multitude of beliefs and myths with regard to albinism are prevalent in society. One of these is the myth that people with albinism are not human. They are believed to be ghosts; they do not die, and will simply disappear at the end of their life (Baker, Lund, Nyathi, & Taylor, 2010; Brocco, 2015). There is also the belief that the mothers of children with albinism have been cursed and punished (Baker, et al., 2010; Cruz-Inigo, Ladizinski, & Sethi, 2011). Another belief, that the body parts of people with albinism can bring good fortune, is responsible for attacks on the lives of people with albinism (Brocco, 2015; Bryceson, et al., 2010; Cruz-Inigo, et al., 2011). The various beliefs about albinism in Tanzania influence the way society perceives and acts towards people with albinism (de Groot, Meurs, & Jacquet, 2019).

The exclusion and discrimination of people with albinism are manifestations of health-related stigmatisation. Stigmatisation has been observed with respect to many health-related conditions, in a variety of cultural settings. However, the responses to similar conditions can vary over cultural settings (van Brakel, et al., 2019). In this study, the definition of stigmatisation by Link and Phelan (2001) will be used: "stigma exists when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold". The process of stigmatisation negatively influences the lives of stigmatised people; people with albinism in Tanzania face discrimination in everyday life, in areas such as education, employment and marriage (Baker, et al., 2010; Brocco, 2016).

Till today, there are no validated Scales in Tanzania or elsewhere, to measure the stigma related to albinism among adults. Validated instruments are needed to get a clearer picture of the extent of the problem and to assess the effectiveness of interventions. The aim of this study is to validate two instruments constructed to assess the level of stigma towards people with albinism in the Tanzanian adult community: a Social Distance Scale (SDS) and the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS). Instruments like these are also of use to study the effectiveness of efficient stigma reduction interventions (Heijnders & van der Meij, 2006).

### SDS

Social Distance Scales ask respondents about their personal attitudes towards a stigmatised person in a certain social relation. This Scale builds upon the work of Bogardus (1925) on feelings of acceptance towards ethnic groups in the United States (Parrillo & Donoghue, 2005). Bogardus' SDS was adapted and used in many countries, such as Nigeria (Adewuya & Makanjuola, 2005), the USA (Brown, 2008) and Japan (Sakuragi, 2008). The SDS has been used to measure people's attitudes towards other people with all kinds of characteristics and health-related stigma, e.g., HIV-AIDS (Leiker, Taub, & Gast, 1995), mental illness (Corrigan, et al., 2002), and leprosy (Peters, et al., 2014). The SDS version used by Link, Cullen, Frank, & Wozniak (1987) and Peters et al. (2014) examines feelings that consider seven social relationships towards someone with a stigmatising condition: renting out a room, working together, living next to one, having one take care of your children, your child marrying someone with a stigmatising condition, introducing one to someone you know and recommending for a job with a

friend. The items of the SDS are often accompanied by a vignette with a description of a person with a stigmatising condition (Link, et al., 1987; Peters, et al., 2014).

## EMIC-CSS

The EMIC-CSS has been developed and used by Weiss (1997). The EMIC-CSS measures community stigma, asking respondents how people in their community feel about persons with the stigmatising condition. The EMIC-CSS has been adapted and used in relation to different cultures, such as Nigeria (Brieger, Oshiname, & Ososanya, 1998), Indonesia (Peters, et al., 2014) and Ghana (Stienstra, van der Graaf, Asamoah, & van der Werf, 2002). The EMIC-CSS has been adapted to different health-related conditions, such as onchocercal skin disease (Brieger, et al., 1998), leprosy (van Brakel, et al., 2012; Peters, et al., 2014), and buruli ulcer (Stienstra, et al., 2002). The version used by van Brakel et al. (2012) and Peters et al. (2014) measures seven aspects of stigmatisation: (1) concealment, (2) process of discrediting, (3) shame and embarrassment, (4) avoidance/keeping distance/isolation, (5) problems with getting married or ongoing marriage, (6) problems for family or other people, and (7) problems with work (van Brakel, et al., 2012; Peters, et al., 2014).

## METHODS

### STUDY DESIGN

The study described in this article is part of a larger research project that required adapted validated measurement instruments to measure stigma for an adult population. Five equivalences were tested: conceptual, item, semantic, operational and measurement. The framework that was used was based upon the work of Herdman, Fox-Rushby and Badia (1998), Terwee et al. (2007), Stevelink and van Brakel (2013), and Peters et al. (2014). A range of research methods were used to test these equivalences. Table 1 describes the definitions of the equivalences and the methods used.

Equivalences	Methods
<i>Conceptual</i> The correspondence of conceptual meaning between cultures in relation to the measured stigmatising attitude.	<ul style="list-style-type: none"> <li>• Workshops with university students (n=83),</li> <li>• In-depth interviews with people with albinism (n=11)</li> <li>• Piloting surveys among people working in the field of stigma reduction (n=13)</li> <li>• Findings from the adolescent validation (de Groot, Peters, van Brakel, Maurs &amp; Jacquet, 2020)</li> </ul>
<i>Item</i> The equivalency of items between cultures in usefulness, relevancy and acceptability.	
<i>Semantic</i> The correspondence in linguistic meaning.	<ul style="list-style-type: none"> <li>• Translation and re-translation by experts in language and albinism</li> <li>• Piloting surveys among people working in the field of stigma reduction (n=13)</li> </ul>
<i>Operational</i> The suitability of the practical implementation of the research in the specific culture.	<ul style="list-style-type: none"> <li>• Piloting surveys among people working in the field of stigma reduction (n=13)</li> <li>• Findings from the adolescent validation (de Groot, et al., 2020)</li> <li>• Advice by research assistants</li> </ul>
<i>Measurement</i> The psychometric properties: test-retest reliability and scale consistency.	<ul style="list-style-type: none"> <li>• Test and re-test (n=101)</li> </ul>

Table 1 Equivalences and methods (Herdman, Fox-Rushby, & Badia, 1997; Herdman, et al., 1998; Terwee, et al., 2007; Stevelink & van Brakel, 2013; Peters, et al., 2014)

The study by de Groot et al. (2020) describes the validation of the SDS and EMIC-CSS for an adolescent population. For the current validation study - the validation of the scales for an adult population - data was gathered simultaneously with the data gathering for the adolescent population.

As a starting point for the current validation of the SDS, the SDS items as developed by Peters et al. (2014) were used since they were developed for an adult population. For the validation of the EMIC-CSS, the items as validated in de Groot et al. (2020) were used as a starting point because they investigate the community's attitude and the community of reference is equal for adults and adolescents. In the article that follows, the adapted scales will be called the Albinism Social Distance Scale (A-SDS) and the Albinism Explanatory Model Interview Catalogue Community Stigma Scale (A-EMIC-CSS).

#### STUDY SETTING

The conceptual, item, semantic and operational equivalences are described in detail in the study by de Groot et al. (2020). This article briefly touches upon these four equivalences, but focuses mainly on the measurement equivalence. To determine the measurement equivalence, the scales were piloted in Morogoro, a landlocked region in the east of Tanzania. In addition to the scales, some demographic data was gathered, such as age, religion, job type and highest level of education. The pilot study aimed for a minimum of 100 respondents. The first author was assisted by four Tanzanian Master's graduates of Mzumbe University (two male, two female) to conduct the test-retest.

#### STUDY SAMPLE

To reduce dropout of respondents, a specific sampling scheme was developed. Most people in Tanzania affiliate to either a Christian (61%) or Islamic institution (35%) (Bureau of Democracy, Human Rights, and Labour, 2017). Since people frequently visit religious institutes, these institutes could function as places for easy recruitment of respondents for the test and retest. Experts were consulted to gain an overview of the religious denominations prevalent in the rural and urban areas of Morogoro. From all the denominations at least one institute was chosen and emphasis was laid on a rural-urban division; in total 24 institutes were selected. In the case of Christianity, the largest denominations were chosen twice. The institutions were randomly assigned to the assistants by the researcher, without knowing the preference of the assistants. Assistants were later re-assigned if it was found that they were assigned to their own religious institute. In each religious institute, the assistants aimed to select six respondents, balanced on categories of gender and age (18-30, 31-50, 51+), through purposive sampling, to allow an equal representation of gender and age.

#### DATA ANALYSIS

IBM SPSS Statistics 24 (IBM, Armonk, New York) was used for data analysis, except for the estimation of the reliability measures. Gwet's AC1 and Cohen's Kappa were calculated using R version 3.5.0 (The R Foundation for Statistical Computing). The tested psychometric properties and corresponding statistical methods to determine the measurement equivalence of the scales are described below:

- **Internal consistency:** The skewed distribution of the A-SDS Scale did not permit the researchers to conduct an Exploratory Factor Analysis (EFA) or Confirmatory Factor Analysis (CFA); however, EFA and Principal Component Analysis (PCA) were used for the A-EMIC-CSS. As a measure of internal consistency, Cronbach's alpha was consulted; an alpha between 0.70 and 0.95 is classified as good (Terwee, et al., 2007).
- **Reproducibility:** Due to the skewed distribution, the non-parametric measures –Kendall's Tau and Wilcoxon signed rank tests - were used to assess the test-retest relationship at item level. Gwet's AC1 was used because of its more stable inter-rater reliability coefficient than Cohen's Kappa and less sensitivity for skewed distribution (Gwet, 2008; Wongpakaran, Wongpakaran, Wedding, & Gwet, 2013).

- **Construct validity:** Analysed by exploring the relationship between the A-SDS and the A-EMIC-CSS through correlation, and deemed sufficient when a moderate positive correlation exists (Spearman correlation between 0.4 and 0.8) (Terwee, et al., 2007).
- **Floor and ceiling aspect:** Observed when 15% of the responses have the highest or lowest score (Terwee, et al., 2007).
- **Interpretability:** Observed through the difference in means between the three subgroups and with that attaching meaning to the data.
- **Generalisability of the sample:** Participant characteristics tested for significant differences between groups.

## ETHICS APPROVAL

The Tanzanian Commission for Science and Technology (COSTECH) gave permission for the conducted research. Written or oral informed consent was obtained from individual participants. Some respondents refrained from signing the informed consent form because they were reluctant to have their name on an official form. However, they gave oral consent for participation.

## RESULTS

### BRIEF OVERVIEW OF CONCEPTUAL, ITEM, SEMANTIC AND OPERATIONAL EQUIVALENCE

#### A-SDS

Participants in the workshops and the interviewees indicated that the main concepts under study (e.g., 'stigma' and 'social distance') are relevant in their setting. Some items of the original Scale did not fit the Tanzanian context, such as: O-S1 ('How would you feel about renting a room in your home to someone like Rahman/Rahmi?'). Since not many people in Tanzania have a spare room to rent out, the item seemed irrelevant and was changed into A-S1 ('How would you feel to visit a house of someone like John/Joyce?'). Item O-S5 ('How about having one of your children marry someone like Rahman/Rahmi?') was seen as an irrelevant item. According to the respondents, a child would always ask permission from his/her parent to get married, therefore the item was changed into A-S5 ('Would you permit your child to marry someone like John/Joyce?'). Respondents thought items were missing about situations that were frequently encountered. Therefore, items were added that considered: sitting next to someone with albinism in the bus (A-S8), having a friend with albinism (A-S9) and shaking hands with someone with albinism (A-S10) (see Table 2).

Original items	Adolescent items	Adult items
O-S1 How would you feel about renting a room in your home to someone like Rahman/Rahmi?	N-S1 How would you feel to visit a house of someone like John/Joyce?	A-S1 How would you feel to visit a house of someone like John/Joyce?
O-S2 How about being a worker on the same job with someone like Rahman/Rahmi?	N-S2 How would you feel to be in the same class with someone like John/Joyce?	A-S2 How would you feel working together with someone like John/Joyce?
O-S3 How would you feel having someone like Rahman/Rahmi as a neighbour?	N-S3 How would you feel to sit next to someone like John/Joyce in class?	A-S3 How would you feel having someone like John/Joyce as a neighbour?
O-S4 How would you feel about having someone like Rahman/Rahmi as caretaker of your children for a couple of hours?	N-S4 How would you feel having someone like John/Joyce, who is older, as a teacher?	A-S4 How about having someone like John/Joyce taking care of your children for a couple of hours?

O-S5 How would you feel about having one of your children marry someone like Rahman/Rahmi?	N-S5 How would you feel to have someone like John/Joyce as a family member?	A-S5 Would you permit your child to marry someone like John/Joyce?
O-S6 How would you feel about introducing Rahman/Rahmi to a young woman you are friendly with?	N-S6 How would you feel to introduce John/Joyce to your friends?	A-S6 How would you feel about introducing John/Joyce to a young woman you are friendly with?
O-S7 How would you feel about recommending someone like Rahman/Rahmi for a job working for a friend of yours?	N-S7 How would you feel helping someone like John/Joyce with a question about school work?	A-S7 How would you feel about recommending someone like John/Joyce for a job working for a friend of yours?
<b>Extra items</b>		
	N-S8 How would you feel to have John/Joyce as a friend?	A-S9 How would you feel to have John/Joyce as a friend?
	N-S9 How would you feel shaking hands with someone like John/Joyce?	A-S10 How would you feel shaking hands with someone like John/Joyce?
	N-S10 How would you feel if your friend knew that you had someone like John/Joyce in your family?	
	N-S11 How would you feel if someone like John/Joyce was your teammate when playing games/sports?	
	N-S12 How would you feel being in the same school with someone like John/Joyce?	
		A-S8 How would you feel to sit next to John/Joyce in the bus?

Table 2 Changes in the items of the SDS to achieve item and semantic equivalence

In terms of semantic equivalence, when translating the items of the A-SDS some changes were made to the wording of the items to improve understanding. Item O-S2 ('How about being a worker on the same job with someone like Rahman/Rahmi?') was changed because respondents were afraid people would interpret this type of question wrong, by putting emphasis on the type of 'job' people with albinism perform. People might expect someone with albinism to do a low-level job and they would not like to have the same kind of job. Therefore, this item became A-S2 ('How would you feel working together with someone like John/Joyce?') (see Table 2). Additionally, as for the adolescent Scale, the names Rahman/Rahmi in the original Scale were changed to the more common Tanzanian names - John and Joyce.

In terms of operational equivalence, the answer possibilities were adapted. This was because a direct translation or the original answer possibilities ('definitely willing', 'probably willing', 'probably not willing', 'definitely not willing') do not exist in Swahili (for more information see de Groot et al., 2020). The answering categories were changed to: '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 vignette was adapted to an adult version in which a person with albinism is described. Among other things, it is mentioned that the person is looking for another job and wants to get married. Again, there were two versions: one for men, one for women.



## A-EMIC-CSS

The A-EMIC-CSS asks the respondents how people in their community think or feel about people with albinism. Workshop participants and those working in the field of stigma reduction advised that the same questions could be posed to both adolescents and adults: conceptual, item and semantic equivalences were deemed sufficient.

In terms of operational equivalence, to allow for more precise responses and to reduce extreme answering behaviour, answer possibilities were extended. The three answer categories ('yes', 'possibly', 'no') were changed into five ('it never happens', 'it rarely happens', 'it happens sometimes', 'it happens often', 'it happens always').

## MEASUREMENT EQUIVALENCE

### PARTICIPANT CHARACTERISTICS

In total, 101 respondents filled out the test questionnaire (54.5% male and 45.5% female) and 79 respondents filled out the retest. Of the respondents, 63.4% were from the urban area, and 36.6% were from the rural area. Christians represented 56.4% of the respondents, while 43.6% were Muslim. Age-wise, the sample was divided into groups of 18-25 years (29%), 26-30 years (22%), 31-50 years (31%), and 51+ years (18%). Participants had different types of jobs: a paid job (22.8%), own business/farmer (52.5%) or housewife (24.8%). In the sample, 1% did not know how to read or write, 5% had not finished primary school, 20% had finished primary school, 42% had finished high school, and 32% had finished a form of higher education. Almost all respondents (98%) had seen people with albinism, 73.5% knew a person with albinism, and 12.9% of the respondents had a family member with albinism (see Table 3).

<b>Variables</b>		<b>Respondents (N=101)</b>
<i>Sex</i>	Male	54.5%
	Female	45.5%
<i>Knows a person with albinism</i>		73.5%
<i>Has a family member with albinism</i>		12.9%
<i>Geographic area of residence</i>	Rural	36.6%
	Urban	63.4%
<i>Religion</i>	Christian	56.4%
	Muslim	43.6%
<i>Age</i>	18-25	29%
	25-30	22%
	30-50	31%
	50<	18%
<i>Job type</i>	Paid job	22.8%
	Business/Farmer	52.5 %
	Housewife	24.8%
<i>Highest level of education</i>	Illiterate	1%
	Literate (not finished primary school)	5%
	Primary school	20%
	High school	42%
	Higher education	32%

Table 3 Demographics of the participants

## ITEM CHARACTERISTICS

The item characteristics of the test are shown below (Tables 4 and 5). For the A-SDS, the score of '1' ('I do not have a big problem') represents the lowest level of stigma and '4' the highest level ('I do have a big problem'). For the A-EMIC-CSS, the score of '1' represents the lowest level of stigma ('It never happens'), and '5' the highest level ('It happens always').

Code	Item	N	Mean	Std. Deviation
A-S1	How would you feel to visit a house of someone like John/Joyce?	100	1.18	0.539
A-S2	How would you feel working together with someone like John/Joyce?	99	1.27	0.712
A-S3	How would you feel having someone like John/Joyce as a neighbour?	99	1.21	0.52
A-S4	How about having someone like John/Joyce taking care of your children for a couple of hours?	99	1.27	0.568
A-S5	Would you permit your child to marry someone like John/Joyce?	95	1.47	0.77
A-S6	How would you feel about introducing John/Joyce to a young woman you are friendly with?	99	1.28	0.623
A-S7	How would you feel about recommending someone like John/Joyce for a job working for a friend of yours?	99	1.2	0.473
A-S8	How would you feel to sit next to John/Joyce in the bus?	99	1.18	0.46
A-S9	How would you feel to have John/Joyce as a friend?	99	1.19	0.467
A-S10	How would you feel shaking hands with someone like John/Joyce?	99	1.16	0.445

Table 4 Descriptive statistics A-SDS

Code	Item	N	Mean	Std. Deviation
A-E1	Would the family of someone with albinism keep this person hidden out of shame?	101	2.22	1.026
A-E2	Would the family of someone with albinism feel worthless?	101	2.22	1.045
A-E3	In your community, does albinism cause shame or embarrassment?	101	1.64	0.82
A-E4	Would people think less of a person with albinism?	100	2.25	1.114
A-E5	Would people in your community avoid a person with albinism?	100	1.87	1.002
A-E6	Would others refuse to visit the home of a person with albinism?	99	1.77	0.946
A-E7	Would people in your community think less about the family of a person with albinism?	100	1.86	1.045
A-E8	Would albinism cause any problems for the family in the community?	101	1.61	0.916
A-E9	Is albinism a problem for a person to get married?	101	2.14	1.14
A-E10	Would getting a child with albinism cause problems in a marriage?	101	2.33	1.141
A-E11	Would having a relative with albinism cause problems for someone to get married?	101	2.16	1.102
A-E12	Would people buy goods or services from a person with albinism?	100	2.64	1.299
A-E13	Would people call people with albinism bad names?	101	2.3	1.188
A-E14	Would people in your community gossip/talk badly about a person with albinism?	98	2.38	1.117
A-E15	Do people in general fear people living with albinism?	100	2.19	1.098

Table 5 Descriptive statistics A-EMIC-CSS

## INTERNAL CONSISTENCY

### A-SDS

Due to the extremely skewed distribution of the A-SDS items, only non-parametric procedures can be applied, and the Cronbach's alpha measure has to be used with caution. All items of the A-SDS are skewed, with skewness ranging from 1.66 (A-S5 'Would you permit your child to marry someone like John/Joyce?') up to 3.68 (A-S1 'How would you feel to visit a house of someone like John/Joyce?'); and the prevalence for 'I do not have a big problem' and 'I do not have a problem' ranging from 89% (A-S1 again) up to 99% (item A-S7, A-S8, A-S9 and A-S10). Cronbach's alpha is 0.927 based on 10 items; however, deleting items results in a three-item scale (Alpha: 0.972) existing out of the newly added items: sitting next to someone with albinism in the bus (A-S8), having a friend with albinism (A-S9) and shaking hands with someone with albinism (A-S10).

### A-EMIC-CSS

Due to the distribution of the A-EMIC-CSS (skewness ranging from 0.43 to 1.65, systematically towards 'never' or 'rarely'), it was decided to run a PCA based on four components, deduced from an EFA that showed four components. However, only one item loads on the fourth component: item A-E12 ('Would people buy goods or services from a person with albinism?'). Cronbach's alpha also showed that this item should be removed, so it was followed by a PCA based on three components. Conceptual ambiguity arises since there are two items loading on two components: A-E3 ('In your community, does albinism cause shame or embarrassment?') and A-E10 ('Would getting a child with albinism cause problems in a marriage?'). It was decided to remove all the items with an unclear factor loading in an analysis for two or three components, to get to a point in which all items could be divided over two components (Table 6).

Code	Item	Component	
		1	2
A-E1	Would the family of someone with albinism keep this person hidden out of shame?	0.758	<del>0.251</del>
A-E2	Would the family of someone with albinism feel less worth?	0.729	<del>0.326</del>
A-E4	Would people think less of a person with albinism?	0.721	<del>0.283</del>
A-E6	Would others refuse to visit the home of a person with albinism?	0.686	<del>0.293</del>
A-E9	Is albinism a problem for a person to get married?	0.698	<del>0.191</del>
A-E11	Would having a relative with albinism cause problems for someone to get married?	0.696	<del>0.065</del>
A-E13	Would people call people with albinism bad names?	<del>0.269</del>	0.836
A-E14	Would people in your community gossip/talk badly about a person with albinism?	<del>0.275</del>	0.881
A-E15	Do people in general fear people with albinism?	<del>0.197</del>	0.805

Table 6 Rotated component matrix A-EMIC-CSS

Cronbach's alpha on the complete A-EMIC-CSS is 0.895 based on 15 items. When deleting item A-E12, alpha 0.913 remains over 14 items; removing item A-E8 ('Would albinism cause any problems for the family in the community?') increases the alpha to 0.916 for 13 items. More items could be deleted to get a Scale with fewer items; however, this would lower the alpha. Starting out from the deduced components, the six items in component 1 have a good Cronbach's alpha score of 0.851. Component 2, consisting of three items, has a Cronbach's alpha of 0.857; however by deleting item A-E15 ('Do people in general fear people living with albinism?') the Cronbach's alpha increases (0.871), which leaves insufficient number of items to be able to perceive it as a subscale/component.

## REPRODUCIBILITY

Reproducibility for the A-SDS values range between the 0.031 and 0.221 of Kendall's Tau and Gwet's AC1 0.54 and 0.71. For A-EMIC-CSS, Kendall's Tau has values between 0.39 and 0.48, and Gwet's AC1 0.17 and 0.53. The results showed that the pre-test and the post-test did not differ significantly from each other on almost all items for the A-SDS Scale and A-EMIC-CSS, except for items A-S8, A-S9 and A-S10. All differences between test and re-test are negative, as can be seen from the Z score on the Wilcoxon signed rank test (see Appendix F).

## CONSTRUCT VALIDITY

Correlation between the two scales is low with Spearman's rho of 0.167 (correlation significant at the 0.01 level 2 tailed, 0.001).

## FLOOR AND CEILING ASPECTS

On the A-SDS, the lowest possible score was seen with 53.7% of the respondents, while 1.1 % of the respondents had the highest score. On the A-EMIC-CSS, 3.3% of the respondents had the lowest score; this is below the limit of 15%. No one had the highest score.

## INTERPRETABILITY

The total scores of the scales are only used to point out the difference between the subgroups. In this way the interpretability of the scales is illustrated (Table 7).

<b>Variables</b>		<b>A-SDS Total score mean (SD)</b>	<b>A-EMIC-CSS Total score mean (SD)</b>
<i>Gender</i>	Male	1.27 (0.53)	2.14 (0.13)
	Female	1.22 (0.33)	1.99 (0.60)
<i>Profession</i>	Paid job	1.15 (0.26)	2.20 (0.66)
	Own business/Farmer	1.33 (0.54)	1.98 (0.71)
	Housewife	1.15 (0.30)	2.13 (0.62)
<i>Urban/Rural</i>	Urban	1.15 (0.29)	2.03 (0.66)
	Rural	1.43 (0.61)	2.12 (0.73)

Table 7 Interpretability

## DISCUSSION

Until very recently there were no scales available to assess stigma related to albinism. This study is the first to validate two scales to measure stigmatising attitudes towards people with albinism among adults. It can therefore be used to measure the effectiveness of stigma reduction interventions.

### A-SDS

Cronbach's alpha alone shows that the A-SDS is internally consistent and therefore fit to measure stigma related to people with albinism. However, due to the distribution of the A-SDS Scale, Cronbach's alpha can be misleading (Sheng & Sheng, 2012). The floor effect of the A-SDS Scale is very large, with 53.7% of the people scoring the lowest possible score of '1'. This means more than half of the respondents did not portray stigmatising feelings on even one of the items. From the results of the A-EMIC-CSS, which portray higher stigmatising attitudes in the community, and other studies on the stigmatisation of people with albinism (Baker, et al., 2010; Brocco, 2015; Bryceson, et al., 2010; Cruz-Inigo, et al., 2011), one would have expected to measure higher levels of personal stigma. One of the explanations for the floor effect could be that atrocities against people with albinism are widely condemned in the Tanzanian media's representation of the situation of people with albinism. Media, government and action groups all spread the message to protect people with albinism (Burke, Kaijage,

John-Langba, 2014). When the norms that prescribe the social acceptance of people with a stigmatising condition, in this case albinism, are strong and socially valued, people tend to be motivated to show that they are more tolerant than most people (a false uniqueness effect), and therefore tend to provide a socially desirable answer. The Social Distance Scale is sensitive for this so-called false uniqueness effect. Since the A-SDS presents social situations, it provides respondents with the opportunity and the motivation to show their agreement with socially expected attitudes (Sigelman, 1991). The A-SDS items are quite explicit in asking about attitudes towards people with albinism; therefore it is easy for the respondent to choose the 'right' but maybe not the honest answer. This is also acknowledged in the review by Stier and Hinshaw (2007), which concluded that when it is not socially desirable to portray prejudice respondents will try to present themselves as being accepting in an explicit measure.

Due to the potential of a social desirability effect, one should be careful in using and interpreting the A-SDS in the future. When willing to use the A-SDS as an effect measure for stigma reduction interventions, one possibility is to only use the items that measure the highest level of stigma (A-S2, A-S4, A-S5, A-S6). Another possibility is to dichotomise the answers: by separating scores that portray stigma (scores of 2, 3, 4) and those that do not portray any stigmatising attitude (score of 1). Otherwise, developing less explicit items in quantitative or qualitative research might reduce this risk of social desirability, and therefore be an addition to the A-SDS. As was also recommended in de Groot et al. (2020), the measurement of social desirability through a Social Desirability Scale could also be an addition to the Scale to be able to take social desirability into account when analysing the data (Beretvas, Meyers, & Leite, 2002; Crowne & Marlowe, 1960; Perry, Murphy, & Dovidio, 2015).

#### A-EMIC-CSS

The A-EMIC-CSS is internally consistent, and the distribution of the A-EMIC-CSS is acceptable with no floor or ceiling effects. First, respondents might be less inclined or likely to have extreme answer behaviour because they feel more comfortable talking about the attitudes of others in the A-EMIC-CSS than talking about their own attitudes as requested in the A-SDS. Secondly, this might be a result of extending the answer categories. Item A-E12 ('Would people buy goods or services from a person with albinism?') again does not seem to add to the good, internal consistency of the A-EMIC-CSS, which might be caused by the positive formulation (de Groot, et al., 2020).

The A-EMIC-CSS in Peters et al. (2014) is a one-dimensional scale, with all items loading on two strongly correlating factors. However, this is not the case for the current Scale, which can be divided into two components. In the second component of the A-EMIC-CSS, two of the three items ask about discriminating actions towards people with albinism: A-E13 ('Would people call people with albinism bad names?') and A-E14 ('Would people in your community gossip/talk badly about a person with albinism?'). When willing to keep the second component, adding more items on discriminating behaviour towards people with albinism might be a solution. This could be a valuable means of measuring more aspects of stigmatisation.

The results of the A-EMIC-CSS could be used for an improved Scale through item selection, as portrayed in Table 5. However, since the A-EMIC-CSS has in the past proven to be a valuable measurement instrument in its current form, it is worthwhile to hold on to the existing Scale.

#### RECOMMENDATIONS AND LIMITATIONS

For both scales, reproducibility values are low. First of all, this could be explained by the reluctance of the respondents to participate in the retest. Some respondents no longer wanted to help and demanded compensation. Their unwillingness to participate voluntarily might have caused a change in answering behaviour. Consequently, all scores of items in the retest showed less stigmatisation than the items in the test. Either the scales by themselves seem to be an intervention or a selection effect might be present. It is possible that people discussed the scales after the test and subsequently

changed their attitude. An intervention effect of the A-SDS and A-EMIC-CSS could be cautiously mentioned since this effect was also seen in the validation study of the adolescent Scale (de Groot, et al., 2020). To exclude or reduce the intervention effect, the scales could be tested with more time between test and retest.

The low correlation between the A-SDS and A-EMIC-CSS cannot be used as an argument for Scale validation as was the case in Peters et al. (2014). The A-EMIC-CSS might not work in a direct effect measurement of a stigma reduction intervention since it asks about the community's opinion, where it is unlikely to expect people to have changed directly after having participated in an intervention. Only long-term effects in the community could be assessed with this Scale, as opposed to the A-SDS, which can measure personal attitudinal change right after a stigma reduction intervention and also the long-term effects.

It becomes clear from the demographic data that the respondents in the sample had a relatively high level of education. This can be explained by the fact that Morogoro is a university city. One should therefore be careful in generalising the validity of the Scale to a less educated sample.

## CONCLUSION

The insights gained in this article can add to the development of tools to measure stigma cross-culturally and across stigmatising conditions. The equivalences for the A-SDS are sufficient and the Scale has potential for short and long-term effect measurement; however, in the context of Tanzania, social desirability seems very much of an issue and more research is needed to further develop this Scale. For the same reason, the A-SDS should not be used on its own but in combination with other scales. The A-EMIC-CSS has adequate validity to assess stigmatising attitudes in the community and therefore to assess the long-term effects of an intervention. In the end, not only is a combination of both scales needed to gain understanding about the effects of stigma reduction interventions, but also the combination of qualitative and quantitative approaches is necessary to enhance knowledge about the effects of stigma reduction interventions.

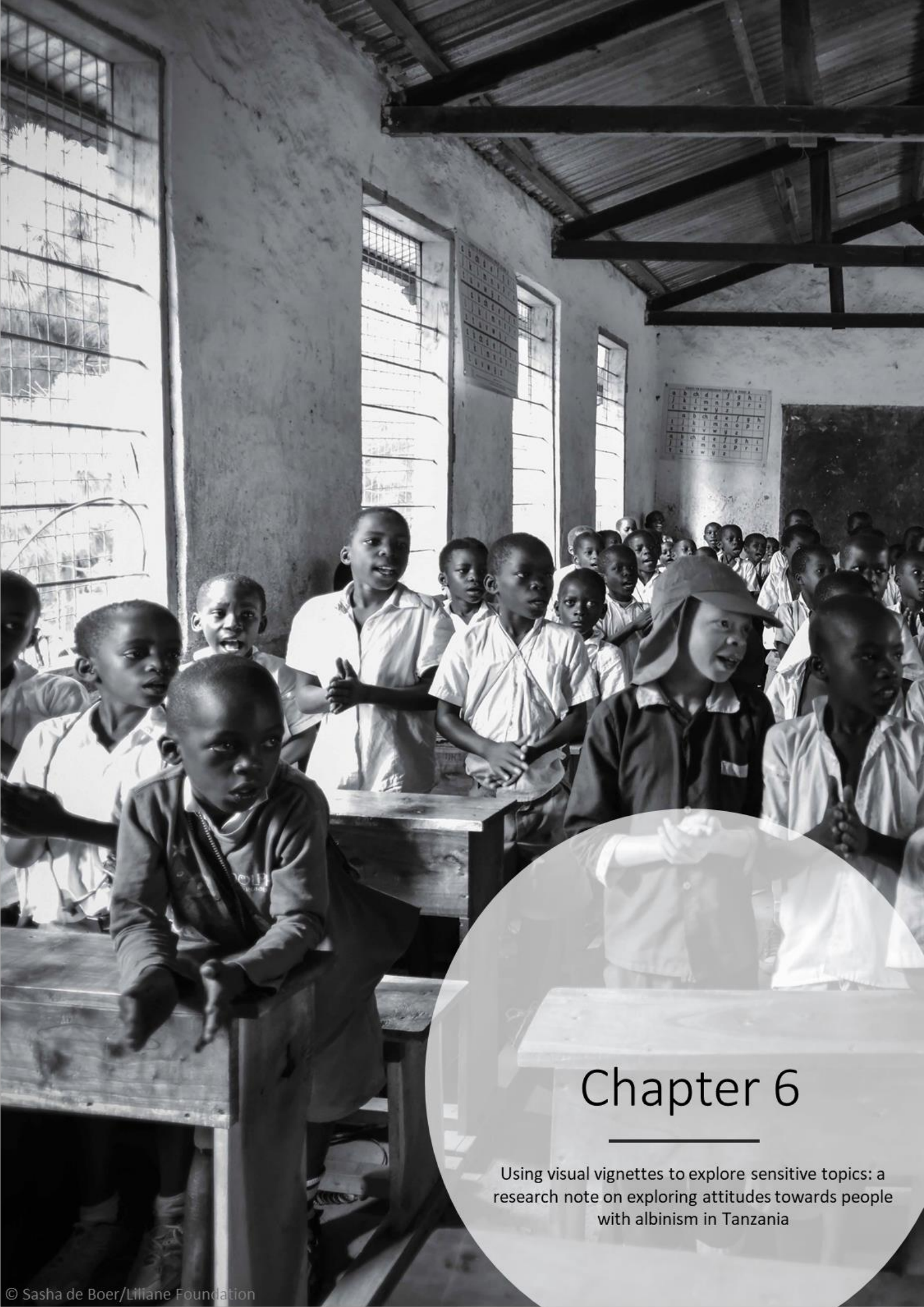
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## Chapter 6

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Using visual vignettes to explore sensitive topics: a research note on exploring attitudes towards people with albinism in Tanzania

## CHAPTER 6: USING VISUAL VIGNETTES TO EXPLORE SENSITIVE TOPICS: A RESEARCH NOTE ON EXPLORING ATTITUDES TOWARDS PEOPLE WITH ALBINISM IN TANZANIA.

*Published as: de Groot, T., Jacquet, W., De Backer, F., Peters, R., & Meurs, P. (2020) Using visual vignettes to explore sensitive topics: a research note on exploring attitudes towards people with albinism in Tanzania. International Journal of Social Research Methodology, 23(4).*

This study is one of the first to explore the use of (drawn) visual vignettes in qualitative research in Africa. The vignette method was used to discuss the sensitive topic of people's attitudes towards people with albinism in Tanzania among high school students. Focus was on two key questions: (i) To what extent was the vignette method implemented as intended?; (ii) Has the vignette method achieved its goal?. This research note discusses the effectivity of the visual vignette method as a tool to gain a better insight into people's attitudes towards people with albinism, but also describes the possibilities of visual vignettes as a tool for research on other sensitive topics.

Keywords: visual vignettes, health-related stigma, albinism, Tanzania

## INTRODUCTION

Some research topics are considered 'sensitive' because they discuss intimate, discreditable or incriminating behavior. These topics can therefore cause difficulties in research (Renzetti & Lee, 1993). In empirical research, the use of material that represents real situations can help explore people's attitudes towards sensitive topics (Naylor, Maye, Ilbery, Enticott, & Kirwan, 2014). Several scholars (Barter & Renold, 1999; Finch, 1987; Hughes, 1998) propose the use of vignettes. Vignettes provide representations of hypothetical situations, to which the interviewee is asked to respond, in order to explore perceptions, opinions, beliefs and attitudes present in a community. A variety of formats exist, such as written stories, audiotape, and photography (Dixon, Murray, & Daiches, 2012; Hughes, 1998). Vignettes are used in both qualitative and quantitative research and can be combined with other research methods (Barter & Renold, 1999, 2000). Although vignettes are often used, Gourlay, et al. (2014) point to the lack of research into the methodology itself.

## THE VISUAL VIGNETTE

Visual methodology can improve data generation. An image can facilitate the presentation of situations in the same way as lingual representation and can stimulate spontaneous reaction and discussion (Hazel, 1995, Naylor, et al., 2014). Images enable more inclusive research because they allow children, people with a lower level of literacy and limited cognitive capacity to participate (Dixon, et al., 2012; Morrison, 2015). Images can cross linguistic (Hughes & Huby, 2004) and cultural boundaries (Harper, 2010). Images are therefore utilized in cross-cultural research (Morrison, 2015). As Harper (2010) explains, the use of images instead of words can sometimes make it easier to give people insight into another culture or situation, that they have never been in. Harper claims that by discussing an image, differences in perception are sometimes more easily defined, compared and understood by respondents from different backgrounds. When examining sensitive topics, images can help to discuss contextual factors. Photographs are the most commonly used visual vignette, but other materials may also be considered, such as paintings or cartoons (Harper, 2010).

Very little is known about the use of (visual) vignettes in low-income countries, since most studies focus on high-income countries (Gourlay, et al., 2014). General literacy levels in low-income countries are lower, with generally educational differences between gender, rural and urban areas. Therefore, in addition to crossing cultural barriers, methodologies that apply to illiterate people and correct for a possible bias towards literacy are extremely useful.

Gourlay and her co-authors (2014) were the first to reflect on the use of written story vignettes in Africa. They used these vignettes in researching people's attitudes towards the use of HIV prevention of mother-to-child transmission services in Tanzania. Research via visual vignettes in the format of photo elicitation already occurred in Tanzania (Fischer, 2016; Jakobsen, 2012; Miles & Kaplan, 2005). However, the method itself is not yet studied, although it could be useful for research on sensitive topics. Because of the promising possibilities for research on sensitive topics, we used the visual vignette method in our research on the attitudes of people towards people with albinism in Tanzania. In this research note we reflect on our experiences and explore the possibilities of the visual vignette method as a tool to gain a better understanding of people's attitudes towards a sensitive topic.

## RESEARCHING ATTITUDES ON ALBINISM IN TANZANIA WITH THE USE OF VISUAL VIGNETTES

Approximately 1 in 16.000 people in Tanzania has albinism (The United Republic of Tanzania, 2014). This condition causes them to suffer from health problems such as skin cancer and poor vision (Hong, Zeeb, & Repacholi, 2006). Albinism can lead to fierce stigmatization, caused, among other things, by superstitious beliefs (de Groot, Meurs, & Jacquet, 2019). These beliefs even led to the killings of people

with albinism in the past because of the myth that their body parts can provide good fortune (Brocco, 2016).

This study was part of a larger study into the development and assessment of stigma reduction interventions related to albinism. In this study, (drawn) visual vignettes were used during 10 focus group interviews with high school students (n=52) in two different high schools in Tanzania. The visual vignettes in this study were based on the concept of social distance, also used in social distance scales (SDSs). SDSs assess the attitudes of people in different social relationships towards others, such as people with a stigmatizing condition (de Groot, Peters, van Brakel, Meurs & Jacquet, 2020; Link, Cullen, Frank, & Wozniak, 1987). Therefore, the five visual vignettes used in this research portray social situations in which stigmatization can occur against people with albinism (portrayed within Table 1). The situations portrayed in the visual vignettes were used as topics for discussion in the focus group interviews. The corresponding questions when presenting the visual vignettes to the respondents were: ‘Can you explain what you see in the image?’ and ‘How would people feel in this situation?’. The vignettes used for this research were designed by the creative therapists of ‘Happy made by’ who are familiar with Tanzania and the situation of people with albinism. This was carried out in close consultation with the research team and employees of NGOs working with people with albinism.

To gain insight into the effectiveness of the visual vignette as a tool for investigating people’s attitudes, it is important to know whether the method functioned as intended and whether the research goal was achieved. This is addressed in the following key questions which are initially based on Gourlay, et al. (2014) because these questions proved to be effective for the analysis of vignettes in the past.

- Key question 1: To what extent was the vignette method implemented as intended? This question was answered by analysing whether the respondents understood this way of doing research and by investigating the challenges encountered when implementing the vignette method.
- Key question 2: Has the vignette method achieved its goal? To answer this question, the findings were analysed to assess whether the findings were useful in providing insight into attitudes towards people with albinism.

The analysis of the transcribed data was done thematically and according to the key questions.

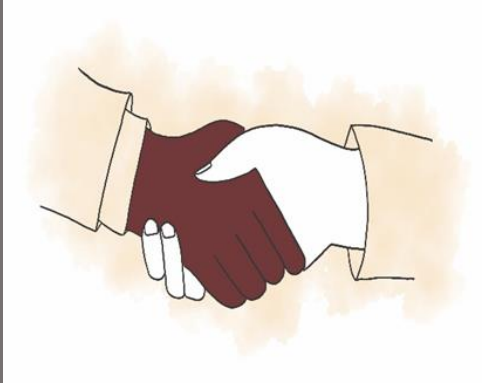
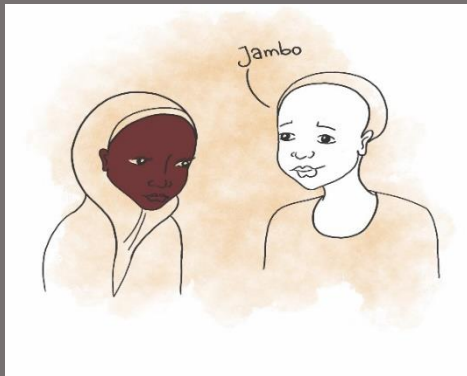
Vignettes	Quotes
<p>Figure 1: Shaking hands</p> 	<p><i>“People who have an education about albinism, they don’t segregate the albino because they know that they are different in colour only, and that they are human beings like others (Student, Female)”</i></p> <p><i>“There are some people who believe that if I will give a hand to someone with albinism, I will change by getting albinism. Or when I get pregnant, I will give birth to someone with albinism, but that is not true (Student, Female).”</i></p> <p><i>“I think that these people didn’t prefer to have this condition, they just found themselves having this. So, we should just take them as other people, we should not discriminate them (Student, Female).”</i></p>

Figure 2: Greeting



*"The albino tries to find cooperation, tries to find love in the society but the people there are not ready to participate with him or her due to his colour (Student, Male)."*

*"If somebody sees you talking with the person who has albino, the albino, they will come and ask for you where he or she lives so that they can go and kill her or him. That is why you can find the people who have got no albinism to stay far away from the people with albinism (Student, Female)."*

Figure 3: Sitting next to each other



*"In this photograph, how I think, it mainly means that this guy, this African, was given that seat by mistake. He shows no cooperation to this girl and he is very rude, because his face is so tough, meaning that he is not ready to share anything with the lady (Student, Male)."*

*"The normal person is wearing goggles, goggles are special needs assistance. People with albinism have eye problems. That is why these special needs assistance should be given to the person with albinism (Student, Male)."*

*"According to the picture here, it shows that a person with albinism and a person who does not have albinism can stay together and they can share [...] also they can be lovers (Student, Male)."*

Figure 4: Being cared for by a nurse with albinism



*"What I have seen is that even people with albinism can be educated to be professions like doctors, teachers [...] God is the one who created them and God has given them various talents (Student, Male)."*

*"...and that working capacity is similar to us (Student, Male)."*

*"From the picture I can see that there is an albino woman taking care of a normal child, who is normal by nature and it seems like the child is not appreciating that (Student, Male)."*

Figure 5: Getting a child



*"It also symbolizes that a normal person can give birth to an albino, that this may be just a case of inheritance (Student, Male)."*

*"She tries to think: how will my child proceed in learning? How will this child help me? How will the people look at my child (Student, Male)."*

*"Long ago our fathers and our grandfathers and our grandmothers they believed that a child with albinism was born, this was about (bad) luck. They would kill him or her (Student, Female)."*

*"...her husband can leave her because he got a baby with albinism (Student, Male)."*

Table 1 Examples of responses with each vignette

## KEY QUESTION 1: TO WHAT EXTENT WAS THE VIGNETTE METHOD IMPLEMENTED AS INTENDED?

### UNDERSTANDING THIS WAY OF DOING RESEARCH

Respondents focused their attention on the visual vignettes and took the time to look at them. Respondents answered the question of the researcher with each vignette. They explained what they saw in the vignettes and how others would feel in the situation presented in the vignette.

The discussion topics of the focus group discussion seemed to be clear to the respondents because of the images. People were paying attention during the focus group discussion and listened to their peers. In the experience of the researcher, in interviews without the use of vignettes respondents tend to repeat the same myths about albinism over and over when asked to explain people's attitude on albinism. However, it seems that the visual vignettes succeeded in providing guidelines for the discussion. In three out of ten focus group interviews, the interviewer did not repeat the prompting questions with each vignette because the respondents understood the exercise. Respondents also responded to their co-respondents without the interviewer's interference, which allowed for a dialogue.

However, the enthusiasm shown by respondents when asked to discuss the visual vignettes varied. Some respondents were excited to talk about the vignettes, others were reluctant to talk. Especially at the beginning of some interviews, some respondents did not answer the researcher's question. When that happened, the researcher explained the vignette as factually as possible (e.g.: 'I see two people in the picture shaking hands.') to stimulate the discussion. Then, the initial questions were asked again. If respondents were still hesitant to respond, the researcher gave examples of simple emotional connotations (e.g.: 'Do they feel happy?'). After these prompts, most respondents felt comfortable sharing their views.

Some difficulties arose because of the vignettes and the accompanying questions. In some cases, the respondents' answers did not correspond to the intention of the question. For example, in response to the question: 'How would people feel in this situation?' some respondents gave their own opinion on the matter or explained what they knew about albinism, usually to conclude that they would not discriminate against someone with albinism. Others explained the pictures as a lesson, like an image in a schoolbook that shows the right example. For example, Figure 4 of a nurse with albinism was explained as a lesson, i.e. people with albinism can do work like everyone else. The explanation of these 'lessons' by the respondents also provided an opportunity to gain insight into the respondents' knowledge about albinism. An example of this is the explanation that was often given

for vignette 5, which shows a mother without albinism with a child with albinism. Many respondents stated based on this image that albinism is a genetic condition.

There was little misunderstanding about the meaning of the vignettes. Respondents interpreted the situation portrayed in the vignettes correctly: they grasped the actual representation of a person with albinism in a specific situation. All respondents knew what albinism was and understood that the light-skinned person in the figure was someone with albinism. In some cases, the situation on the vignettes was not described in detail by the respondents, but only superficially as a situation in which two persons, one with and one without albinism, were together. This often happened when respondents interpreted the vignette as a lesson.

Respondents sometimes saw a different emotion in the same characters. For example, one respondent interpreted the person's expression on a vignette as 'very rude and unwilling to cooperate', while another considered the same expression to be positive. This shows that situations portrayed in visual vignettes leave room for the respondents' own interpretation.

### KEY QUESTION 2: HAS THE VIGNETTE METHOD ACHIEVED ITS GOAL?

Rich information was collected about people's attitude towards people with albinism. Many respondents expressed that they did not have stigmatizing feelings towards people with albinism themselves but explained about the attitudes of others. Table 1 shows examples of the variety of responses that were provided with each vignette.

### DISCUSSION

This research note presents an exploration of the use of (drawn) visual vignettes in qualitative research. The vignettes were used to discuss people's attitudes towards people with albinism in Tanzania, which is a sensitive topic. Two key questions were explored in this research note, that will be answered in this discussion.

To answer key question 1, it can be stated that the vignette method has been implemented as intended to a great extent. The respondents understood the methodology quite easily, sometimes some extra prompting was necessary to get the respondent to talk. The vignettes themselves were clearly understood. The benefits of this method were, firstly, that using questions from a third person perspective was efficient in exploring the attitudes of people in the community. Secondly, the expression of the characters in the images gave the respondents the opportunity to develop their own interpretation. This was shown by the respondents' contradicting explanations of the emotions of the characters on the vignettes, which triggered the discussion. Thirdly, using visual vignettes determined clear topics for the discussion, which resulted in straightforward responses.

One of the problems with the methodology was that respondents interpreted the images as lessons, more specifically as stigma reduction interventions. This may be caused by the school setting in which the focus group took place and the familiarity of the students with the social disapproval of discrimination against people with albinism. The visual vignettes present examples of situations someone could be in with someone with albinism. Possibly respondents never imagined themselves being in the portrayed situation, but by seeing the image people might realize the possibility to be in this situation. For example, figure 4 shows a nurse with albinism, which might have made people realize that it would be possible to meet a nurse with albinism. As a side effect, visual vignettes proved to be an effective visual stimulus to generate data about people's knowledge about albinism, because people not only expressed possible attitudes, but also often tried to explain albinism.

Key question 2 is also answered positively. The vignette method caused the respondents to provide their views on people's attitude towards people with albinism. Several stigmatizing attitudes came to the foreground by discussing the situations depicted on the vignettes. Visual vignettes helped to fragment the stigmatization of people with albinism into little, more orderly pieces which together helped to portray a broad range of stigmatizing attitudes. Especially in situations when the



respondents would not hold stigmatizing feelings towards people with albinism themselves or did not want to express these feelings, the discussion of the images would still provide insights.

Limitations to consider when using the visual vignette method are the following. Firstly, developing a visual vignette is difficult and time consuming. These vignettes should not only be tailored to the research questions, but also to the context of the research.

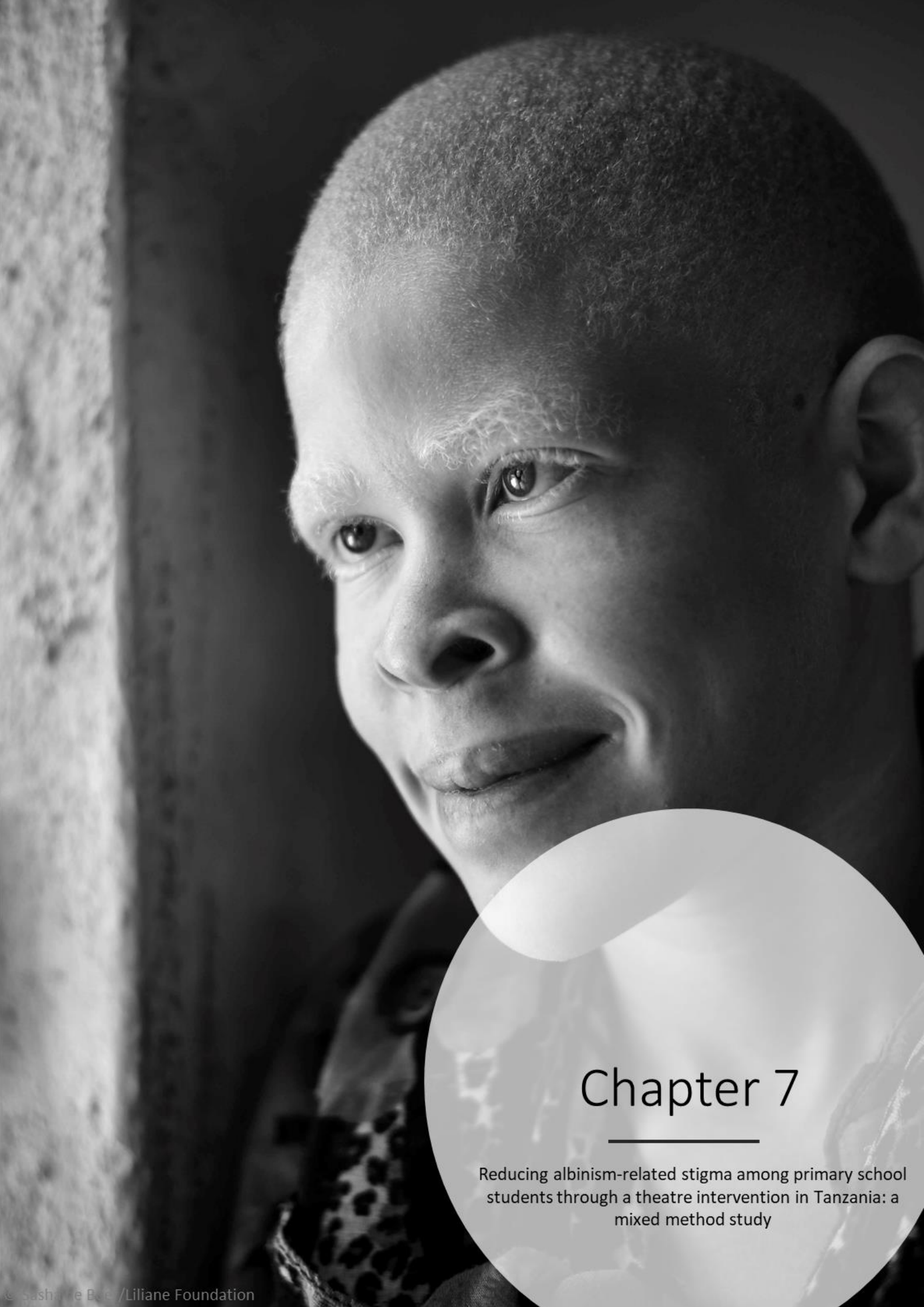
Second, the static nature of visual vignettes can limit the response possibilities of respondents. One visual image can not reflect the complexity of social life (Barter & Renold, 2000; Finch, 1987; Naylor, et al., 2014), nor the complexity and dynamics surrounding the stigma. The current study presented only five situations for the respondents to reflect on. This limited the discussion about all attitudes towards people with albinism.

To conclude, this research note outlines the possibilities in terms of visual vignettes in research into a sensitive topic such as people's attitude towards people with albinism. Applying visual vignettes to gain insight into people's attitudes towards a sensitive topic in an African setting is useful, although some limitations were identified. This conclusion is in line with previous research on other sensitive topics (Barter & Renold, 2000; Naylor, et al., 2014). To overcome limitations of the visual vignette methodology, this tool can be used in combination with other methods within multi-method research. Furthermore, a study specifically aimed at the use of the vignette method among various respondents and contexts is recommended to gain more insight into the possibilities. With this research note we hope to inspire people to explore and use the (drawn) visual vignette method more. Especially with regard to a sensitive topic and with less literate respondents, this method has proven to be able to gain rich insights.

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## Chapter 7

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Reducing albinism-related stigma among primary school students through a theatre intervention in Tanzania: a mixed method study

## CHAPTER 7: REDUCING ALBINISM-RELATED STIGMA AMONG PRIMARY SCHOOL STUDENTS THROUGH A THEATRE INTERVENTION IN TANZANIA: A MIXED METHODS STUDY

*Under review as: De Groot, T., Meurs, P., Almasi, M., Peters, R., & Jacquet, W. (under review). Reducing albinism-related stigma among primary school students through a theatre intervention in Tanzania: a mixed methods study. Journal of African Cultural Studies.*

In Tanzania many harmful beliefs exist about albinism, causing fierce stigma related practices towards the people with this condition. Theatre interventions have been used as stigma reduction interventions and educational methods in different cultural contexts and in relation to a large variety of health conditions. This study explores the possibilities for using theatre as a stigma reduction intervention in relation to albinism in Tanzania. Through this study recommendations can be made for future use of this type of interventions. This mixed method study evaluates a theatre play on albinism that was implemented in three different primary schools in the Lake Region in Tanzania. The theatre production, *Haki Yetu (Our Rights)*, showed several situations in which a person with albinism was being discriminated. Qualitative methods (including observations) were used to gain insight into the content of the play, the strategies used to attract the audiences' attention and the response of the audience. Quantitative methods were used pre- and post-intervention to analyse changes in knowledge about albinism and stigmatizing attitudes towards people with albinism.

Keywords: Albinism, Health-related Stigma, Stigma Reduction, Theatre for Development, Entertainment Education, Tanzania

## INTRODUCTION

*'Teacher you are mistaking, you are discriminating, teacher he is asking permission to go stand in the shade because his skin is sensitive, not like our skin.'* (Primary school student, girl)

In the spring of 2018, the organizations of Under the Same Sun (UTSS), European Committee for Training and Agriculture (CEFA) and the Global Network of Religions for Children (GNRC) in co-operation with Dar Creators organised the *Haki Yetu* (Our Rights) theatre tour in Tanzanian primary schools and communities, which aimed to raise awareness on albinism. The quotation above is from a primary school student who intervened during a theatre play (with audience participation) about albinism that was performed at primary schools in Tanzania. The student criticised the teacher in the theatre play who was not supportive towards a student with albinism in his classroom.

A play like this can be placed in the tradition of Theatre for Development (TfD) (Kvam, 2012). This theatre genre is based on the work of Freire (1972) and Boal (1979) on 'Pedagogy of the oppressed' and 'Theatre of the oppressed', which entails among other things a bottom-up approach to education. According to the 'Pedagogy of the oppressed', education should be based on real life situations and knowledge arises from the cooperation between learners and teachers (Freire, 1972). 'Theatre of the oppressed' builds on this principle by involving the audience through active participation in theatre (Boal, 1979).

TfD is as a theatre methodology for social interventions in order to improve the quality of people's life (Kerr, 2014). Difficulties arise, however, with the use of this type of intervention. Because a theatre intervention often addresses a wide and diverse audience, who all need to understand the lessons provided in the intervention, there is little possibility to transfer messages for specific groups in the society, which might be more effective in influencing that specific group (Mitchell, et al., 2001). For example, a program focussing on out of school youth, can start from the specific situation of out-of school youth as a starting point (as described in Bagamoyo College of Arts, Tanzania Theatre Centre, Mabala & Allen, 2002), might be more efficient for that specific group than an intervention targeting the whole society. Additionally, theatre interventions are often not sustainable, nor grassroots-based, since they are often initiated and sponsored by outside organizations, often foreign NGOs (Kvam, 2012; Valente, et al., 1995). This leaves the communities with little control of their own development issues (Prentki, 2007; Shule, 2014). Kerr (2014) takes this critique further, adding that NGOs often focus on one specific sector, which can result in flat characters with little embeddedness in the local history of current problems. Often expertise on theatre and the socio-political and economic situation is lacking resulting in difficulties with the design of proper interventions (Shule, 2011). However, these drawbacks could be overcome through proper community-based research and community participation (Bakari & Materego, 2008).

Indeed, TfD has its disadvantages, however it also offers many possibilities. Through TfD, people in the community are involved in discussing situations in their own society (Bakari & Materego, 2008; Kvam, 2012; Mlama, 2002; Valente, Poppe, Alva, De Briceño, & Cases, 1995). Furthermore, TfD allows the participant in the intervention to ask questions (Mitchell, Nakamanya, Kamali, & Whitworth, 2001), and uses their own language and culture to find solutions for problems (Kerr, 2014). The strength of a theatre intervention is its' accessibility for a large part of the society and the possibilities for participation and co-creation. The strengths of TfD make this a promising intervention type.

## THEATRE AS STIGMA REDUCTION INTERVENTION

Literature on stigma reduction describes several effective stigma reduction strategies, such as contact, education and entertainment, and we now turn to explore how these strategies can be present in a theatre intervention.

Through theatre the public can come into 'contact' with people with a stigmatizing condition. In stigma reduction interventions (SRI), a contact strategy implies that (unaffected) people are brought into 'positive contact' with someone with a health-related stigma, with the intention of changing stereotypes (Heijnders & van der Meij, 2006). Contact can decrease the 'outgroup' homogeneity (the assumption that people with a stigmatizing condition are all the same), reduce anxiety through emotional bonding with the presenter with a stigmatizing condition and increase empathy (Brown, Macintyre, & Trujillo, 2003; Herek & Capitanio, 1997). This can all lead to behavioural change (Bos, Schaalma, & Pryor, 2008; Herek & Capitanio, 1997; Pettigrew, 1998).

Through the theatre intervention, people are educated on a stigmatizing condition, providing information to increase knowledge and decrease misinformation, for example by challenging erroneous stereotypes and myths (Corrigan, Morris, Michaels, Rafacz, & Rüschi, 2012; Heijnders & van der Meij, 2006). An increase in knowledge can contribute to stigma reduction. However, on its own, it does not necessarily cause a change in attitude (Stangl, Lloyd, Brady, Holland, & Baral, 2013; Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008). Therefore, a combination of contact and education strategies results in more effective interventions (Brown, et al., 2003). Contact and education often target the so-called drivers of health-related stigma (Stangl, et al., 2019), in targeting the beliefs and misinformation surrounding a condition.

The entertainment strategy also plays an important role in theatre interventions. Entertainment Education (EE) is suggested as an approach to stigma reduction (Sallar & Somda, 2011) and is defined as: "the process of purposely designing and implementing a media message to both entertain and educate, in order to increase audience members' knowledge about an educational issue, create favourable attitudes, shift social norms, and change overt behaviour" (Singhal & Rogers, 1999, p. 9).

## THEATRE INTERVENTION TO REDUCE ALBINISM-RELATED STIGMA

Theatre interventions have been used as stigma reduction interventions and educational methods in different cultural contexts and in relation to a variety of health conditions (Michalak, et al., 2014; Mitchell, 2001; Valente & Barath, 1999) or in relation to other types of stigmatization, such as the stigmatization of lesbian, gay, bisexual, and transgender people (Logie, et al., 2018). Also, in the field of albinism, theatre interventions have been implemented to reduce stigma.

The genetically inherited condition of oculocutaneous albinism causes a lack of melanin in the skin, hair and eyes of people with albinism, which are therefore light in colour. It also causes the skin to be sensitive to ultraviolet radiation and the lack of melanin in the eyes means that people with albinism have low vision (Hong, Zeeb, & Repacholi, 2006).

People with albinism are fiercely stigmatized and are often excluded from society in Tanzania but also in other African countries. The Health Stigma and Discrimination Framework by Stangl et al. (2019) will be partly used to describe albinism-related stigma. The drivers behind the health-related stigma (Stangl, et al., 2019) of albinism in Tanzania are multiple, but mainly exist out of the beliefs surrounding albinism. There are multiple myths surrounding the outstanding physical appearance of people with albinism, such as the belief that people with albinism are not human, people with albinism are cursed, and the belief that the body parts of people with albinism bring good fortune (Brocco, 2015; Bryceson, Jønsson, & Sherrington, 2010). These beliefs are facilitated (Stangl, et al., 2019) by the prominent belief in witchcraft in the Tanzanian society (Bryceson, Jønsson, & Sherrington, 2010). These beliefs have manifested in the exclusion of people with albinism from society and even in violent

attacks on the lives of people with albinism (Brocco, 2015; Bryceson, et al., 2010; Cruz-Inigo, Ladizinski, & Sethi, 2011). The outcomes of the stigmatization of people with albinism are far reaching and result in people with albinism having difficulties with obtaining a good education (Lynch, et al., 2014) and to finding a job (Braathen & Ingstad, 2006; Kiprono, Joseph, Naafs, & Chaula, 2012) jeopardising their livelihood and quality of life.

The government is aiming to reduce discrimination of people with albinism through condemning the killings and through improved inclusion in the society (Brocco, 2015). They are being helped by a variety of NGOs such as UTSS and the Tanzanian Albinism Society (TAS).

Little evidence is available on the effects of a theatre intervention related to albinism. Chinyowa & Chivandikwa (2017) reflect on the impact of a theatre play about albinism in Zimbabwe, but only focus on the impact on the three participating actors. The organization Standing Voice examined the effectiveness of a theatre intervention about albinism in Tanzania that they implemented themselves through interviews, observations and online responses. They concluded that the theatre intervention was an effective strategy to open up dialogue about albinism in the community, to increase knowledge and correct misinformation, and with that to change the negative stereotypes about people with albinism (Clarke & Beale, 2018; Welcome Trust & Standing Voice, 2018). The results sound promising, but an independent study with a systematic measurement of correct knowledge and stigmatizing attitudes is needed to gain more insight. Therefore, this study aims to gain insight into the effectiveness of a theatre intervention related to albinism at primary schools in Tanzania using qualitative and quantitative methods, focusing on the extension of correct knowledge and reduction of stigmatizing attitudes.

## MEASURING THE EFFECTS OF THEATRE INTERVENTIONS FOR ALBINISM

The effect of the theatre intervention was assessed in three public primary schools in the Lake region in Tanzania. These schools were selected by UTSS because of the high prevalence of attacks on people with albinism in this region and presumably high stigmatizing attitudes. All the students in the school watched the theatre show and were observed by the researcher during the theatre play. In each school, a teacher appointed one class to participate in the surveys based on their availability and their ability to read and report their responses independently on the self-reporting survey. All students in this class were informed about aim of the research and the voluntary nature of their participation and were asked if they were willing to participate.

Qualitative data was collected through life observation and video recordings of the three plays. This was done to gain more insight in the content of the play, the methods used to attract people's attention during the play and their reactions to the play.

Quantitative data was collected through a self-reporting survey pre- and post-intervention to assess the influence of the theatre intervention on the level of correct knowledge and stigmatizing attitudes. The survey contained eight demographic items, 12 items testing the knowledge of the respondents about albinism and the ASDS-A (12 items). To our knowledge, no scale exists that assesses knowledge on albinism, therefore 12 items were developed based on what has been considered the most important knowledge about albinism for people in Tanzania by experts in the field. The first three (K-01 – K03) are the 'knowledge explanation items', closed-ended questions that require further written explanation when the respondent answers 'Yes' (e.g. K-01 'Do you know the reason for albinism?', answer categories 'No' and 'Yes' were provided, when a respondent answered 'Yes', the respondent was asked to provide further explanation in the textbox below the question). The rest of the Knowledge items (K-04 – K-12) included nine closed-ended Knowledge items (e.g. K-04 Do you think albinism is contagious?). The concept of social distance was used to measure stigma, through the self-reporting evaluation instrument: The Albinism Social Distance Scale for Adolescents (ASDS-A). The ASDS-A allows to ask questions about people's personal attitude towards different social



relationships with someone with albinism. The ASDS-A only asks after people's attitude and not after actions (de Groot, Peters, van Brakel, Meurs & Jacquet, 2020). Social distance scales have been widely applied in the field of stigma research (Adewuya & Makanjuola, 2005; Altindag, Yanik, Ucok, Alptekin, & Ozcan, 2006; Anderson & Austin, 2013; Brown, Evans, Espenschade, & O'Connor, 2010; Chan, Mak, & Law, 2009; Peters, et al., 2014; Pinfold, et al., 2003; Stier & Hinshaw, 2007). The ASDS-A was preceded by a written gender specific vignette about an agemate with albinism. An example of an ASDS-A item: S-03 'How would you feel to sit next to someone like John/Joyce in class?'. Four answer possibilities were provided: I do not have a big problem (1 point), I do not have a problem (2 points), I do have a problem (3 points), I do have a big problem (4 points).

The baseline measurement was conducted between one hour and a few minutes before the intervention, post-tests took place a few hours after the intervention in school 2 and 3, and three days later, due to exams, in school 1. The items were read out loud to the respondents by the classroom teacher to reduce difficulties in reading and misunderstanding. The researcher and the teacher emphasized to the students that the surveys were not an exam, that the data would be used anonymously, and that the teacher would not have access to the surveys. Survey items were written in Swahili to ensure accessibility to the respondents.

#### ANALYSING OUTCOMES OF THE THEATRE PLAY

The main events in the video recordings of all the three plays were written out, including a description of the responses of the audience, by the first author and later, for comparison, by the third author (MA) who is from Tanzania.

Data were entered and analysed using a content analyses approach in NVIVO 12. The data was coded thematically to deduce messages and explanations provided in the theatre play that were later discussed with Dar Creators, a Tanzanian group of performers who developed the theatre play. Other codes were created to analyse the used methods to attract the audiences' attention and the responses by the audience.

Quantitative data was analysed using IBM SPSS statistics 25. The following steps were taken in the process of data analysis:

- Demographic items were analysed item-wise, participant characteristics were used for testing significant differences between groups.
- Knowledge items were analysed item-wise and recoded into dichotomous items: 'Correct answer' vs. 'False answer' (existing out of the answer category 'wrong' and 'I don't know'). Change in knowledge of the paired sample (baseline and post-test) was analysed through the non-parametric McNemar's test (McCrum-Gardner, 2008). A sum of the items K-04 up to K-12 was used pragmatically, because the Knowledge items together do not form a scale, to test for significant changes in knowledge through Wilcoxon Signed-Rank Test. The explanation to the knowledge explanation items (K-01, K-02, K-03) were coded using NVIVO 12, dividing the answers in correct and wrong answers, followed by a comparison to the original answer on the knowledge explanation item.
- Because of skewed distribution the items and average score of the ASDS-A were analyzed in their original form through the Wilcoxon Signed-Rank Test.

#### SCRIPT WRITING

The theatre play was developed by Dar Creators, commissioned by UTSS, an organization with the goal to improve the lives of people with albinism. Dar Creators explored the attitudes of the community, for use in the play through the following steps: a. generating information on the situation of people with albinism in Tanzania in the media, b. analysing the frequent problems people with albinism face with the help of UTSS experts, c. observing the target audience. Prior to the theatre intervention there

was an introduction with games, dance, music and speeches in which the participating organizations introduced themselves (30 to 45 minutes). The theatre plays lasted for 30 to 45 minutes (10-12 minutes without interaction of the audience) and were performed outside the schools. The group of performers consisted of 11 actors and 1 moderator. At least one representative from each organization was present, some of whom had albinism.

#### ETHICAL CONSIDERATION

Research approval was provided by the Tanzania Commission for Science and Technology (COSTECH). The first author was invited by the main initiator of the *Haki Yetu* tour, Under The Same Sun, to observe the intervention for which they had permission by the regional commissariat and all participating schools. Individual participants were informed about the aim of the research, they provided oral informed consent, participation was voluntary, and participants were told they could stop at any time. The head teachers of the participating high schools provided written informed consent for their pupils to participate in the study.

### EFFECTS OF THEATRE INTERVENTIONS FOR ALBINISM

#### THE AUDIENCE

In total, 210 students participated in the baseline study (101 boys, 109 girls) of which 175 respondents (84 boys, 91 girls) participated in the post-test (Table 1). In school 2 there was one student with albinism enrolled who was also in the audience during the intervention, but who did not participate in the quantitative part of this study.

Variables		Respondents baseline N=210	Respondents post-test N=175
<i>Schools</i>	School 1	60 (28.6%)	51 (29.1%)
	School 2	79 (37.6%)	75 (42.9%)
	School 3	71 (33.8%)	49 (28%)
<i>Sex</i>	Male	101 (48%)	84 (48%)
	Female	109 (52%)	91 (52%)
<i>Age</i>	Average	14.6 years	14.7 years
	Minimum age	9	9
	Maximum age	19	19
<i>Knows a person with albinism (yes)</i>		170 (83.7%)	144 (84.2%)
<i>Has a family member with albinism (yes)</i>		22 (10.9%)	16 (9.5%)

Table 1 Socio-demographic characteristics respondents (N=210)

#### CONTENT ANALYSIS

The story line of *Haki Yetu* existed out of three scenes. In each scene a situation was presented in which the same person with albinism was being discriminated. In school 1 the play was paused after every scene to discuss the play. In school 2 and 3, the scenes were first played without interference, after which they were replayed scene by scene with room for participation and further explanation. The reason for the different order according to Dar Creators was that these orders felt fitting with the audience at the time of implementation.

Scene 1 concerned beliefs and myths about albinism which result in everyday discrimination of people with albinism. The topics were chosen based on situations that people with albinism often encounter. In this scene a father did not allow a classmate (Bahati) of his daughter to enter his house

and he also forbade him to walk to school with his daughter because Bahati has albinism. The mother and the daughter who were also present in this scene did not agree with the father and they protested against him. This scene tried to convey the following messages: Firstly, albinism does not cause nor is caused by bad fortune. The father in the play questioned the others on stage and the audience on how it is possible that Bahati has a white skin but his parents have a dark skin. This challenge by the father caused people from the audience to provide the biomedical explanation on the cause of albinism. Secondly, it is shown that albinism is not contagious. The mother in the play is pregnant and the father was trying to protect her from being close to, or in contact with, Bahati because he thought the baby could be infected with albinism or being influenced by bad fortune because of Bahati. Additionally, the father was afraid that albinism can be transmitted through physical contact with someone with albinism. However, again through biomedical explanation it is aimed to teach the audience that albinism is not contagious. Additionally, the audience was shown an example of people from the audience and the father being comfortable to touch Bahati. Thirdly, the father called Bahati *zeruzeru* (meaning ghosts) during the play. When discussing this scene this term was objected to and it is being explained that people with albinism should be called by their name or being referred to as a person with albinism.

Scene 2 is about the physical problems of people with albinism, and how these influence the lives of people with albinism. During the scene a classroom teacher did not provide necessary assistance to a student with albinism when the student asked for this, the other students and the teacher are mocking the student with albinism. The following topics were treated: Firstly, Bahati asked if he can go stand in the shadow because the sun is hurting his skin, however the teacher did not assist him. After this incident the audience was provided with the medical explanation on how the sun can hurt the skin of people with albinism and how people with albinism should be assisted. Secondly, the play showed that Bahati has troubles reading the blackboard. Because Bahati was sitting far away from the blackboard he walked up and down to the front of the classroom. He was forbidden to do so by the teacher and his classmates laugh at him. In the end he was unable to finish his work in time for which he was being punished and ridiculed for by the teacher. Subsequently, medical information was provided about the low vision of people with albinism. When Bahati, and people with albinism in general, are lagging behind in class this is often attributed to the belief that people with albinism do not have the same mental capacities and abilities as people without albinism. To disprove this belief a 'real-life' example was provided by the actor with albinism who played the role of Bahati, through explaining how he finished his own studies successfully. Additionally, he provided recommendations on how to assist people with albinism.

Scene 3 had to do with beliefs, attacks on and discrimination of people with albinism. This scene opened up the discussion on the most devastating type of discrimination that people with albinism face, which is also the myth that dominates public conversation about albinism in Tanzania. In the scene, two men were plotting an attack on a person with albinism, another man came in and did not agree with the plan. The attack was inspired by the belief that the body parts of people with albinism bring good fortune. This scene aimed to teach the audience that the body parts of people with albinism do not bring good fortune and that persons attacking people with albinism will be convicted for these crimes.

During the theatre intervention two posters were shown, one showing images of people with albinism all over the world to explain that albinism does not only occur in Tanzania. The second poster shows all kinds of animals and even a plant with albinism to explain that albinism also occurs in other creatures.

The observation of the content showed that not all the information provided during the play was clear and can be misinterpreted. For example, the explanation about low vision might have been insufficient since the play focused on how to help people with albinism in terms of vision but not what

low vision entails. Another example of insufficient content can be found when the moderator is explaining about inheritance but leaves out the necessary explanation about recessive genes:

*So that is also the reason that you for example can look like your father or like your grandfather, every child looks like his father, that is organized through the genes, it decides for example if you are thick. (Moderator, school 3)*

## OBSERVATION OF THE THEATRE PLAY

### GETTING THE AUDIENCE'S ATTENTION

To generate and keep the audience's attention three methods were observed during the intervention including an off-topic warming-up session, student participation and an actor with albinism.

Firstly, each theatre show started with some 'warm-up' activities, like dancing and games, that had nothing to do with the topic of the play. The 'warm-up' activities loosened up the students, got them used to the actors and it seemed to cause an enthusiastic attitude towards the upcoming theatre play, in which the participation of students was required.

Secondly, the actors and the moderator played a significant role in ensuring that the audience participation went as desired. The actors and moderator created pauses in the play in which the facilitator asked individuals in the audience for help on how to proceed or improve the situation at hand (e.g., provide further explanation to the actors). The engagement of students really seemed to grab the attention and sympathy of the rest of the audience. Often the whole audience was asked to participate in the play by providing their opinion on the situation. For example, at the end of the play in which the audience was requested to divide the actors in good and bad, by yelling 'good' or 'bad' when they were requested to do so by the moderator. This again caused the whole audience to pay attention.

The moderator made a lot of use of a question and answer repetition mechanism to check if the people in the audience were still paying attention. Through this mechanism he asked the audience a straightforward question (e.g. 'Do you understand?'), to which the students yelled something simultaneously in response, this exercise was often repeated several times.

Finally, to generate the audience's attention in the theatre intervention the audience was brought into contact with a person with albinism through the actor with albinism, who played the role of student with albinism who was called Bahati. He stepped in and out of his role as actor. He was asked questions about his private life, e.g. how he had succeeded with his education. Bahati was often touched by the actors and participating students in the audience to prove that albinism is not contagious. There were also two others with albinism present in the organizations accompanying the theatre play that could be seen by the audience and who sometimes provided some explanation about their organization or about albinism. The observation showed that the presence of someone with albinism in the play generated the attention of the students.

### 'YOU ARE WRONG!': AUDIENCE RESPONSES TO THE PLAY

Responses to the play entail audiences' participation in the play, laughter and attentiveness. When students were invited to participate in the play they responded seriously and were engaged in the play. Sometimes they responded very passionately, by yelling loudly and angrily to convince their opponent, like a student in scene 1 in school 2 wanting to convince the 'father' that people with albinism can go to school:

*Student in the audience: You are wrong! (...) you have to listen, they can go to school, it (albinism) is not contagious!*

The student participation was rewarded with a gift in the form of an information brochure or poster about albinism.

Students were often asked to provide an explanation about albinism, but their clarifications were not always correct. For example, in the first scene in school 1, a student explained that albinism is caused by god, and another student said that it is caused by the transmission of melanin. Since these explanations were not correct, the moderator interfered by providing further information, to ensure they were given the right explanations.

To ensure that the audience received correct information, questions and answers were also used. Sometimes the audience did not receive sufficient information or did not understand the provided information correctly, and more explanation had to be provided by the moderator.

People always laughed a lot at the parts that were intended to be funny and they seemed to enjoy the show. However, sometimes they also responded with laughter during a sad scene for example when the student with albinism was bullied by his classmate and by his teacher. The moderator always made sure to come back to these scenes to make the students aware of the situation.

The audience seemed to pay attention to the play most of the time, watching attentively and not often looking at something else, doing something else or talking to their neighbours. However, they did not pay the same amount of attention throughout the whole theatre play. At some moments their attention was lost, for example, when people with albinism or representatives of organization held quite long monologues. Or when the question and answer mechanism took long and it slowed down the theatre play. Another factor that might have caused students not to be able to focus was the lack of moments of silence or room for questions or reflection. Even when students were shown a poster the moderator kept on talking. Therefore, the actors' and moderator's efforts to constantly ensure people's active attention might have caused students to lose attention or denied students of the necessary reflection time to understand the provided information.

#### 'DO YOU KNOW THE REASON FOR ALBINISM?'

In the baseline test, respondents demonstrated a low level of knowledge on the knowledge explanation items (Table 2). The written explanation provided by the respondents was often incorrect as can be seen in the column 'Explanation' in Table 2, e.g. 30.7% of the respondents answered yes to the closed ended knowledge explanation item K-01 'Do you know the reason for albinism?' whereas only 17.6% of those answered yes, provided the correct explanation. On all items in the pre-test and in the post-test the explanation with the knowledge explanation items was significantly different from the respondents' estimation of their own knowledge, which means that people indicated they knew the answer to a question but out of their explanation it seems they did not. Improvement on the knowledge explanation items was significant, even after the correction based on the explanation of the answer.

Nr.	Item	Baseline			Post-test		
		n	Answered yes (%)	Correct explanation (%)	n	Answered yes (%)	Correct explanation (%)
K-01	<i>Do you know the reason for albinism?</i>	153	30.7	17.7	157	59.2	33.7
K-02	<i>Do you think albinism is inherited?</i>	165	33.3	13.7	163	59.5	34.3
K-03	<i>Do you know what to do to help someone with albinism?</i>	154	61	31.6	138	80.4	56.6

Table 2 Descriptives of the knowledge explanation items

Table 3 below provides a thematic summary of often provided correct and incorrect explanations before and after the intervention. Especially, with question K-03 ‘Do you know what to do to help someone with albinism?’ many vague answers were provided, such as that they should take care of them, love them, cooperate with them: these answers were very general and therefore deemed incorrect.

Item	Explanation if answered yes (marked as correct)	Before	After	Incorrect explanation	Before	After
		N	N		N	N
K-01 Do you know the reason for albinism? (If yes, please explain:)	Lack of melanin/pigment	20	16	Minerals in the body	9	5
	Inheritance family	15	28	People with albinism have soft skin	6	5
	Genes	4	16			
K-02 Do you think albinism is inherited? (If yes, please explain:)	Clan	11	35	Parents that have albinism	5	2
	Parents	10	20	Father OR mother having the albinism gene	3	13
	Genes	2		‘Because they are human beings’		3
	Ancestors	1	9			
	Family		2			
K-03 Do you know what to do to help someone with albinism? (If yes, please explain:)	Hat	40	44			
	General answer	38	38	General answer	38	38
	Protect from the sun	35	28			
	Long/good clothing	29	46			
	Sunglasses	16	29			
	Protect from violence	10	12			
	Protect the body	9	2			
	Protect them (in general)	7				
	Provide a safe environment	4				
	Shade	4	6			
Help with vision		10				

Table 3 Often provided correct and incorrect explanations with the knowledge explanation items

Some examples of noticeable incorrect answers before the intervention are:

*‘Hapana haiwezi kurithiwa kwa sababu mwili wa albino hupewa na mungu’ (It cannot be inherited because albinism comes from God)*

*‘Kumsaidia albino ni jambo la muhimu kwanza anapokuwa shuleni anatakiwa akae upande wa nyuma ili asisumbuliwe na vumbi la chaki’ (Helping someone with albinism is an important thing, even when they are at school, they should sit at the back to avoid them to come in contact with chalk dust)*

Some examples of incorrect answers after the intervention are:

*'Albino una jamii mbili' (Albinism is of two types/kinds)*

*'Unajua ualbino ni hali ya mtu ya saratani yake' (You know, albinism is a condition like cancer)*

With the other closed Knowledge items (K-04 – K-12), five out of nine items proved to be significantly improved (see Figure 1). Among the four items that did not improve significantly two left little room for improvement because before the intervention, a large part of the respondents already answered these Knowledge items correctly (K-07: 95.5%; K-10: 89.3%). The Knowledge items (K04 – K-12) do not form a scale ( $\alpha = 0.481$ ) and should be dealt with individually. However, a sum of the Knowledge items was used pragmatically to see if the knowledge considering albinism changed significantly after the intervention which was the case ( $Z=-5.342, p=0.00$ ).

Even though correct knowledge significantly improved on most items, levels of knowledge still remained low on several items, e.g. 81.9% of the respondents still believed people with albinism must eat special food (K-08). There were also items on which respondents chose the right answer in the baseline but the wrong answer ( $n>10$ ) after the intervention: K-04 ( $n=15$ ), K-05 ( $n=33$ ), K-06 ( $n=13$ ), K-12 ( $n=15$ ), for more information see Appendix G.

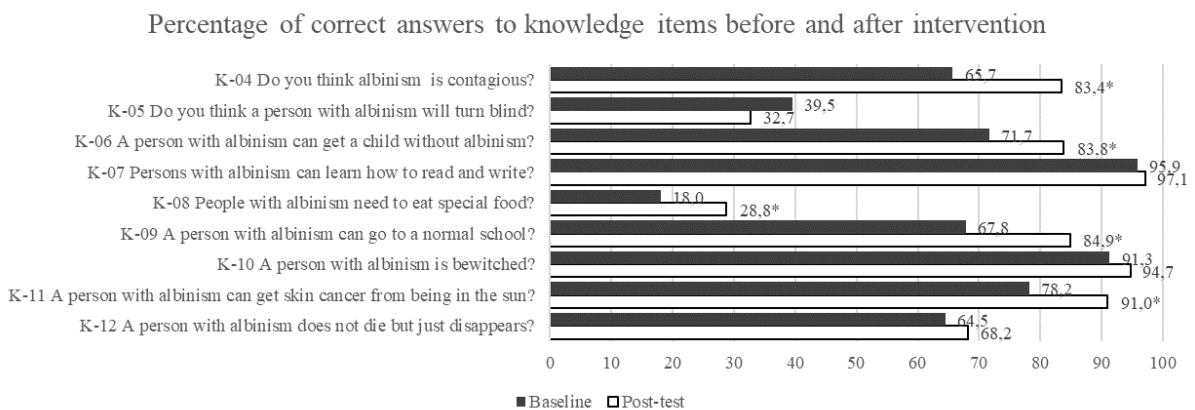


Figure 1 Descriptives Knowledge Items before and after the intervention ( $n$ =between 167 and 174) (\* significant difference  $p<0.05$ )

#### PERSONAL ATTITUDE

The average score of the ASDS-A post-test has been significantly improved in comparison to the baseline study (ASDS-A  $Z=-2.958^b, p=0.003$ ). Cronbach's alpha on 12 items of the ASDS-A was 0.91 (See Appendix H for more information). The means on all items show a reduction of stigmatization. A significant change in personal attitude was measured through five items (see Figure 2). On all items attitudes changed in two directions, for example with item S-01, 24 respondents portrayed lower stigmatizing feelings in the baseline and higher stigmatizing feelings in the post-test, whereas 27 respondents portrayed higher stigmatizing feelings in the baseline and lower stigmatizing feelings in the post-rest (see Appendix H).

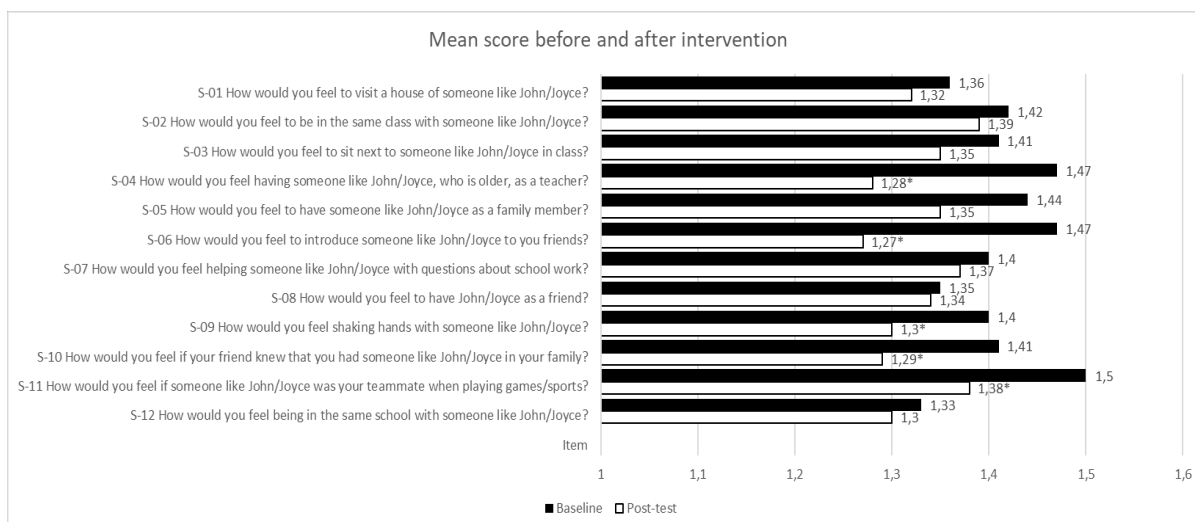


Figure 2. Descriptives ASDS-A Items before and after the intervention (n=between 164 and 172) (\* significant difference  $p < 0.05$ )

### THEATRE FOR STIGMA REDUCTION: DISCUSSING THE FINDINGS

People with albinism in Tanzania often face stigmatization because of their condition. This mixed methods study explored the impact of a theatre intervention on albinism as a SRI in primary schools in Tanzania. The intervention was effective among students in improving correct knowledge on albinism, measured through the Knowledge items, and in reducing stigmatizing attitudes, measured through the ASDS-A, right after the event. Our study adds to the research on the effectiveness of theatre interventions in general (e.g. Dalrymple, 2006; Harvey, Stuart, & Swan, 2000). Our findings counter the negative outcomes of Elliot, Gruer, Farrow, Henderson and Cowan (1996) who observed that theatre in AIDS education does not have a significant impact on HIV knowledge and attitudes.

Previous research in the field of stigma reduction endorsed the effects of the strategies underlying the current theatre intervention: (1) the contact (Cook, Purdie-Vaughns, Meyer, & Busch, 2013; Corrigan, et al., 2012; Paluck, Green & Green, 2018), (2) education (Corrigan, et al., 2012; Heijnders & van der Meij, 2006) and (3) entertainment strategy (Sallar & Somda, 2011; Singhal & Rogers, 1999). The qualitative data gathered in this study showed that all three underlying strategies were present and the results provided insight in the positive effects of these strategies.

Firstly, the intervention established direct contact between someone with albinism and the audience through the actor with albinism in the play. As observed in other research on the contact strategy (Bos, et al., 2008, Herek & Capitano, 1997), a change process was set in motion through contact with someone with a stigmatizing condition who disconfirmed stereotypes, e.g. contrary to some people's expectations the actor showed his ability to act and gave real-life examples on how he succeeded in education. This helped the audience understand that people with albinism can lead a normal life and seems to have led to a reduction of stigma as measured by the ASDS-A. Stigma was reduced by targeting the drivers of stigmatization (Stangl, et al., 2019). Former attitudes and stereotypes about people with albinism were replaced by more positive views by showing the stigmatized going through events in life that the audience can relate to (Bos, et al., 2008; Herek & Capitano, 1997) and by providing convincing disconfirming information (Dalal, 2006).

In addition to the more commonly known advantages of the contact strategy, as described above, we suggest that possibility to physically touch the stigmatized is an advantage of the contact strategy in relation to albinism. The actor with albinism was physically touched by the other actors and the moderator. People from the audience participating in the play also sometimes touched the actor with albinism. This showed the audience that people are not afraid to touch a person with



albinism, possibly because they know that albinism is not transmitted in that way. These results match the findings of Rafferty (2005) in relation to leprosy-related stigma, who suggested that showing people that for example health professionals dare to touch someone with this condition can influence the community's attitude.

Secondly, education was being provided throughout the play by the scenes, the explanations of the participating students, the person with albinism in the play, the moderator and the posters. The education strategy focused on aspects often underlying stigma: stereotypes, incorrect knowledge, myth and beliefs (Thorncroft, et al., 2008, van Brakel, et al., 2019). By targeting these so-called drivers (Stangl, et al., 2019) the theatre intervention did cause an increase in knowledge as portrayed in the result section. Consistent with the literature, this research found that theatre interventions can be an effective tool for spreading knowledge (Dalrymple, 2006; Valente & Barath, 1999) and that contact in combination with education is an effective strategy to reduce stigma (Brown, et al., 2003; Corrigan, et al., 2012; Koller & Stuart, 2016).

Thirdly, in terms of entertainment, the theatre intervention in itself was attractive for the students in this study. The entertainment level was, among others, increased through a warming up session, contact with someone with the stigmatized condition and participation of the audience during the play. People responded very enthusiastically to these methods, they were willing to participate in the play, responded to the play with laughter and were paying attention. When implementing SRI in a school setting, it might be attractive for the students if the SRI strategy is different from the normal curriculum. Entertainment serves multiple goals: a 'warming-up' for information processing (Ritterfeld & Jin, 2006), motivation for people to process the information provided (Ritterfeld & Jin, 2006; Ritterfeld, Klimmt, Vorderer, & Steinhilper, 2005) and reinforcement to learning because of the good experience (Ritterfeld & Weber, 2006). Entertainment therefore seems to be an important underlying strategy in a stigma reduction intervention as was suggested in earlier research in relation to other health-related stigma (Sallar & Somda, 2011; Singhal & Rogers, 1999). As such, in measuring attitudes related to stigma it becomes clear that combining education with entertainment can lead to stigma reduction.

The outcomes of this study are very encouraging; however, some critical findings should be noted. Firstly, correct knowledge significantly improved, however there is room for improvement. (a) For one Knowledge item (K05) the number of correct answers decreased, and low levels of knowledge remained on two items (K-08, K-12). Two of these items were based on common specific myths about albinism: K-05 was based on the belief that the eye-sight of people with albinism will deteriorate over time and could lead to blindness (Lynch, Lund & Massah, 2014) and K-12 was based on the belief that people with albinism will just vanish instead of die (Baker, Lund, Nyathi, & Taylor, 2010). Whereas item K-08 is about the question if people with albinism need special food and is therefore linked to the belief that people with albinism are not the same as (other) human beings (Brocco, 2015) or are at least physically different from other human beings, besides their appearance. The moderate improvement on these items therefore might be caused by the deeply rooted beliefs about albinism, which are hard to change. For future interventions we suggest focusing on these myths specifically for this target audience (Mitchel, et al., 2001). (b) On five items there were more than 10 respondents who selected the right answer in the pre-test and the wrong answer in the post-test, this was possibly caused by the unclear messages spread during the intervention. The unclear messages might be caused by the participative nature of theatre. We would recommend the moderator to emphasize more clearly which information is correct and which is not, possibly through a repetition of standardized, structured and correct information after participation of the audience. This might require better preparation and training of the moderator. (c) The number of correct explanations with the three knowledge explanation items (K-01, K-02, K-03) remained low, and additionally respondents had a

significantly higher estimation about their correct knowledge than was actually the case, meaning that a significant number of the respondents who stated to know the answer to a questions, contradictory provided the wrong explanation. This points to a lack of in-depth knowledge among the participants, which could be resolved by providing room for questions during the intervention, which is currently not provided, (Mitchel, et al., 2001), encouragement of the audience to ask questions and by providing time for reflection by the audience during the intervention. Through more reflection the students get the opportunity to use their own language and understanding to find their own explanation for the situation (Kerr, 2014).

Secondly, the intervention effectively reduced stigmatizing attitudes among the respondents straight after the intervention as measured through the ASDS-A. Nevertheless, one should be aware that at item level, change in attitude was not straight forward in one direction (see Appendix H). Most respondents demonstrated less stigmatizing attitudes after the intervention, however, others portrayed a greater level of stigma after the intervention. The increase of stigmatizing attitudes of individual respondents shows us that there is a risk that a SRI can also have a negative outcome. This can occur because the message students take home after the intervention largely depends on personal interpretation, and there is a risk that by portraying stigmatization in the community, the drama will confirm people's negative attitudes about the stigmatized and therefore reinforce the existing attitudes (Mitchell, et al., 2001). In the theatre play people with albinism are presented as having a lot of problems: being discriminated, having problems in school with low vision and having problems with their skin: which are the focal points of the organizations implementing the intervention. The play does not focus that much on positive aspects of the life of people with albinism: which might be of importance when willing to change negative stereotypes. It is also interesting to ask how much a stigma reduction intervention should focus on the 'stigmatizer'. When an intervention focusses too much on the 'stigmatizer' instead of the drivers behind stigmatization, could this result in increased stigmatization? Which shows us the value of the work by Stangl, et al. (2019) about the importance of not making this dichotomisation of stigmatizer and stigmatized.

Thirdly, not all direct responses to the play were desired, e.g. the audience was laughing during a sad scene and the moderator had to interfere. The fact that the education on albinism was provided through an entertaining intervention, in which there were scenes meant to be funny, but also scenes that are about serious issues might have confused the audience. There is a risk that the entertaining aspect of the intervention overshadows the educational objective of the intervention (Ritterfeld & Weber, 2006). Which again points to the important role that the moderator plays and the importance of proper training for the moderator.

Fourthly, during the interventions two strategies were used by the moderator to control the students understanding of the intervention. The moderator learned about the knowledge and perspectives of individual students during their participation in the play. This provided the moderator with the opportunity to correct the wrong understandings of individuals, however this was only a small number of students. The understanding of the majority of the respondents was controlled through the question and answer repetition mechanism (e.g. moderator asking the whole audience: 'Do you understand?'). This mechanism however, does not leave space for students to express if they do not understand certain information. In a Tanzanian school setting is very unlikely that students will admit that they did not understand something. Overall the understanding and interpretation of the intervention by the audience was weakly evaluated by the organization.

The above arguments show that the impact of the intervention is not as straightforward as expected. Therefore, the intervention in general could benefit from more direct evaluation of the impact of the intervention, using mixed methods, during and after the play to make sure people take the right message home. Suggestions for direct evaluation during the show could be post-show talks in which the audience gets the opportunity to express themselves without being dictated what to say

by the moderator, to ensure people picked up the right knowledge from the play (Mitchell, et al., 2001). Additionally, a discussion could also be an important part of a SRI (van Brakel, et al., 2019). Evaluation of SRI is of importance to control if the intervention is having the expected outcomes (Bartholomew, Parcel, Kok, & Gottlieb, 2006; Bos, et al., 2008). Through evaluation, lessons can be learned for future SRI (Bos, et al., 2008).

Further work is required to investigate the sustainability of this type of intervention, among others in terms of funding and staff: is this a feasible intervention to reach a large part of the Tanzanian population? Also, it is important to evaluate the influence of the intervention on a longer term (Cook, et al., 2013; Thornicroft, et al., 2016). It would be of interest to gain further insight in the influence of the (foreign) donor on the intervention. It should be noted that because of the external funding the theatre intervention is not a sustainable nor-grassroots based initiative (Kvam, 2012; Valente, et al., 1995) which could therefore have influenced its effectiveness, spread and long-term results. This would require further research. Lastly, since the current research was carried out in a school environment among students it would be of interest to repeat this study among adults, to evaluate if this type of intervention could be effective for a larger population.

The results of this study are subject to certain limitations. The surveys could have functioned as an intervention themselves (de Groot, et al., 2020). This 'intervention-effect' cannot be avoided or excluded, however, the 'intervention-effect' in this case might be limited since little time passed between the two tests. Additionally, it should be noted only one indicator of stigmatization, social distance, was used to measure changes in stigma. Lastly, respondents were only questioned about their attitude toward people with albinism and no measurement was conducted regarding their actual behaviour.

## CONCLUSION

This study explored the influence of a theatre intervention about albinism in primary schools in Tanzania. The research has shown the theatre intervention to be an effective tool for improving people's knowledge on albinism and reducing stigmatizing attitudes on a short term. Observation of the play portray some of the methods that can be used to ensure the audience's attention and the responses to this intervention of the audience. These findings endorse the effectivity of the combination of stigma reduction strategies like contact, education and entertainment in changing people's attitude towards a stigmatized condition. The current research adds to the understanding of albinism-related stigma reduction interventions.

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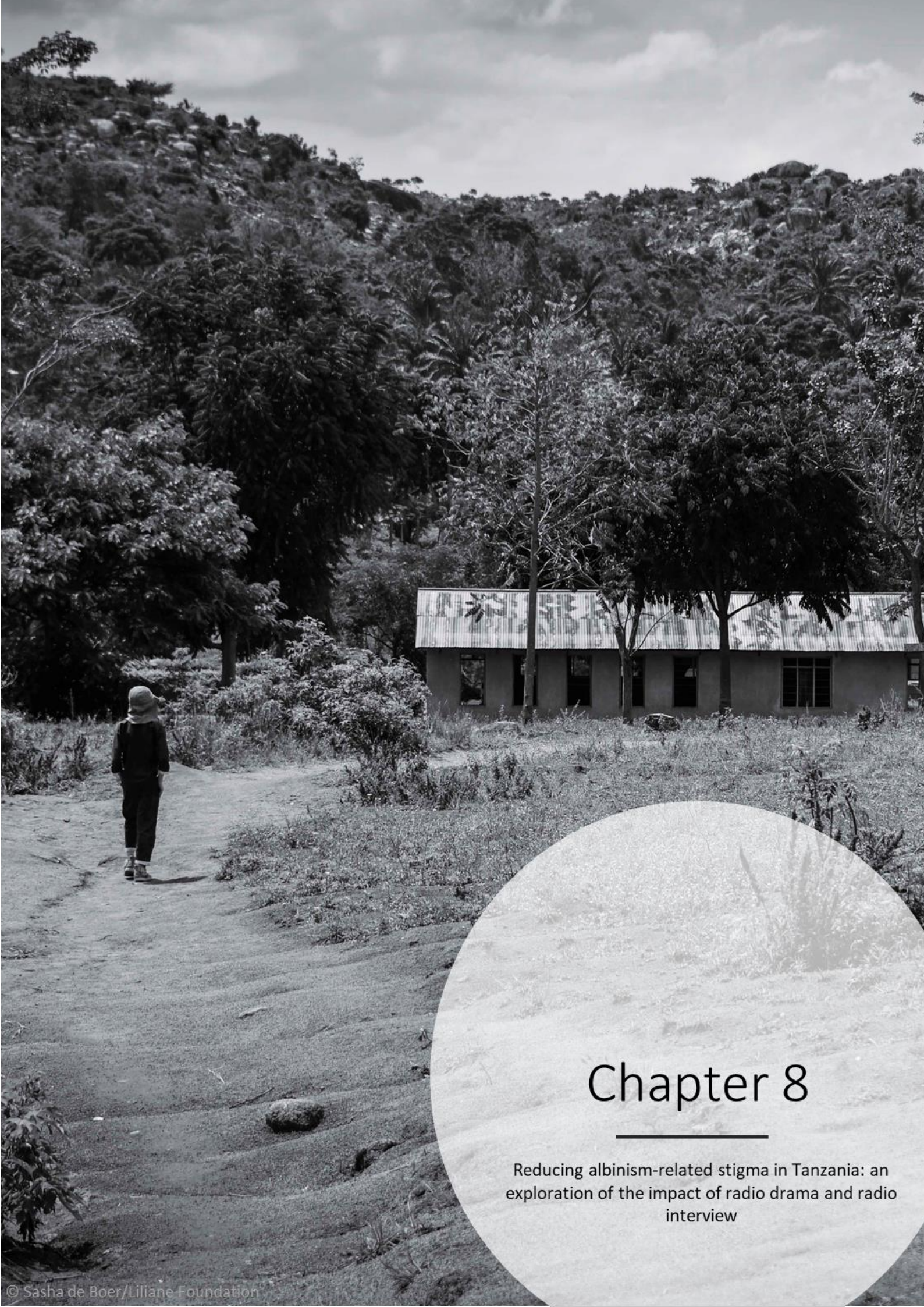
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## Chapter 8

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Reducing albinism-related stigma in Tanzania: an exploration of the impact of radio drama and radio interview

## CHAPTER 8: REDUCING ALBINISM-RELATED STIGMA IN TANZANIA: AN EXPLORATION OF THE IMPACT OF RADIO DRAMA AND RADIO INTERVIEW

*Under review as: de Groot, T., Veldman, M., Jacquet, W., Peters, R. M. H., Vanwing, T., & Meurs, P. (under review). Reducing albinism-related stigma in Tanzania through community radio: exploring drama and interview. Disability & Society.*

Reducing stigma is key to improving the wellbeing of people with albinism in Tanzania. This study aimed to obtain more insight into the effects of two radio interventions with regard to albinism-related stigma: a radio drama and a radio interview. Assessment of the radio interventions was based on two attitude measurement instruments (The Albinism Explanatory Model Interview Catalogue Community Stigma Scale and the Albinism Social Distance Scale), an entertainment scale, and two informal (group) interviews. In total, 111 community members participated in the assessment prior to the radio drama, and 65 after. In the case of the radio interview, 123 community members participated in the assessment prior to the radio show, and 77 after. Following the radio drama, a significant reduction was found in terms of community stigma, and a reduction in social distance was found after both interventions. The entertainment score for both interventions was high, but significantly higher for the radio drama. The respondents indicated that they had gained more understanding of albinism as a result of the interventions, and were positive about this type of education. The current study shows that a radio show in which the listener interacts with someone with albinism can contribute to a reduction in stigma, and demonstrates that different types of radio intervention can have different outcomes.

Keywords: Stigma reduction intervention, community radio, albinism, contact strategy, A-EMIC-CSS, A-SDS.

## INTRODUCTION

The most recent national census concluded that the prevalence of people with albinism in Tanzania is 1 in 2,673 people, meaning that more than 16,000 people in the country have this condition (The United Republic of Tanzania, 2014). However, in reality, numbers could be even higher because people might have been afraid to acknowledge the presence of someone with albinism in their household due to the, sometimes violent, discrimination and stigmatization of people with albinism (Lund & Roberts, 2018).

The disability, entitled oculocutaneous albinism (OCA), is a genetic disorder causing a lack of melanin. Consequently, the skin of people with albinism lacks protection against UV rays, (Hong, Zeeb, & Repacholi, 2006; Kromberg, 2018; McBride, 2014). People with albinism have limited vision. Due to a shortage of melanin in the eyes, the visual acuity of people with albinism is reduced due to foveal hypoplasia and a misrouting of the optic nerves (Grønskov, Ek, & Brøndum-Nielsen, 2007). However, it is often wrongly assumed that they will become blind (Lynch, Lund & Massah, 2014). The main problems persons with albinism experience physically are the high risk of developing skin cancer (Hong, et al., 2006; McBride, 2014) and low vision, the latter of which causes difficulties for people with albinism on a day-to-day basis, for example in attending school (de Groot, Meurs & Jacquet, 2019). Besides the medical implications of albinism, the lack of melanin causes people with albinism to have a light skin, hair and eyes. The skin colour of someone with albinism can range from a pale to a raw redness, and often the skin has dark marks (keratosis). The hair of someone with albinism can be straw-coloured and the eyes can be blue, green or light-brown (Kromberg, 2018).

## STIGMA RELATED TO ALBINISM

Stigmatization results due to people being labelled as 'different' and linking 'the other' to stereotypical beliefs, leading to separation, status loss and discrimination (Link & Phelan, 2001). In Tanzania, the light-coloured appearance of people with albinism stands out in a society in which the majority of the population is darker-coloured. Therefore, those with albinism are labelled as 'different'. The label of being different, and therefore stigmatization, is also experienced by people with other health conditions such as HIV/AIDS, tuberculosis, leprosy and mental health conditions. The results of stigmatization related to albinism can be name-calling, being laughed at, avoidance and exclusion (de Groot, et al. 2019). This stigmatization can also influence the lives of family members of people with albinism (Brocco, 2016).

The attitude of the populace towards people with albinism is also fuelled by a variety of local myths and superstitions. For example, in Tanzania, it is frequently believed that people with albinism are not human, as expressed by an often-used term: *zeruzeru* (ghost) (Brocco, 2015). Furthermore, *waganga* (traditional healers) spread the belief that the body parts of someone with albinism bring good fortune. Some authors point out that this has caused an outbreak of killings of people with albinism (Bryceson, Jønsson, & Sherrington, 2010; Cruz-Inigo, Ladizinski, & Sethi, 2011). Other authors noticed that these beliefs have also spread to other countries such as Malawi (Lynch, et al., 2014). According to a report by Under The Same Sun (UTSS) 76 people with albinism were killed in Tanzania and 182 people with albinism were attacked between 2000 and January 2019 (UTSS, 2019). Additionally, there is the belief that people with albinism are too weak to work in the fields, and therefore it is said that many of them are killed after birth (Bryceson, et al., 2010).

When wanting to put a halt to these human rights violations, action is necessary to change people's attitudes towards people with albinism through so-called stigma reduction interventions. Stigma reduction interventions are intended to reduce the incidence and burden of stigma (Hartog, et al., 2020). Stigma reduction interventions often take the form of awareness raising campaigns that aim to reduce discrimination through a variety of activities. Research is lacking on efficient stigma reduction interventions in general (Bos, Pryor, Reeder & Stutterheim, 2013) and is very limited

regarding albinism-related stigma. This paper aims to explore the possible impact of radio interventions on albinism-related stigma.

#### CONTACT THROUGH COMMUNITY RADIO AS A STIGMA REDUCTION INTERVENTION

Getting people in contact with a person with a stigmatizing condition appears to be a promising strategy to address health-related stigma. Such a contact can be made through radio broadcasts. Instead of direct contact, radio entails para-social contact, which is the interaction between an audience and the representative of a medium, such as actors and presentors, who can generate a social relationship which can reduce prejudice (Giles, 2002; Schiappa, Gregg, & Hewes, 2005). Contact can challenge people's attitude towards persons with a stigmatizing condition (Corrigan & Penn, 1999; Corrigan, et al., 2001). Building a personal relationship with someone with a stigmatizing condition through a contact intervention can generate empathy for the stigmatized, and can correct misinformation (Allport, 1954; Brown, Macintyre, & Trujillo, 2003). Additionally, contact can reduce outgroup homogeneity and anxiety (Herek & Capitano, 1997; Pettigrew, 1998).

Community radio can be (and has been) used as a means of development and education around the world. Community radio differs from mainstream commercial radio in that community radio is small-scale and community-based (Bosch, 2014). The advantages of community radio are that broadcasting is relatively cheap, includes populations with low levels of literacy, and can reach an audience that is not often reached by other media. Therefore, it is a popular mass-medium for two-thirds of the people on the African continent (da Costa, 2013). A large number (61.6%) of households in Tanzania own and listen to the radio (58.1% in rural areas, 68.5% in urban areas) (The United Republic of Tanzania, 2014), which makes it possible to reach the majority of the population through radio. Additionally, radio was also considered a reliable source of health information by respondents in a research study carried out in Tanzania (Mboera, et al., 2007).

#### RADIO AS ENTERTAINMENT-EDUCATION

Radio interventions can often be classified as entertainment-education, which is the combination of an entertaining intervention with educational content (Singhal & Rogers, 1999). To that aim, radio broadcasts can provide listeners with examples of role models leading to a desired change. In the past, radio has been used as a para-social contact strategy with positive outcomes, e.g. a soap opera on HIV/AIDS in Tanzania resulted in behavioural improvement (Vaughan, Rogers, Singhal, & Swalehe, 2000), while identification with the characters in a radio serial drama was associated with testing for HIV during pregnancy in Botswana (Kuhlmann, et al., 2008). In addition, a radio drama succeeded in the promotion of family planning in Gambia (Valente, Kim, Lettenmaier, Glass, & Dibba, 1994). HIV/AIDS stigma in Malawi was reduced through the broadcast of radio 'diaries' in which people with HIV told their personal stories of everyday life (Creel, Rimal, Mkandawire, Böse, & Brown, 2011; Rimal & Creel, 2008). Creel et al. used a variety of indicators to measure changes in attitude: scales measuring fear of casual contact, shame, blame, and willingness to disclose (Creel, et al., 2011), and questions aiming to determine people's attitudes towards the disclosure of HIV-positive status, greater medical expenditure to take care of people with HIV/AIDS, and interaction with people with HIV/AIDS (Rimal & Creel, 2008).

Critics however, question the use of entertainment-education. Obregon and Tufte (2014) argue that entertainment-education focuses mostly on creating change at an individual level instead of addressing aspects of health or other developmental issues, often due to the short-term goals of donors. They emphasize the importance of entertainment-education looking at both individual and societal change. Additionally, Dutta (2006) emphasises the critique that entertainment-education is often a one-way flow, often coming from (foreign) organizations who lay their values upon the respondents in the intervention (Obregon & Tufte, 2014). These types of critic recognize themselves in Singhal and Rogers (1999) who indicate the importance of participation of the audience in an

intervention, an aspect which is hard to realize in a radio intervention. In addition, audience feedback and the outcomes of the intervention in the community easily goes unnoticed in the case of a radio intervention.

#### RADIO TO REDUCE ALBINISM-RELATED STIGMA

More specifically in terms of albinism, Baker and Lund (2017) point to the role of media such as radio for people with albinism and advocacy groups to counter myths and discrimination. In the past, radio has already been used as a means of education on albinism in Tanzania. Commercial radio (such as Radio1Stereo, TBC and Radio1Africa) pleaded against the killings of people with albinism and promoted their acceptance (Brocco, 2015). Lund, Massah and Dart (2014) reported the positive effect of a radio drama with regard to educating teachers and the community about albinism in Malawi. Also, UNESCO implemented an awareness raising campaign on albinism in Tanzania, with community radio being one of the means used to change people's perceptions and practices (UNESCO, 2016). Unfortunately, they do not specifically report on the outcomes of the radio intervention.

The possibilities for radio as a means of stigma reduction in relation to albinism, sounds promising. However, structurally generated data on its effect is lacking. The reports by Lund, Massah and Dart (2014) and UNESCO (2016) were primarily issued as a project evaluation and not as an academic research project. We used a different approach in this research. The aim of this study was to gather structured quantitative and qualitative data to obtain more insight into the effects of two radio interventions - a radio drama and a radio interview - on albinism-related stigma. Both types of intervention have been used for awareness-raising in the past. The purpose of using different forms of interventions was to start exploring which types of radio intervention can be used to change people's attitudes towards people with albinism, and if a difference could be noticed.

### METHODS

#### STUDY AREA AND POPULATION SELECTION

This study used qualitative and quantitative research methods in order to assess the effect of albinism-related radio interventions. This study was conducted in 14 villages, with a population size varying between 10,000 and 20,000, surrounding the town and lake port of Kigoma in North West Tanzania. These villages were chosen in cooperation with community radio 'Kigoma Community College by Radio' (KICORA). The people in these villages had little access to information through educative sources or media, other than radio. This type of population was expected to be receptive to a radio intervention regarding albinism. The population of the 14 selected villages functions as a relevant test case for radio interventions with the aim of reducing stigmatizing attitudes with respect to albinism. The respondents in the villages were found by going 'door to door' and were selected based on; i) their availability, ii) their willingness to participate in the research, and iii) the likelihood of retrieving the respondent (e.g. if the people in the house were temporary visitors from far away, the household was not selected), resulting in a convenience sample. Respondents had to be 18 years of age or older. For reasons of efficiency, respondents were only selected if more than one person was available in the household. This could also include neighbours, friends or customers in the event that the household was engaged in some kind of business venture. The research took place at the house or venture of at least one of the respondents, so that the respondents were more likely to feel comfortable in their own setting and, because this reflects the 'real' situation of listening to a radio.

#### SAMPLE

In total, the sample of the baseline study which took part in the assessment prior to the radio show broadcast, consisted of 234 respondents. The radio drama was played 35 times, with a total of 111 respondents listening (45% men, 55% women). All participated in the 35 informal (group) interviews

that followed the radio drama. Ages varied between 18 and 94 years, with an average age of 41.79 years. Among the respondents 11.4 % had a family member with albinism. Of the respondents, 92.8% belonged to the Muha tribe, which is the most commonly-represented tribe in the Kigoma locality where the research took place. The remaining eight respondents belonged to seven other tribes. For the post-test, the assessment after the radio show, 65 respondents were involved (47.7% men, 52.3% women), with whom 30 informal (group) interviews were conducted. The average age in the post-test was 41.14 years (varying between 18 and 94 years). The composition of the post-test sample did not differ significantly from that of the baseline sample ( $p < 0.05$ ).

Prior to the radio interview, 123 respondents (48% men, 52% women) participated in the baseline study. In total the radio interview was played 31 times, with an average group of four listeners per show. Ages varied between 18 and 84 years with an average age of 41.19. Among the respondents, 17.1% had a family member with albinism. Of these respondents, 84.6% belonged to the Muha tribe, and the others to 12 different tribes. In total, 77 respondents participated in the post-test (39% men, 61% women), all of whom participated in the 30 informal (group) interviews. The average age in the post-test was 42.2 years, with ages varying between 22 and 84 years. The composition of the post-test sample did not differ significantly from that of the baseline sample ( $p < 0.05$ ). Appendix I provides more details of the two samples that participated in the baseline and the post-test.

## INTERVENTIONS

A **radio drama** about albinism was developed and recorded in cooperation with Baraka FM in Mbeya. The 10-minute radio drama told the story of Sara, a young woman with albinism. During the first part of the radio drama, Sara chatted with a classmate about the nursing training that they attend in the South of Tanzania, and the difficulties Sara faced in her studies because of her condition. In the second part Sara and a classmate tried to help an injured boy who was afraid to be touched by someone with albinism until a doctor came in to provide an explanation about albinism. At the end, the radio presenter announced that Sara was getting married to her classmate.

A **radio interview** with Sijajali, a person with albinism was recorded with the help of Radio KICORA and the Tanzanian Albinism Society branch in Kigoma. During a nine-minute radio interview the man with albinism explained about albinism and the problems people with albinism face. The interviewee also answered questions about his personal life: he talked about the education he had received to become a teacher, his family (his wife and five children without albinism) and that he enjoys spending his free time singing.

## MEASURING THE EFFECTS OF THE INTERVENTIONS

The effect of the interventions was measured through a self-administered quantitative questionnaire and through qualitative methods.

### 1. QUANTITATIVE MEASUREMENT

The questionnaire drew on three scales. The first two were developed and validated by de Groot, Peters, van Brakel, Meurs and Jacquet (2020) and de Groot, Jacquet, Meurs and Peters (accepted). Up to the time of writing, these are the only validated measurement tools that exist in terms of measuring people's attitude towards people with albinism in Tanzania. The questionnaires were conducted in Swahili.

- **The Albinism Explanatory Model Interview Catalogue Community Stigma Scale (A-EMIC-CSS)** measured community stigma through the use of 16 items about aspects of stigma that people with albinism and the people around them can face in life (e.g. E-04. Would people think less of a person with albinism?) (de Groot, et al., accepted). There were five response options: (1) it never happens, (2) it rarely happens, (3) it happens sometimes, (4) it happens often, (5) it happens always (Cronbach's  $\alpha = .884$  in baseline with all the respondents).

- **The Albinism Social Distance Scale (A-SDS)** asked about personal attitudes towards people with albinism. The A-SDS was introduced by a vignette about a man (John) or woman (Joyce) with albinism, followed by 10 items asking about the respondents' feelings if they were in certain social situations with John or Joyce (e.g. S-09. How would you feel to have John/Joyce as a friend?) (de Groot, et al., accepted). One choice was available out of four possible answers: (1) I do not have a big problem, (2) I do not have a problem, (3) I do have a problem, (4) I do have a big problem (Cronbach's  $\alpha=.975$  in baseline with all the respondents).
- **Entertainment items** (only post-test) were used to assess the level of entertainment of the intervention through six items, which were based on items used by Ritterfeld and Jin (2006): 1. The show was very entertaining, 2. I had the sense of being pulled right into the show, 3. The show did not interest me (recoded), 4. I wasn't involved in the show (recoded), 5. I very much enjoyed the show, and 6. The show was very involving. The answer possibilities were: (1) I completely disagree, (2) I disagree, (3) I neither disagree nor agree, (4) I agree, (5) I completely agree. Cronbach's alpha for this scale was low ( $\alpha=.426$ ). Therefore, the scale was used pragmatically as an indication of the level of entertainment. However, one should be careful with interpreting these results.

## 2. QUALITATIVE MEASUREMENT

The qualitative assessment consisted of:

- **Informal (group) interview 1 (directly following the radio show):** To obtain insight into respondents' experiences and feelings directly following the radio intervention, the research assistant aimed to discuss the following themes in an informal conversation: 1. opinions about the intervention, 2. lessons learned from the intervention, 3. the cause of albinism, and 4. the most important message delivered in the intervention.
- **Informal (group) interview 2 (two to three weeks after the radio show):** to assess possible impact of the interventions and what the respondents remembered, several topics were discussed with the respondents, such as: 1. memories of the intervention, 2. lessons remembered from the intervention, 3. if the respondents talked about the intervention with others.

## PROCEDURE

A baseline test, prior to the radio show, and a post-test, after the radio show, was set up to measure differences in attitude after the intervention and to exclude influence from previous campaigns as much as possible. Prior to the intervention the respondents filled out the self-completion questionnaires (baseline study: A-EMIC-CSS and A-SDS). Some demographic items were added, asking the respondents about their age, level of education, religion, profession and familiarity with people with albinism. In the event that the respondents were not able to read ( $n=51$ , 25.8% of the respondents in the baseline) the survey questions were read to them by the research assistant.

Because KICORA was not yet broadcasting any radio program, it was decided to conduct research using the recorded versions of the radio drama and the radio interview. These recordings were played to the respondents through a speaker in the household chosen for the purposes of the research. To reduce the possibility of respondents influencing their neighbours with information with regard to the other intervention, only one of the two interventions was played in the same neighbourhood. The baseline for the radio drama intervention was carried out prior to the baseline for the radio interview intervention, and data was gathered until a sufficient sample size ( $n>100$ ) was achieved. The intervention was followed by a survey on the level of entertainment and with the informal (group) interview 1 with all respondents that participated in the survey.

After two to three weeks the respondents that could be retrieved filled out the survey (post-test: A-EMIC-CSS, A-SDS, Entertainment items) (for one respondent after 4.5 weeks and another after

6 weeks), and with all the respondents that were retrieved the informal (group) interview 2 (1 - 6 respondents in each interview) was conducted with regard to the intervention. Retrieving respondents was hard since the researchers depended on the presence of the respondents in, or close to, the household in which the baseline had taken place. To guarantee anonymity, the names of the respondents were not recorded. The research assistant administered the tests in those households in which the baseline study had taken place and the people in the household or neighbours helped gather the respondents. To match the baseline and post-test, respondents' dates of birth were recorded. The national language - Swahili - was used throughout the research. The data was gathered by a female master student from the Netherlands, under the supervision of the main researcher who is a female PhD student from the Netherlands. They were assisted by a female research assistant from the region who spoke Swahili.

## ANALYSIS

### QUANTITATIVE ANALYSIS

For the quantitative data analysis IBM SPSS statistics v25.0 (SPSS Inc., Armonk, NY.) was used. Both interventions and samples were described and analysed separately, followed by a comparison of the impact of the two interventions. The demographic items were analysed item-wise. Descriptive statistics were obtained for all items. For the A-EMIC-CSS and A-SDS, differences between baseline and post-test were analysed item and scale-wise through Wilcoxon Signed Rank for non-parametric data, with the exception of a paired t-test that was carried out between the A-EMIC-CSS baseline and the post-test due to low kurtosis of the sum-scale. A difference-variable was computed for each item (post-test score minus the base-line score) in order to compare the effects of the interventions.

The sum scales (including the entertainment scale) and the difference-variables were used to compute differences between interventions through One-way ANOVA for parametric data (A-EMIC-CSS baseline, post-test and difference-variable and entertainment scale) and the Mann-Whitney U test for non-parametric data (A-SDS baseline, post-test and difference-variable).

### QUALITATIVE ANALYSIS

Notes were taken during the informal interviews. The answers were not recorded because it was believed this would distract the respondents too much and would make them less free to talk. First the notes were categorized, followed by a thematic ordering, by making use of NVivo 12 and Excel 2016. When analysing the data, it was decided to refer to the number of informal interviews, in which a certain theme was discussed instead of the exact number of respondents who spoke about this theme.

### ETHICAL CONSIDERATION

This study was part of a larger research study that has been approved by the Tanzanian Commission for Science and Technology (COSTECH), from whom a research permit has been obtained (Permit Number: 2018-237-NA-2017-40). The respondents of the research were informed about the procedure and goals of the research, and were made aware that participation was voluntary, that the data gathered from them was confidential, and that it would be used anonymously. Anonymity was guaranteed by not recording respondents' names or other contact information. Only their dates of birth were recorded so that the baseline and post-test could be matched. They were asked for verbal consent by the research assistant. People who did not want to participate refrained from doing so.



## RESULTS

### RADIO DRAMA

#### QUANTITATIVE FINDINGS AFTER THE RADIO DRAMA

A post-test was conducted two to three weeks after the intervention, providing the researchers with the following quantitative results with regard to the radio drama: firstly, the mean of the sum-scale in the baseline was 1.85 (n=59) and of the post-test 1.67 (n=65), which was significantly different ( $t(58)=3.275$ ;  $p=0.002$ ). A significant reduced score was found after the radio drama on the A-EMIC-CSS in terms of four items, presented in the table below.

Item	Z	p
<i>E-02. Would the family of someone with albinism feel less worth?</i>	-2.627	0.009
<i>E-05. Would people in your community avoid a person with albinism?</i>	-2.493	0.013
<i>E-06. Would others refuse to visit the home of a person with albinism?</i>	-2.108	0.035
<i>E-07. Would people in your community think less about the family of a person with albinism?</i>	-2.744	0.006

Table 1 Significantly reduced A-EMIC-CSS items after the radio interview

Secondly, when the researchers computed the A-SDS, the baseline mean was 1.50 (n=61) while in the post-test it was 1.26 (n=65). The Wilcoxon signed-rank test showed that the intervention caused a significant reduction in personal stigmatizing attitude ( $Z=-1.974$ ;  $p=0.048$ ). The intervention significantly changed respondents' attitude on the social distance scale on six items, presented in the table below.

Item	Z	p
<i>S-01. How would you feel to visit a house of someone like John/Joyce?</i>	-2.483	0.013
<i>S-03. How would you feel having someone like John/Joyce as a neighbour?</i>	-2.013	0.044
<i>S-04. How about having someone like John/Joyce taking care of your children for a couple of hours?</i>	-2.036	0.042
<i>S-06. How would you feel about introducing John/Joyce to a young woman you are friendly with?</i>	-2.072	0.038
<i>S-09. How would you feel to have John/Joyce as a friend?</i>	-2.364	0.018
<i>S-10 How would you feel shaking hands with someone like John/Joyce?</i>	-2.335	0.02

Table 2 Significantly reduced A-SDS items after the radio drama

Thirdly, on a 1 to 5 scale (1 meaning low level of entertainment, 5 meaning high level of entertainment) the average entertainment score was 4.3.

#### QUALITATIVE FINDINGS AFTER THE RADIO DRAMA

Most respondents expressed in the informal (group) interviews that they were positive about the intervention; they thought it was educative, interesting and nice. The respondents thought it was a good way to educate individuals, e.g. someone mentioned that people mostly do not listen to the radio but if they hear that there is a radio drama even the less-educated will be excited enough to listen to such a drama (note from informal interview 20, radio drama). Surprisingly, in two informal interviews, the respondents recommended that the drama should be on tv instead of on the radio, even though they did not own a tv.

The qualitative results showed that directly after the intervention, the respondents identified seven main lessons as displayed in Table 3. The respondents in 13 of the interviews mentioned that they learned that people with albinism are human beings or the same as anyone else, and in 11

informal interviews the respondents mentioned that they learned about the cause of albinism and that people with albinism should not be mistreated (often expressed in terms such as loved/cooperated with/helped). In 13 informal interviews directly following the radio drama the respondents noted that they learned nothing from the radio drama. However, in five of these cases, later on in the interview the respondents mentioned something that they had learned. In only two informal interviews did the respondents mention that they had learned something about the skin of people with albinism, and likewise their low vision. Interestingly, only one respondent mentioned that he learned that some people think that albinism was contagious (informal interview 8, radio drama).

<b>Main Lesson</b>	<b>Informal interview 1</b>	<b>Informal interview 2</b>
<i>1 People with albinism are human beings or the same as anyone else</i>	13	10
<i>2 Cause of albinism</i>	11	3
<i>3 People with albinism should not be mistreated but treated well</i>	11	13
<i>4 People with albinism have the same abilities as others</i>	7	6
<i>5 No longer to be afraid of people with albinism</i>	5	3
<i>6 Albinism is not contagious</i>	4	1
<i>7 Europeans can also have albinism</i>	4	0

Table 3 Main lessons (mentioned in >4 informal interviews) learned from the radio drama according to the audience directly after intervention

When discussing the cause of albinism, in seven of the informal interviews the respondents knew the correct explanation. However, incomplete explanations were provided in six of the informal interviews (e.g. albinism comes from parents who have something missing in their body (note from informal interview 1, radio drama)) and in one informal interview an incorrect explanation was provided. In four informal interviews the respondents explained the cause of albinism through a religious discourse, i.e. albinism is caused by God. Respondents in eight informal interviews provided some suggestions about how to assist people with albinism. For example, it was suggested that people with albinism should be kept away from fire and flies.

When respondents were asked what they thought was the most important message of the intervention respondents in 12 of the informal interviews mentioned that the message was about not mistreating people with albinism. The second most common message was only mentioned in four interviews: people with albinism are like other human beings.

Two to three weeks after the intervention most of the respondents remembered that the intervention was about albinism. In only four of the informal (group) interviews did the respondents mention that they did not remember anything. In the longer term the respondents mainly remembered that the radio drama was about not mistreating people with albinism. This was mentioned in 13 of the informal (group) interviews, and that people with albinism are human beings or the same as anyone else, was mentioned in eight of the informal (group) interviews. In 11 of the informal (group) interviews the respondents remembered parts of the story line. One respondent mentioned that he started greeting a woman with albinism in his village and giving her a hand after the intervention (note from informal interview 25, radio drama).

In most of the second round of informal group interviews, 20 respondents mentioned that they had talked to someone else about the intervention. Respondents often spoke about it with people close to them, while in six of the informal (group) interviews the respondents discussed it with their spouse, in four interviews with their family, and in four with their friends. Respondents in one

informal (group) interview mentioned that they did not talk to anyone, because the topic was very important to them and they were afraid that others would take it too lightly (note from informal interview 10, radio drama).

## RADIO INTERVIEW

### QUANTITATIVE FINDINGS AFTER THE RADIO INTERVIEW

In terms of the quantitative findings with regard to the radio interview, on the A-EMIC-CSS there was no item that changed significantly after the intervention. When the researchers computed the A-EMIC-CSS, the mean in the baseline was 1.93 (N=71), while in the post-test it was 1.92 (n=74). The t-test shows that the intervention did not cause a significant reduction ( $t(68)=0.565$ ;  $p=0.574$ ). The mean of the baseline A-SDS was 1.3 (N=76) and in the post-test 1.16 (n=74), and the Wilcoxon signed-rank test showed that the intervention caused a significant reduction in personal stigmatizing attitudes ( $Z=-2.236$ ;  $p=0.025$ ). Subsequently however, the intervention changed respondents' attitude significantly on four items on the social distance scale as presented in the table below (Table 4). Additionally, the average entertainment score was 4.11.

Item	Z	p
<i>S-02. How would you feel working together with someone like John/Joyce?</i>	-2.138	0.033
<i>S-07. How would you feel about recommending someone like John/Joyce for a job working for a friend of yours?</i>	-2.884	0.004
<i>S-08. How would you feel to sit next to John/Joyce in the bus?</i>	-2.202	0.028
<i>S-10. How would you feel shaking hands with someone like John/Joyce?</i>	-2.555	0.011

Table 4. Significantly reduced A-SDS items after the radio interview

### QUALITATIVE FINDINGS AFTER THE RADIO INTERVIEW

The qualitative data showed that the respondents were enthusiastic about the radio interview; many positive terms such as interesting, educative and nice were used. However, in one informal interview it was not believed that the person interviewed was really a person with albinism because he was married to a woman without albinism and his children did not have albinism. This opinion was not shared in other informal interviews and was countered in, for example, interview 18, in which one respondent explained that the radio interview showed that people with albinism are the same as them, they can marry, have children and enjoy life.

The six main lessons learned from the radio interview, mentioned in five or more informal (group) interviews, are displayed in Table 5. The respondents mentioned in 14 of the informal interviews that they learned about the cause of albinism, and that people with albinism can have a baby without albinism. Some other interesting but less frequently mentioned lessons were as follows. The respondents in three of the first informal interviews and in four of the second informal (group) interviews mentioned that they no longer believe that people with albinism do not die but disappear, and in three informal interviews the respondents mentioned that they do no longer believe that people with albinism can see in the dark (like cats). However, it was noted by respondents in four informal interviews that they learned nothing from the intervention.

Main Lesson	Informal interview 1	Informal interview 2
1 Cause of albinism	14	4
2 People with albinism can have a baby without albinism	14	3
3 People with albinism are human beings or the same as anyone else	8	13
4 People with albinism can marry (someone without albinism)	8	6
5 Learned about skin problems of people with albinism/the sensitivity to the sun	7	4
6 People without albinism can have a baby with albinism	5	1

Table 5 Main lessons learned from the radio interview according to the audience directly after the intervention

After the radio interview the cause of albinism was explained correctly in 18 informal interviews, incompletely in five informal interviews and incorrectly in one informal interview. In five of the informal interviews, the respondents mentioned that they were unable to provide an explanation, and in one informal interview the respondents were convinced that albinism was caused by God. In 15 informal interviews, the respondents correctly explained that the albinism genes of the mother and father 'need to meet'.

Additionally, when asked what respondents thought was the most important message of the intervention, the respondents in fourteen informal interviews mentioned the message that people with albinism should not be mistreated. In 11 of the informal interviews the respondents mentioned that they thought the message that people with albinism are like other human beings was the most important.

After two to three weeks the respondents in 13 of the second informal (group) interviews remembered that people with albinism are human beings or the same as anyone else and in six of the second informal (group) interviews, the respondents remembered that people with albinism can marry. However, the other main lessons that were mentioned in the informal interviews (1, 2, 5, 6) were no longer mentioned. Instead, after two to three weeks the respondents indicated lessons that were not mentioned often directly after the intervention: that people with albinism should not be mistreated (in nine of the informal (group) interviews) and that they were no longer afraid of people with albinism (in eight of the informal (group) interviews).

A few weeks after hearing the radio interview, the respondents remembered that people with albinism are human beings or the same as anyone else (in 11 of the informal (group) interviews) and that people with albinism should not be mistreated (in six of the informal (group) interviews). The respondents also remembered, in seven of the informal (group) interviews, information about the skin problems of people with albinism and in eight of the informal (group) interviews the respondents mentioned that they remembered the cause of albinism. In five of the informal (group) interviews the respondents said that they only remember that the radio show was about albinism, but remembered nothing else.

In 18 of the informal interviews the respondents mentioned that they had spoken about the intervention to the people close to them (spouses in five interviews, family in three interviews and friends in six interviews).

#### COMPARISON OF THE IMPACT OF INTERVENTIONS

No significant difference was found between the samples based on demographics, nor in the baseline on the A-EMIC-CSS ( $F(1,128)=.519, p=.473$ ) and A-SDS ( $Z=-.138, p=.890$ ).

Even though the radio drama showed a significant effect on the A-EMIC-CSS and the radio interview did not, there was no significant difference on the change variable between the interventions ( $F(1,126)=3.081, p=.082$ ). However, the post-test score of the A-EMIC-CSS showed a

significantly higher score after the radio interview in comparison to the radio drama ( $F(1,137)=6,750$ ,  $p=.010$ ).

The radio drama and the radio interview were both effective in reducing A-SDS scores significantly. However, no difference was found on the difference-variable ( $Z=-.264$ ,  $p:.792$ ), and scores after the radio drama were not significantly different ( $Z=-1.467$ ,  $p:.142$ ).

In terms of entertainment the radio drama scored significantly higher than the interview ( $F(1,166)=4.735$ ,  $p=.031$ ).

## DISCUSSION

This study showed the possibilities for using radio interventions to reduce stigma related to albinism in Tanzania. This is the first study of its kind in terms of exploring the outcomes of radio interventions in the form of a radio drama and a radio interview, as methods for stigma reduction with regard to albinism in Tanzania. In addition, this study aimed to enable the evaluation of content, form and impact on community stigma and social distance towards people with albinism. Quantitative methods (the A-EMIC-CSS, A-SDS and an entertainment scale) and qualitative methods (two rounds of informal interviews) were combined to generate insights with regard to the outcomes of the interventions. Data was generated at the time of the implementation of the intervention and two to three weeks after the intervention in order to obtain an insight into the longer-term outcomes.

The following findings were promising for the future use of radio interventions for stigma reduction. Firstly, both radio interventions were effective in reducing social distance, as portrayed by the A-SDS results and as was confirmed by the qualitative findings. Secondly, following both radio interventions, the respondents pointed out that as a main lesson they had learned about the cause of albinism. Therefore, the radio shows have been successful in spreading knowledge with regard to the cause of albinism, although for some respondents a religious explanation remains as the cause. Thirdly, respondents were very positive about the interventions and saw them as a good means of educating society. Fourthly, the qualitative findings endorse the view that many respondents discarded their past beliefs about albinism, such as the belief that people with albinism are not human (Brocco, 2015), they do not die but disappear, albinism is contagious (Baker, Lund, Nyathi, Taylor, 2010), they do not have the same abilities, albinism is caused by the mother (Cruz-Inigo, et al., 2011) and people with albinism see better at night time (like cats). The correction of false beliefs about people with albinism might also add to the observed reduction of fear towards people with albinism. Fifthly, after two to three weeks the respondents still remembered a large part of the intervention and the lessons learned from the intervention. This could point to the possible longer-term effects of such an intervention, although this would require confirmation. Lastly, many respondents spoke to others about the intervention, which can point to a wider dissemination of the intervention than just among the respondents who listened to the radio. More research would also be necessary to obtain more insight into what was told and the effect of this.

The current findings on contact interventions through radio were in line with other research into the effectiveness of contact interventions on stigma reduction (Corrigan, Morris, Michaels, Rafacz, & Rüscher, 2012; Gronholm, Henderson, Deb, & Thornicroft, 2017; Paluck, Green, & Green, 2018; Peters, et al., 2015; van Brakel, et al., 2019) and the effectiveness of radio interventions in conveying messages (Kuhlmann, et al., 2008; Singhal, et al., 2006; Vaughan, et al., 2000). Para-social contact can have similar effects as real-life contact (Giles, 2002; Schiappa, et al., 2005). Through the radio intervention, the respondents had the opportunity to come into contact with someone with a stigmatizing condition, which challenged their former attitudes (Corrigan & Penn, 1999; Corrigan, et al., 2001). In our research the respondents came to understand that people with albinism were like them, as was often repeated in the qualitative interviews, for example by stating that people with albinism also go to school, can be a nurse, can get married and have children. Insights generated

through contact interventions can correct misinformation and reduce anxiety (Allport, 1954; Brown, et al., 2003; Herek & Capitanio, 1997; Pettigrew, 1998) as can be seen in the things respondents learned from the intervention, with respondents even mentioning that they were no longer afraid of people with albinism.

Additionally, the fact that the stigmatized themselves can play an active role in stigma reduction is counteracting people's perceptions of people with a stigmatizing condition. People with a stigmatizing condition are often thought of as being passive victims. Consequently, having them involved in stigma reduction increases their agency, confidence and status. In addition, their input can improve the value of the intervention (Cook, Purdie-Vaughns, Meyer, & Busch, 2013; Heijnders & van der Meij, 2006).

However, the outcomes of the intervention were not always as intended. For example, the intervention strategy was not effective in the household in which respondents did not believe that the person interviewed on the radio was a person with albinism, exactly because he was countering their beliefs about albinism that it was impossible for the interviewee to be married to a woman without albinism and to have children without albinism. These unintended outcomes again prove the importance of proper stigma reduction development.

#### COMPARISON OF THE IMPACT OF RADIO DRAMA AND RADIO INTERVIEW

Both the radio drama and the radio interview were effective in reducing social distance. Differences between the two radio shows were found in terms of community stigma and entertainment. The radio drama was effective in reducing community stigma as measured through the A-EMIC-CSS, though the radio interview was not significantly effective. All items showed a reduction in stigma. However, we need to be careful in drawing the conclusion that the radio drama was a more effective intervention in terms of stigma reduction at the level of the community because no difference on the difference-variable was found. Considering the level of entertainment, the entertainment score of the radio drama was significantly higher than that of the radio interview. The respondents enjoyed both interventions but liked the radio drama more, which also had slightly more effect on the respondents' attitudes.

#### LIMITATIONS

The fact that the (foreign) researcher(s) were in the household of the respondents might have influenced the respondents' attention to the radio show, and possibly the outcome of the measurements among others, in terms of socially desirable answering, and the intervention effect of the scales themselves. More research needs to be carried out to obtain insight into the long-term effects of such an intervention.

Another limitation of this study was the measurement tool in combination with the sample. The area of study consisted of a relatively low educated population, with many being unable to read or write. The self-completion surveys had to be read out to these respondents. Even though the scales have been validated in Tanzania before on an adult population, they might be too lengthy for a population with limited education.

Additionally, it is important to bear in mind that this research did not measure actual behavioural change. Instead, it only measured attitudinal change. However, some respondents did mention behavioural change, such as the respondent who started greeting a woman with albinism in his village.

The radio shows also had some unintended outcomes, which again shows the importance of proper follow-up and a validation of interventions, and raises an ethical difficulty of stigma reduction through media: 'Who is responsible for the intended/unintended outcomes of a programme?' (Brown & Singhal, 1990). In attempts to reduce stigma through media, it is harder to control the response of

each receiver of the intervention than might be the case in real-life. One has to be careful in using media. One should validate interventions and secure a proper follow-up.

#### CONCLUSION

This study set out to explore the impact of radio interventions with regard to reducing albinism-related stigma in Tanzania. The research has shown that a radio contact intervention on albinism, through a radio drama or a radio interview, can cause a reduction in stigma and can improve the listener's knowledge of albinism. Interestingly, in a comparison between the two types of intervention the radio drama was perceived as being more entertaining and to have a larger effect on community stigma. The differences between the types of radio intervention and the aspects of contact interventions and entertainment education as pointed out in this research, would be a fruitful area for further work. The findings will be of interest to organizations in the field of stigma reduction, but also add to the understanding of stigma reduction in general, and with regard to albinism specifically. Radio shows are an effective and pleasant way to be educated about albinism. They are relatively easy and cheap to develop, and can reach many people in the community. Radio shows are a promising stigma reduction intervention, which can be a step on the way towards further improvement with regards to the wellbeing of people with albinism, but also for people with other stigmatizing conditions. The findings of this study support the importance of the evaluation of stigma reduction interventions as part of disability policy.

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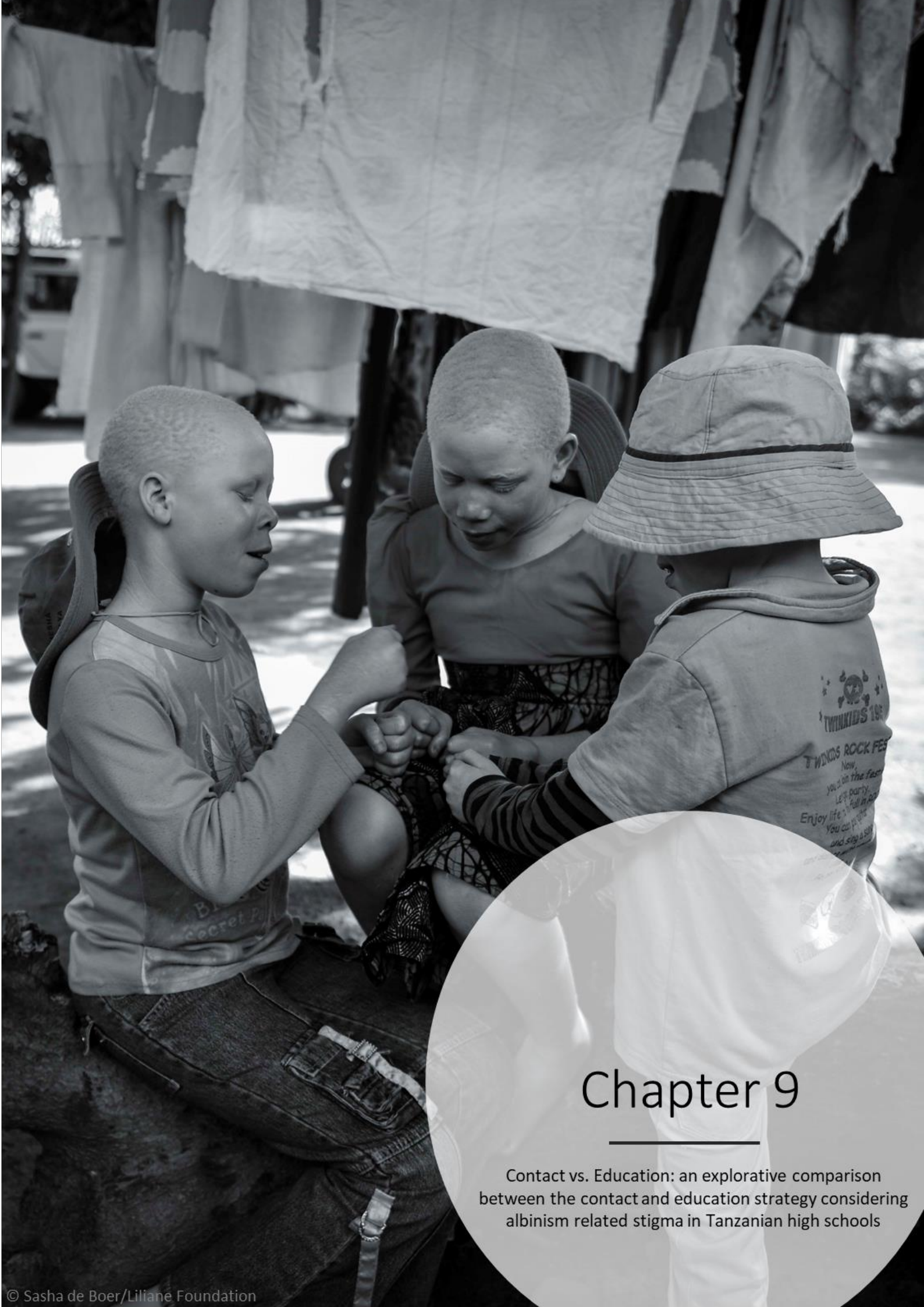
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## Chapter 9

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Contact vs. Education: an explorative comparison between the contact and education strategy considering albinism related stigma in Tanzanian high schools

## CHAPTER 9: CONTACT VS. EDUCATION: AN EXPLORATIVE COMPARISON BETWEEN THE CONTACT AND EDUCATION STRATEGY CONSIDERING ALBINISM-RELATED STIGMA IN TANZANIAN HIGH SCHOOLS

*Under review as: de Groot, T., Meurs, P., Jacquet, W., & Peters, R. (under review). Contact vs. Education: an explorative comparison between the contact and education strategy considering albinism-related stigma in Tanzanian high schools. Foundation of Science.*

Albinism in Tanzania causes fierce health-related stigma. Little research has focused on the impact of stigma reduction strategies aiming to reduce albinism-related stigma. Therefore, this research assessed the impact of two short filmed interventions among high school students in Tanzania on their attitude towards people with albinism: a contact intervention (n=95) and an education intervention (n=97). A mixed method design was used. Directly before and after the interventions impact was measured among all participants through the Albinism Social Distance Scale for Adolescents (ASDS-A), Knowledge items, and Entertainment items. After these measurements focus group discussions were conducted, 16 in total (n=80). Both interventions caused a significant increase in the levels of correct knowledge about albinism. The education intervention entailed a significant positive change in attitude measured through the ASDS-A, whereas the contact intervention did not have a significant effect. In terms of entertainment value, the respondents were more enthusiastic about the contact intervention. The study suggests that education interventions on their own can be a successful tool in decreasing albinism-related stigma. Additionally, qualitative findings show many positive outcomes for the contact intervention. Therefore, we would recommend using a combination of these two interventions, which has also proved successful in the past. However, more research on the effect of a combination of the two strategies is recommended.

Keywords: Albinism, health-related stigma, stigma reduction, ASDS-A

## INTRODUCTION

Health-related stigma has a large negative effect on the lives of people with albinism in Sub-Saharan Africa (Affram, Teye-Kwadjo, & Gyasi-Gyamerah, 2019; Braathen & Ingstad, 2006; Bradbury-Jones, Ogik, Betts, Taylor, & Lund, 2018; Brocco, 2016). Albinism is an inherited recessive genetical condition causing people with albinism to have little to no pigmentation in the eyes, hair and skin (Kromberg, 2018a). The absence of the melanin pigment causes the skin to lack the natural protection against UV-rays, which makes people with albinism sensitive to sunlight, resulting in a large risk to suffer from skin cancer (Lookingbill, Lookingbill, & Leppard, 1995). The lack of melanin in the eyes also causes low vision (Williams, 2018). Besides these physical impairments the lack of melanin also causes the skin, hair and eyes of people with albinism to be light of colour, which is noticeable in a population in which most of the people has a darker skin-colour.

In Tanzania albinism has resulted in fierce stigmatization that is accompanied by a large variety of myths and beliefs (Brocco, 2016; Bryceson, Jønsson, & Sherrington, 2010; Kromberg, 2018b). One of the myths associated with albinism is the belief that the body parts of people with albinism provide good fortune, which has been causing violent attacks on people with albinism (Bryceson, et al., 2010; Cruz-Inigo, 2011). Other stories adding to the dehumanization of people with albinism are the belief that people with albinism are ghosts and they do not die but will at one moment just disappear (Baker, Lund, Nyathi, & Taylor, 2010; Brocco, 2015). Public health interventions to reduce the stigmatization of people with albinism are recommended (Cruz-Inigo A. E., 2011; Hong, Zeeb, & Repacholi, A, 2006; Mostert, 2016; Uromi, 2014), however little research has assessed the impact of stigma reduction strategies in relation to albinism in Tanzania.

Nonetheless, a number of strategies to address health-related stigma in respect to other health-related conditions have been studied. Two often used strategies in stigma reduction are (1) the contact strategy and (2) the education strategy. Together with a third strategy (3) protest, found to be less effective by Brown, Evans, Espenschade and O'Connor (2010), they form the three strategies considered by Corrigan and Penn (1999). (1) Contact strategy contains an interaction, either life or indirect, with someone with a stigmatizing condition with the goal of reducing stigmatizing attitudes (Heijnders & van der Meij, 2006). The contact strategy is based on the contact hypothesis by Gordon Allport (1954), who stated that intergroup contact reduces prejudice. Contact has often proven to be an effective stigma reduction intervention (Pettigrew & Tropp, 2006; Yamaguchi, et al., 2013). For example, Brown, et al. (2010) showed a decrease in stigma related to mental illness through a filmed contact intervention. The potential of contact strategy lies in its ability to build a personal relationship, generate empathy and correct misinformation (Allport, 1954; Brown, Macintyre, & Trujillo, 2003; Pettigrew, 1998).

(2) Education strategy entails the provision or amelioration of knowledge on a certain stigmatizing condition, so that people are less likely to have stigmatizing feelings towards the stigmatized (Heijnders & van der Meij, 2006). An advantage of the education strategy is its' easy exportability (Corrigan, Larson, Sells, Niessen, & Watson, 2007). Some authors have demonstrated the success of education strategies (Cook, Purdie-Vaughns, Meyer, & Busch, 2013; Corrigan, Morris, Michaels, Rafacz, & Rüschi, 2012; Tanaka, Ogawa, Inadomi, Kikuchi, & Ohta, 2003), while others obtained less convincing results about the role education plays in stigma reduction (Brown, et al., 2003; Corrigan & Penn, 1999; Herek, Capitanio, & Widaman, 2002). Various authors recommend combining the education strategy with another strategy in order to achieve greater effectiveness (Brown, et al., 2003; Stangl, Lloyd, Brady, Holland, & Baral, 2012; Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008).

(3) Often, stigma-reduction interventions aim to be entertaining to attract people's attention and to increase impact. Singhal and Rogers (1999) describe this strategy as Entertainment Education (EE). EE functions as motivation for people to process the information provided in an intervention

(Ritterfeld, Klimmt, Vorderer, & Steinhilper, 2005) and also improves this processing (Ritterfeld & Weber, 2006). Additionally, EE increases participation (Murphy, Frank, Moran, & Patnoe-Woodley, 2011; Vorderer, Klimmt, & Ritterfeld, 2006), and decreases counter arguing by the participants (Slater & Rouner, 2002).

In stigma reduction research, little studies have compared the effectiveness of contact and education strategy (Brown, et al., 2010). Three comparison studies on mental illness stigma in the US demonstrate the greater effectiveness of contact interventions (Corrigan, et al., 2001; Corrigan, et al., 2002; Corrigan, et al., 2007). In this study, we will compare the effectiveness of the contact and education strategy in relation to albinism in Tanzania taking into account the entertainment level. In order to do so, this study evaluated the impact of two brief movies about albinism: (1) a contact intervention and (2) an education intervention. Through the comparison of these interventions we also hope to gain more insight in the role that knowledge plays in stigma reduction.

## METHODS

To compare the contact strategy with the education strategy, a standardized intervention was chosen in the format of two movies: a movie focussing on personal contact with someone with albinism and one focussing on education about albinism. Both movies were based on a Tanzanian movie about people with albinism “Watu Kama Sisi” (People Like Us), which was created by Albino Peacemakers, an organization that supports people with albinism in Tanzania. For the contact interventions fragments were chosen of five people with albinism (a fish trader, a shop owner, a kinder garden teacher, a mother, a student) who introduced themselves and explained aspects of their lives, recombined in a movie of 10.46 minutes. As suggested by Penn, Chamberlin and Mueser (2003) only fragments were chosen that unambiguously disconfirmed the stereotype of a person with albinism by displaying success stories. For the education intervention fragments were chosen in which a doctor and two traditional healers explained about albinism, its’ causes and effects, this movie has a total duration of 9.14 minutes.

The two movies were tested among high school students in four different schools. In three of these schools two groups were formed, one group saw the contact intervention and one group saw the education intervention. In one school, school 4, all groups saw both movies. A pre-test post-test study design was used. A pre-test was conducted right before the intervention, and a post-test straight after the intervention. In school 4, students had an extra survey after the viewing of the second movie, as explained below. Afterwards focus group discussions (FGDs) were conducted with a selection of the respondents.

The quantitative measures used in the pre- and post-test are the following:

- **The Albinism Social Distance Scale for Adolescents (ASDS-A).** Changes in attitude towards people with albinism were measured through the 12-item ASDS-A, measuring social distance (e.g. S-05 How would you feel to have someone like John/Joyce as a family member?). Answer possibilities: I do not have a big problem (1 point), I do not have a problem (2 points), I do have a problem (3 points), I do have a big problem (4 points). Social distance scales have proven to be a proper measurement tool in stigma research (e.g. (Adewuya & Makanjuola, 2005; Koller & Stuart, 2016; Peters, et al., 2015) and this particular scale has been validated for the use with albinism in Tanzania (de Groot, Peters, van Brakel, Meurs & Jacquet, 2020).
- **Knowledge items.** To measure a change in correct knowledge, 12 items were developed accordingly. Items were based on information about albinism that many people in Tanzania do not know according to experts in the field. Three items (K-01 – K-03) are ‘knowledge explanation items’, for which a written explanation is required by the respondent (e.g. K-01 ‘Do you know the reason for albinism?’, in case respondents say that they know the answer to this question they have to provide clarification). These items were followed by closed-

ended 'knowledge-items' (K-04 – K-12) (e.g. K-04 Do you think albinism is contagious?). Answer possibilities were: Yes, No, I don't know.

- **Entertainment items.** To measure the entertainment level of the interventions six items were added, based on items used by Ritterfeld and Jin (2006), asking the respondent how they felt about the intervention (e.g. E-01 The show was very entertaining). The items were scored on a 5-point agreement scale.

In the pre-test demographic data was gathered, among others about age, gender, tribe, place of birth, and familiarity with people with albinism. The pre-test existed out of demographic questions, Knowledge items, and the ASDS-A. The post-test existed out of the Knowledge items, the ASDS-A, and Entertainment items. The extra survey, conducted in school 4 after the viewing of the second movie, existed out of Entertainment items and two comparison question for which written clarification had to be provided (C1. Which movie did you like more? C2. From which movie did you learn more?).

To get an impression of which parts of the movie were interesting to the respondents FGDs were conducted after each intervention. The method of FGD was chosen because in the experience of the researcher adolescent respondents in Tanzania feel more at ease to talk to an adult researcher when they are in a familiar group. Respondents were asked the following questions (or variations of these questions): "What did you see in the movie?", "What did you learn from the movie?", "What did you/didn't you like in the movie?", "Was there something missing in the movie?" and "Do you have any questions?". In the school 4 respondents were also asked to compare the first and the second movie: "Which movie did you prefer and why?" and "From which movie did they learn more and why?". For each FGD four to six students were selected. Participants were selected by dividing the group in subgroups based on gender, followed by systematic sampling from these two groups, students were selected based on regular intervals from the total sample (e.g. every fourth student in the row, depending on the number of students in the total sample).

To control for the possible effect of the pre-test as an intervention itself in reducing stigmatizing attitudes (de Groot, et al., 2020), approximately only half of the respondents filled out the pre-test, the other half was provided with a substitute survey only existing out of demographic questions, after which they were presented with a written story about animals.

Schools and students participated on a voluntary basis, this was explained to them by the researcher and an assisting teacher. This study was part of a larger research that has been approved by the Tanzanian Commission for Science and Technology (COSTECH), from whom a research permit has been obtained. The headmasters in charge of the participating schools provided the researcher with written consent, and oral consent was obtained from the participating students.

## SAMPLE

The sample consists of students from four different private high schools in Mbeya, in the south of Tanzania, and covered the first four classes of high school (in Tanzania these are called the four *forms* of the ordinary level). The choice for a private school was based on convenience. The schools and students were selected based on their availability. The participating groups were purposefully sampled so that all *forms* would be represented. The researcher also tried to have a balance of gender in the samples. Groups existed out of students from the same *form*, except for the group students in school 3 where *forms* 1 and 3 were combined.

## DATA ANALYSIS

Quantitative data was analysed using IBM SPSS statistics 25 (SPSS Inc., Armonk, NY.). Samples were compared using Pearson Chi-Square. Respondents that only participated in the pre- or post-intervention were removed from the data set (two respondents from post-test, three respondents from pre-test).



Reliability of the scales was calculated using Cronbach's alpha. Differences between pre- and post-test of the same interventions on item level were calculated through McNemars test for the Knowledge items (which were dichotomised by 1. Correct answer, 2. Wrong answer existing out of the wrong answer and I don't know), and through Wilcoxon Signed-Rank Test for the ASDS-A. A difference variable for the ASDS-A items was calculated to get an insight in the impact of the intervention on the attitudes of the respondents towards people with albinism (post-test score minus pre-test score). On scale level all items were computed and compared using Wilcoxon Signed-Rank Test.

Differences between interventions were calculated using the Mann-Whitney U test for non-parametric data. Correlation between the scales based on Knowledge items (K-04 – K-12) and the ASDS-A was calculated through Spearman's rank correlation. Differences between groups within the sample are calculated through the Mann-Whitney U or Kruskal-Wallis test.

Qualitative data was analysed using NVivo 12. The FGDs were recorded and transcribed. The transcription was coded through recurring themes in the discussions, after which the interventions were compared, and the data was summarized so that conclusions could be drawn.

## RESULTS

### QUANTITATIVE DATA

#### DEMOGRAPHICS

Demographics are presented in Table 1. In total 192 respondents (52.1% man, 47.9% woman) participated in this study, 95 students participated in the contact intervention, 97 in the education intervention. The baseline study was filled out by 103 respondents, the substitute survey was filled out by the remaining respondents (n=89).

Respondents from *form 1, 3 and 4* of ordinary level education participated in this study. Due to exams, no sample of *form 2* students was found to participate in the education intervention. Since all schools were boarding schools only 40.1% of the respondents came from Mbeya the others came from a large variety of other areas in Tanzania. A large variety of tribes (54) was represented in the sample including Mnyakyusa (n=52), Mkinga (n=17) and Mchaga (n=10). The parents' education backgrounds varied, but all were literate. Almost everyone (98.4%) had seen someone with albinism and 87.7% knew someone with albinism. Of the respondents 4.2% indicated to have a family member with albinism. Ages varied between 13 and 26 years old, with an average age of 16.35. There are no significant differences between the samples of the two different interventions.

<b>Variables</b>		<b>Respondents (n=192)</b>
<i>School</i>	<i>1</i>	28 (14.6%)
	<i>2</i>	69 (35.9%)
	<i>3</i>	55 (28.6%)
	<i>4</i>	40 (20.8%)
<i>Gender</i>	<i>Men</i>	100 (52.1%)
	<i>Women</i>	92 (47.9%)
<i>Form</i>	<i>One</i>	43 (22.4%)
	<i>Two</i>	22 (11.5%)
	<i>Three</i>	85 (44.3%)
	<i>Four</i>	42 (21.9%)
<i>Seen someone with albinism</i>	<i>No</i>	3 (1.6%)
	<i>Yes</i>	189 (98.4%)
<i>Know someone with albinism</i>	<i>No</i>	24 (12.3%)
	<i>Yes</i>	168 (87.7%)
<i>Family member with albinism</i>	<i>No</i>	184 (95.8%)

	Yes	8 (4.2%)	
		Mother	Father
Education level parents	Literate	38 (19.7%)	33 (16.9%)
	primary school	37 (19.1%)	22 (11.6%)
	ordinary level	51 (26.6%)	42 (21.7%)
	advanced level	10 (5.3%)	15 (7.9%)
	higher education	44 (22.9%)	66 (34.4%)
	don't know	12 (6.4%)	14 (7.4%)

Table 1 Demographics

## SOCIAL DISTANCE

The reliability of the ASDS-A scale is  $\alpha=.941$  in the pre-test (12 items). No significant difference was found between respondents who filled out the substitute survey and survey 1. Using the ASDS-A sum score no significant change was found within the sample after the contact intervention. Also, on individual items there was no significant change after the contact intervention.

With regard to the education intervention, a significant change was found after this intervention ( $Z=-3.196, p=0.001$ ). Item-wise a significant decrease of social distance took place on four items: S-04 How would you feel having someone like John/Joyce, who is older, as a teacher?; S-05 How would you feel to have someone like John/Joyce as a family member?; S-07 How would you feel helping someone like John/Joyce with a question about school work?; S-10 How would you feel if your friend knew that you had someone like John/Joyce in your family? (See Table 2).

When comparing the outcomes of the two interventions, the necessity of equal samples for both interventions was met, no significant difference was found on the ASDS-A before the intervention between the intervention groups. However, also after the intervention no significant difference between the interventions was found on the sum-scale and item-wise. Additionally, there was no significant difference between the intervention groups on the difference variable sum-scale. Only item-wise, the difference variable, showed one significant difference on item S-04. How would you feel having someone like John/Joyce, who is older as a teacher? ( $Z=-3,052, p=.002$ ).

Items	Baseline	Contact	Education
	Mean	Mean	Mean
S-01 How would you feel to visit a house of someone like John/Joyce?	1.26	1.25	1.24
S-02 How would you feel to be in the same class with someone like John/Joyce?	1.32	1.32	1.19
S-03 How would you feel to sit next to someone like John/Joyce in class?	1.31	1.28	1.22
S-04 How would you feel having someone like John/Joyce, who is older, as a teacher?	1.31	1.32	1.23*
S-05 How would you feel to have someone like John/Joyce as a family member?	1.37	1.29	1.28*
S-06 How about introducing John/Joyce to your friends?	1.33	1.24	1.31
S-07 How would you feel helping someone like John/Joyce with a question about school work?	1.3	1.22	1.2*
S-08 How would you feel to have John/Joyce as a friend?	1.27	1.22	1.2
S-09 How would you feel shaking hands with someone like John/Joyce?	1.26	1.25	1.22
S-10 How would you feel if your friend knew that you had someone like John/Joyce in your family?	1.4	1.31	1.29*
S-11 How would you feel if someone like John/Joyce was your teammate when playing games/sports?	1.33	1.31	1.23
S-12 How would you feel being in the same school with someone like John/Joyce?	1.27	1.23	1.15

Table 2 ASDS-A

## KNOWLEDGE

According to the McNemars test there was no significant change in knowledge after the contact intervention. After the education intervention four items portrayed a significant difference in knowledge (see \* in Table 3 below): K-01 Do you know the reason for albinism?; K-02 Do you think albinism is inherited?; K-03 Do you know what to do to help someone with albinism?; K-12 A person with albinism does not die but just disappears?.

Subsequently, the intervention effects were compared. Before the interventions the intervention groups are equal according to Pearsons Chi-Square, except for item K-11 'A person with albinism can get skin cancer from being in the sun?' on which the education intervention group portrayed to be more knowledgeable. After the intervention there was a significant difference between the contact and the education sample on four items (see highest underlined scores in Table 3 below). In three cases the education intervention group scored higher than the contact intervention group: K-01 Do you know the reason for albinism?; K-02 Do you think albinism is inherited?; K-11 A person with albinism can get skin cancer from being in the sun? In one case the contact intervention group scored higher: K-06 A person with albinism can get a child without albinism?

The pragmatic sum scales (K-04 up to K-12) ( $\alpha=.582$ ) of both interventions portrayed significantly improved correct knowledge concerning albinism (contact intervention  $Z=-1.990$ ,  $p=0.047$ ; education intervention  $Z=-2.085$ ,  $p=0.037$ ). Before and after the intervention no significant difference between intervention groups was found on the pragmatic knowledge sum scale.

Items	Pre-test	Contact	Education
<i>K-01 Do you know the reason for albinism?</i>	34,5	33,8	<u>56,6*</u>
<i>K-02 Do you think albinism is inherited?</i>	30,2	31	<u>50,6*</u>
<i>K-03 Do you know what to do to help someone with albinism?</i>	51,9	66,7	64,4*
<i>K-04 Do you think albinism is contagious?</i>	80,2	87,1	83,2
<i>K-05 Do you think a person with albinism will turn blind?</i>	44,3	50,6	45,3
<i>K-06 A person with albinism can get a child without albinism?</i>	85,6	<u>94,7</u>	85,4
<i>K-07 Persons with albinism can learn how to read and write?</i>	98	98,9	99
<i>K-08 People with albinism need to eat special food?</i>	43,1	52,7	51,1
<i>K-09 A person with albinism can go to a normal school?</i>	89	96,8	91,8
<i>K-10 A person with albinism is bewitched?</i>	96,1	95,8	99
<i>K-11 A person with albinism can get skin cancer from being in the sun?</i>	84	75,3	<u>94,8</u>
<i>K-12 A person with albinism does not die but just disappears?</i>	81,4	90,4	93,8*

Table 3 Knowledge items

## ENTERTAINMENT

The reliability of the entertainment scale is  $\alpha=0.594$ . According to Terwee et al. (2007) this is below the criterion for good internal consistency ( $0.7<$ ) and the scale is therefore not reliable. When looking at pragmatic scale level and item level no difference in entertainment level between the interventions can be found (Table 4).

Items	Contact	Education
	Mean	Mean
<i>E-01 The show was very entertaining</i>	3.86	3.91
<i>E-02 I had the sense of being pulled right into the show</i>	4.11	4.11
<i>E-05 I very much enjoyed the show</i>	4.39	4.39
<i>E-06 The show was very involving</i>	4.4	4.45
<i>E-03 The show did not interest me*</i>	3.89	3.93
<i>E-04 I wasn't involved in the show*</i>	3.58	3.74

Table 4 Entertainment items (\*recoded items)

#### CORRELATION BETWEEN SCALES

There is a low correlation between the Knowledge items and ASDS-A Correlation pre-test .215 ( $p=.05$ ), post-test .246 ( $p=001$ ).

#### DIFFERENCES BETWEEN GROUPS

When looking for differences in scores between different groups within the sample one finds a significant difference between the scores of boys and girls on the knowledge questions after the intervention (on the total sample) ( $p=0.002$ ), when specifying the intervention groups one finds there is a significant difference based on gender after the contact intervention ( $p=0.001$ ), and not after the education intervention ( $p=.184$ ). The boys seem to have more knowledge after the contact intervention than the girls. When looking further into this difference it seems the interventions both have been significantly effective in improving correct knowledge for the boys, but have not been significantly effective for the girls.

The school year that the students attend made a significant difference on the knowledge level and ASDS-A post-test ( $p=0.001$ , and  $p=.018$ ). When comparing *forms*, a significant difference is found on the knowledge re test between *form 1* and *4* and the ASDS-A before and after the intervention (lower mean ranks for *form 4*). There is also a significant difference between *form 1* and *3* on the re-test of the knowledge and the ASDS-A scale (lower mean ranks for *form 3*). There is also a significant difference on the pre-test of *form 2* and *1* but *form 2* has a very low  $n$  (11).

There is a significant difference between the education level of the father and the post knowledge scale.

#### EXTRA SURVEY

In school 4 respondents were asked to watch both movies. When asked comparison question 1 (Which movie did you like more?) in the extra survey, 32 respondents preferred the contact movie, and 10 the education movie. Respondents mentioned they preferred the contact movie because: 'they learned people with albinism are normal people/like you and I' ( $n=10$ ), people with albinism marrying people without albinism ( $n=6$ ), they learned people with albinism could have children without albinism ( $n=5$ ) and it was about assisting people with albinism ( $n=5$ ). Among the respondents who preferred the education movie the most often provided reason was that the movie was about the fact that people with albinism are normal human beings/like you and I ( $n=5$ ), and because people with albinism should not be discriminated ( $n=5$ ).

As a result of comparison question 2 (From which movie did you learn the most?) 30 respondents preferred the contact movie and 11 the education movie (1 missing). The respondents who found the contact movie more educational, expressed this was among others because it was about real-life situations ( $n=5$ ), positive situations such as the marriage of someone with albinism ( $n=3$ ), or negative such as discrimination ( $n=8$ ). The reason for stating one learned more from the

education movie was mostly that this intervention explains the cause of albinism (n=4) and people with albinism are normal human beings (n=4).

#### QUALITATIVE DATA

In total 16 FGDs were conducted, in which 80 respondents participated (43 men, 37 women).

#### FOCUS GROUP DISCUSSION AFTER CONTACT INTERVENTION

When discussing the contact intervention, respondents mostly referred to two of the five characters who were portrayed in the movie: the *form* four student (named specifically in seven FGDs), and the fish trader (named specifically in six FGDs). The student might be recalled because she was in the same phase of life as the respondents, secondary school students. Through these two characters, respondents seem to have realised that people with albinism have the same capabilities as people without albinism. This view was confirmed in six FGDs. Two illustrative quotes:

*... now we learn that albinos can stand on their own without even the help of anyone else and can make changes, like the student in form four going to the NECTA examination on the eleventh month (Student, male).*

*There was a fish trader who was stigmatized by some people that, even with his business, people would not buy something from [someone with] his condition. However, he still has clients and he is well known in the community. So, he values his business just like other people. Like normal people (Student, female).*

Some themes recurred in the interviews such as the capabilities of people with albinism and marriage. The majority of the participants remembered the fish trader because of his marriage to someone without albinism (named in seven focus group discussions) and his children without albinism (in six focus group discussions). This was a recurring theme in the FGDs, respondents for example mentioned the following about this:

*I was surprised, I do not believe at all that somebody would agree to marry somebody who has albinism. [...] that [a person with albinism marrying someone without albinism] surprised me and made me see that each and everything is possible under the sun (Student, male).*

*What we've been able to learn from the movie is that if an albino gets married to another, he can be found with a non-albino child. But also, we should not exclude albinism because they are capable of doing things that we and others with normal skin can do (Student, male).*

One interviewee directly related this lesson to himself:

*What I have come to discover and know more about after watching the movie is that, I realized that I could marry an albino and then we would have beautiful children like the albino who married a non-albino woman and gave birth to three children who are normal non-albinos (Student, male).*

Commenting on the issue of marriage, one interviewee stated that people with albinism also have the right to be loved:

*... even this albino has the right to be loved as normal people [...]. Before the movie I thought albino marrying an ordinary man is a dream, so why? It's hard to be accepted by someone with whom a relationship is difficult. And that's why we see even her parents, said to their daughter: why would you marry someone with the skin of an albino, but the girl stood in her position saying I love this one. That fact has shown that even albinism has the power to be loved (Student, female).*

In one case participants had to laugh when they saw the fish trader in the movie, later they explained that they laughed because they thought people with albinism were too weak to sell fish, as one interviewee said:

*It is precisely here [when the students were laughing because of the movie] that we see why a person with albinism, even in the ordinary society around us becomes oppressed by the people. He is considered a weak person who can't work, we say you can't compare him to a normal coloured (person), we think he is a man who can't do market business, that he can't sell fish, which is why even when people take the picture he sells fish and start laughing (Student, male).*

Respondents stated that people with albinism should not be discriminated (in eight focus group discussions), and they should be supported (eight focus group discussions). In all focus group discussions (ten) respondents discussed that people with albinism are normal people/like them/human, illustrated by the following quote:

*They can do things that are good for the world, because there are some people who are albino, there are doctors who are albinos and in many services there are workers with albinism. That means, albinos are people like us, have all rights like us, let us say: rights to live, worship and all rights that humans have in this world (Student, female).*

When the respondents were asked what was missing in the movie the following issues came up. Firstly, in two FGDs the respondent mentioned that stories about the problems of people with albinism should be included. The bad treatment of people with albinism was discussed in six FGDs and in seven FGDs respondents referred to superstitious beliefs about people with albinism. Secondly, in one focus group discussion it was mentioned that more should be explained about the cause of albinism, which was endorsed by the questions respondents had after the intervention: three times participants asked for more explanation about the cause of albinism. Besides that, three times respondents asked about the eye problems of people with albinism, other questions were asked about the skin of people with albinism and how to assist students with albinism. One respondent asked afterwards if the body parts of people with albinism bring good fortune.

#### FOCUS GROUP DISCUSSION AFTER EDUCATION INTERVENTION

Main themes after the education intervention were the cause of albinism, discrimination of people with albinism, and witchcraft. After the education intervention the respondents discussed the cause of albinism (in all ten FGDs). As an example, one respondent explained that before the intervention they thought the cause of albinism was witchcraft: *"but when I saw the movie I learned that, I have learned that it is inherited from parents (Student, male)"*. However, in two FGDs respondents provided the wrong explanation about the cause of albinism, one respondent expressed: albinism is caused by parents lacking vitamin G and another thought albinism was caused by a parasite.

Respondents often stated that one should not discriminate people with albinism (mentioned in seven out of eight FGDs) and people with albinism are human beings/like you and I/normal people (mentioned in all eight FGDs). This was summarized by the two quotes below:

*So, first we were isolating them [people with albinism] as if they were nobody. We were isolating them like they are not human creatures, but after the education we got, you know... We can now interact with them (Student, female).*

*Albinos, at first, we were excluding them but now I have learned that albinos are just like other people and they should not be isolated (Student, female).*

In all eight FGDs witchcraft in general and some superstitious beliefs were discussed. The following myths came up in the FGDs:

- Body parts of people with albinism bring good fortune
- People with albinism do not die but disappear
- Albinism brings bad fortune
- People with albinism do not have value
- Albinism is contagious (through touching)
- People with albinism are bewitched

Some respondents learned that they will not get rich by selling body parts of people with albinism, as stated by the respondent below:

*I am going to talk about what I learned. [...] I thought that, if you get the albino albinism organ, you can get wealth. So, after watching that movie now I have got the confirmation... That's it, we cannot get wealth from albinos (Student, male).*

When asked what was missing in the movie, it was suggested more information should be provided about the eyes of people with albinism (in two FGDs) and it was suggested to provide more information on the skin of people with albinism (in one FGD). Additionally, in two FGDs respondents asked questions about the eyes of people with albinism, and in one FGD someone mentioned not to have understood part of the explanation about genetics. Interestingly, in one FGD it is suggested to show people with albinism that have succeeded: in another FGD it was mentioned they missed someone with albinism in the movie: “he (a person with albinism) could explain that, he is just a person like us and he could be some of thing that he or she may like to prefer like other people who have not got albinism (Student, female)”.

The traditional healers in the movie were named in four FGDs, the medical doctor in three FGDs). The two traditional healers in the movie explain that people with albinism are just normal human beings and that the myths, about for example the body parts of people with albinism, are not true. The medical doctor explains about the scientific genetic causes of albinism in the movie. The explanation of these healers seemed to have made an impression on the respondents.

#### COMPARISON OF INTERVENTIONS

When asking the respondents in school 4, who saw both the movies, which movie they preferred, 14 out of 21 respondents preferred the contact intervention. The following quote summarizes the respondents' view on the contact intervention:

*Yeah! It [the contact movie] has taught us more than the first [education movie] because we have seen a person with albinism can marry a non-albino person and may give birth to a non-albino child (Student, male).*

To which another student added:

*I [liked the] second movie [contact movie most], because it teaches me that someone with albinism can do great things, you see? As far as I knew a person with albinism maybe cannot read, could not possibly end up in lower education, see? Like the sister (student with albinism in the movie) who proceeded to form four see? So that's what I learned (Student, male).*

However, the respondents who preferred the contact movie also noticed that they learned a lot from the doctor in the other movie who explained about albinism. Even though respondents are still wondering after the two interventions how albinism happens. Seven out of 21 respondents preferred the education movie, because they liked the proper explanation about albinism.

## DISCUSSION

This study evaluated the impact of two strategies to reduce albinism-related stigma and increase knowledge on albinism in a high school setting in Tanzania: the contact strategy and the education strategy. Research focussing on comparing the contact and education strategy is limited and has mainly focused on mental health-related stigma in the US (Corrigan, et al., 2001; Corrigan, et al., 2002; Corrigan, et al., 2007). The effect of the strategies has been measured through mixed methods: the ASDS-A, Knowledge items, Entertainment items and FGDs.

Firstly, through quantitative methods this study found the following. The contact intervention did not have significant influence on the change in attitude towards people with albinism measured through the ASDS-A. These findings contradict other studies in which contact interventions were associated with improved attitudes (Pettigrew & Tropp, 2006; Yamaguchi, et al., 2013). The contact intervention did cause a significant increase in correct knowledge on albinism. The education intervention had a significant influence in reducing the student's social distance towards people with albinism and increased their levels of correct knowledge. Our findings are not in line with previous studies that suggest that an educational intervention by itself is not very effective in influencing stigmatizing attitudes (Brown, et al., 2003; Corrigan, et al., 2001; Corrigan, et al., 2002; Corrigan & O'Shaughnessy, 2007; Stangl, et al., 2012; Thornicroft, et al., 2008; Herek, et al., 2002). Penn, et al, for instance state that educational strategies alone, like this one, are unlikely to affect all aspects of psychiatric stigma and that other strategies, including personal contact, may be required. Even though the contact strategy was not significantly effective in reducing social distance towards people with albinism and the education strategy was, no significant difference could be found between the outcomes of both interventions, nor between their effects. Therefore, it can not be concluded that one intervention is more effective than the other.

Secondly, in terms of entertainment value of the intervention, quantitative findings show that respondents found both interventions entertaining. However, one should be careful drawing conclusions from the entertainment scale because of the low reliability of the scale. Qualitative findings indicate that respondents preferred the contact intervention over the education intervention.

Thirdly, the focus group discussions after the interventions provided us with the following insight. After the contact intervention respondents kept on emphasizing that people with albinism are normal human beings. This might point to an effect of the intervention in reducing stigmatizing attitudes. The characters that were mostly recalled after the contact intervention, a *form* four student and a fish trader, might be recalled because respondents identify with aspects of the lives of these characteristics. Identification with characters in interventions can influence behavioural change (Basil, 1996; Kuhlman, et al., 2008). These characters named above seemed to be the strength of the contact



intervention, living up to the expectations of a contact intervention to generate empathy and correct misinformation (Allport, 1954; Brown, et al., 2003; Pettigrew, 1998).

In relation to the education intervention, the qualitative findings show that especially learning about the cause of albinism was important to the respondents. This is in accordance with the recommendation of Masanja, Mvena and Kayunze (2014) who recommend the provision of knowledge to improve the attitudes of children towards PWA and goes against Brocco (2015), who stated that even though (bio) medical knowledge about albinism was lacking in the community, perceptions about PWA did change. As recommended by Heijnders and Van der Meij (2006) and Penn, et al. (2003) the education intervention succeeded in providing respondents with enough disconfirming knowledge to change people's beliefs and stereotypes, as could be read in the qualitative findings.

Additionally, the use of the extra survey provided us with the opportunity to conclude that the survey did not function as an intervention itself. Respondents who filled out the extra survey before the intervention instead of the pre-test did not differ in outcome on the post-test compared to the respondents that filled out the pre-test. This contrary to the possible limitations of the measurement instrument as presented in de Groot et al. (2020).

#### LIMITATIONS

This research is subject to several limitations. Firstly, future research is necessary to determine the outcomes of these types of interventions on the longer term. Secondly, one needs to be careful with generalizing the outcomes of this research: the data collection took place in private high schools which highly effects the sample, e.g. the education level of the parents of the children is relatively high: which can influence the outcomes. Thirdly, one should be aware the attitudes of the respondents were only measured through a social distance scale, which might be sensitive to socially desirable answering but also does not tell us anything about how people would actually behave towards people with albinism. Fourthly, it should be noted that both strategies were filmed and not do not consist of a live intervention. A factor which could also have influenced the outcome of the interventions, even though other research has proven this does not have an influence (Reinke, Corrigan, Leonhard, Lundin, & Kubiak, 2004).

#### CONCLUSION

The outcomes of this study show the importance of the implementation of, and research into stigma reduction interventions. Findings suggest among others that the education strategy, in the form of a short educational movie, on albinism can be effective in reducing stigmatizing attitudes and improving knowledge among high school students in Tanzania towards people with albinism. Since these findings contradict some past research, that has mostly been carried out in the US and Europe, it would be of interest to set up a larger research on this topic and to research the outcomes of different stigma reduction strategies in other contexts and in relation to other stigmatizing attitudes. Qualitative findings also showed many positive responses to the contact strategy. Elements that were missing in one strategy could be found in the other, which points again to the complementary value of both strategies. Giving the positive responses with regards to different aspects of the contact intervention and the education intervention, we would recommend using both, since a combination of these two interventions also have proven successful in the past (Brown, et al., 2003; Peters, et al., 2015). This would open up opportunities for a comparative research. Additionally, the advantages of the use of these films were that they are easily to disseminate and does not require the presence of a teacher (for the education intervention) nor a person with albinism (for the contact intervention), however we should consider that not all schools in Tanzania will have the means and/or infrastructure in place to play these movies.

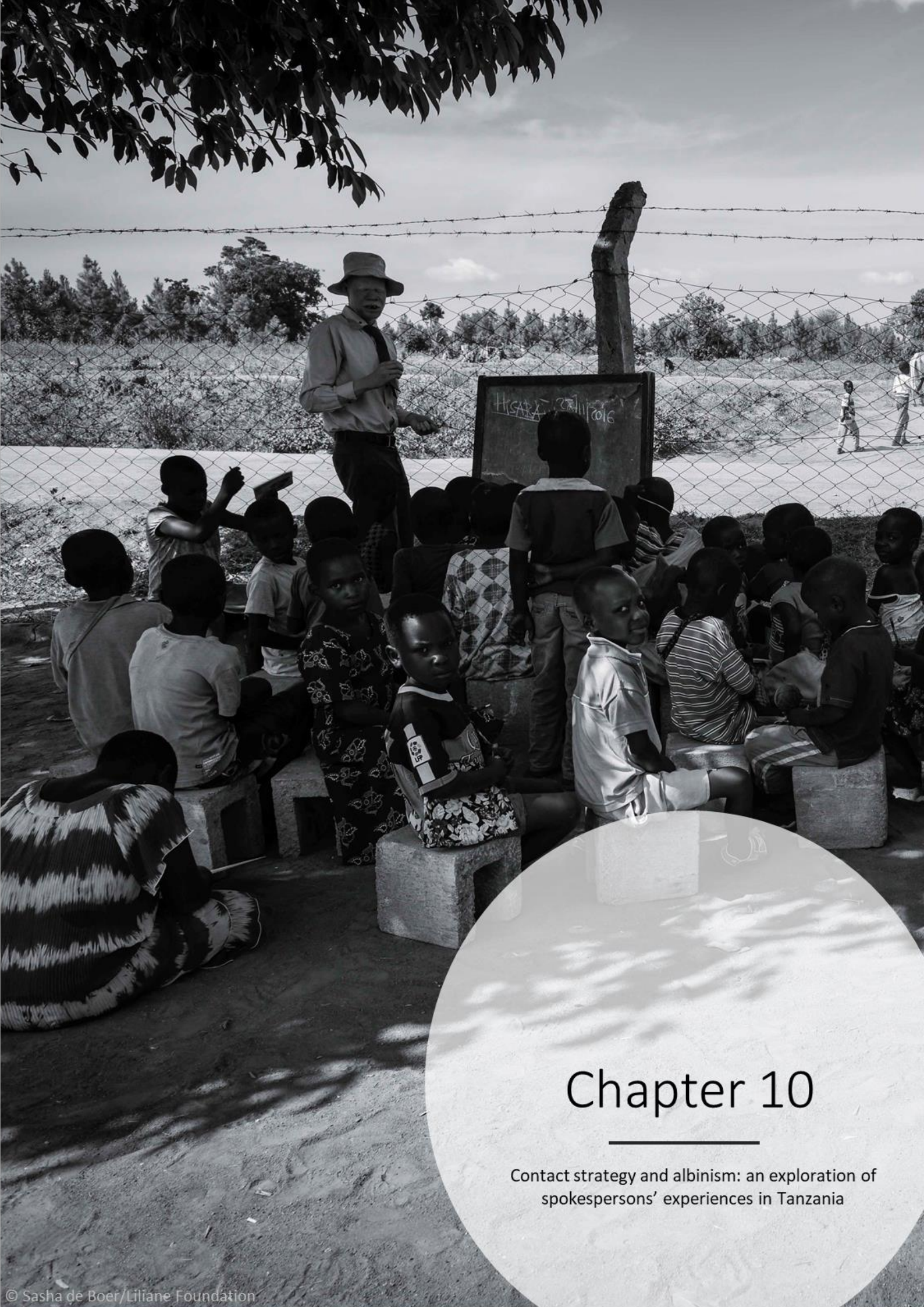
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## Chapter 10

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Contact strategy and albinism: an exploration of  
spokespersons' experiences in Tanzania

## CHAPTER 10: CONTACT STRATEGY AND ALBINISM: AN EXPLORATION OF SPOKESPERSONS' EXPERIENCES IN TANZANIA

*Under review as: de Groot, T., Peters, R., Jacquet, W., Mesaki, S., & Meurs, P. (under review). Contact strategy and albinism: an exploration of spokespersons' experiences in Tanzania. Disability Studies Quarterly.*

This study is the first to focus on the experience of people with albinism presenting on their own condition in a contact intervention to reduce stigmatization related to albinism in Tanzania. Semi-structured in-depth interviews were conducted with 13 so-called spokespersons with albinism and the interviews were analysed thematically. On a personal level, respondents mainly had positive experiences as spokespersons: the work brought them satisfaction, made them proud, and provided them with opportunities for personal development. On a community level the respondents experienced a reduction in stigma, according to them the following mechanisms of the contact intervention achieved this: their presentation showed the community a good example of an educated person with albinism, their ability to speak in public and their humanity. According to the respondents, important characteristics of being a spokesperson were: confidence, knowledge about albinism, knowing and accepting yourself, a good level of education, status, and the ability to 'read' the audience. The article concludes that being a spokesperson completely counteracts people's expectations of those with albinism. Being a spokesperson is an act of agency and a demonstration of this agency to others. Proper training is necessary to prepare spokespersons for their job and to develop effective contact interventions.

Keywords: Health-related stigma, albinism, Tanzania, contact strategy, stigma-reduction intervention

## INTRODUCTION

It is estimated that one in 2,673 people in Tanzania has albinism. According to the latest national census in Tanzania, 16,477 people have albinism (Franklin, Lund, Bradbury-Jones, & Taylor, 2018). In reality this number might be higher, as people might fear reporting those with albinism in the census due to the perceived risk of discrimination (Lund & Roberts, 2018). Due to a shortage of melanin, people with albinism have a partial or complete lack of pigment. People with albinism have pale-coloured skin, hair and eyes. People with albinism often suffer from skin cancer because their skin is highly vulnerable to ultraviolet radiation, (Hong, Zeeb, & Repacholi, 2006; Kromberg, 2018a). Hypopigmentation of the eyes causes low vision for people with albinism, the eyes of people with albinism make unintentional movements (involuntary nystagmus), and are highly sensitive to light (Kromberg, 2018a; Yahalom, et al., 2012).

In a country where most people have dark skin, the light skin colour of people with albinism makes them stand out, termed 'the visible difference' by Baker (2011). This has given rise to the many beliefs and superstitions about albinism in Tanzania. For example, albinism is perceived a curse and a sign of bad luck (Bucaro, 2010), people with albinism are believed to have special powers and body parts or people with albinism are thought to bring good fortune (Bryceson, Jønsson, & Sherrington, 2010; Cruz-Inigo, Ladizinski, & Sethi, 2011). People with albinism are believed to be ghosts (Baker, Lund, Nyathi, & Taylor, 2010) and 'disappear' instead of die (Baker, et al., 2010; Lund & Gaigher, 2002). These beliefs are connected to the language people use. Terms used for people with albinism are 'zeruzeru' (ghosts), 'mzungu' (white person) and 'dili' ('deal', as it is believed that the body parts of people with albinism bring good fortune and therefore they are seen as valuable goods) (Brocco, 2016). These beliefs and superstitions have contributed to the stigma towards people with albinism in Tanzania.

People with albinism in Tanzania are, in general, treated badly which is a violation of their basic human rights as described in the United Nations Convention on the Rights of Persons with Disabilities (United Nations Human Rights Council, 2013). In Tanzania people with albinism have been physically attacked due to their condition because of superstition (Lynch, Lund, & Massah, 2014). According to a report by Under The Same Sun (UTSS), an NGO that supports people with albinism in Tanzania, there were 182 attacks, of which 76 were fatal, between 2000 and January 2019 (UTSS, 2019). It has been said that babies born with albinism have been murdered (International Bar Association, 2017) because of the belief that they are physically unable to support their families (Bryceson, et al., 2010) or because they are believed to be evil spirits (Machoko, 2013). The United Nations Human Rights Council (UNHCR) states that people with albinism cannot fully and effectively participate in society, and that their dignity is not respected (United Nations Human Rights Council, 2013).

### THE CONTACT STRATEGY IN STIGMA REDUCTION INTERVENTIONS (SRI)

A wide range of SRI have been developed and assessed for a variety of health-related stigmas such as HIV/AIDS, leprosy and mental illnesses (Brown, Macintyre, & Trujillo, 2003; Heijnders & van der Meij, 2006; Peters, et al., 2015; van Brakel, et al., 2019). Health-related stigma is an anticipated or experienced social process of exclusion, rejection, blame or devaluation caused by experience, perception or reasonable anticipation of a negative social judgement about a person or group on the basis of the identification with a health-related condition (Weiss, Ramakrishna, & Somma, 2006).

Previous research shows that an effective intervention to reduce stigma exists in a combination of education about the condition and contact with a person with the condition (Brown, et al., 2003; Cross, Heijnders, Dalal, Sermrittirong, & Mak, 2011). As a strategy, education involves providing knowledge about the condition to rectify the misconceptions about it. Research in changing attitudes towards people with stigmatizing conditions mostly focuses on the contact strategy (Allport,



1954; Paluck, Green, & Green, 2018; Zhou, Page-Gould, Aron, Moyer, & Hewstone, 2018). The contact strategy provides people with an opportunity to get to know someone with a stigmatizing condition (Corrigan & O'Shaughnessy, 2007). Contact refers to:

*All interactions between the public and persons affected, with the specific objective to reduce stigmatising attitudes. Contact can either be direct and face-to-face, or indirect (e.g. through the media). Interventions derived from the contact strategy can be targeted at groups, individuals and, as some authors have proposed, even to an entire nation. (Heijnders & van der Meij, 2006, p. 359)*

The effectiveness of stigma reduction through the contact strategy can be explained by the personal relationship with a stigmatized person that helps to demystify worldviews, correct any misinformation and generate empathy (Brown, et al., 2003; Zhou, Page-Gould, Aron, Moyer, & Hewstone, 2018).

Through the contact strategy, people with a stigmatizing condition play an active role in reducing stigma (Howarth, 2006). The knowledge and experience of the stigmatized can be used to develop effective SRI which then in turn, can boost the morale (Cook, Purdie-Vaughns, Meyer, & Busch, 2013; Heijnders & van der Meij, 2006; Lusli, et al., 2015; Peters, Zweekhorst, van Brakel, Bunders, & Irwanto, 2016; UNAIDS, 2000).

A substantial amount of research on the contact strategy has been carried out. However, none of this research has focused on the effectiveness of the contact strategy in relation to the cultural specific situation of albinism on the African continent. When wanting to improve the wellbeing of people with albinism it is of major importance to reduce stigmatization, therefore it could prove valuable to further investigate the effects of the contact strategy (de Groot, Meurs & Jacquet, 2019; Kromberg, 2018b).

#### PERSONAL EFFECTS OF THE CONTACT STRATEGY

The personal effect of presenting on one's stigma is often researched in the light of disclosure (Muula & Mfutso-Bengo, 2005; Paxton, 2002a; Stutterheim, et al., 2011). Disclosure is described as the presenting of a stigmatized condition which would otherwise be invisible. Many stigmatizing conditions, such as HIV/AIDS or a mental illness, are 'invisible, or can be invisible for most of the time, so in cases of 'invisible stigma' it is necessary for spokespersons to be willing to disclose their conditions (Corrigan & O'Shaughnessy, 2007).

Albinism is a visible health-related stigma which cannot be hidden. Therefore, the advantages and disadvantages of presenting in a contact-based intervention can differ from those of people with a concealable condition. Especially, since little is known about the way in which people with albinism cope in the stigmatizing society around them (Kromberg, 2018b), it is important to know more about the personal effect of presenting on ones' condition in that stigmatizing society.

#### CRITIQUES ON THE CONTACT STRATEGY

There are some critiques of the contact strategy. It is hard to roll out a contact intervention on a large scale since it requires the involvement of people who are prepared to come forward (Corrigan & O'Shaughnessy, 2007). Furthermore, the so-called 'spokespersons' (the people with a stigmatizing condition who present themselves in a contact intervention), need to be trained and must be willing to talk about their condition (Corrigan & O'Shaughnessy, 2007; Stuart, 2006). Asking people to disclose private information can have negative outcomes (Boevink, in Heijnders & van der Meij, 2006) and one must ensure that when breaking down stereotypes new ones do not arise (Howarth, 2006; Macrae, Bodenhausen, Milne, & Jetten, 1994).

In a country such as Tanzania, where people with albinism are stigmatized, it can be difficult for people with albinism to present themselves in unfamiliar communities, because it could lead to

further discrimination and physical harm. Therefore, the question remains as to whether organizations can use contact strategies without placing a heavy burden on the stigmatized.

Previous research has addressed a variety of aspects of contact interventions. Its' dynamics have been analysed and its' effectiveness to reduce health-related stigma has been demonstrated (Brown, et al., 2003; Cross, et al., 2011; Heijnders & van der Meij, 2006), however not yet in relation to albinism in Tanzania. Little research addressed the perspective of a spokesperson in a contact strategy. Only the aspect of disclosure, in relation to otherwise invisible conditions, has been discussed (Corrigan & O'Shaughnessy, 2007; Muula & Mfutso-Bengo, 2005; Paxton, 2002a; Stutterheim, et al., 2011). Because albinism is a visible condition that cannot be hidden, it is of importance to look into the effects of presenting on albinism-related stigma for the spokespersons. Therefore, the aim of this study was to describe the spokespersons' experiences related to the contact intervention on personal and community level. Through this research recommendations can be provided for the development of future contact interventions.

## METHOD

To gain insight into the experience of being a spokesperson in the SRI on albinism, individual in-depth interviews were conducted with spokespersons with albinism.

### STUDY POPULATION AND SELECTION

The research was carried out with help from two Tanzanian organizations, the Tanzanian Albinism Society (TAS) and Under the Same Sun (UTSS), who assist people with albinism in all aspects of life: education, information, health care and awareness raising in the community. The respondents were found with the help of these organizations, who referred the researcher to their members who functioned as spokespersons. All respondents worked on a voluntary or paid basis for TAS and/or UTSS. Since TAS and UTSS are the main organizations in Tanzania to work with spokespersons with albinism for their awareness raising campaigns, the spokesperson connected to them seemed to form a good base to gain a general insight in spokesperson's' experience. Semi-structured in-depth interviews were conducted with 13 people who had presented about albinism. Through in-depth interviews, qualitative data was gathered up to a point that the researchers concluded that no more data had to be collected to provide an overview of spokespersons' experiences.

### DATA COLLECTION

Because of the explorative nature of the study a semi-structured interview guideline was designed based on the literature on contact strategy and the implications of disclosure as set out by Corrigan and Matthews (2003). Themes included: a) the experienced influence of albinism on their lives, b) the personal experience of being a spokesperson, c) the experienced outcomes of the contact intervention, d) characteristics of a spokesperson. The first theme that was discussed in the interview (a. the experienced influence of albinism on the lives of people with albinism) was analysed and the results are published in the article by de Groot, Meurs and Jacquet (2019). The focus of the current paper is on the other three themes. This focus is essential if we want to understand the experience of spokespersons in a contact intervention and through this article we want to emphasize the importance of questioning the influence of a contact intervention on spokespersons themselves.

Although most of the spokespersons (three females, ten males) were fluent in English, two interviews were conducted in Swahili. One interview took place with two spokespersons simultaneously. Interviews lasted between 30 up to 98 minutes and took place at the respondents' house, workplace of the respondent or at a café close to the respondents' house.

## DATA ANALYSIS

The interviews were recorded with a voice recorder, transcribed and translated by the first author. The interviews were then coded and organised by making use of recurring themes in the interviews, the analysis was repeated through an iterative process, followed by a comparison and summarization of the data to draw conclusions. This thematic analysis was carried out with Atlas.ti 8.

## ETHICAL CONSIDERATIONS

The ethical review board of the Vrije Universiteit van Brussel decided that the research was exempt from ethical approval since the respondents with albinism are healthy volunteers and their condition does not limit them from making informed decisions during the research. The study was approved by the Tanzanian Commission for Science and Technology (COSTECH). Respondents were recruited through organizations who work with the contact strategy, who supported and endorsed this research. Participants were informed about the aim of the research beforehand and that their participation was voluntarily. Written consent was provided by all respondents. The focus of the current research could in itself be described as an ethical issue: what are the consequences of being a spokesperson for the people with albinism themselves? We will deliberate on this in the discussion.

## RESULTS

### INTRODUCING THE SPOKESPERSONS

*'I call myself a professor in albinism, because I know albinism by reading about it and living with it. So, practice and theory has merged in the same person.'* (Interview 6, male)

The respondent above referred to himself as a professor in albinism by being a spokesperson. He is one of the 13 respondents (three females, ten males) in this research explaining about their role. The experience of the spokespersons varied from having presented in communities, school classes and churches to awareness raising events in rural and urban areas. Some had recently started while others have been a spokesperson for over 20 years. The respondents' ages varied between 25 and 55 (3 missing). The respondents live in different regions of Tanzania (Dar es Salaam, Mbeya, Kilimanjaro, Kigoma, Mara and Mwanza) and have varied educational backgrounds, ranging from teacher training to environmental sciences, however all of them finished high school and completed or were completing a form of higher education. The spokespersons interviewed were all at different phases of life, some were studying, others were working and their employment varied. Five respondents were, or were training to be, teachers. Four were working, and were paid (sometimes part time), to raise awareness of albinism, while for ten of the respondents being a spokesperson was voluntary. Some participants were used to being interviewed, especially by the media.

### PERSONAL EXPERIENCE OF BEING A SPOKESPERSON

During the interviews several feelings and experiences about being a spokesperson came up. Feelings about being a spokesperson were mainly positive, respondents mentioned their work brought them satisfaction, others stated they enjoyed their work and were proud of one's activities as a spokesperson. Often the respondents saw the work they did as rewarding, and as doing something for others. People talked with pride about the work they did and their achievements in life.

Presenting as a spokesperson with albinism also came forth out of feelings of being responsible for changing the way people think about people with albinism. Nine respondents said that they felt responsible for doing something for their society and for taking the initiative in making changes in Tanzanian society. They said they wanted to help.

Being a spokesperson offered opportunities for personal development. Respondents mentioned to have gained confidence from presenting about albinism to an audience, one of these respondents describes this process as follows:

*'Another advantage is confidence. The more you talk the more you get more confidence, that is another advantage with the talking to the crowds.'* (Interview 8, male)

When discussing whether respondents sometimes felt afraid in their role as a spokesperson, most mentioned the fear of standing in front of a crowd. A few expressed how anxious they were before presenting but how they felt more positive about the experience afterwards. To some respondents, in the beginning talking about albinism felt like a taboo and talking about one's own condition was hard. Someone else described the negative effect of not talking about it and the relief talking can bring.

*'Ah, when you have a problem and you just squeeze it in, squeeze it in, squeeze it in, it just gets bigger, and then you go to bed, and you cry yourself to sleep, in the morning you just pretend everything is ok, it is not healthy.'* (Interview 5, female)

Two people brought up their fear of something happening to spokespersons because of their presentation. Respondents considered their security, but did not experience any direct personal risk or threat of violence as a consequence of their work.

*'At midnight, I can't go and present to people, I am going noon.'* (Interview 10, female)

#### MECHANISMS OF CONTACT INTERVENTION IN THE COMMUNITY

Respondents have the experience that presenting about albinism by a person with albinism will reduce stigmatizing attitudes in the community. Several mechanisms to create better understanding for people with albinism were named by the respondents: 1) through the presentations the audience is provided with a good example of an educated person with albinism, 2) it shows the ability of people with albinism to speak in public, 3) it proves the humanity of people with albinism, 4) knowledge from the experience of the spokesperson is provided, and misinformation can be corrected and 5) even friendship and feelings of empathy can be raised to achieve a reduction of stigma. But they also identified mechanisms that could backfire.

Firstly, the respondents mentioned the importance of showing to the audience an example of an educated person with albinism, since this changes people's stereotypical views that people with albinism cannot be educated or have a low level of education, as illustrated in the quote below.

*'So, people were amazed, because normally when they meet people with albinism, they meet them as if they are very weak and they are not educated.'* (Interview 2, male)

Respondents emphasise the importance of demonstrating to the audience their status, caused by having a good level of education or a job, in changing people's attitude about people with albinism. Having a certain level of education, is necessary according to the spokespersons not only to demonstrate a 'good example' but also to grab people's attention, so their presentation will be taken seriously. The importance of status arose in many interviews. This was also represented by the fact that five of the respondents wanted to become members of parliament, which is a position with high

status. In addition is suggested that a good level of education enables people to present and generate sufficient knowledge of albinism.

Secondly, besides educational level, the portrayal of the ability of people with albinism to speak in public also changes people perceptions about them:

*'You speak to them with reason and they get stunned that even people with albinism can speak this way.'* (Interview 5, female)

Thirdly, through the spokespersons, the audience experiences that people with albinism are 'human beings' and can physically touch them. From the respondent's perspective, this is key to changing the beliefs about people with albinism being ghosts, as for example described in the quote below:

*'You know, Africans have weird beliefs, if someone has always known that you are a ghost, they need to touch you, to understand that you are human.'* (Interview 5, female)

Fourthly, the respondents expressed that they not only provided theoretical knowledge but also experiential knowledge which made their presentations interesting as well as trustworthy. Another advantage of this method is that they can correct any misinformation and the audience has the opportunity to ask questions directly. The possibility to ask questions 'to the right person' is perceived as a large advantage of the contact strategy.

*'You can present, you can touch someone, and you can raise up the hand and instantly you can give answer, sharing together, delivering knowledge directly.'* (Interview 9, male)

Fifthly, respondents considered making friends a goal of the presentation. They wanted people to understand them and accept them as friends, to see them as normal and human. By raising empathy among the audience and by becoming their friends the spokespersons want to reduce stigmatization. One respondent mentioned the following about this:

*'I was making friends. So people, even my close friends would be like my advocate saying, ok he is just normal, he will not disappear, he is a normal human being, he is intelligent he is funny, has a good heart so, I was using those techniques and that helps me a lot.'* (Interview 2, male)

Respondents also noted that the mechanism of them presenting on their conditions themselves could be a disadvantage in influencing people. They assumed that some people might not trust them and think that the spokespersons are advocates for themselves, as illustrated in the quote below.

*'They (the audience) are thinking I am advocating myself. ... If I explain albinism is a lack of melanin, that is all, they say: 'what does it mean? He's advocating himself, they (the people with albinism) wanted us (the audience) to agree but it is not true, he is a less human being, he is not a human being. He is a less human being; he is a ghost'. So, to proof this issue there is a long way to go.'* (Interview 8, male)

## CHARACTERISTICS OF A SPOKESPERSON

The respondents were asked what they thought were important characteristics for being a spokesperson. The characteristics the respondents considered important in a spokesperson were: confidence, knowledge about albinism, knowing and accepting yourself, a good level of education, status, and the ability to 'read' the audience. There is an overlap between the mechanisms and the characteristics of spokespersons, specifically considering the importance of a good level of education and status, which are already explained above. The respondents noted that many people with albinism do not have these characteristics. Besides that, they pointed to the importance of proper facilitation and training for the presentation.

Confidence is considered necessary to be a good spokesperson. Firstly, to be brave enough to present and secondly, to be able to speak confidently so that people listen and trust the spokesperson. According to the respondents, many people with albinism lack the confidence to be a spokesperson because they often feel inferior and ashamed of their condition.

The respondents considered it crucial that a convincing spokesperson should have sufficient knowledge about albinism because it is important to explain how the condition is caused. Often people with albinism do not understand their own condition, which the respondents expressed as 'not knowing yourself'. Understanding and accepting the condition of albinism is therefore important for becoming a spokesperson, which is also intertwined with having confidence, as explained in the following quote:

*'...others they feel inferior. They have not yet accepted their condition that this is how they are, that they have to live with it. So, you find that those kinds of people do not come out front to express themselves.'* (Interview 2, male)

Spokespersons put emphasis on the characteristic of being able to 'read' the audience, to ensure a positive effect and reduce the risk to the spokespersons. Respondents stressed that the presentation should fit the audience to not create unnecessary risks:

*'I cannot go to a village somewhere and say my body is worth thousands of dollars, they will kill me. So, in whatever I present I choose. For this part of people, I give them this content, for this part of people and give them this content.'* (Interview 5, female)

In obtaining some of the characteristics such as confidence in presenting and knowledge on albinism the respondents recommend that future spokespersons be trained on albinism knowledge and in how to deliver a presentation. Being familiar with talking to crowds also provides some respondents with confidence but this is intertwined with education levels and status.

## DISCUSSION

This study is the first to focus on the experience of spokespersons in a contact intervention to reduce stigmatization related to people with albinism in Tanzania. In general spokespersons experienced many positive outcomes of the contact intervention in their society and at a personal level. As stated in the literature, the positive outcomes of a contact strategy include, demystification, correcting misinformation and generating empathy (Brown, et al., 2003), as confirmed from the experience of the spokesperson.

Past research on the contact intervention showed that personal contact can change the way people look at people with a stigmatizing condition (Brown, et al., 2003; Corrigan, Morris, Michaels, Rafacz, & Rüsck, 2012). However, the effects of the contact intervention in relation to albinism have yet to be explored (de Groot, et al., 2019). Additionally, research considering the role of the

spokespersons within a contact intervention is limited as well. Therefore, the current article shines a light on this aspect of the contact strategy.

The mechanisms named by the respondents in a contact intervention demonstrate how presentations counter the beliefs about people with albinism. People with albinism are looked down on by some people in society (Franklin, et al., 2018), and there are others who expect them to lack education, abilities, status and confidence, and believe them not to be human. For many people with albinism this becomes a self-fulfilling prophecy, and they often feel inferior because this is projected on to them by some in their society. Being a spokesperson completely counteracts people's expectations of those with albinism. Spokespersons show that people with albinism can be educated and successful. They are capable of doing things people without albinism can also do. They also demonstrate they have self-worth and that they are human. Which is in line with findings of Bradbury, et al. (2018) who stated that some of the people with albinism they interviewed in Uganda spoke about becoming role models and advocates for people with albinism being successful, among others in school and work. Being an agent in presenting about albinism goes against the acts of stigmatizing of among others denying the stigmatized agency (Howarth, 2006; Taylor, Bradbury-Jones & Lund, 2019). Being a spokesperson can therefore be seen as an act of agency and a demonstration of this agency to others. Wan (2003) calls this an activist coping strategy in raising public awareness about albinism. Nine respondents saw it as their responsibility to teach people about albinism and saw themselves as the most capable to do this job due to the mechanisms they named to change people's beliefs about albinism. This was also seen with counsellors with leprosy who felt it their responsibility to share knowledge which they have the experience and therefore trust of others when explaining about leprosy (Lusli, et al., 2015).

In the interviews, the concepts of confidence, education and status were mentioned several times. A higher level of education increases status and confidence. Higher status produces more confidence, and more confidence improves status. Together, these three aspects are important in a contact strategy because people trust and pay more attention to the spokesperson. Additionally, being a capable spokesperson also raises the status and confidence of the spokesperson themselves. This process of gaining status and confidence through being a spokesperson can counteract the status loss as a result of stigmatization (Link & Phelan, 2001).

Due to the discrimination and violence experienced by people with albinism (Bradbury-Jones, et al., 2018; Bryceson, et al., 2010), it was expected that they would be afraid of the consequences of presenting, as is the case with presenters on other health-related stigma (Boevink, in Heijnders & van der Meij, 2006; Corrigan & Matthews, 2003). Therefore, presenting as a spokesperson with albinism could form an ethical risk. However, only two respondents raised the risk of being attacked and even they saw it as something that could be overcome. Therefore, it is recommended for organizations working with spokespersons to make the necessary security arrangements and provide information about albinism to the audience in a way that does not put spokespersons at risk. Nevertheless, when organising a contact strategy, organizations are ethically obliged to ensure the spokespersons' safety, as there is a reasonable possibility of negative outcomes for people with albinism in the society and for the spokesperson at a personal level. Safety measures organizations could take are for example providing presentations in the daytime and not at night, and to be careful with providing information about the money that people earn through the trade of body parts of people with albinism.

The strength of the contact strategy is the interaction with a person with a stigmatizing condition (Corrigan & O'Shaughnessy, 2007). In the case of spokespersons with albinism, the interaction can sometimes go a step further than seeing or hearing about the experiences and abilities of stigmatized persons. Respondents mentioned that the opportunity to physically touch a person with albinism was important for people to understand the 'humanness' of the stigmatized and from this, to reduce the stigmatization. In relation to other stigmatizing conditions touching someone with

this condition is often dreaded out of fear for contagion, such as with onchocerciasis (Brieger, Oshiname, & Ososanya, 1998), leprosy (Brieger, et al., 1998; Dadun, et al., 2017; Rafferty, 2005) and HIV/AIDS (Chapman, 2000; Steward, et al., 2008). This is also the case with albinism (Baker, et al., 2010; Baker & Lund, 2017; Cruz-Inigo, et al., 2011) however, this was not named by the respondents as part of the mechanism of touching for stigma reduction. As Rafferty (2005) suggests touching someone with leprosy can show that for example a health professional is not afraid of touching someone with leprosy: this can influence the community's perception. As could also be the case with albinism, showing you can touch someone with albinism can reduce stigmatization in the community.

#### THE IMPORTANCE OF TRAINING

This study shows that people with a stigmatizing condition can play a role in reducing stigma. They are not passive agents (Cook, et al., 2013; Heijnders & van der Meij, 2006; UNAIDS, 2000). Spokespersons emphasized the importance of training in delivering a presentation for a positive outcome of the intervention. It is important that they receive proper support, e.g. by being trained on how to present themselves and what to disclose about their condition (Heijnders & van der Meij, 2006; Paxton, 2002a; Paxton, 2002b). Training should include presentation skills but also and more importantly, training about albinism. Training can improve the confidence of the people who deliver the presentations and should be provided by the organizations working with the spokespersons. People with albinism can feel ashamed of their condition and should therefore become more knowledgeable about their condition to understand that they are not cursed (Bucaro, 2010) and helped to gain confidence. The negative feelings about their condition can change through making a presentation and some respondents experience presenting as a relief. Training is also necessary to overcome possible risks for the spokespersons and should be an ethical consideration.

#### LIMITATIONS OF LIVE PRESENTATIONS

As stated by Corrigan and O'Shaughnessy (2007) implementing a contact strategy with live testimonies on a large scale presents some difficulties. In Tanzania one could think of problems with sustainability since live presentations are costly and time-consuming because it is difficult to reach everyone in the country, let alone recurrently. To change people's attitudes in the long-term requires the participation of many people with albinism. Research has been carried out on the effectiveness of video presentations instead of using a spokesperson because this is easier to distribute and does not depend on the willingness, ability or time of spokespersons (Corrigan & O'Shaughnessy, 2007; Peters, et al., 2016; Stuart, 2006). However, the use of video was demonstrated to be less effective in challenging stigma than personal contact (Corrigan, et al., 2012) and distributing it in a country without regular video access or the necessary infrastructure for watching a movie can be problematic. A radio intervention might be a solution (Creel, Rimal, Mkandawire, Böse, & Brown, 2011; Nambiar, et al., 2011) as more people in Tanzania have access to radio (Kuhlmann, et al., 2008). These alternatives are of interest for further research.

Besides the practicalities, there are some ethical issues associated with asking people with a stigmatizing condition to talk about such a personal and sensitive topic. One could ask whether becoming a paid spokesperson as part of a job is entirely voluntary and therefore ethically sound. Employment for people with albinism can be difficult due to discrimination and due to the fact that people with albinism should not work in the sun (Baker, et al., 2010).

#### LIMITATIONS AND RECOMMENDATIONS FOR FURTHER RESEARCH

Since not many people with albinism dare to present on albinism and take part in an interview, the potential respondents were limited. As well, because all the respondents in the research are spokespersons, it would be interesting to learn more from the perspective of people with albinism who are not spokespersons or spokespersons that were less willing or confident to participate in this



research than the current respondents. In addition, it would be relevant to ask whether the public's experience matches that of the spokespersons.

In conclusion, being a spokesperson is an act of agency that can counteract a society's stigmatizing beliefs about people with albinism. It is, according to the respondents, a predominantly positive and rewarding experience which seems to change attitudes, and which makes the spokespersons proud, and increases their status and confidence.

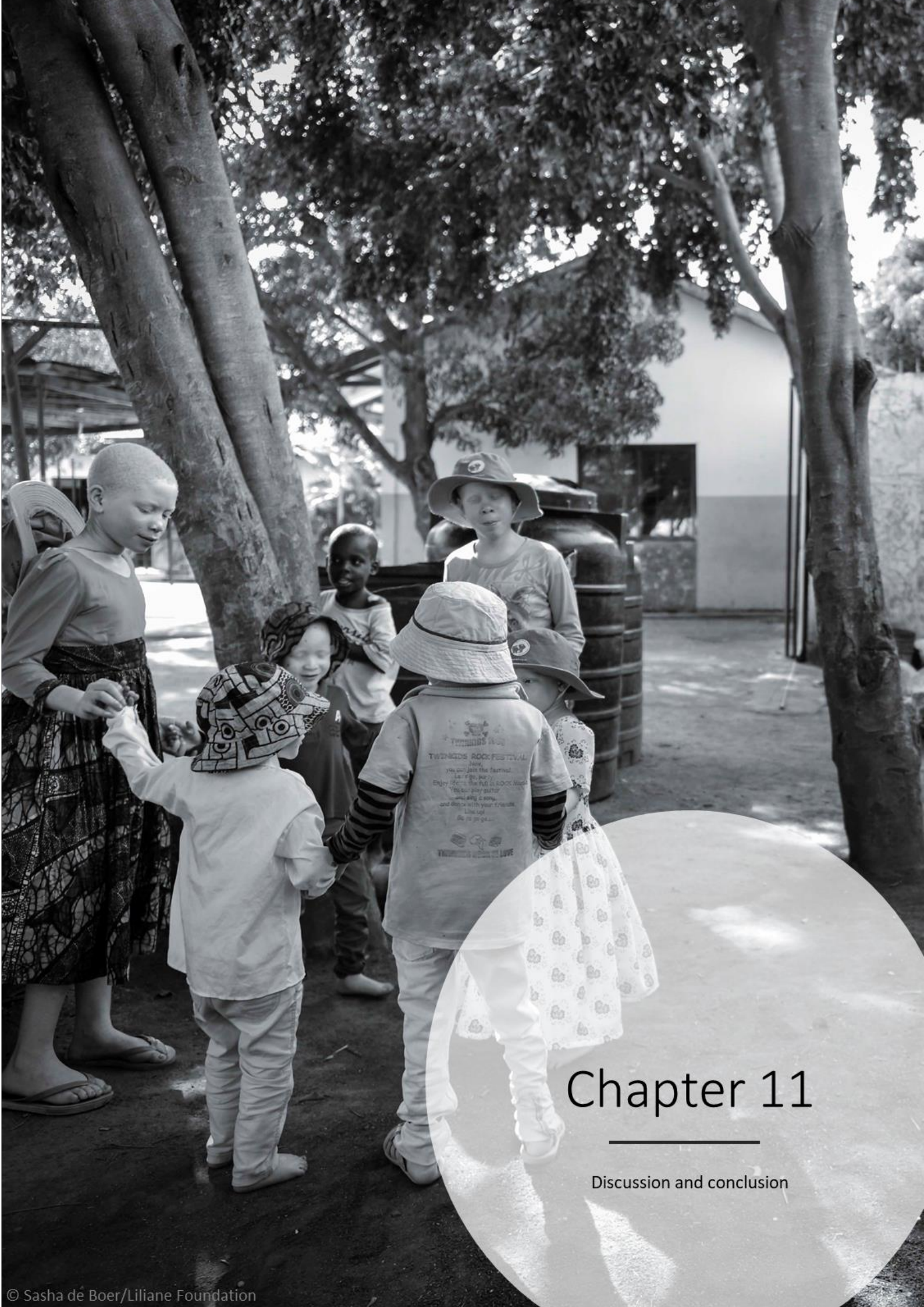
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# Chapter 11

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Discussion and conclusion

## CHAPTER 11: DISCUSSION AND CONCLUSION

Albinism is an often-occurring condition in Tanzania and the impact of stigmatization on people's lives is far reaching. People with albinism suffer from social exclusion and even face threats to their lives (Brocco, 2015; Bryceson, Jønsson, & Sherrington, 2010; Cruz-Inigo, Ladizinski, & Sethi, 2011). Little research has yet focused on stigma reduction in relation to albinism. This research explored the applicability of the education, contact and entertainment strategies, that have proven to be effective in relation to other health-related stigma, in the context of Tanzania in relation to albinism. To explore possibilities for stigma reduction related to albinism, the main research question was: **How to reduce stigma related to albinism in Tanzania on a community level using the education and contact strategy?** To answer this question, six sub-research questions were formulated as portrayed in Table 1 below.

<b>Sub-research question</b>	<b>Chapter</b>
1. <i>What are people's attitudes towards people with albinism in Tanzania?</i>	1, 4, 5 & 10
2. <i>How can attitudes towards people with albinism in Tanzania be measured?</i>	4, 5 & 6
3. <i>What are the effects of an education strategy on albinism-related stigma and knowledge in Tanzania?</i>	7, 8, & 9
4. <i>What are the effects of a contact strategy on albinism-related stigma and knowledge in Tanzania?</i>	7, 8, & 9
5. <i>What role does entertainment play in stigma reduction intervention related to albinism in Tanzania?</i>	7, 8, & 9
6. <i>What are the effects of a contact strategy on spokespersons with albinism in Tanzania?</i>	10

Table 1 Sub-research questions and chapters

People's attitudes towards people with albinism in Tanzania have been described in Chapter 1, 4, 5 and 10 (RQ1), see Table 1. In order to measure these attitudes, stigma measurement scales were adapted to albinism and the specific context. These scales were validated, as explained in Chapter 4 and 5. I explored the use of visual vignettes to gain more understanding of people's attitudes towards persons affected by albinism, as discussed in Chapter 6 (RQ2). In Chapter 7, 8 and 9 several interventions and strategies to reduce albinism-related stigma were evaluated. Three types of interventions were tested (1. a theatre intervention, 2. a radio intervention, 3. a filmed intervention). These chapters discussed the stigma reduction strategies of education, contact and entertainment (RQ3, RQ4 and RQ5). In Chapter 10 the role of people with albinism who present in a contact intervention on albinism was further considered. Insight was gained into the effects of this strategy on the so-called spokespersons with albinism themselves (RQ6).

This chapter starts with the discussion of each individual sub-research question. The answers to the sub-research questions constitute an overview of the findings and implications of this research, after which the more broadly formulated main research question of this thesis will be answered. A discussion of the validity of the findings and ethical considerations of the research follow. The chapter ends with recommendations for the development and implementation of stigma reduction interventions and recommendations for further research.

## SUB-RESEARCH QUESTIONS

### RESEARCH QUESTION 1: WHAT ARE PEOPLE'S ATTITUDES TOWARDS PEOPLE WITH ALBINISM IN TANZANIA?

In many African countries people have stigmatizing attitudes towards people with albinism. The myths about people with albinism can vary per culture, as does the fierceness of the stigmatization and its' outcomes (Affram, Teye-Kwadjo, & Gyasi-Gyamerah, 2019; Baker, Lund, Nyathi, & Taylor, 2010; Bradbury-Jones, Ogik, Betts, Taylor, & Lund, 2018; Dapi, Tambe, & Monebenimp, 2018; Franklin, Lund, Bradbury-Jones, & Taylor, 2018; Taylor, Bradbury-Jones, & Lund, 2019). In Tanzania people with albinism are fiercely stigmatized. This stigmatization comes forth out of a variety of myths, such as the belief that the body parts of people with albinism bring good fortune and often people with albinism are perceived to be ghosts (Brocco, 2016; Bryceson, et al., 2010). The research findings confirmed that people in Tanzania have stigmatizing attitudes towards people with albinism. People with albinism were not seen as someone 'like you and me', sometimes they were even perceived as not being human.

In this thesis more insights were gained into albinism-related stigma and the applicability of existing literature about other health-related stigma on the condition of albinism. Some similarities and differences between albinism-related stigma and other health-related will be further discussed here. This also provides us with a deeper understanding of albinism related stigma. Six of the seven aspects of stigmatization as distinguished by van Brakel et al. (2012), that were also found by Peters et al. (2014) for persons affected by leprosy, were also identified in relation to albinism, namely: (1) the process of discrediting, (2) shame and embarrassment, (3) avoidance/taking distance/isolation, (4) problems with getting married or ongoing marriage, (5) problems for family or other people and (6) problems with work. The seventh aspect, 'concealment', was not applicable to albinism because in contrast to many other stigmatised health conditions, albinism cannot be covered. During the validation study of the scales, it became clear that people without albinism often did not feel comfortable in social relations with people with albinism, as will be explained in further detail when discussing sub-research question 2. As an addition to the other aspects of stigma I suggested that the aspect of 'fear' also forms a prominent aspect of the stigma related to albinism, as described in Chapter 4. Outcomes of the study in Chapter 4 also showed that respondents feel less comfortable to have a close social relation with someone with albinism (e.g. being family) and feel more comfortable to have a larger social distance from a person with albinism (e.g. going to the same school).

Stigmatizing attitudes within the community varied largely. As described in Chapter 4, students often did not express stigmatizing attitudes themselves but did express that the community in general had stigmatizing attitudes towards people with albinism. According to these young and educated respondents the level of stigmatization is depending on age, culture and education level. The respondents who were in high school expressed that older people have more traditional beliefs, and they stated that in combination with a low education level this causes older people to have a greater level of stigmatizing attitudes towards people with albinism. In studies regarding another health-related stigma, leprosy, it was found that a higher level of stigma could be linked to older age and fewer years of education (Kaehler, Adhikar, Raut, Marahatta, & Chapman, 2015; Rao, Raju, Barkataki, Nanda, & Kumar, 2008). I did not research this further in relation to albinism, but this could be an interesting topic for further research.

Several drivers (Stangl, et al. 2019) underly stigmatization, as also found in this study on the stigmatization of people with albinism:



1. Fear of contagion: People fear to be infected with albinism by being close to someone with albinism. People fear that if they touch someone with albinism they or their children will get albinism.
2. Perceived dangerousness: People with albinism are often considered dangerous. People often fear being close to someone with albinism because they believe that this can result in bad fortune.
3. Lack of knowledge: A lack of knowledge about the condition adds to the stigmatization of people with albinism. People often do not know what the cause is of albinism and what the condition of albinism entails.
4. Cultural beliefs and myths: The cultural beliefs and myths about albinism, such as the belief that people with albinism are not human and that their body parts bring good fortune, add to the stigmatization of people with albinism.
5. Concealability: The fact that albinism cannot be concealed also does not help in tempering the stigma.

The effect of stigmatizing attitudes towards people with a variety of stigmatized health-conditions was translated into an overview by van Brakel (2006). For albinism-related stigma it was found that a lot of outcomes of stigma, overlap with those presented by van Brakel (2006). Therefore, a column was added to this overview, so that the outcomes of albinism-related stigma can be easily described and compared (Table 2).

<b>Effect on the individual and/or community</b>	<b>Leprosy</b>	<b>HIV/AIDS</b>	<b>TB</b>	<b>Mental illness</b>	<b>Epilepsy</b>	<b>Disability</b>	<b>Buruli ulcer</b>	<b>Onchocerciasis</b>	<b>Albinism</b>
1. Emotional stress and anxiety	X	X	X	X	X	X	X	X	X
2. Problems in marriage or in getting married	X	X		X	X	X	X	X	X
3. Problems in friendships and social relationships	X	X	X	X	X	X	X	X	X
4. Problem with employment or in getting a job	X	X		X	X	X		X	X
5. Reduced educational opportunities	X	X		X	X	X			X
6. Increased inequities between those affected and those who are not	X	X		X	X	X			X
7. Concealment of the disease after diagnosis	X	X	X	X	X				n/a
8. Poor(erg) prognosis	X	X	X	X					n/a
9. Other participation restrictions (e.g. economic dependency, denied access to loans and credit etc)	X	X		X	X	X	X		
10. Isolation	X	X	X	X	X	X		X	X
11. (Increased) psychological and psychiatric morbidity	X	X	X	X	X	X		X	
12. Lack of motivation to continue treatment	X	X	X						
13. Motivation to continue treatment	X		X	X	X				
14. Increased disability and physical damage	X	X	X	X					X
15. Increased gender differences	X	X	X						
16. Empowerment (e.g., positive self-image and confidence developed in resistance to discrimination)	X	X		X	X	X			X

Table 2 Overview of effects of stigmatization on individuals (van Brakel, 2006)

As can be seen in Table 2 above, many outcomes of albinism-related stigma are comparable to outcomes of other health-related stigma. Throughout the thesis it was confirmed that people with albinism live in anxiety for discrimination, some even fear to be attacked for their body parts (1). As was found in Chapter 4 and 5 people with albinism face difficulties with getting married, social relationships and finding a job (2, 3, 4). People with albinism lack opportunities in life. For example, because many people believe people with albinism lack certain physical and/or intellectual capabilities those with albinism have reduced educational opportunities as was among others expressed in Chapter 10 by the spokespersons (5). They expressed that presentations by people with albinism can function as a way to show people that people with albinism have the same abilities as people without albinism. Throughout the studies carried out in this research it was found that people with albinism are often socially excluded, they are feared by those in the society and therefore they are not given equal opportunities in life (6). People with albinism are isolated from society, as among others expressed by Imafidon (2017) and expressed by people with and without albinism in Chapter 4 and 9 (10). Additionally, when the physical difficulties of people with albinism are neglected, such as their skins' sensitivity to sunlight, this can result in increased physical damage. For example, when people with albinism are requested to work in the sun this can result in skin cancer (14). Examples of empowerment can also be found, some people gained confidence in resistance to their discrimination, among others through presenting on albinism as described in Chapter 10 (16).

To answer sub-research question 1: Attitudes towards people with albinism are varying within the society. This research confirmed that stigmatizing attitudes are present in Tanzanian society. People's negative attitudes are based on a variety of drivers, of which the most prominent drivers are: a lack of knowledge, cultural beliefs and myths and fear of contagion, direct or indirect. People with albinism are often not seen as 'human beings'. The results in a variety of negative outcomes for people with albinism, they are excluded from society, fiercely and sometimes violently discriminated and they lack equal opportunities in life.

RESEARCH QUESTION 2: HOW CAN ATTITUDES TOWARDS PEOPLE WITH ALBINISM BE MEASURED?  
"Essential to the scientific understanding of stigma is our capacity to observe and measure it" (Link, Yang, Phelan, & Collins, 2004, p. 511). For the evaluation of stigma reduction interventions proper evaluation methods need to be used. Through fitting measurement instruments people's attitudes can be researched and changes in attitudes can be analysed. After a literature search no validated measurement tools were found that measured people's attitudes towards people with albinism. Because it is of major importance to confirm the validity of measurement instruments when used in a different cultural setting (Peters, et al., 2014; van Brakel, 2006) a validation study was carried out. Two quantitative measurement instruments, for an adolescent and an adult population were validated, as described in Chapter 4 and 5. In addition to the validation of quantitative measurement instruments, qualitative methods were explored as well. The qualitative visual vignette method was explored in Chapter 6.

#### THE EMIC-CSS AND THE SDS

For the scale validation two already existing scales were chosen as a starting point for the development of a new tool. These scales were selected because they had proven to be reliable in a variety of settings, they had been adapted to a variety of different health-conditions and because the scales complement each other: the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) (Brieger, Oshiname, & Ososanya, 1998; Peters, et al., 2014; Stevelink & van Brakel, 2013; Stienstra, van der Graaf, Asamoah, & van der Werf, 2002; van Brakel, et al., 2012; Weiss, 1997) and the Social Distance Scale (SDS) (Bogardus, 1925; Corrigan, et al., 2002; Crandall & Moriarty, 1995; Leiker, Taub, & Gast, 1995; Link, Cullen, Frank, & Wozniak, 1987; Mak, Chong, & Wong, 2014; Penn, et al.,

1994; Peters, et al., 2014). The EMIC-CSS investigates community stigma: how do people in the community feel towards people with albinism? The SDS measures the respondents' desired social distance towards persons affected as a proxy for their attitudes: how do you feel in a certain social relationship with someone with albinism?

#### SCALES TO MEASURE ATTITUDES AMONG ADOLESCENTS

The validation study of the EMIC-CSS and SDS among adolescents in Tanzania, Chapter 4, demonstrated sufficient conceptual, item, semantic and operational equivalence for both scales. Only the measurement equivalence was insufficient, however this was explained by the population sampled. Firstly, the sample existed out of high school students who were familiar with people with albinism and who had knowledge about albinism. Therefore, many of the respondents did not have stigmatizing feelings towards people with albinism, which influenced the measurement equivalence. Secondly, the reproducibility statistics showed a low correlation between the test and the re-test, which can also be explained by the sample. As suggested in Chapter 4 this low correlation might be caused by the test itself. The research can have led the students to discuss the research topic further, which is likely in a population living closely together as was the case for the respondents who were students in boarding school. This caused the respondents to portray improved attitudes in the re-test. This effect was named the 'the intervention effect'. However, in Chapter 9 the intervention effect of the ASDS-A was tested and the results did not confirm the effect. Additionally, the internal consistency of both scales was excellent. The above clarification led me to conclude that the scales were a valid tool to measure albinism-related stigma. However, the results presented a need for testing the scales among another population as was done in Chapter 5. The SDS was renamed into the Albinism Social Distance Scale for adolescents (ASDS-A) because of the number of changes that were made to the original SDS.

Additionally, the use of a self-administrative scale among this population proved to be an efficient method of generating data. However, one should be aware that the validation study was done among a very specific sample. Secondary school students in general have a relatively high literacy level, they are familiar with reading and writing for a longer time period and have a larger vocabulary in comparison to other samples that have a lower education level. Therefore, the findings of this validation study should not be generalized to the whole population, but are limited to a specific group in society.

#### SCALES TO MEASURE ATTITUDES AMONG ADULTS

The validation study of the two scales to measure attitudes towards people with albinism among adults, as discussed in Chapter 5, proved the validity of these scales for an adult population. The scales were renamed into the Albinism Explanatory Model Interview Catalogue Community Stigma Scale (A-EMIC-CSS) and the Albinism Social Distance Scale (A-SDS). Equivalences of both scales were sufficient. As with the scales for adolescents there were reasons for concern about the validity of the scales because of low reproducibility values and the skewed distribution. Firstly, it is most likely that the low reproducibility was caused by the reluctance of the respondents to participate in the retest. Again, the scales were internally consistent, however the skewed distribution of the A-SDS caused me to take a closer look at the samples. Especially because the A-EMIC-CSS does portray high levels of stigmatizing feelings within the community. The large floor effects, a large number of respondents stating they do not have any negative feeling about people with albinism, might point at problems regarding social desirable answering: the tendency of respondents to provide answers that are favourable for themselves or answering the way they think the researcher wants them to answer. The difference between the findings of the A-EMIC-CSS and A-SDS can be explained by the so-called false uniqueness effect (Sigelman, 1991). Respondents were aware of the discrimination that people with albinism face in Tanzania. In many media coverages and other messages that people receive about the situation of

people with albinism, people in the community are requested to condemn this discrimination and to protect people with albinism (Burke, Kaijage, & John-Langba, 2014). Therefore, people are very much aware of the prescribed norm: to accept people with albinism. This socially valued norm can lead respondents to be more motivated to show that they are more tolerant than others: the false uniqueness effect (Sigelman, 1991). Especially, with explicit items, such as the A-SDS items, it is not likely for respondents to portray prejudice (Stier & Hinshaw, 2007). Therefore, respondents might tend to describe the community as having a stigmatizing attitude towards people with albinism in the A-EMIC-CSS, whereas they portray themselves as not having stigmatizing feelings at all in the A-SDS.

Studies considering stigma are prone to bias (e.g. Smythe, Adelson, & Polack, 2020) as was also found in this study. Suggestions for dealing with the social desirability bias of the A-SDS for future use, were provided in Chapter 4 and 5, they entail introducing a balanced scale, mixing positively and negatively formulated items, or items with a less distinct meaning. Another possibility would be the introduction of a social desirability scale (Beretvas, Meyers, & Leite, 2002; Crowne & Marlowe, 1960; Perry, Murphy, & Dovidio, 2015). Additionally, as pointed out in Chapter 5, it might be more effective to use a selection of the A-SDS items that measure the highest level of stigma (A-S2, A-S4, A-S5, A-S6) or dichotomising answers in the analyses: either stigmatizing attitude or non-stigmatizing attitude. As compared to the adolescent scale, the less extreme answering behaviour in the adult scales might have been caused by the extension of answer categories.

As experienced in Chapter 8, the scales were harder to use among a relatively low educated population, of which many respondents were unable to read or write. The surveys had to be read to the respondents, which might have influenced responses and showed the scale's limitation, which among others is too lengthy for a population having difficulties with reading. For future use of the scales among a lower educated population the scales can be interviewer-administered, however this will also have its consequences for the scales' validity, e.g. since people cannot be completely anonymous, respondents will be likely to provide socially desirable answers.

The studies in this thesis teach us the strengths and weaknesses of both scales. The strength of the A-SDS scale is that it is very useful as a direct effect measurement, for which the A-EMIC-CSS cannot be used. Respondents did not often expect change in the 'whole community' directly after an intervention, especially if not everyone in the community participated. However, the strength of the A-EMIC-CSS is that it asks after the communities' attitude, which respondents most likely feel less reluctant to reveal than their own personal attitudes in the A-SDS. The A-EMIC-CSS can even be experienced as safe way for respondents to express their own attitude. The A-EMIC-CSS can be a very useful tool in measuring attitudinal change on a longer term. Therefore, this study taught us that in the future these scales are to be used together and one should be hesitant in using these scales on their own.

Throughout the thesis suggestions were made for adaptations to the scales, such as e.g. the removal or addition of items, this has been described in Chapter 5. However, not all of the proposed changes were applied to the scales used in the studies presented in the thesis. The aim was to stay as close as possible to the tested scales that had proven to be an effective measurement instruments in their existing form. The suggested adaptations would have required further validation for which there was no time within this thesis' research.

The two validation studies prove the scales' validity to measure stigmatizing attitudes towards people with albinism in Tanzania, as long as attention is paid to social desirability, the intervention effect and the population in which the scale is conducted. In measuring attitudes through a quantitative tool, it is important to consider the following question: is the scale measuring the real attitude of the respondents? Especially, because it is also possible that the sample of a study does not hold stigmatizing attitudes, in this case the study's outcomes cannot be blamed on for example

invalidity of the scale or the social desirability bias. To be able to answer this question accompanying qualitative studies are indispensable as well as appropriate sampling methods.

#### QUALITATIVE METHODS

To be able to learn more about people's attitudes towards people with albinism a mixed methods approach was most appropriate. Quantitative methods, such as the A-EMIC-CSS and the A-SDS, proved to be good tools to measure attitudes, analyse changes in attitudes and they can provide us with generalizable data when a proper sample is used. Qualitative methods can help us to gain more in-depth knowledge. Personal interviews and focus group discussions were applied. During this study the use of innovative approaches to qualitative research were explored. Because of the cultural setting and the sensitivity of the topic it was decided to explore the possibilities of using (drawn) visual vignettes in research. Visual vignettes provide visual representations of hypothetical situations, to which the interviewee is asked to respond, in order to explore perceptions, opinions, myths, beliefs and attitudes present in a community. Visual vignettes have been used in other studies (e.g. Fischer, 2016; Gourlay, et al., 2014; Jakobsen, 2012), however little was known about the use of the visual vignette method in low-income countries (Gourlay, et al., 2014). As described in Chapter 6 it was found that visual vignettes offer a promising tool in doing research on sensitive topics such as albinism in Tanzania. Through the visual vignette questions were asked from a third person perspective ('What do others think?'), which made it easier for the respondents to participate in the discussion. As with the quantitative tools, respondents also found it easier in qualitative interviews to talk about others instead of themselves. Using images may strengthen the respondents' own interpretation of the topics that were discussed and images might increase personal reflections. Also, the visual vignettes assisted in the organization of the interviews, because of the images the topics that were being discussed were clear. However, there were also disadvantages involved with using visual vignettes. Many respondents interpreted the images as lessons 'the way it should be'; this might be caused by the school setting in which the research took place. Students knew what the social desirable situation in relation to albinism was and came up with explanations of the images in which this was portrayed. Again, as recommended with the quantitative measurement tools it is of importance to use this method in combination with other approaches. To conclude, the visual vignette methodology proved to be very effective in gaining insights into respondents' attitudes towards people with albinism.

To answer sub-research question 2, to be able to evaluate changes in attitude towards people with albinism the EMIC-CSS and A-EMIC-CSS, measuring attitudes on a community level, and ASDS-A and A-SDS, measuring attitudes on a personal level, proved to be effective instruments. These are the first scales to be validated in relation to albinism-related stigma. A combination of both scales can provide a more holistic insight into attitudes and attitudinal change. These quantitative measures should however be supported by qualitative methods to gain a more in-depth insight. For this, the use of visual vignettes was found to be a promising tool to research stigmatizing attitudes.

#### RESEARCH QUESTION 3: WHAT ARE THE EFFECTS OF AN EDUCATION STRATEGY ON ALBINISM-RELATED STIGMA AND KNOWLEDGE IN TANZANIA?

In this thesis several stigma reduction interventions related to albinism were explored. Chapter 7 analyses the possibility of a theatre intervention about albinism to reduce stigma among primary school students. In Chapter 8 two types of radio interventions, a radio drama and a radio interview, were evaluated within Tanzanian communities among an adult population. Chapter 9 compares two filmed interventions among high school students: one is education based and the other is contact based. The theatre and radio intervention (Chapter 7 and 8) existed out of a combination of stigma reduction strategies: the education and contact strategy. In each intervention an entertaining component was present.

To answer sub-research question 3, the education strategy is further evaluated. An education strategy, entails providing information about the condition (Heijnders & Van der Meij, 2006), education is the most commonly used form in reducing stigma (Hartog, et al., 2020; Kemp, et al., 2019). All but one intervention evaluated in this thesis made use of the education strategy. Only the filmed contact-based intervention as discussed in Chapter 9, did not make use of the education strategy. An overview of intervention types, stigma reduction strategies and outcomes can be found in Table 3.

The effect of the stigma reduction strategies in this thesis were analysed using a variety of qualitative and quantitative measurement instruments. The quantitative methods to measure attitudes towards people with albinism have been explained above: the EMIC-CSS/A-EMIC-CSS and the ASDS-A/A-SDS. Additionally, to be able to analyse changes in correct knowledge, (12) Knowledge items were used in Chapter 7 and 9. These items were developed in cooperation with experts in the field of albinism, and were based on, according to these experts, important information about albinism that many people in Tanzania do not know. These items were used pragmatically because they do not form a scale. Furthermore, to measure the entertainment value of the intervention, Entertainment items were used in Chapter 8 and 9. Entertainment items were based on entertainment measurement items by Ritterfeld and Jin (2006). These items were discussed with representatives from Tanzanian organizations that aim to improve the lives of people with albinism and with staff from schools that were collaborating with the researcher. As with the Knowledge items, the items do not form a scale so were only used pragmatically. Table 3 shows the use of measurement instruments and their summarized outcomes for each chapter.

Ch.	Intervention	Strategies	Used methods and outcomes
Ch. 7	Theatre	Education Contact Entertainment	<ul style="list-style-type: none"> <li>• <i>Knowledge items</i>: knowledge improved (short term)</li> <li>• <i>ASDS-A</i>: social distance reduced (short term)</li> </ul>
Ch. 8	Radio Drama	Education Contact Entertainment	<ul style="list-style-type: none"> <li>• <i>A-SDS</i>: social distance reduced (after two to five weeks)</li> <li>• <i>A-EMIC-CSS</i>: community stigma reduced (after two to five weeks)</li> <li>• <i>Entertainment items</i>: high entertainment value, higher than radio interview</li> <li>• <i>Informal (group) interviews</i>: positive feedback, intervention was very educative</li> </ul>
	Radio Interview	Education Contact Entertainment	<ul style="list-style-type: none"> <li>• <i>A-SDS</i>: social distance reduced (after two to five weeks)</li> <li>• <i>A-EMIC-CSS</i>: community stigma not significantly reduced (after two to five weeks)</li> <li>• <i>Entertainment items</i>: high entertainment value, lower than radio interview</li> <li>• <i>Informal (group) interviews</i>: positive feedback, intervention was very educative</li> </ul>
Ch. 9	Filmed Contact	Contact Entertainment	<ul style="list-style-type: none"> <li>• <i>Knowledge items</i>: knowledge improved (short term)</li> <li>• <i>ASDS-A</i>: social distance not significantly reduced (short term)</li> <li>• <i>Entertainment items</i>: high entertainment value, higher than filmed education</li> <li>• <i>Focus group discussions</i>: more positive outcomes than filmed education</li> </ul>
	Filmed Education	Education Entertainment	<ul style="list-style-type: none"> <li>• <i>Knowledge items</i>: knowledge improved (short term)</li> <li>• <i>ASDS-A</i>: social distance reduced (short term)</li> <li>• <i>Entertainment items</i>: high entertainment value, lower than filmed contact</li> <li>• <i>Focus group discussions</i>: fewer positive outcomes than filmed contact</li> </ul>

Table 3 Overview of intervention types, stigma reduction strategies, measurements instruments and outcomes

The education strategy has proven to be effective in reducing health-related stigma in relation to other conditions. The education strategy has proven to be effective in increasing people's knowledge on a stigmatizing condition and improving people's attitudes towards people with such a condition (Cook, Purdie-Vaughns, Meyer, & Busch, 2013; Corrigan, Morris, Michaels, Rafacz, & Rüsçh, 2012; Griffiths, Carron-Arthur, & Parsons, 2014). The combination of the education and the contact strategy has often proven to be successful (Dadun, et al., 2017; Peters, et al., 2015; Stuart, et al., 2014). In relation to albinism, the findings showed that interventions of which the education strategy was a part caused an improvement of correct knowledge on albinism directly after the interventions (Chapter 7 and 9). A reduction in stigma towards people with albinism was found, directly after the interventions (Chapter 7 and 9) and two to five weeks after the intervention (Chapter 8).

The one intervention that did not make explicit use of an education strategy is the filmed contact-based intervention reported in Chapter 9. In the contact-based intervention no specific information about the condition of albinism was provided. People with albinism introduced themselves and explained about their lives on film. Interestingly, this intervention did not result in a significantly improved attitude as measured through the ASDS-A directly after the intervention. However, the qualitative findings on this strategy did show many positive influences on attitudes of the intervention. The findings do prove the importance of the education strategy in improving attitudes related to albinism. However, it is not possible to make statements about the non-effectiveness of interventions that do not use an education strategy.

Additionally, in Chapter 9 it was found that the education-based intervention by itself was effective in decreasing albinism-related stigma. This disconfirms other researches in which it was found that an education based intervention on its own is not very effective in changing attitudes (Brown, Macintyre, & Trujillo, 2003; Corrigan, et al., 2001; Corrigan, et al., 2002; Corrigan & O'Shaughnessy, 2007; Herek, Capitanio, & Widaman, 2002; Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008). It might be the case that people are very open to learn about albinism and that therefore the education strategy is very effective. Maybe it is not the unwillingness of the community towards learning and understanding albinism but simply the availability of information.

Some more detailed findings about the education strategy include:

1. In Chapter 7, it was found that it was hard to improve respondents' correct knowledge on certain aspects. For example, some respondents did not learn from the intervention that albinism does not lead to blindness, nor that people with albinism can also die and do not just 'disappear'. Respondents kept on believing that people with albinism need to eat special food. In other words, even though respondents were educated about albinism, they did have a hard time to start believing that people with albinism are just like every other human being. Therefore, as a recommendation for intervention development it is important to focus specifically on some deeply rooted beliefs (Mitchel, et al 2001) and to assess the interpretation of information provided in the.

2. The qualitative findings that were gathered two to five weeks after the radio interventions showed that respondents mostly did not explain albinism through beliefs in witchcraft. However, they continued explaining albinism through a monotheistic religious discourse. The religious explanation of albinism mostly contained the reasoning that all people are created by God, and therefore are equal. This religious explanation can also result in a reduction in stigma. This causes the question in what direction stigmatizing attitudes should be changed: is it desirable to shift from one mythological discourse to another?

3. The qualitative findings in Chapter 9 show that it is important for people to learn about the cause of albinism, even though Brocco (2015) stated that attitudes towards people with albinism can change when (bio)medical knowledge is not present. The importance of the explanation about the condition's cause is in line with the 'attribution theory'. This theory states that motivation and

emotion come forth from the causal understanding of things (Corrigan, 2006; Weiner, Perry & Magnusson, 1988). When applying this theory, the stigmatization of people with albinism can be a result from the causal understanding of albinism: the beliefs in witchcraft of people in Tanzania cause the negative attitudes towards people with albinism. The (bio)medical explanation of albinism can therefore assist in changing people's understanding of the condition's cause which can change their attitudes. However, critiques on this theory exist (e.g. Kvaale, Haslam, & Gottdiener, 2013; Read, Haslam, Sayce, & Davies, 2006) and in the case of albinism one should be aware that the genetic explanation of albinism does for some people in Tanzania not build on existing biological knowledge. For people who have not attended education on biology, the genetic explanation must therefore be hard to understand. This biological explanation can be interpreted by the participants as just another 'belief' about albinism. For people lacking a base of bio-medical knowledge, the genetic explanation can be hard to understand. A religious explanation might be easier for them to grasp. As was the case for many of the adults in the sample of the radio intervention in Chapter 8, who were low educated. For the high school children in school however, the cause of albinism might fit better with their existing knowledge and the scientific explanation was therefore more effective. Also, in other research it has been found that supernatural explanations for illness and disease do not come forth out of ignorance or were necessarily replaced by a biological explanation. Both explanations can exist next to each other (Legare, Evans, Rosengren, & Harris, 2012; Legare & Gelman, 2008). It would be of interest to go further with research on the necessity for people to know the cause of albinism.

Research sub-research question 3 can be answered by stating that the education strategy can be effective to reduce albinism-related stigma. Getting to know more about the condition itself and the cause of albinism helps people to understand what albinism is, which changes their perspectives and reduces fear and other stigmatizing attitudes towards people with albinism.

#### RESEARCH QUESTION 4: WHAT ARE THE EFFECTS OF A CONTACT STRATEGY ON ALBINISM-RELATED STIGMA AND KNOWLEDGE IN TANZANIA?

The contact strategy has been researched in Chapter 7, 8 and 9. An overview of intervention types, stigma reduction strategies and outcomes can be found in Table 3 above. The contact strategy is based on the assumption that intergroup contact decreases prejudice. Contact in stigma reduction refers to the interaction between someone with a stigmatizing condition and someone without this condition (Heijnders & van der Meij, 2006). Contact with someone with a stigmatizing condition has often proved to be effective in reducing stigma for a large variety of conditions (Corrigan, et al., 2012; Gronholm, Henderson, Deb, & Thornicroft, 2017; Paluck, Green, & Green, 2018; Peters, et al., 2015; van Brakel, et al., 2019). However, a number of reviews temper the findings regarding the contact strategy (Brown, et al., 2003; Couture & Penn, 2003; Jorm, 2020; Mak, Mo, Ma, & Lam, 2017). In this thesis, several formats were used to get people into direct and indirect contact with someone with albinism: theatre, radio and film.

The findings considering the contact-based interventions were as follows. Firstly, all contact-based intervention resulted in improved knowledge: one must be careful not only to link the education strategy to knowledge. Secondly, outcomes of the contact strategy in relation to attitudinal change were not always straightforward. The theatre show, the radio drama and radio interview, in which contact was one of the applied strategies, did result in significantly improved attitudes considering social distance. However, the radio interview, in which contact was also one of the strategies, and the filmed contact-based intervention, in which contact was the single strategy, did not result in significant attitudinal change as measured through quantitative methods. Nevertheless, no significant difference was found between the changes made by the education strategy and the contact strategy. Thirdly, the contact-based intervention as tested in Chapter 9 was found to be more entertaining by the



participants than the education strategy and in the qualitative interviews participants also emphasised that they thought the contact-based intervention was more effective in changing attitudes than education.

#### ASPECTS OF A CONTACT STRATEGY

Several mechanisms can be at work in a contact strategy related to albinism. These mechanisms were explained in Chapter 7 and Chapter 10.

1. The person with albinism in an intervention can provide an example of capabilities of someone with albinism. For example, they prove to their audience that people with albinism are able to speak in public or act in a theatre show.
2. Through the contact strategy spokespersons get the opportunity to share their real-life experiences, as was also pointed out as an important ingredient of a contact intervention by Corrigan and colleagues (2014). This enables them to explain the audience about their personal successes. For example, they can share their educational achievements and successes in their career.
3. A positive feature of real-life contact with someone with albinism is that participants can physically touch someone with albinism. It proves the humanity of people with albinism. Many people are afraid that albinism can be transmitted by touching, the fact that an audience can see disconfirming proof adds to the intervention's effectiveness. This positive mechanism of physical contact was also found by Rafferty (2005) in relation to leprosy-related stigma.
4. Through personally meeting someone with albinism, feelings of empathy and friendship can develop.

Throughout the research it became clear that through contact with someone with albinism, the participants in an intervention realised that people with albinism were just like them: people with albinism also go to school, can be a nurse, can get married and have children (without albinism). In the case of albinism this can be taken very literally, it is often believed people with albinism are not human, the contact-based interventions proved them the opposite.

During contact-based interventions it is important for the participants to be able to identify with people in the intervention. From the film using contact strategy in Chapter 9, respondents mainly remembered the people in the film with certain characteristics, characteristics they could identify themselves with, such as being in school or having a family. Also, in the theatre play in Chapter 7, respondents experienced the life of a person with albinism that was quite similar to theirs: going to school and making friends. The identification with spokespersons in stigma reduction interventions is important to be able to influence behavioural change as was also suggested by Basil (1996) and Kuhlman et al. (2008). Through identifiable characters it becomes easier for respondents to generate empathy and correct misinformation (Allport, 1954; Brown, et al., 2003; Corrigan, et al., 2014; Pettigrew, 1998).

Unfortunately, it is not always possible to make use of direct contact in an intervention. Interventions existing out of live presentations by people with a stigmatizing condition are hard to implement on a large scale (Corrigan & O'Shaughnessy, 2007), as is also the case with albinism-related interventions. It would be costly and time-consuming to make use of live presentations when trying to reach the majority of the Tanzanian population. As a solution other media can be used to bring people in the society in contact with people with albinism. Indirect contact can also result in stigma reduction (Morgan, Reavley, Ross, Too, & Jorm, 2018; Reinke, Corrigan, Leonhard, Lundin, & Ubiak, 2004, Schiappa, Gregg, Hewes, 2005) as confirmed by the current research in which interventions through radio and film were also effective in reducing albinism-related stigma.

When there is a spokesperson present in a contact-based intervention, it is of major importance that the spokesperson is trustworthy. There is the risk that the audience does not believe what is being said because someone with albinism is participating. This was noticed by spokespersons with albinism in Chapter 10 and also stated by some respondents in Chapter 8. After the radio intervention some respondents thought that the person with albinism in the radio show was an actor, because the respondents did not believe that a person with albinism can really be married to someone without albinism or get children without albinism. Additionally, people might not trust information provided by people with albinism because it is interpreted as preaching to the choir.

The contact strategy also offers the opportunity for people with a stigmatizing condition to play an active role and empower them, as further explained in sub-research question 6.

#### COMBINATION OF EDUCATION AND CONTACT

As was found in many other studies (e.g. Corrigan, et al., 2012; Dadun, et al., 2017; Koller & Stuart, 2016; Peters, et al., 2015) a combination of contact and an education strategy is very effective in reducing health-related stigma. This research shows that the outcomes of stigma reduction strategies are not always straightforward, and the combination of strategies is a way to get 'the best of both worlds'. Not all people are the same and what works for some might not work for others. It should be noted that because many interventions tested in this thesis made use of a combination of strategies (Chapter 7 and 8) it is hard to measure the effect of one specific strategy, which I aimed at in Chapter 9.

Research question 4 can be answered by acknowledging the importance of contact, either in real-life or through media, in getting people to understand that people with albinism are just like you and me. Contact with someone with albinism who people can identify with, proves to participants that people with albinism have the same capabilities and aspirations in life as anyone else, and that getting close to people with albinism does not have to be feared. However, the contact strategy also has its challenges, for example it is important for an effective intervention that the audience trusts the person with the stigmatizing condition in the intervention.

#### RESEARCH QUESTION 5: WHAT ROLE DOES ENTERTAINMENT PLAY IN STIGMA REDUCTION INTERVENTIONS RELATED TO ALBINISM IN TANZANIA?

The role of entertainment in stigma reduction interventions for albinism has been explored in chapter 7, 8 and 9. Entertaining components could be found in each of these studies. In Chapter 7, a theatre show, participation, games, music, singing and dancing were used to entertain the audience. The radio shows in Chapter 8 used life stories as an entertainment component. In Chapter 9, the filmed stories of several characters added to the entertainment level of the intervention.

Entertainment added to the interventions' effectiveness, as was also observed in articles by Dalrymple (2006) and Harvey, Stuart and Swan (2000). An entertaining component in an educative intervention, labelled as Entertainment Education (EE), can increase motivation, participation and receptiveness of the audience. A pleasant experience can also improve the processing of information (Ritterfeld & Jin, 2006). EE can assist in creating a favourable attitude, shifting norms and through this change behaviour (Singhal & Rogers, 1999). There are four points of interest considering EE in relation to albinism that I will discuss here.

(1) One must be careful that the entertainment aspect of an intervention does not overshadow the educational goal. An example of this can be found in the theatre intervention. The audience of the theatre play did not always respond to scenes as expected because the entertainment aspect of the play confused the audience. Sometimes the audience was laughing about situations that were actually quite distressing. The audience expected everything in the play to be fun and because of that they did not always realize how distressing and serious certain aspects of the theatre play were.

To overcome difficulties arising from entertainment in an intervention the following recommendation can be made based on the current study:

1. One should repeat the main messages and lessons from the intervention, this can for example be done by a moderator. This moderator should receive proper training to do so.
2. One should provide the opportunity for the participants to participate in and reflect on the intervention. Through these reflections the audience will be able to formulate the lessons from the intervention in their own language, which can lead to their own explanation (Kerr, 2014).
3. Interventions should be properly piloted and evaluated to gain insight into which messages people take home, so that, when necessary, the intervention can be adjusted.

(2) An entertaining intervention in the context of stigma reduction, often exists of stories in which people with a stigmatizing condition play a role. One must be careful that these stories do not confirm people's negative attitudes towards people with a stigmatizing condition, nor reinforce them (Mitchell, Nakamanya, Kamali, & Whitworth, 2001). In the observed theatre intervention in Chapter 7 the person with albinism faces discrimination and other problems in each scene, which risks the strengthening of negative stereotypes about people with albinism. I would recommend putting emphasis on the positive aspects of the lives of people with albinism, for example by showing that they can have a loving family, a job and can be successful in education.

(3) In Chapter 9, the contact strategy was found to be more entertaining than the education strategy according to the Entertainment items. However, according to the quantitative findings the contact strategy was not significantly effective in changing people's attitude. In the qualitative findings respondents expressed that this strategy had a proper influence. This warns us to be careful to evaluate interventions purely on qualitative data. People's enjoyment with a certain intervention can overshadow their judgement of the intervention's outcomes. Therefore, I would recommend the use of mixed methods while evaluating interventions.

(4) It should be noted that effect of interventions can reach further than the original audience by 'word of mouth'. Especially, when an intervention is very enjoyable there is the chance that people will discuss the intervention with others, which will result in a wider spread of the intervention. However, if the intervention is 'too much fun' there is the risk that only the fun bits are being discussed and the actual informative content of the intervention is left out. Therefore, using entertainment as a strategy can be useful but can also have negative side effects. However, these anticipated effects of stigma reduction interventions should be evaluated more (Hartog, et al., 2020) to be able to draw conclusions on this matter.

To conclude by answering research question 5, entertainment within a stigma reduction intervention can be very useful to gain people's attention and to get people engaged. Their enjoyment with an intervention can strengthen the outcomes of an intervention. However, when an intervention is too much fun this enjoyment can overshadow the original goal of the intervention, recommendation are being provided to prevent this.

#### RESEARCH QUESTION 6: WHAT ARE THE EFFECTS OF A CONTACT STRATEGY ON SPOKESPERSONS WITH ALBINISM IN TANZANIA?

People with albinism who present in a contact intervention, the so-called spokespersons, indicated that presenting on albinism can be a positive experience (Chapter 10). They explained that their work made them proud and had many positive outcomes for themselves. Among others it gave them more confidence, status and it was part of their personal development. Through being a spokesperson, they

counteracted expectations of others. Through their personal presentations they had the feeling to be contributing to, and changing society. Being a spokesperson was seen as an act of agency, and a way to present their agency to the society.

People with a stigmatizing condition are often labelled as passive victims. By engaging them in stigma reduction interventions they have a chance to prove that they can be active agents. This will lead to attitudinal change among the audience, but it can also lead to an attitudinal change on the personal level of people with albinism. Additionally, the input of people with a stigmatizing condition can improve interventions (Cook, et al., 2013; Heijnders & van der Meij, 2006; Rai, et al., 2018; Thornicroft, et al., 2008). As discussed in Chapter 10 the lack of ability that is imputed on people with albinism often becomes a self-fulfilling prophecy: people with albinism are thought to be inferior, which makes them believe that they are inferior and act on it through self-stigma. This cycle can be broken by showing that spokesperson with albinism can play an important and active role in stigma reduction.

The spokespersons interviewed in Chapter 10 stated that there are several requirements to become a spokesperson: spokespersons need to be confident, have knowledge about albinism, should accept themselves, have a good level of education, a certain status, and the ability to 'read' the audience. Spokespersons can be trained in some of these requirements. This training would also serve as empowerment for the participating people with albinism. Spokespersons emphasised that proper training is essential to prepare spokespersons. Spokespersons should be trained so that they have the confidence to provide a presentation but also to enable them to provide an effective presentation. Additionally, spokespersons stated they were not afraid that they would be discriminated or attacked because of their role as spokespersons. However, they did emphasize organization should make security arrangements when necessary.

To answer the last research question, 6, through interviews with spokespersons it was found that spokespersons can personally benefit from being a spokesperson with albinism on a personal level: they gain self-confidence and status and the opportunity for them to develop themselves further. Spokespersons present their agency by being a spokesperson, through this the audience can see that people with albinism are not passive victims. However, it is important that they are trained and secured well by the organizations that they are working with.

## GENERAL CONCLUSION

People with albinism are often not perceived as being human and this worldview is deeply rooted. Health-related stigma cause difficulties for people with a large variety of diseases and conditions worldwide. Besides the physical problems caused by a disease or condition, people with a stigmatizing condition are confronted with negative attitudes towards them leading to social exclusion, discrimination and self-isolation. In order to improve the wellbeing of people with albinism, stigma should be reduced and therefore stigmatising worldviews should be changed. Therefore, this research set out to explore the applicability of strategies and interventions that have proven to be effective in reducing stigma in relation to other health-related stigma to the stigma reduction in relation to albinism in Tanzania. The main research question was: **How to reduce stigma related to albinism in Tanzania on a community level using the education and contact strategy?**

A first step in the reduction in stigma on a community level and transformation of worldviews, is the acknowledgement of the contexts in which people live. It is of major importance to understand this context and to be aware where stigmatizing attitudes arise from. Changing attitudes and improving knowledge request a variety of strategies that need to be properly adapted to its context and target audience. After I gained more understanding of the social context, underlying worldviews and people's attitudes towards people with albinism several types of stigma reduction interventions

were explored (1. a theatre intervention, 2. a radio intervention, 3. a filmed intervention). In the tested interventions two strategies that have proven to be effective in reducing stigma in relation to other condition were present: the education and contact strategy. In this research both strategies proved to be effective in improving people's knowledge on albinism and improving people's attitudes towards people with albinism. A combination of the interventions is recommended. The findings of the current research showed that it can be rewarding to add entertaining components to stigma reduction interventions, however one should pay attention that that 'fun' does not diminish the message of the intervention.

The outcomes of the tested stigma reduction interventions were not always as expected. To improve the outcomes of interventions proper development and evaluation is of major importance. This is the role that we can take on as educational scientists, who are well suited to make the translation between people's worldviews as they are and how they could be (Meurs, 2017). This is done among others through the proper development and testing of strategies to bring about attitudinal change in people. To this aim, to control the effect of stigma reduction interventions and to be able to improve them, several quantitative measurement instruments were developed: Knowledge items, EMIC-CSS/A-EMIC-CSS and ASDS-A/A-SDS. These tools proved to be valid to assess knowledge and stigma and evaluate stigma reduction interventions. However, these findings also proved the importance of using mixed methods to be able to gain proper insights, for example by using visual vignettes.

Involving people with albinism in the development and implementation of stigma reduction interventions is of added value. People with albinism are knowledgeable of the context and stigmatization, as they live it on a daily basis. The development of the intervention will highly benefit from their involvement. Showing that people with albinism are active agents in improving their situation will improve the outcomes of the interventions and also empower people with albinism themselves. By being part of stigma reduction interventions persons with a stigmatizing condition can counteract society's expectations. Many people with albinism internalize the negative society's expectations. By showing that people with albinism are assisting in stigma reduction interventions, by showing their agency and capabilities, this vicious circle can be broken.

## VALIDITY OF THE FINDINGS

### INTERNAL VALIDITY

Was the research conducted properly and to what degree do the findings represent the actual situation? In terms of internal validity there are a few aspects to discuss. Firstly, the validity of the research methods used in this research and their appropriateness for the setting. Secondly, the extent to which the researcher herself influenced the research outcomes.

Qualitative and quantitative methods were used during this research. The quantitative tools used in this research were: EMIC-CSS, A-EMIC-CSS, ASDS-A, A-SDS, Knowledge items and Entertainment items. The EMIC-CSS and SDS were validated for an adult and adolescent population in relation to albinism in Chapter 4 and 5. These scales were based on existing scales that were previously validated in relation to different types of health-related stigma and in another cultural context. For example, the scales have been used to measure leprosy-related stigma in Indonesia (Peters, et al., 2014). However, the use of the adult version caused difficulties with respondents who had difficulties with reading, which might have influenced the outcomes. The Knowledge items were thoroughly discussed with experts on albinism and were considered by them as the most important aspects of knowledge related to albinism. In both studies that used the Knowledge items (Chapter 7 and 9) the items were discussed individually, and the sum scale was only used pragmatically because of low internal consistency as indicated in the studies. The Entertainment items were based on items by Ritterfeld and Jin (2006). Before using these items, they were discussed with representatives from

Tanzanian organizations who commit themselves to improving the lives of people with albinism and schools that were collaborating with the researcher. The items were judged fit to measure entertainment levels of intervention. The Entertainment items were used in Chapter 8 and 9. However, their internal consistency did not prove sufficient, therefore the items were discussed separately and only used in a pragmatic scale, as indicated in the chapters.

It should also be noted that the attitude measurement scales used in this thesis do not measure all dimensions of stigma. The evaluated stigma reduction strategies can have influenced dimensions of stigma that were not measured by the used tools. As stated by Pescosolido & Martin (2015) the multidimensionality of the stigma concept is often overlooked in studies on stigma. Stigma-related dimensions include: intolerance, exclusion fear and mistrust (Pescosolido & Martin, 2007). There is no agreement as through which dimension stigma can best be measured and there are also external factors (such as respondent availability, resources and time) that limit the number of stigma dimensions that can be measured within a study. The operationalization of stigma most often used in studying stigma (Pescosolido & Martin, 2015) as was also used in this study, was social distance. What are respondents' feelings about being in a certain social relation with someone with albinism and their desire for social distance? Operationalisations for measuring stigma that were not focused on in this study include: traditional prejudice, exclusionary sentiments, negative affect, treatment carryover, disclosure carryover and perceptions of dangerousness.

The following qualitative methods were used in this research: in-depth interviews, workshops, focus group discussion, including focus group discussions in which I made use of visual vignettes and observations. In each study making use of qualitative methods, qualitative data gathering continued until data saturation was being reached. All research took place with assistance from representatives of organizations or schools and during the research the methods used were discussed with and approved by these collaborators. Especially, the use of visual vignettes in focus group discussions proved to be a great tool in doing research on a sensitive topic such as albinism, as can be read in Chapter 6. Most importantly, in all studies I tried to make use of mixed methods for triangulation of the data. Some interesting findings in relation to the importance if this triangulation has been discussed in the individual chapters and is also summarized in the conclusion above. Shortly, it proved very valuable to use several research methods.

Some other points need to be emphasized. Because of time constraints the research did not succeed in carrying out long-term measurements and therefore it is not possible to discuss the long-term effects of the stigma reduction interventions that were tested, as is the case in many studies on stigma reduction (Brown, et al., 2003; Mak, et al., 2017). However, to expand insights into the effect of stigma reduction interventions further, knowledge on long-term effects is of importance. Additionally, in the research, attitudinal change was measured, but we did not measure actual behavioural change. Behavioural change was indicated by the respondents, but not structurally researched. In stigma reduction research the measurement of behavioural change is often lacking (Dalky, 2012; Janoušková, et al., 2017; Jorm, 2020; Mak, et al., 2017). Behaviour and behavioural change are hard to measure and attitude measurements are often used in stigma research to evaluate interventions.

#### ROLE OF THE RESEARCHER: BEING A MZUNGU

Because the researcher does not originate from the country of research and clearly stands out as a Dutch woman in a Tanzanian setting, this must have influenced the internal validity of the research. The different appearance of the researcher was always pointed out by her surroundings by calling her '*mzungu*'. The word '*mzungu*' is used in Tanzania to describe people with a 'white skin'/'European appearance'. Being a *mzungu* never goes unnoticed in Tanzania. It should also be noticed that in the researchers' experience people would not link/compare/confuse people with albinism, with a light

skin, and the foreign researcher, with a light skin as such. As discussed before there is a high risk of respondents providing socially desirable answers to a foreigner. Sometimes the fact that a foreign researcher was involved, set expectations, such as that respondents would be paid for participation or would receive another benefit from participation in the research. During the research I tried to be fully aware at all times of the possible influence of the researcher. In some studies, I tried to overcome this possible influence by making use of local research assistance. When I carried out the data-gathering myself I always spent time in the beginning of the session to build rapport with the participants.

However, it was also experienced by the researcher that sometimes the fact that the researcher was an 'outsider' was an advantage in gathering data. Firstly, respondents tended to provide extensive explanations about certain phenomena because they expected the Dutch researcher not to know anything about it. This provided the researcher with in-depth insights. Secondly, being an outsider provided the researcher with an excuse to ask many questions, whereas a local researcher might have experienced suspicion about why all these questions were being asked and would potentially make own interpretations sooner, based on own knowledge. Thirdly, because the researcher was not part of the existing hierarchy, respondents felt free to discuss certain subjects. Especially in schools, were normally students are reluctant to discuss with adults, because they are all teachers and therefore higher in rank. The researcher, however, did not belong to this existing system and students felt at ease to discuss with an outsider. Fourthly, often respondents enjoyed being able to talk to a *mzungu*, as this is something new and interesting to them, this aspect I will discuss further under ethical considerations.

Sometimes the respondents felt more comfortable to speak Swahili with me instead of English. This made focus group discussions livelier and the data gathering easier. However, I also sometimes experienced that respondents thought it was very strange to talk Swahili to a foreigner. People do not expect a *mzungu* to speak Swahili, and therefore, preferred to talk to me in English. Especially in a school setting, where English is the language of instruction.

In terms of internal validity many aspects should be taken into account. Firstly, the quantitative methods were properly adapted and validated for their purpose and were able to evaluate the outcomes of the stigma reduction interventions tested in this thesis. Qualitative measures were thoroughly considered and adapted to the setting and therefore successful in providing clear insight in the situation. The limitations of the methods were considered. Secondly, the influence of the foreign researcher was taken into account. By being aware of strengths and limitations of methods I trust to have been able to provide representative insights into the situations studied in this thesis.

#### EXTERNAL VALIDITY

To what extent can the findings be generalized and are they applicable in other contexts? There are many similarities across different health-related stigma (Hofstraat & van Brakel, 2016; van Brakel, 2006), as is also the case for albinism in relation to other health related conditions. These similarities open the opportunity for using similar stigma reduction strategies and intervention types for a variety of health-related stigma. For which this research can serve as an inspiration. However, as often pointed out in this thesis, the situation of people with albinism in Tanzania is based on specific cultural beliefs. This research wants to emphasize that one should be very careful in generalizing results in other cultural contexts. One should always keep on evaluating measurement tools and stigma reduction interventions.

The research findings can be used as an inspiration for other scale validations, use of methods and development of stigma reduction interventions. The scale validation proved the promising possibilities for adaptations of the existing EMIC-CSS and SDS scale to another context. The discussion

of visual vignettes in Chapter 6 shows the promising possibilities for using this method in research in relation to other sensitive topics.

### ETHICAL CONSIDERATIONS

Documents for ethical approval were submitted to the Tanzanian Commission for Science and Technology (COSTECH) and to the Ethical Committee for Human Sciences (ECHS) of the Vrije Universiteit Brussel. COSTECH approved the study and ECHS decided that the research was exempt from ethical approval. The research was done in accordance with the ethical code of scientific research in Belgium, the European charter for researchers, and the Framework for Research Ethics (FRE) of the European and Social Research Council of the European Commission.

In this research emphasis has been put on (1) privacy and confidentiality, (2) the presentation of the outcomes, (3) informed consent and (4) harm minimization.

As described by Millum, Campbell, Luna, Malekzadeh and Karim (2019) research with people who experience stigma has two additional risks as compared to groups who do not face stigmatization. (1) Firstly, researchers have to pay even more attention to privacy and confidentiality because the consequences of glitches here can be far reaching. I had to protect the personal information of people with albinism carefully, so that no harm can be done with it. Additionally, as observed in the research, the respondents in the research were fully aware that stigmatization of people with albinism is not socially desirable. Therefore, I had to make sure that all data provided on someone's attitude were confidential, so that respondents had the opportunity to safely express both their negative and positive attitudes. Often the names of participants were not noted down but respondents were appointed a number so that anonymity was guaranteed.

(2) As a second additional risk Millum et al. (2019) point out that one should be careful not to put third parties at risk by publications of findings that can have negative outcomes or can even be misused in further disadvantaging the stigmatized. Therefore, one should be very careful which results to share and how to frame them. In the case of albinism for example, we should be careful when describing the difficulties people with albinism have in schools, that are mostly related to their low vision. It should always be pointed out that these difficulties can be overcome by the right devices and that these difficulties have nothing to do with their learning capabilities. People should not be left believing that people with albinism are not capable to be successful in schools when reading about difficulties people with albinism face. It is not expected that the research outcomes would disadvantage people with albinism because when appropriate, the chapters in this thesis have discussed the capabilities and agency of people with albinism. Therefore, research articles should always balance the information regarding barriers faced with the agency and capacities of people with a stigmatizing condition such as albinism.

(3) Informed consent was provided by all participants in this research. Either written or verbally. Often it was decided to request informed consent verbally because respondents indicated to not be willing to write down their names in terms of anonymity. Some respondents were even afraid that the government would use the forms to check on the participants, I explained this would not be the case. Also, when requesting for written consent respondents often created unrealistic expectations for the research, some would think it was an official test, others that it would take a lot of time or that they would receive compensation for their participation, even though the form itself explained it was not the case

(4) An ethical risk in this research existed out of people with albinism exposing themselves to a large group of (unfamiliar) people as spokespersons in a stigma reduction intervention. By presenting themselves in life presentations as spokesperson to the public they might risk (violent) discrimination. This aspect has been considered in Chapter 10. Interestingly, this risk was contradicted



by the spokespersons with albinism themselves. They all mentioned not to experience any risk because of a presentation as long as they were properly prepared for their presentation and proper security arrangements were made. This spokespersons' perception might add to a statement that was made by Millum et al. 2019 when discussing ethical challenges in health-related stigma research. In their article they discuss that we should be careful not to be overprotective towards people with a stigmatizing condition. We should be aware that people with a stigmatizing condition also have a say in the matter. They should not be denied their own voice by labelling them as vulnerable. Whereas labelling people as vulnerable can even promote stigmatization and/or can result in a self-fulfilling prophecy.

Some questions concerning ethics have risen during the research, of which I will discuss four here. Questions are raised about people with albinism being spokespersons as part of a paid job, controlling for negative long-term outcomes of stigma reduction interventions, and the role of the foreign researcher.

An ethical dilemma was raised in the Chapter 10. In many contact-based interventions persons with albinism are present. For some people with albinism, being a spokesperson is part of a paid job. Giving the fact that it is hard for people with albinism to find a job, one could question if people with albinism would refuse a job as a spokesperson when they would not feel comfortable presenting themselves to an audience. People with albinism have difficulties with finding employment due to discrimination and some limitations they face for possible jobs, such as working outside in the sun (Baker, et al., 2010). Therefore, one can question if asking people with albinism to be a spokesperson as part of a job is ethically sound.

Stigma reduction interventions, as also tested in this research can have unintended outcomes. In this research I have tried to control these outcomes as much as possible through evaluation of possible positive and negative effects of interventions, and the provision of information on albinism. However, we do not control the outcomes on the long run. This consideration has also been discussed by Brown and Singhal (1990). They notice that when entertainment education is used through media it is hard to check who is receiving these messages and how they are interpreted: 'With whom does the responsibility lay for the (un)intended outcomes of a programme?'. Part of this issue can be overcome by a pilot of the intervention in which the interventions outcomes can be evaluated. Additionally, we should be careful people do not understand the bio-medical explanation of albinism as a motivation to refrain from having children with someone with albinism or people with the albinism gene, this line of thought could create a new form of stigma.

Another question I ask myself is that I found that respondents often enjoyed talking to a *mzungu*, as explained above when describing the role of the researcher. Is it fair that respondents participate for this reason? Aren't we anticipating on the (neo)colonial sentiments in the country through this? Certainly, we want respondents to participate in a research because of the topic, rather than because of the researcher. This needs to be addressed since it was experienced in this research that Tanzanian research assistants faced much more resistance among respondents to participate in the study. So, there are important questions with regards to the privilege of the white researcher. Or is respondents' willingness to participate in the study only based on false expectations of receiving something in return from the researcher, because that is what they expect from a *mzungu*, even though this is clearly communicated? Can we allow this?

This research focused on the efficiency of stigma reduction interventions. Which inevitably led to a number of ethical issues that were not the prime focus of the research as neither were the physical and genetical consequences of albinism. Nonetheless is important to minimally address these philosophical, societal, and ethical issues although they exceed the scope of this thesis. When people

with albinism have children, they pass on the albinism gene, when people with the albinism gene have children there is a chance they will have a child with albinism and/or pass on the albinism gene. In case stigma with respect to albinism reduces and people with albinism are more included in society they will have higher chances of having a family. Consequently, when people with albinism have families with children in greater numbers, the number of people having albinism and carrying the gene might rise. However, when a decrease in stigma is accompanied by an increase in knowledge in the biology of the disease and its dynamics in the population it is impossible to predict the extent of such rise. As such challenges remain to avoid novel stigma induced by this knowledge. To assist people with albinism or people who know they might be carriers of the albinism gene (for example because family members have albinism) genetic counsel is recommended. So that people will be able to make informed choices about having children that might have albinism. However, as already mentioned, this line of thought touches upon very important philosophical and ethical considerations and questions, which were not the prime focus of this research.

Considering the ethical aspects of this study some lessons can be learned from this study. Firstly, in stigma research, we should be careful not to reinforce stereotypes in articles. This can be accomplished through adding information to articles about the agency and capacities of people with stigmatizing conditions. Secondly, written informed consent forms in a community where one is not used to forms, and associates this with official governmental forms causes reluctance for people to participate in a research and can create false expectations. When informed consent information can also be provided verbally, this might be more comfortable for the respondents. Thirdly, to be able to control (un)intended (long-term) outcomes of stigma reduction interventions, pilot studies are of major importance.

### RECOMMENDATIONS FOR STIGMA REDUCTION INTERVENTIONS

In this part of the discussion I want to provide some recommendations for the future development of stigma reduction interventions in relation to health-related stigma in general and to albinism-related stigma in particular. Recommendations were made considering the target audience of interventions and the associated content, intervention strategies, important aspects of the contact strategy and the role of entertainment. I conclude this section by discussing possibilities for evaluation of interventions.

It should be emphasized that large varieties in attitudes, knowledge and beliefs exist within a community. Attitudes can vary throughout a country but can also depend on other factors such as age and education level. Therefore, interventions should target different populations within a society (Mak, et al., 2017; Mehta, et al., 2015). In terms of albinism, older and less educated people seem to hold stronger beliefs towards people with albinism. Therefore, an intervention targeting adults in a community should have a different format and different content, such as the radio intervention in Chapter 8, than an intervention targeting a student audience in schools.

When considering different content for different audiences in relation to explanation on the cause of albinism, one should among others be aware of the target audience's knowledge level and background. Explaining the genetic cause of albinism to an audience with no basic biological knowledge might not be the most effective way of changing attitudes. In some cases it is decided to explain albinism through a religious discourse, however the outcomes of this approach should be researched in the future. Additionally, spokespersons with albinism noticed that one should be careful with what information to provide where. The example was provided in an interview that one should be careful to talk about the trade in body parts. Providing information that body parts of people with albinism are sold for large amounts of money, might not be the most tactful way of addressing albinism-related stigma in poor communities because this might give them ideas and may even increase stigma.

Interventions to reduce albinism-related stigma should specifically aim to target the drivers behind the stigmatization: (1) fear of contagion, (2) perceived dangerousness, (3) lack of knowledge, and (4) cultural beliefs and myths (Stangl, et al., 2019). Additionally, when addressing these drivers within an intervention it is important to treat the following topics explicitly because it was found hard for people to grasp these topics from interventions that did not mention these specifically. Firstly, interventions should emphasize that albinism does not lead to blindness and secondly, they should mention that people with albinism also die and cannot just 'disappear'. What I mean with this, is that by simply explaining or showing that people with albinism are human does not necessarily influence or replace deep grounded beliefs, therefore these myths need to be treated specifically.

It is recommended to make use of a combination of stigma reduction strategies: education and contact. Even though the education strategy has proven to be effective on its own, it is recommended to use a combination of the two. Especially, because many people doubt the 'humanness' of people with albinism, it is important to have people understand people with albinism are just like 'you and I'. Not only by explaining what albinism is, but also through showing that people with albinism have the same abilities as people without albinism. People can for example change their ideas about people with albinism by seeing an example of a person with albinism who succeeded in education and/or is successful in his/her job. Also showing that people with albinism can have a normal family life, are married, have children can assist in changing people's attitudes. Also, try to discuss some everyday things such as hobbies and potentially shared interest. Preferably choose simple examples, the examples should not be seen as exceptional. These kind of aspects of an intervention seem to make a large impression on the participants in an intervention.

The mechanisms at work in a contact-based intervention as described above can be valuable facets of a stigma reduction intervention. I would recommend that the spokespersons present in a contact-based intervention have certain characteristics that participants can identify with. Within the interventions these characteristics should also be clear to the participants to improve the identification process. For example, in a school setting, get the participants into contact with someone with albinism who is also in a school setting. Show the participants that people with albinism go to school like them, and that they can also be successful in their education.

Entertainment can play a valuable role in stigma reduction interventions to engage the audience. However, one must be careful that the intervention still reaches its' goal of education and stigma reduction and that this is not surpassed because of entertainment. I would recommend to keep on repeating the main messages and lessons you want people to take home after an intervention. Preferably, there would be someone 'outside' the intervention, such as a moderator, to emphasize these messages. A moderator would however need to receive proper training to take on this role. Also, I would like to recommend providing room for reflections during or after the interventions. This will provide the participants with the chance to reflect on the messages they received in the intervention. I also highly recommend proper evaluation, to be able to monitor the effect of the intervention and to, when necessary, improve future interventions. Additionally, when making use of stories about people with albinism I would recommend to emphasis positive stories. When the stories presented about people with albinism focus too much on the discrimination and problems faced by people with albinism, it is possible these stories only reinforce existing negative attitudes.

Also, it is questionable to what degree an intervention should be entertaining in relation to the costs of this entertainment. Even though an intervention such as theatre can be very effective and entertaining, these types of interventions also carry their costs. Therefore, they are limited in terms of sustainability and reach. Another, maybe more simple intervention, might be less entertaining, but can be cheaper and/or be able to reach more people, such as for example a radio intervention.

When making use of people with albinism in a contact-based intervention it is very important to provide them with proper training and support. Spokespersons need to be confident to present so

that the presentations do not have negative personal outcomes. Training is also important for them to feel confident and be able to provide effective presentations. It is very important that spokespersons are deemed trustworthy by the audience. We do not want participants to come out of an intervention that confirmed their negative expectations about someone with albinism. Also, these presentations must be facilitated properly to ensure the spokespersons' safety.

To conclude these recommendations, I would again like to emphasize the importance of proper development, pilot testing and evaluation of stigma reduction interventions: do people take home the message as was intended by the intervention? For this purpose, the described methods in this thesis can be used: the EMIC-CSS, A-EMIC-CSS, ASDS-A, A-SDS, and Knowledge items. These methods have been developed for use among adolescents and adults. I would recommend combining these quantitative methods with qualitative methods, such as focus group discussions using visual vignettes. Evaluation should preferably not be carried out by someone who has been taking part in the implementation of the interventions because this will cause a strong social desirability bias. By proper evaluation stigma reduction interventions can be improved and can achieve the most effective outcome.

Evaluating interventions purely on qualitative interviews might give a distorted view on the interventions' outcomes. Especially if people enjoy an intervention very much, for example through songs or theatre, they are very likely to say that they thought the intervention was nice and that attitudes will change because of it. However, this does not provide much proof on the actual influence of the intervention. Therefore, a combination with quantitative measures is necessary to provide less biased insights.

## RECOMMENDATIONS FOR FUTURE RESEARCH

As with all research trying to give answers, new questions come up. I have selected possible topics for future research. However, in Chapter 12 other initiatives that were started during this research, but that did not result in scientific articles, are being discussed. The recommendations about their possibilities for further research are discussed there.

Possibilities to reduce the social desirability bias of the measurement tools used in this thesis (EMIC-CSS, SDS) should be tested. For example, some more balanced items (positive and negative formulated items) can be added and the meanings of the items can be less distinct.

As discussed in the section on the validity of the thesis' findings, there is a need for more research on the long-term impact of stigma reduction interventions related to albinism in Tanzania using a larger sample and a randomized controlled trial. This to be able to generate more generalizable data and to be able to gather long term data on their impact. When we want to provide people with albinism with equal chances it is of uppermost necessity that people's attitudes towards people with albinism are sustainably changed, so that negative beliefs about and behaviour towards people with albinism are banished for good.

It would also be of interest to do more research on the difference between outcomes of face to face and para-social interventions in relation to albinism. How necessary is the presence of someone with albinism in real-life within an intervention? Especially, when research would show that real life presence is not essential it might be easier and more sustainable to facilitate indirect contact to scale up stigma reduction campaigns.

In relation to the above I also would recommend research that evaluates the cost-effectiveness of stigma reduction interventions (Kemp, et al., 2019). When it would be possible to deduce the cheapest type of intervention with the largest effect this can prove valuable for the scaling up of interventions, especially in countries with limited resources.

As described in Chapter 3 I have not succeeded to perform a participative action research in this thesis, in which interventions would have been developed together with the stakeholders. I would

highly recommend a more extensive research in which it will be made possible to create stigma interventions with these stakeholders, so that interventions that will be more fitting with their context can be tested for effectiveness.

As discussed before, it would be of interest to investigate the role of knowing the cause of albinism in a stigma reduction intervention. Is it necessary for people to know the genetic explanation of albinism to be able to change attitudes? Especially when this information is not building on existing biological knowledge. I would suggest exploring the role of the attribution theory in relation to reducing albinism-related stigma. Additionally, other explanations provided for the condition of albinism through a religious discourse could be explored further. How effective can a religious intervention be? And is this a desirable approach?

To conclude, people will always find reasons to label people who are not like them as 'others'. This seems to be human nature and I am aware that eradicating stigma completely is not an achievable goal (Brown, et al., 2001). Stigma reduction will not likely take place on its own (Schnittker, 2008), however, as also proven in this thesis, stigma can actively be reduced. Therefore, I hope this thesis can motivate others to keep researching the best possible ways of reducing stigmatization and to keep on implementing these interventions that can have such a life changing outcome.

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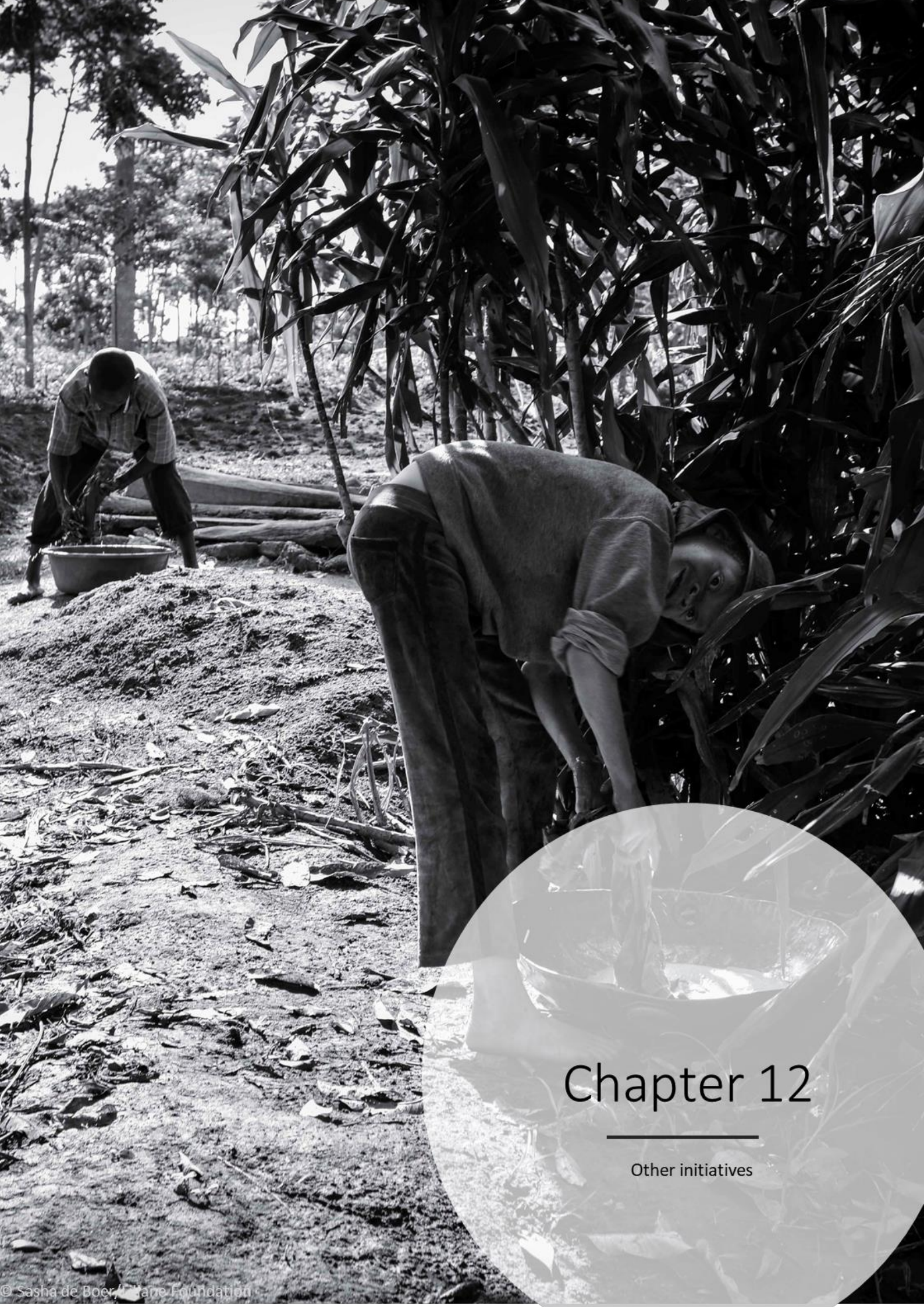


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## Chapter 12

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Other initiatives

## CHAPTER 12 OTHER INITIATIVES

Not all initiatives that have been rolled out for this research and observations that were done during this have been communicated through scientific articles. Nonetheless, these activities did in some cases, lead to an addition of knowledge on the circumstances people with albinism live in and provided the researcher with a better understanding of the field. Also, (im)possibilities of stigma reduction interventions were explored and insights with respect to methodology was gained. There is a variety of reasons why these initiatives have not led to articles. Some initiatives have only been used to gain better insight in the stigmatization of people with albinism, so that decisions could be made considering methodology and stigma reduction interventions. Other initiatives were used as an exploration of stigma reduction interventions, however, did not prove to be seminal enough to continue developing. Yet for other initiatives time or funding was lacking to proceed within the framework of this PhD thesis, but follow up might be interesting in the future. Below more information is provided on these initiatives, so that lessons learned might contribute to future research. The initiatives can be divided in: (a) the testing of other research instruments, (b) perspectives on the stigmatization of people with albinism and (c) stigma reduction interventions.

### A. TESTING OTHER RESEARCH INSTRUMENTS

#### DRAW-AND-WRITE METHOD

One of the studies set out to gain a better insight into the attitudes towards people with albinism among primary school students. The final aims of this study were the development of a child scale and the development of fitting stigma reduction strategies for primary school students. As research with children can be difficult (Pridmore, 1996), a fitting methodology had to be found to discuss the topic with primary school students. Because of its promising results in the past (Punch, 2002) the draw-and-write method was selected. By drawing certain situations, the respondents have the opportunity to communicate their own perspectives. Triangulation was done by using interviews after the drawing sessions in which children could explain and talk about their drawing (Onyangouma, Aagaardhansen, & Jensen, 2004). A reason for choosing this method was that most children like drawing, which makes it a fun and creative way to get children involved in a research. Also, through this method chances are lower that adults impose their own views on the research (Punch, 2002) through which the power balance between children and adults can be overcome.

Three primary schools in Mbeya participated in this exploratory research. In total 64 students from a variety of educational stages participated. The primary school students participating in the research were asked to make three drawings:

1. a drawing of their own family,
2. a drawing of a family of someone with albinism and
3. a drawing of someone with albinism in school.

After finishing their drawings, the Ugandan research assistants of the organization Child Support Tanzania, asked the children about their drawing. The children were asked what they had drawn and why.

Problems arose with gathering in-depth data on the respondents' attitude. The respondents seemed to have difficulties explaining their views to the research assistants. A possible explanation for this could be that the research was conducted in a school setting. In the observation of the researcher, students in Tanzanian schools are not encouraged to express their personal views. During the implementation of this exercise it turned out it was hard to overcome the beforementioned power balance between adults and children. Generating data from the drawings alone did not seem valid,

since the explanation of the respondents was necessary to gain further insight in the meaning of the drawings. Therefore, it was decided to discontinue data gathering through this method. As a next step in gaining more insight in children's perspectives on albinism another method might be explored.

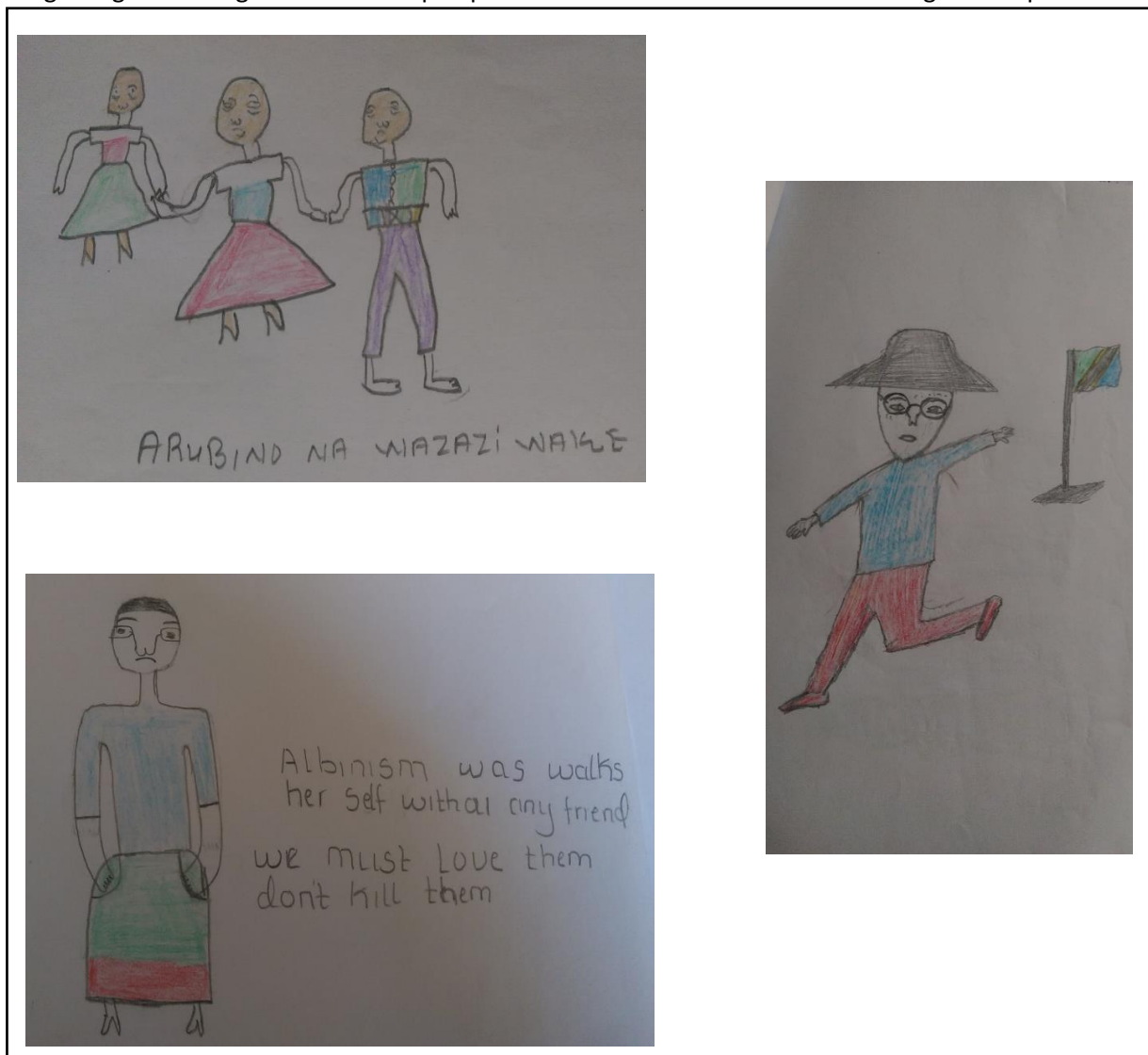


Figure 1 Examples of drawings draw and write method

#### ATTITUDE TOWARDS DISABLED PEOPLE SCALE

When exploring possibilities for scales measuring stigmatizing attitudes, the Attitude Towards Disabled People scale (ATPD) seemed promising. Among others because of its' simplicity, in terms of administration and scoring. Also, it has proven to be a useful tool in previous research assessing attitudes towards people with a disability (Devkota, Murray, Kett, & Groce, 2017; Litvack, Ritchie, & Shore, 2011; Yaker, Block, & Young, 1970). In comparison to the items of the ATDP scale do form a balanced scale through the alternately positively and negatively formulated items.

This scale was adapted to albinism. Examples of items are: 'People with albinism are usually friendly', 'Most people with albinism do not feel sorry for themselves'. Answers could be given on a five-point scale ranging from 'strongly agree' till 'strongly disagree'. The new version of the scale was tested in several religious institutes in Moshi. In total 100 respondent (65 female, 35 male) participated in the pilot study of the scale.

The analysis of the outcomes of the test did not seem promising enough to continue with the validation of this scale in the time that was still left for the research. Mostly because people seemed

to be confused by the alternating positively and negatively formulated items. Also, because the other scales as described before, the A-EMIC-CSS and A-SDS, seemed to be valid to measure albinism-related stigma, it was decided to continue with the development and use of those scales instead of the ATDP scale. However, it could be of interest for further research to continue with the development of this scale to gain further insight in albinism-related stigma.

#### IMAGE SOCIAL DISTANCE SCALE

An exploratory test was done with a social distance scale based on images. This scale consisted out of images drawn by the organization Happy Made By and artist Dita Aleman-Goudriaan. It was expected that an image scale would make it easier for adults and children with lower literacy levels to participate in research. Through images respondents might be less influenced by the formulation of specific items. Additionally, the use of an image scale could exceed language boundaries. All images in the scale portrayed social relations in which one could be with a person with albinism. As with a conventional social distance scale, respondents were asked how one would feel in this situation. Feelings about each situation could be indicated by circling an emoticon. An example item has been portrayed below:

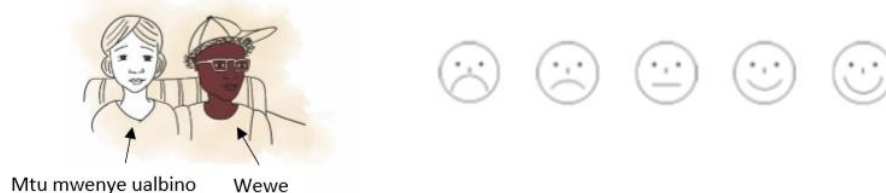


Figure 2 An example of an item from the image social distance scale

However, when testing this scale, the respondents seemed to be confused about what they had to do. They were unfamiliar with filling out surveys in general and when asked to comment on the image by circling an emoticon they often did not know what to do. Confusion might also be caused because forms, this is how a survey is probably seen, that include images are very uncommon. Having said that, the idea of an image scale seems feasible. The proper development of this scale would need a substantial effort and rethinking of the process.

#### ACCEPTANCE OF PEERS SCALE

Another aim of the research was to develop a scale measuring the attitude towards people with albinism among children. A scale was developed that was based on the 'Acceptance of Peers' scale (Maierson, Roberts, & Prentice-Dunn, 1996). In the past this measurement instrument had proven to be a valid tool and to be easily adaptable to new contexts. The Acceptance of Peers scale was originally designed to measure children's reactions toward peers with HIV/AIDS. This instrument measures three attitudinal dimensions: (1) the affective, (2) behavioural and (3) cognitive dimension. (1) The affective dimension refers to feelings and emotions: how do people feel about people with a stigmatizing condition? (2) The behavioural dimension is about actual or intended actions: how do people act towards people with a stigmatizing condition? (3) The cognitive dimension entails beliefs and knowledge: what do people think about people with a certain condition? (Rosenbaum & Armstrong, 1987; Triandis, 1971; Vignes, et al., 2008).

The adapted items were discussed with experts in the field: staff members from NGO working with children with disabilities, schoolteachers and children themselves. Example items of the new scale were: 'Would it make you afraid to be around this child?', 'Would you eat lunch with this child at school?', 'Would this child be popular?'. Items could be answered by choosing from the answer possibilities: "no chance, almost no chance, some chance, a good chance and a very good chance".

By making use of a convenience sample 124 students participated in the test (58,1% boys, 40,3% girls), and a week later 103 of them participated in the re-test. The respondents had an average



age of 11 years and they attended standard 5 and 6 in a public school in the south of Tanzania. The results showed low scores for reproducibility and high ceiling aspects on all aspects measured in the scales. The results suggested that negatively formulated items confused the respondents. Also, the operationalisation of a written survey for this age group in Tanzania might not be fitting. Because of these disappointing results it was decided to look at other ways to measure attitudes towards people with albinism among children. Further development of this scale can be considered for future research.

#### DIFFERENT ANSWERING POSSIBILITIES

One of the difficulties with the attitude scales was that respondents tended to provide extreme answers, causing large floor or ceiling effects. To overcome this problem, it was thought that answers might be mediated when the respondents would be given the opportunity to express their feelings on a continuous line. Instead of being forced to choose from predefined answers, respondents would be able to express their attitudes more precisely. On the continuous answering line respondents could express their opinion between the following answer possibilities: I do not have a big problem and I do have a big problem. Besides a written experiment with this line, the researcher also experimented with people filling out their answers on a tablet. On the tablet respondents could just move a bar to place it on the line.

The researcher experimented with these methods in a teacher training college (n=40) in which groups of 5 students at the time were asked to fill out their answers to the questions, either on paper, or on the tablet. In both instances the exercise of choosing a point on a line, was confusing for the respondents. Most respondents did not know what to do with this line, and extensive explanation by the researcher was necessary to have some people understand what to do. In most cases respondents provided the answer options as portrayed on the line. Therefore, this method also did not result in less extreme answering behaviour and it was decided not to make use of this answering technique.

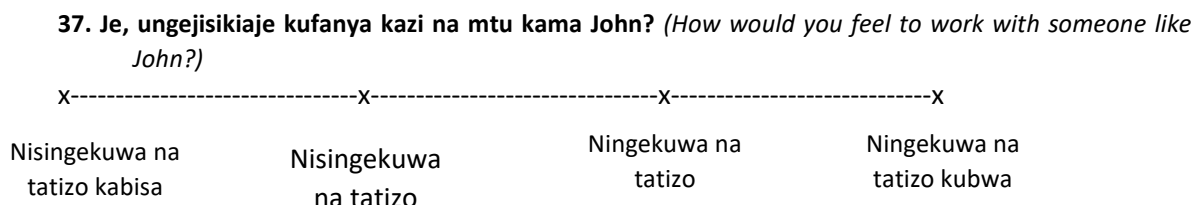


Figure 3 Example item and 'answer line'

## B. DIFFERENT PERSPECTIVES

### RELIGIOUS LEADERS

In discussing the stigma related to people with albinism and stigma reduction interventions, people often incorporated monotheistic religious views. Albinism was often explained out of a religious discourse and stigmatizing acts towards people with albinism were convicted based on religious explanations. As discussed before, it was suggested that religion could function as a stigma reduction intervention. Therefore, it was decided that it might be interesting to explore religious explanations of albinism from the perspective of religious leaders. It was expected that many of them would have a religious explanation that could maybe be used in stigma reduction. The aim was to find out how albinism was embedded in religious explanations, and stigma reduction could be motivated out of religious beliefs. However, during the exploratory interviews with five religious' leaders (four Christian, one Muslim), it was found that religious leader lacked in-depth explanation for albinism out of a religious discourse. Most would refer to: God created everyone equally but had difficulties to go more in depth. It would be interesting to develop more religious based stigma reduction interventions. However due to time constrains development and testing of this type of interventions could not be

include this in this PhD research. Since religion is an important influencing factor it remains a worthwhile but challenging, line of thought.

#### FAMILIES OF PEOPLE WITH ALBINISM

It was observed that most of the families and people with albinism who participated in this research did not know the genetical explanation of albinism. However, most of them did talk about how albinism influences the whole family. This was expressed through several ideas. Some people would describe that whole families feel cursed with albinism. Others expressed that someone in the family must have done something wrong, causing a child to get albinism. Again, another belief is that marrying someone with albinism causes bad fortune or albinism. Others feel ashamed that they have someone with albinism in the family. It is interesting how people are aware of a link between family and albinism, without knowing/believing the scientific genetic explanation of albinism. The initiative was taken to explore this link further by starting interviews with the families of people with albinism. Further research is recommended.

### C. STIGMA REDUCTION INTERVENTIONS

#### INTERACTIVE VOICE RESPONSE

Another intervention that was explored was the Interactive Voice Response (IVR). This intervention was suggested by Gamariel Mboya, who has albinism himself, who has experience in raising awareness on albinism in Tanzania. Through this IVR people with and without albinism would be able to gain information on albinism through the phone. By calling a certain phone number they would be able to reach a navigation menu leading them to automated messages explaining about albinism. This IVR was developed with the help of André Baart. Although the IVR was ready for testing, testing could not be carried out due to a lack of funds.

#### EDUCATIVE GAME

An educative game was developed by the researcher in cooperation with several organizations and schools. In setting up the interventions the possibilities for an educative game were discussed with NGO's and secondary school students. They all indicated that people in Tanzania are not familiar with playing boardgames and in general people do not frequently play games. When first explained by the researcher the educative game was not deemed efficient by the respondents. However, since the respondents did not seem to grasp the idea of an educative game the researcher decided to develop an example educative game.

To be sure that all participants would be able to grasp the game without an elaborate introduction, the game of 'memory' was chosen for its versatility and its simple rules. Besides that, memory is relatively cheap to print, and therefore easy to spread. The images of the memory game were based on a story about a giraffe with albinism (for more information on the story and a sample of the educative game see Appendix J). All the frequently asked questions about albinism were embedded in the images and story of the game. The story is written on the memory cards together with the images, the cards are numbered and when put in the right order one can read the story after playing the educative game. The memory duo exists out of one card with the story written on it and one card without the story written on it, that can later be used for other educative game/story tell opportunities, however this aspect is not the focus of the current research. After the game and the reading of the story the class can discuss what they have learned from the game.

The educative game was compared to a traditional class about albinism. Both interventions were implemented at two secondary schools in the South of Tanzania. Ten research assistants who were students from St. Aggrey teacher training college (five men, five women) assisted the researcher.

In total 238 respondents participated in the pre- and post-test. The pre- and post-test consisted of Knowledge items and the albinism social distance scale. After the intervention, some of the respondents participated in a focus group discussion with one of the research assistants.

Both interventions, the traditional class and the educative game, seemed to influence the correct knowledge on albinism of the respondents. Both interventions caused a decrease in stigmatizing attitude. No difference was found between the interventions. In terms of level of entertainment, it was hard to reach conclusions. Quantitative findings showed an extreme skewness of the response. The focus group discussions were not conducted systematically and there is large difference between focus group discussions. Some of the research assistants has quite an 'aggressive' tone in asking questions, which might have influenced the respondents answer. Therefore, it was decided these findings could not be used. All this causes the possibilities for comparison between the interventions to be limited. This is possibly caused by social desirability or the composition of the sample. Another explanation is that because the intervention is already a break from normal schoolwork, both interventions were experienced as fun and interesting (something is better than nothing). A lesson that was learned however, was that unfamiliarity of people with a certain intervention does not only have to be a weakness, it can also be its strength: people can be very enthusiastic about something new, they might even pay more attention and will tell others about it.



Figure 4 Images from the memory game

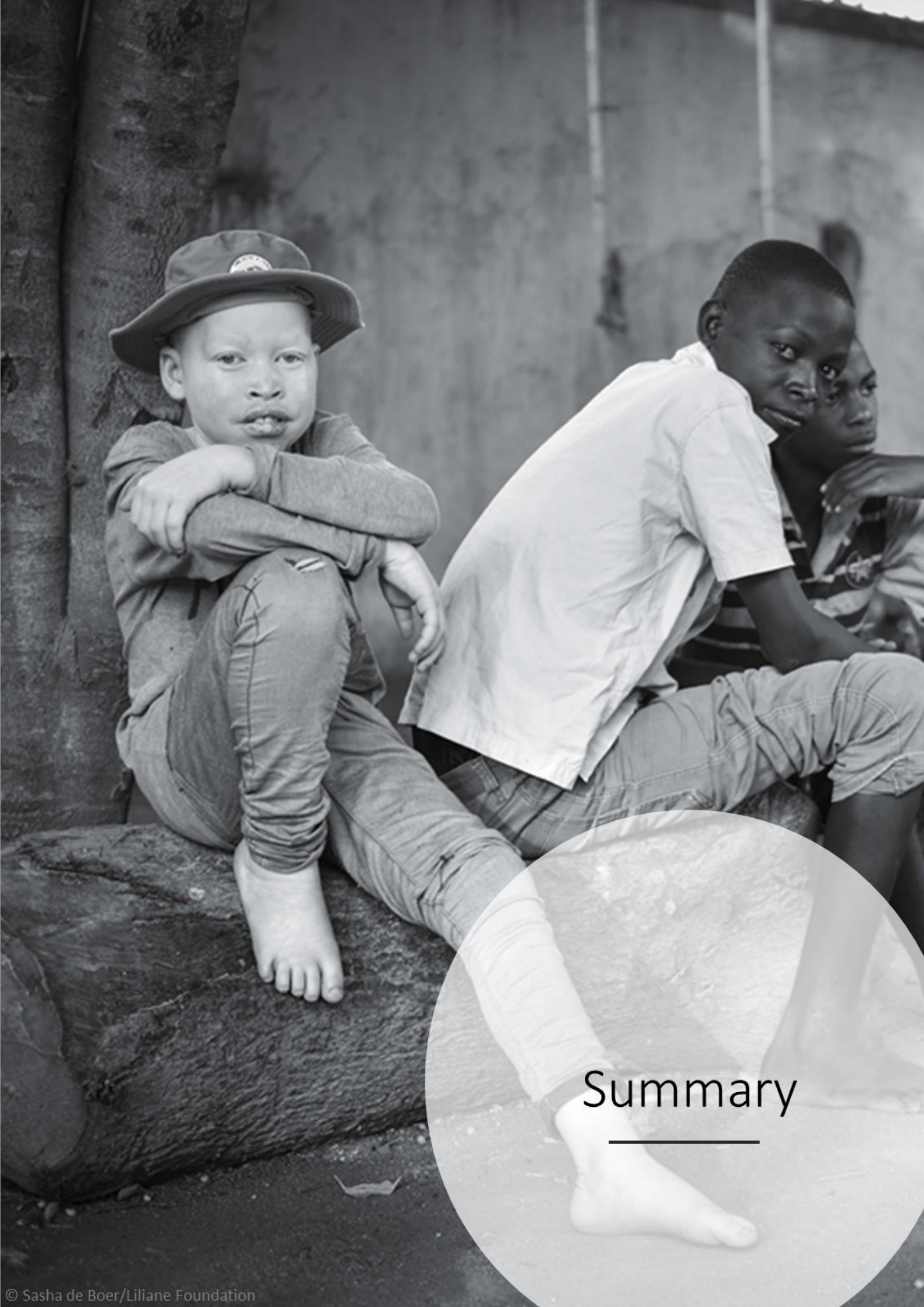
#### PERSONAL PRESENTATION VS FILM

At the end of the research I also started working on a comparison between real-life presentations of people with albinism, a filmed presentation by people with albinism and a filmed introduction to the family of people with albinism. However, due to a lack of time the research could not be continued.

To conclude this section, it could be said that the large amount of initiatives for this PhD thesis form a chaotic way of approaching a research. However, from earlier experience while working in Tanzania the researcher knew that planned activities do not always go as one would expect. Among others due to the researchers' dependency on organizations, it was decided to go with the opportunities that would open up while carrying out the study. Therefore, a multitude of initiatives could be started but could not always be continued.

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## Summary

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# SUMMARY

## ENGLISH SUMMARY

### INTRODUCTION

Albinism in Tanzania causes fierce stigmatization. A melanin shortage in the body of people with albinism causes them to have light-coloured skin, hair and eyes. People with albinism are very noticeable in a country in which most people have a darker-coloured appearance. The condition of albinism gave rise to a variety of explanations and myths about the cause and influence of the condition, such as the belief that people with albinism are not human beings and that their body parts will bring good fortune. These myths have caused severe discrimination, social exclusion and even violent attacks in which people with albinism have been killed.

Health-related stigmas cause difficulties for people with a large variety of diseases and conditions worldwide. Besides the physical problems resulting from the disease or condition, people with a stigmatizing condition are confronted with negative attitudes leading to social exclusion, discrimination and self-isolation. Stigma reduction interventions aim to reduce the level of stigma towards people with a stigmatizing condition. There is a variety of stigma reduction strategies. Among others the education and contact strategy have proven to be successful in the past in reducing health-related stigma on a community level. The education strategy entails the provision of knowledge on a certain condition, whereas the contact strategy aims to reduce stigma through getting the participant into contact with someone with a stigmatizing condition. In addition to these strategies, interventions often have an entertainment component to attract the participants attention.

The overall aim of this thesis is to gain a better understanding into albinism-related stigma and the effectiveness of stigma reduction interventions on a community level. The existing body of research on health-related stigma and stigma reduction interventions has not yet focused on the condition of albinism. In former research on health-related stigma the education, contact and entertainment strategy have proven to be effective. In the current thesis we wanted to gain more insight into the applicability of these strategies in albinism-related stigma reduction interventions in Tanzania. Therefore, these strategies were explored in the stigma reduction interventions that were tested in this thesis: theatre, radio and filmed interventions. Through our research, we want to add to the existing literature on stigma and stigma reduction and to provide recommendation to governments and NGOs to improve existing stigma reduction interventions. Therefore, this study set out to answer the following main research question: ***How to reduce stigma related to albinism in Tanzania on a community level using the education and contact strategy?***

The main question was divided into six sub-research questions.

1. **What are people's attitudes towards people with albinism in Tanzania?**
2. **How can attitudes towards people with albinism in Tanzania be measured?**
3. **What are the effects of an education strategy on albinism-related stigma and knowledge in Tanzania?**
4. **What are the effects of a contact strategy on albinism-related stigma and knowledge in Tanzania?**
5. **What role does entertainment play in stigma reduction intervention related to albinism in Tanzania?**
6. **What are the effects of a contact strategy on spokespersons with albinism in Tanzania?**

The research described in this thesis has been carried out in seven different areas of Tanzania. The study population existed out of primary school students, secondary school students and adults with and without albinism. During this study the researcher was assisted by the staff of primary schools, secondary schools, teacher training colleges, university and several NGOs.

To answer the research questions a mix of qualitative and quantitative methods has been applied. The methods used among others consisted of in-depth interviews, focus group discussions, some making use of visual vignettes, observations, Knowledge items, Entertainment items and scales to measure stigma. The Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) and the Albinism Social Distance Scale (ASDS) have been adapted and validated in this thesis to measure stigmatizing attitudes towards people with albinism in Tanzania. In order to confirm the validity of the findings a mix of methods has been used. Ethical issues, such as the sensitivity of the topic and the position of the foreign researcher, were considered.

#### METHODS TO ANALYSE ATTITUDES TOWARDS PEOPLE WITH ALBINISM

When aiming to better understand the stigmatization of people with albinism and the effect of stigma reduction interventions stigma needs to be evaluated. Chapter 4 and 5 describe the cultural validation of two scales to measure albinism-related stigma. Two existing scales were adapted to the context of albinism in Tanzania: the EMIC-CSS and the SDS. In **Chapter 4** the scale validation among adolescents is described. Using a mixed-method strategy the scales were adapted and tested. It was found that the scales were valid to measure albinism-related stigma to a certain degree. However, some difficulties were found when considering the measurement equivalence. Because the respondents in the pilot test of the article were educated high school scholars who were familiar with people with albinism, they portrayed low levels of stigma and even portrayed lower levels of stigma in the re-test than in the test, which was most likely caused by discussing the topic of albinism between these tests. Therefore, the chapter concludes that the scales are adequate to measure albinism-related stigma but also require further investigation. More testing was carried out in **Chapter 5** in which the A-EMIC-CSS and A-SDS-A were tested among adults. Again, the validation study showed adequate validity to measure albinism-related stigma to a certain extend. However, as in Chapter 4, the measurement equivalence defined as adequate psychometric properties, showed problems considering the internal consistency of the ASDS-A and the skewness of its distributions and reproducibility in the re-test. The most likely explanation is that people tended to be willing to show that they were more tolerant than most people, a so-called false uniqueness effect. Respondents were hesitant to portray stigmatizing attitudes, causing us to be careful about this when using these scales.

**Chapter 6** provides insight into a qualitative research method implemented in this study: the use of (drawn) visual vignettes in focus group research. Visual vignettes portraying a situation in which stigmatization can occur against people with albinism (e.g. a child without albinism is being helped by a nurse with albinism) were used to explore people's attitudes towards people with albinism. When presented with this image the respondents were asked what they thought the person without albinism in the image would think in this situation. Respondents were at ease talking about the images, among others because a third person perspective was used, so one did not have to talk about personal feelings. Visual vignettes proved to be a promising tool when researching a sensitive topic such as albinism in Tanzania. However, sometimes the images were interpreted as lessons: "the way it should be". This was most likely because the vignettes were used in a school setting.

#### STIGMA REDUCTION INTERVENTIONS

To gain more insight into the applicability of the education and contact strategy in albinism-related stigma reduction interventions, as well as the influence of entertainment components within these interventions, three types of stigma reduction interventions were explored: theatre (Chapter 7), radio (Chapter 8) and filmed interventions (Chapter 9). The strategies of education, contact and

entertainment had proven to be effective in relation to other health-related stigma and are often applied in albinism-related stigma reduction interventions on a community level.

In **Chapter 7** a theatre intervention about albinism in primary schools in Tanzania is being evaluated. Theatre interventions have been used to educate and raise awareness on a large variety of topics worldwide. The observation of the play showed that the audience responded enthusiastically to the play, they were paying attention most of the time and were engaged in the play. A significant increase in albinism-related knowledge was found among the respondents who attended the theatre intervention, although maybe not as large as expected. The theatre intervention also resulted in a significant decrease in social distance, proving the theatre intervention combining an education strategy with a contact strategy, to be an effective tool in reducing stigma. Critical notes accompanying this intervention include the warning that one should be careful the entertainment value does not overshadow the final outcome of the intervention.

**Chapter 8** explores the possibilities for radio interventions to reduce albinism-related stigma among adults. The advantages of using radio as a stigma reduction intervention include that this is a relatively cheap and an easy to spread tool. Two types of radio interventions were tested: a radio drama about albinism and a radio interview with someone with albinism. In these radio interventions the strategies of education, contact and entertainment were combined. The radio interventions were alternately played to a small group of adult participants. Both radio shows proved to be effective in reducing stigmatizing feelings towards people with albinism after a two- to five-week period. The radio drama significantly reduced community stigma, and both radio shows reduced social distance. The entertainment score for the radio interventions was high, and significantly higher when compared to the radio drama. The qualitative findings showed among others, that the contact with someone with albinism through the radio shows, by hearing that people with albinism can live a normal life, positively influenced people's attitudes. A combination of the different types of radio interventions is recommended, because they each have their own strengths.

The interventions discussed in Chapter 7 and 8 combine the stigma reduction strategies of education and contact. In former research on stigma reduction strategies these strategies have proven effective in influencing attitudes. To be able to learn about the influence of each of these strategies separately, **Chapter 9** provides an explorative comparison study of the strategies. A filmed contact and a filmed education-based intervention were compared among secondary school students. Both strategies positively influenced correct knowledge related to albinism directly after the intervention. The education-based intervention significantly influenced a positive change in attitudes, whereas the contact intervention did not. The qualitative findings showed many positive outcomes for both interventions, and the respondents were very enthusiastic about the contact intervention in particular. Chapter 9 shows that the education strategy on its own can be a promising tool in reducing albinism-related stigma. However, this might be caused by the receptivity and base of knowledge of this student population among whom the strategies were tested. As other research in the past has recommended, we would also recommend the use of a combination of these strategies. More research needs to be carried out on the influence of each of these strategies in reducing albinism-related stigma, especially among different populations.

**Chapter 10** deals with the experience of people with albinism in a contact intervention. In this chapter spokespersons with albinism, people who present on their condition in an intervention were questioned with respect to their experiences in this role. The spokespersons expressed that they mainly had positive experiences as spokespersons on a personal level. The spokespersons enjoyed their roles. Among others it offered them the opportunity for personal development, improved their self-confidence, it provided them with more status, and made them proud. They were also convinced that their presentations were causing a reduction in stigma on the community level. According to the spokespersons, the mechanisms making a contact intervention effective were the following: their



presence provides people in the community with a good example of a person with albinism, and the spokespersons can demonstrate that they are able to speak in public and they can explain to the audience that they can be successful in life, e.g. in jobs or education. According to the respondents, spokespersons should be self-confident, have knowledge about albinism, and they should have accepted their condition. It is also important spokespersons have a certain status, for example through a good level of education and one should be able to 'read' the audience. The chapter concludes that spokespersons counteract the audiences' expectations of people with albinism. Being a spokesperson is an act of agency and a demonstration of this agency to others. In the chapter recommendations are being made to develop effective contact interventions and on how to properly prepare spokespersons for their role.

## CONCLUSION

This thesis concludes that reducing stigma in relation to albinism in Tanzania is not a straightforward practice. People with albinism are often not perceived as being human and this worldview is deeply rooted. To be able to start the reduction of stigma and transformation of worldviews, the acknowledgement of the contexts in which people live is of major importance. Changing attitudes and improving knowledge request a variety of strategies that need to be properly adapted to its context and target audience. The education and contact strategy have both proven to be effective in improving people's knowledge on albinism and improving people's attitudes towards people with albinism. A combination of the strategies is recommended. Our findings showed that it could be rewarding to add entertaining components, however one should pay attention that that 'fun' does not diminish the message of the intervention. The findings show that the education, contact and entertainment strategies that have proven to be effective in reducing stigma in relation to other health-related stigma on a community level, are also applicable on albinism-related stigma in Tanzania.

However, the outcomes of the tested stigma reduction interventions were not always as expected. This proved the major importance of proper development and evaluation of stigma reduction interventions. This is among others done through the proper development and testing of strategies to influence people. To this aim, to control the effect of stigma reduction interventions and to be able to improve them, several quantitative measurement instruments were developed: Knowledge items, A-EMIC-CSS and A-SDS. These tools proved to be valid to evaluate stigma reduction interventions. However, our findings also proved the importance of using mixed methods to be able to gain proper insights, for example by using visual vignettes.

The research also showed us that people with albinism can play an important part in stigma reduction interventions, which can not only improve the intervention but can also positively influence the spokesperson. Again, we would like to emphasize that the stigmatized is not a passive victim and can assist in changing attitudes: by showing agency stigmatized can counteract expectations in society by breaking the vicious circle in which they are being seen as being less worth and being forced to act on this.

## DUTCH SUMMARY - SAMENVATTING

### INTRODUCTIE

Albinisme in Tanzania veroorzaakt ernstige stigmatisering. Een melaninetekort in het lichaam van mensen met albinisme zorgt ervoor dat ze een lichtgekleurde huid, haar en ogen hebben. Mensen met albinisme vallen erg op in een land waar de grote meerderheid van de mensen een donkere huidskleur heeft. Albinisme geeft aanleiding voor een verscheidenheid aan verklaringen en mythes omtrent de oorzaak en invloed van de aandoening. Zo zijn er mensen die geloven dat mensen met albinisme geen mensen zijn en dat hun lichaamsdelen geluk zullen brengen. Deze mythes hebben geleid tot ernstige discriminatie, sociale uitsluiting en zelfs tot gewelddadige aanvallen waarbij mensen met albinisme zijn vermoord.

Gezondheid gerelateerde stigma's veroorzaken wereldwijd problemen voor mensen verschillende ziekten en aandoeningen. Naast de fysieke problemen die worden veroorzaakt door een ziekte of aandoening, krijgt men vaak te maken met negatieve attitudes die kunnen leiden tot sociale uitsluiting, discriminatie en zelf-isolatie. Stigmareductie-interventies zijn gericht op het verminderen van het stigma richting mensen met een stigmatiserende aandoening. Er zijn verschillende strategieën voor het verminderen van stigma's. Onder andere de educatie- en contactstrategie zijn in het verleden succesvol gebleken in het reduceren van stigma op gemeenschapsniveau. De educatiestrategie omvat het verstrekken van kennis over een bepaalde aandoening, terwijl de contactstrategie gericht is op het verminderen van stigma door deelnemers in contact te brengen met iemand met een stigmatiserende aandoening. Naast deze strategieën bevatten interventies vaak een entertainmentcomponent om de aandacht van de deelnemers te trekken.

Het algemene doel van dit proefschrift is om een beter begrip te krijgen van albinisme-gerelateerd stigma en de effectiviteit van stigmareductie interventies op gemeenschapsniveau. Het bestaande onderzoek naar gezondheid gerelateerde stigma's en stigmareductie interventies heeft zich nog niet gericht op albinisme. In eerder onderzoek naar gezondheid gerelateerd stigma bleken de onderwijs- en contactstrategie effectief te zijn. In dit proefschrift willen we meer inzicht krijgen in de toepasbaarheid van deze strategieën in stigmareductie interventies gericht op albinisme in Tanzania. Deze strategieën werden toegepast in drie stigmareductie-interventies die in dit proefschrift werden getest: theater-, radio- en gefilmde interventies. Met ons onderzoek willen we de bestaande literatuur over stigma en stigmareductie aanvullen en aanbevelingen geven aan regeringen en ngo's om stigmareductie interventies te verbeteren. In deze studie willen we daarom de volgende hoofdvraag beantwoorden: **Hoe kan albinisme gerelateerd stigma op gemeenschapsniveau in Tanzania verminderd worden door gebruik te maken van de educatie- en de contactstrategie?**

Deze hoofdvraag was onderverdeeld in zes sub-vragen:

1. **Wat zijn de attitudes van mensen tegenover mensen met albinisme in Tanzania?**
2. **Hoe kunnen de attitudes tegenover mensen met albinisme in Tanzania worden gemeten?**
3. **Wat zijn de effecten van een educatiestrategie op stigma en kennis met betrekking tot albinisme in Tanzania?**
4. **Wat zijn de effecten van een contactstrategie op stigma en kennis met betrekking tot albinisme in Tanzania?**
5. **Welke rol speelt entertainment in albinisme gerelateerde stigmareductie interventies in Tanzania?**
6. **Wat zijn de effecten van een contactstrategie op mensen met albinisme in Tanzania?**

Het in dit proefschrift beschreven onderzoek is uitgevoerd in zeven verschillende gebieden van Tanzania. De studiepopulatie bestond uit basisschoolleerlingen, middelbare scholieren en volwassenen met en zonder albinisme. Tijdens dit onderzoek werd de onderzoeker bijgestaan door de staf van basisscholen, middelbare scholen, lerarenopleidingen, universiteiten en diverse ngo's.

Om de onderzoeksvragen te beantwoorden is een mix van kwalitatieve en kwantitatieve methoden toegepast. De gebruikte methoden bestonden onder meer uit diepte-interviews, focusgroepdiscussies, sommige gebruikmakend van visuele vignetten, observaties, Kennisitems, entertainmentitems en schalen om stigma te meten. De "Explanatory Model Interview Catalogue Community Stigma Scale" (EMIC-CSS) en de "Albinism Social Distance Scale" (A-SDS) zijn aangepast en gevalideerd in dit proefschrift om de stigmatiserende attitudes ten opzichte van mensen met albinisme in Tanzania te meten. Om de validiteit van de bevindingen te bevestigen, is een mix van methoden gebruikt. Er werd gekeken naar ethische kwesties, zoals de gevoeligheid van het onderwerp en de positie van de buitenlandse onderzoeker.

#### METHODEN VOOR HET ANALYSEREN VAN ATTITUDES TEGENOVER MENSEN MET ALBINISME

Wanneer meer inzicht willen krijgen in de stigmatisering van mensen met albinisme en het effect van stigmareductie-interventies beter willen begrijpen, moeten deze stigmatiserende attitudes geëvalueerd worden. Hoofdstuk 4 en 5 beschrijven de culturele validatie van twee schalen om albinisme-gerelateerd stigma te meten. Twee bestaande schalen zijn aangepast aan de context van albinisme in Tanzania: de EMIC-CSS en de SDS. In **Hoofdstuk 4** wordt de schaalvalidatie onder adolescenten beschreven. Met behulp van een *mixed-methods* strategie werden de schalen aangepast en getest. Het bleek dat de schalen valide waren om tot op zekere hoogte albinisme-gerelateerd stigma te meten. Er werden echter enkele problemen gevonden aangaande de meetequivalentie. Omdat de respondenten bij de verkennende test in Hoofdstuk 4 opgeleide middelbare scholieren waren, die bekend waren met mensen met albinisme, portretteerden ze in eerste instantie al lage stigma niveaus. In de daaropvolgende controle test portretteerde men zelfs nog lagere stigma niveaus, wat hoogstwaarschijnlijk was veroorzaakt door het bespreken van het onderwerp albinisme na de eerste test. Daarom concludeert Hoofdstuk 4 dat de schalen geschikt zijn om albinisme-gerelateerd stigma te meten, maar er wordt ook aangegeven dat verdere testen van de schaal onder een andere populatie zijn vereist voor verdere validatie. De A-EMIC-CSS en A-SDS worden dan ook in **Hoofdstuk 5**, onder volwassenen getest. Opnieuw toonde de validatiestudie dat de schalen voldoende valide zijn om albinisme-gerelateerd stigma te meten. Evenals in Hoofdstuk 4 vertoonde de meetequivalentie echter problemen met betrekking tot de interne consistentie. De meest waarschijnlijke verklaring hiervoor is dat mensen geneigd waren te laten zien dat ze toleranter waren dan de meeste andere mensen, een zogenaamd "false uniqueness effect". Respondenten zijn terughoudend met het erkennen van mogelijk stigmatiserende attitudes.

**Hoofdstuk 6** geeft inzicht in een kwalitatieve onderzoeksmethode die in dit onderzoek is gebruikt: het gebruik van (getekende) visuele vignetten in focusgroep onderzoek. De gebruikte visuele vignetten beeldden een situatie uit waarin stigmatisering tegen mensen met albinisme kan optreden (bijv. een kind zonder albinisme wordt geholpen door een verpleegster met albinisme). De vignetten werden gebruikt om de attitude van mensen ten opzichte van mensen met albinisme te onderzoeken. Wanneer dit beeld werd gepresenteerd, werden de respondenten gevraagd wat zij dachten dat de persoon zonder albinisme in het vignetten in deze situatie zou denken. Respondenten praatten op hun gemak over de beelden, onder meer omdat er gebruik werd gemaakt van een derde persoonsperspectief, zodat men niet over persoonlijke gevoelens hoefde te praten. Visuele vignetten bleken een veelbelovend hulpmiddel te zijn bij het onderzoeken doen naar gevoelig onderwerp zoals albinisme in Tanzania. Soms werden de beelden echter geïnterpreteerd als lessen, en werden de

situaties uitgelegd door de studenten zoals zij dachten dat de situatie zou moeten zijn. Dit werd hoogstwaarschijnlijk veroorzaakt doordat de vignetten in een schoolomgeving werden gebruikt.

#### STIGMA REDUCTIE INTERVENTIES

Om meer inzicht te krijgen in de toepasbaarheid van de onderwijs- en contactstrategie bij albinisme-gerelateerde stigma-reductie-interventies, evenals de invloed van entertainmentcomponenten binnen deze interventies, werden drie soorten stigma reductie interventies onderzocht: theater (Hoofdstuk 7), radio (Hoofdstuk 8) en gefilmde interventies (Hoofdstuk 9). De onderwijs, contact en entertainmentstrategieën hebben in relatie tot andere gezondheid gerelateerde stigma's bewezen effectief te zijn en worden vaak toegepast bij albinisme-gerelateerde stigma-reductie -interventies op gemeenschapsniveau.

In **Hoofdstuk 7** wordt een theaterinterventie aangaande albinisme, op basisscholen in Tanzania geëvalueerd. Theaterinterventies worden wereldwijd gebruikt om te onderwijzen en te sensibiliseren met betrekking tot een grote verscheidenheid aan onderwerpen. Uit de observatie van het stuk bleek dat het publiek enthousiast reageerde op het theater, het grootste deel van de tijd hield men de aandacht bij het stuk en men was zeer bij het theater betrokken. Onder de respondenten die de theaterinterventie bijwoonden, werd een significante toename van albinisme-gerelateerde kennis gevonden, hoewel deze toename misschien niet zo groot was als werd verwacht. De theaterinterventie resulteerde ook in een aanzienlijke afname van de *social distance*, wat bewees dat de theaterinterventie, waarin een educatiestrategie gecombineerd werd met een contactstrategie, een effectief instrument is om stigma te verminderen. Kritische opmerkingen bij deze interventie omvatten de waarschuwing dat men voorzichtig moet zijn dat de entertainmentwaarde van een interventie het uiteindelijke resultaat van de interventie niet overschaduwet.

**Hoofdstuk 8** onderzoekt de mogelijkheden voor radio-interventies om albinisme-gerelateerd stigma bij volwassenen te verminderen. De voordelen van het gebruik van radio als stigmareductie-interventie zijn onder meer dat deze methode relatief goedkoop en gemakkelijk verspreid kan worden. Er zijn twee soorten radio-interventies getest: een radiodrama over albinisme en een radio-interview met iemand met albinisme. In deze radio-interventies werden de educatie-, contact en entertainment strategie gecombineerd. De twee radio-interventies werden afwisselend gespeeld voor een kleine groep volwassen deelnemers. Beide radioshow bleken na twee tot vijf weken effectief te zijn in het verminderen van stigmatiserende gevoelens jegens mensen met albinisme. Het radiodrama verminderde het gemeenschapsstigma aanzienlijk en beide radioshow verminderden de *social distance*. De entertainmentscore voor de radio-interventies was hoog en significant hoger wat betreft het radiodrama. De kwalitatieve bevindingen lieten onder meer zien dat het contact met iemand met albinisme een positieve invloed heeft op mensen hun attitudes, onder andere door te horen dat mensen met albinisme een normaal leven kunnen leiden. Een combinatie van de verschillende soorten radio-interventies wordt aanbevolen, omdat ze elk hun eigen sterke punten hebben.

De interventies die in Hoofdstuk 7 en 8 worden besproken, combineren de educatie- en contactstrategieën voor stigmareductie. In eerder onderzoek bleken deze strategieën effectief in het beïnvloeden van attitudes. Om meer inzicht te krijgen in de invloed van de afzonderlijke strategieën biedt **Hoofdstuk 9** een explorerende vergelijkende studie van deze strategieën. Een gefilmde op contact gebaseerde interventie en een gefilmde op educatie gebaseerde interventie werden vergeleken onder middelbare scholieren. Beide strategieën hadden een positieve invloed op correcte kennis over albinisme direct na de interventie. De op educatie gebaseerde interventie had een significante positieve invloed op de attitude tegenover mensen met albinisme, terwijl de contactinterventie geen significante invloed had. De kwalitatieve bevindingen lieten veel positieve invloed zien van beide interventies en de respondenten waren vooral erg enthousiast over de op contact gebaseerde interventie. Hoofdstuk 9 laat zien dat de educatiestrategie op zichzelf een

veelbelovende methode kan zijn om albinisme-gerelateerd stigma te verminderen. Deze positieve resultaten van de educatiestrategie op zich kunnen echter veroorzaakt zijn door de ontvankelijkheid en kennisbasis van de studentenpopulatie waaronder de strategieën zijn getest en we moeten dus voorzichtig zijn deze bevindingen te generaliseren. Zoals ander onderzoek in het verleden heeft aanbevolen, raden ook wij een combinatie van de educatie- en contactstrategie aan. Er moet meer onderzoek worden gedaan naar de invloed van elk van deze strategieën bij het verminderen van aan albinisme gerelateerd stigma, met name met betrekking tot het effect van deze strategieën op verschillende bevolkingsgroepen.

**Hoofdstuk 10** gaat over de ervaring van mensen met albinisme in een contactinterventie. In dit hoofdstuk werden mensen met albinisme die zichzelf presenteren in contact interventies, zogenaamde woordvoerders, gevraagd naar hun ervaringen in deze functie. De woordvoerders gaven aan dat ze vooral op persoonlijk vlak positieve ervaringen hadden als woordvoerder. De woordvoerders genoten van hun rol. Het bood hen onder meer de mogelijkheid tot persoonlijke ontwikkeling, verbeterde hun zelfvertrouwen, gaf hen meer status en maakte hen trots. Ze waren er ook van overtuigd dat hun presentaties een vermindering van het stigma op gemeenschapsniveau veroorzaakten. Volgens de woordvoerders waren de mechanismen die een contactinterventie effectief maken de volgende: hun aanwezigheid geeft mensen in de gemeenschap een goed voorbeeld van een persoon met albinisme, en door zelf te presenteren kunnen woordvoerders aantonen dat ze in het openbaar kunnen spreken. Het geeft hen de mogelijkheid aan het publiek uit te leggen dat ook mensen met albinisme succesvol kunnen zijn, bijv. in hun werk en in hun educatie. Volgens de respondenten moeten woordvoerders zelfverzekerd zijn, kennis hebben van albinisme en het feit dat ze albinisme hebben accepteren. Het is ook belangrijk dat woordvoerders een bepaalde status hebben in de samenleving, bijvoorbeeld door een goede opleiding en men moet het publiek kunnen 'lezen'. Het hoofdstuk concludeert dat woordvoerders de verwachtingen over mensen met albinisme tegenspreken. Presenteren over albinisme komt voort uit *agency*, en door zelf te presenteren kunnen woordvoerders hun *agency* ook aan andere tonen. In het hoofdstuk worden aanbevelingen gedaan om effectieve contactinterventies te ontwikkelen en om woordvoerders goed voor te bereiden op hun rol.

## CONCLUSIE

Dit studies die in dit proefschrift werden beschreven, tonen aan dat het verminderen van het stigma in verband met albinisme in Tanzania niet eenvoudig is. Mensen met albinisme worden vaak niet als mens gezien en dit is een diepgeworteld wereldbeeld. Om te kunnen beginnen met het verminderen van stigma en de transformatie van wereldbeelden, is het belangrijk om begrip te hebben van de contexten waarin mensen leven. Om attitudes en kennis te verbeteren zullen verschillende strategieën moeten worden aangepast aan de lokale context en de doelgroep. De educatie- en contactstrategie zijn beide effectief gebleken bij het verbeteren van kennis over albinisme en bij het verbeteren van de attitude van mensen ten opzichte van mensen met albinisme. Een combinatie van de strategieën wordt aanbevolen. Onze bevindingen toonden aan dat het lonend zou kunnen zijn om entertainmentcomponenten toe te voegen aan stigmareductie interventies, mits deze vervolgens correct worden ingezet. De bevindingen tonen aan dat de onderwijs- contact- en entertainmentstrategieën, die bewezen hebben effectief te zijn in het verminderen van stigma in relatie tot andere gezondheid gerelateerde stigma's op gemeenschapsniveau, ook effectief zijn in relatie tot albinisme-gerelateerd stigma in Tanzania.

Echter, de uitkomsten van de stigmareductie interventies waren niet altijd zoals verwacht. Dit onderschrijft het grote belang van een goede ontwikkeling en evaluatie van stigmareductie interventies. Dit kan onder andere gedaan worden door stigmareductie strategieën goed te ontwikkelen en te testen. Om het effect van stigmareductie interventies goed te kunnen controleren

en deze zo te verbeteren, zijn in dit proefschrift verschillende kwantitatieve meetinstrumenten ontwikkeld: Kennisitems, EMIC-CSS, A-EMIC-CSS, ASDS-A en A-SDS. Deze instrumenten bleken valide om stigmareductie interventies te evalueren. Onze bevindingen hebben echter ook het belang aangetoond van het gebruik van *mixed methods* om een volledig inzicht te krijgen in de effecten van stigmareductie interventies, zo kunnen bijvoorbeeld visuele vignetten worden gebruikt om meer inzichten te verwerven.

Het onderzoek toonde ook aan dat mensen met albinisme een belangrijke rol kunnen in stigmareductie interventies. Door hen bij interventies te betrekken kunnen niet alleen de interventies worden verbeterd, maar het deelnemen aan interventies kan ook een positieve invloed hebben op mensen met albinisme zelf. Nogmaals, we willen benadrukken dat mensen met albinisme geen passieve slachtoffers zijn en kunnen bijdragen bij het veranderen van attitudes: door te laten zien dat door het laten zien van hun *agency* in een interventie gaan mensen met albinisme in tegen de verwachtingen van de samenleving, zo doorbreekt men de vicieuze cirkel waarin mensen met albinisme als minderwaardig worden gezien en men zich als gevolg hiervan hiernaar gaat gedragen.

## SWAHILI SUMMARY – MUHUTASARI

### UTANGULIZI

Ualbino nchini Tanzania umesababisha kuwepo kwa unyanyapaa mbaya. Upungufu wa madini ya melanini katika miili ya watu wenye ualbino ndio chanzo kikuu cha wao kuwa na rangi nyeupe katika ngozi, nywele na macho yao. Watu wenye ualbino wamekuwa wakitambulika kwa haraka kutokana na watu wengine kuwa na ngozi nyeusi hapa nchini Tanzania. Hali hii ya ualbino imesababisha kuzuka kwa fafanuzi na Imani mbalimbali kuhusu chanzi na visababishi vya ualbino, baadhi huamini watu wenye ualbino sio binadamu wa kawaida na viungo vyao vinaleta bahati maishano. Imani hizi zimechangia kusababisha ongezeko la ubaguzi, kuwatenga na hata kuwavamia kwa lengo la kuwauwa watu wenye ualbino.

Unyanyapaa unaohusiana na changamoto za kiafya umekuwa kikwazo kwa watu wenye magonjwa mbalimbali hapa duniani. Nje ya changamoto za kiafya zinazosababishwa na magonjwa au hali nyingine, watu wanaokumbana na unyanyapaa wamekuwa wakikabiliana na mtizamo hasi dhidi yao inayosababisha kubaguliwa, kunyanywa na kujitenga. Mkakati wa kupunguza na kuingilia unyanyapaa umekusudia kupunguza kiwango cha unyanyapaa dhidi ya watu wanaokabiliwa na hali za unyanyapaa. Kuna mikakati mbalimbali za kupunguza unyanyapaa. Kati ya mikakati hio ipo mikakati ya elimu na ushirikishwaji ambayo imeonesha mafanikio makubwa kipindi kilichopita kwa ngazi ya Jamii. Mkakati wa elimu umejikita katika kutoa maarifa juu ya hali fulani, wakati huo mkakati wa ushirikishwaji unakusudia kupunguza unyanyapaa kupitia kuwakutanisha pamoja washiriki na mtu anayekumbana na unyanyapaa. Nyongeza juhusu mikakati hii, muingiliano umekuwa na viashiria vya kuburudisha na kuvutia umakini wa washiriki.

Lengo la utafiti katika unyanyapaa unaohusiana na sababu za kiafya na njia za kupunguza na kuingilia unyanyapaa halijagusa masuala ya ualbino. Katika utafiti uliopita ulioangazia eneo la Unyanyapaa unaotokana na Sababu za kiafya, Mkakati wa Elimu, Ushirikishwaji na Kuburudisha imeonekana ikileta mafanikio makubwa. Katika utiti huu tunataka kujikita zaidi katika kuangalia utekelezwaji wa mikakati hii muhimu kama njia za kupunguza na kuingilia unyanyapaa kwa watu wenye Ualbino nchini Tanzania. Hivyo basi, mikakati hii ilizingatiwa katika njia mahususi za kupunguza na kuingilia unyanyapaa zilizopimwa katika utafiti huu; maeneo ya simena, redio na filamu za kuingilia. Lengo kuu la utafiti huu ni kupata uelewa mpana kuhusu unyanyapaa unaotokana na ualbino na ufanisi wa njia za kupunguza na kuingilia unyanyapaa ngazi ya jamii. Lengo la jumla la utafiti huu ni kupata uelewa sahihi juu ya unyanyapaa unaotokana na ualbino na ufanisi wa mikakati ya kuingilia na kupunguza kwa ngazi ya Jamii. Kupitia utafiti wetu, tunataka kuongeza maandiko kuhusu unyanyapaa na mikakati ya kupunguza na kutoa mapendekezo kwa serikali na mashirika yasiyo ya kiserikali katika kuuboresha njia zilizopo za kupunguza na kuingilia unyanyapaa. Hivyo basi, utafiti huu unatarajiwa kujibu swali mahususi la utafiti: ***Kwa vipi tutapunguza unyanyapaa unaotokana na ualbino nchini Tanzania katika ngazi ya jamii kupitia mikakati ya elimu na ushirikishwaji?***

Swali kuu liligawanywa katika vipande vidogo sita :

1. **Upi ni mtazamo wa watu juu ya watu wenye ualbino nchini Tanzania?**
2. **Kwa namna gani mtizamo wa watu juu ya watu wenye ualbino unaweza kupimwa?**
3. **Kuna athari gani katika kutumia mkakati wa elimu katika masuala yanayohusiana na unyanyapaa kwa watu wenye ualbino na uelewa nchini Tanzania?**
4. **Kuna athari gani katika mkakati wa ushirikishwaji katika masuala yanayohusiana na unyanyapaa kwa watu wenye ualbino na uelewa nchini Tanzania?**
5. **Ipi kazi kubwa ya mbinu ya maburudisho katika kupunguza na kuingilia unyanyapaa unaotokana na ualbino nchini Tanzania?**

## 6. Kuna athari gani katika kutumia mkakati wa ushirikishwaji kwa wasemaji wa watu wenye ualbino nchini Tanzania?

Utafiti uliofafanuliwa katika nadharia hii, umefanyika katika maeneo saba ya nchini Tanzania. Utafiti ulifanyika kwa wanafunzi wa shule za msingi, wanafunzi wa shule za sekondari, watu wazima wenye ualbino na wasio na ualbino. Katika utafiti hii mtafiti alisaidiwa na waalimu wa shule za msingi na sekondari, wakufunzi wa vyuo vya ualimu, vyuo vikuu na baadhi ya mashirika yasiyo ya kiserikali.

Katika kujibu maswali ya utafiti huu mchanganyiko wa njia za kupima ubora na wingi zilitumika. Njia zilizotumiwa Zaidi kuliko zote ni pamoja na mahojiano ya kina, majadiliano ya vikundi, baadhi walitumia Picha za kufikirisha, kuchunguza, vipimia maarifa, vitu vya kuburudisha na vipima viwango kupima unyanyapaa. Kipimo cha: Maelezo ya Mahojiano kuhusu Unyanyapaa Ngazi ya Jamii (KMMUNJ) na Kipimo cha Umbali wa Kijamii katika Ualbino (UKU) vilithibitwa katika utafiti huu kupima mitazamo ya unyanyapaa kwa watu wenye ualbino nchini Tanzania. Ili kuhakiki usahihi wa takwimu mbinu mchanganyiko zilikuwa zikitumika. Mambo ya maadili, kama umakini katika maada na nafasi ya mtafiti ngeni ilizingatiwa.

### NJIA ZA KUCHAMBUA MITAZAMO DHIDI YA WATU WENYE UALBINO

Wakati tumekusudia kupata maarifa sahihi ya unyanyapaa kwa watu wenye ualbino, athari za kupunguza na kuingilia unyanyapaa zinahitajika kufanyiwa tathimini. Sura ya 4 na 5 zinafafanua vithibishi vya kiutamaduni katika vipimo viwili vya unyanyapaa unaohusiana na ualbino. Vipimo viwili vilitumika katika kuangazia masuala ya ualbino nchini Tanzania; kipimo cha KMMUNJ na UKU. Katika **Sura ya 4**. Viwango vya uthibitisho katika kundi la vijana wadogo vimefafanuliwa. Kwa kutumia mikakati ya njia mchanganyiko vipimo vilizingatiwa na kupimwa. Ithibitika kuwa vipimo vilikuwa sahihi kupima unyanyapaa unaohusiana na ualbino kwa kiwango fulani. Hata hivyo kulionekana ugumu katika Kuzingatia usawa wa vipimo. Kwa sababu wahojiwa katika upimaji wa majaribio wa utafiti huu walikuwa wanazuoni kutoka elimu ya juu ambao wanaufahamu kuhusu watu wenye ualbino, walionesha kiwango kidogo cha unyanyapaa na pia walionesha kiwango kidogo zaidi cha unyanyapaa katika kipindi cha marudio, kitu ambacho kilisababisha mjadala wa mada ya ualbino katika majaribio. Hivyobasi, Sura ilimaliza kwa maelezo kuwa vipimo vinauwanya mpana kupima sababu za unyanyapaa zinazohusiana na ualbino lakini pia kunahitajika vipimo zaidi na zaidi. Upimaji zaidi uliendelea katika **Sura ya 5** ambapo KMMUNJ na UKU vilitumika kwa watu wazima. Lakini pia, ilitibitika kwepo njia nyingi kupima unyanyapaa unaohusiana na ualbino. Ingawa katika Sura ya 4, vipimo vya usawa vilionesha tatizo katika kupima mtazamo wa ndani. Maelezo mengi yaliyotolewa yalionesha watu wako tayari kuonesha kukubaliana kuliko watu wengine, hii huitwa athari za uongo wa kipekee. Wahojiwa waliogopa kuonesha hali za unyanyapaa, hivyo kusababisha tuwe makini sana katika kutumia vipimo.

**Sura ya 6** inatupatia ufafanuzi kuhusu njia za utafiti wa ubora zilizotekelezwa katika utafiti huu: utafiti ulitumia (mchoro) picha za kufikirishakatika vikundi vya utafiti. Picha za kufikirisha vilionesha mazingira ambayo unyanyapaa unaweza kutokea dhidi ya mtu mwenye ualbino (mfano. Mtoto asiye na ualbino anasaidiwa na muhudumu wa afya mwenye ualbino) ambapo ilitumika kutambua mitazamo ya watu juu ya watu wenye ualbino. Ilipowasilishwa kwa kutumia picha hii washiriki waliulizwa wanafikiri nini juu ya mtu asiye na ualbino aliyeko kwenye picha atafikiri nini kutokana na hali ile. Washiriki walikuwa rahisi kuzungumza kuhusu picha mbalimbali zilizoonekana, zaidi walitumia mtazamo wa nafsi ya tatu, hivyo hakuna aliyetoa hisia zake moja kwa moja kuhusu. Picha za kufikirisha vimethibitika kutumika kwa wakati mwingine wakati wa utafiti wa mada mahususi kama ualbino nchini Tanzania. Hata hivyo, wakati mwingine picha zilihajika kutafsiriwa kama funzo. “namna inavyotakiwa kuwa”. Hii ni muhimu kwa sababu picha za kufikirisha zilitumika zilitumika katika mazingira ya shule.



## MBINU ZA KUPUNGUZA NA Kuingilia UNYANYAPAA

Ili kuweza kupata taarifa za kina kuhusu utendaji kazi wa mkakati wa elimu na mkakati wa ushirikishaji katika mambo yahusianayo na mbinu za kuingilia na kupunguza unyanyapaa unaotokana na ualbino, pamoja na ufanisi vipengele vya maburusisho katika utafiti huu, aina tatu za njia za kupunguza na kuingilia unyanyapaa ziliangaziwa: Sinema (Sura ya 7), Redio (Sura ya 8), na Filamu za kuingilia (Sura ya 9). Mikakati hii ya kielimu, ushirikishwaji na maburudisho imethibitika kuwa na ufanisi katika masuala yanayoendana na unyanyapaa unaotokana na sababu za kiafya pia zimeonekana zikileta matokeo chanya katika njia ya kuingilia na kupunguza unyanyapaa kwa watu wenye ualbino ngazi ya jamii.

Katika **Sura ya 7** uingiliaji kwa njia ya maonesho au sinema kuhusu ualbino katika shule za msingi Tanzania ulidavuliwa. Uingiliaji wa sinema umekuwa ukitumika kuelimisha na kuongeza uelewa kuhusu mada mbalimbali duniani kote. Uchunguzi wa filamu ulionesha watazamaji wakiwa na mwamko wa juu, na walikuwa makini muda mwingi walipokuwa wakitazama filamu. Faida za kuongezeka kwa uelewa kuhusu ualbino zilionekana kwa watazamaji waliohudhuria maonesho, ingawa labda haikuwa sana tofauti na ilivyotarajiwa. Kuingilia kupitia maonesho sinema ilisaidia kupunguza umbali wa kijamii, kupelekea njia ya maonesho ukichanganya na mkakati wa elimu na mkakati wa ushirikishwaji, zinakuwa njia zenye ufanisi zaidi katika kupunguza unyanyapaa. Uwezekano wa kutumia njia ya maonesho kama njia ya kupunguza na kuingilia unyanyapaa imejadiliwa na mapendekezo yametolewa kutumika katika wakati ujao kama njia ya kupunguza na kuingilia unyanyapaa unaohusiana na ualbino. Maelezo ya kina yanayoambatana na njia ya maonesho yanajumuisha tahadhari kuwa unahitajika umakini kuburudisha kusifunike matokeo makubwa ya mkakati huu.

**Sura ya 8** imedadavua uwezekano wa njia ya redio kupunguza unyanyapaa unaohusiana na ualbino kwa vijana. Faida za kutumia redio kama njia ya kupunguza na kuingilia unyanyapaa inajumuisha sababu kuwa njia hii ni nafuu na husambaa kwa urahisi. Aina mbili za njia za redio zilipimwa: mchezo wa redio kuhusu ualbino na kipindi cha redio pamoja na mtu mwenye ualbino. Katika njia hizi za redio mikakati ya elimu, ushirikishwaji na maburudisho ilichanganywa. Njia hii ya redio ilihusisha kundi dogo la washiriki vijana. Njia zote za redio zilionesha njia zenye ufanisi katika kupunguza unyanyapaa na hisia dhidi ya watu wenye ualbino katika kipindi cha wiki mbili-tano. Michezo ya redio ilifanikiwa kupunguza unyanyapaa wa jamii, na njia zote za redio zilipunguza umbali wa kijamii. Eneo la maburudisho kupitia njia za redio zilikuwa nyingi kulingana na michezo ya redio. Kipimo cha ubora kilionesha kati ya yote, mkakati wa ushiriki wa mtu mwenye ualbino kupitia vipindi vya redio, kwa kusikika kuwa watu wenye ualbino wanaweza kuishi maisha ya kawaida, iliweza kujenga mtizamo chanya kwa watu. Mchanganyiko wa programu mbalimbali za redio unapendekezwa kwa sababu kila moja ina umuhimu wake.

Mbinu zilizojadiliwa katika Sura ya 7 na 8 zinajumuisha mikakati ya elimu na ushirikishwaji ya kupunguza unyanyapaa. Katika utafiti uliopita eneo la kupunguza unyanyapaa, mikakati hii imeonesha kuwa na ufanishi na imebadili mitazamo. Ili kuweza kujifunza kuhusu faida za kila mkakati kwa utofauti, **Sura ya 9** inajikita kutoa mfanano wa hii mikakati. Mkakati wa filamu ya uelimishaji na filamu ya ushirikishwaji ililinganishwa kwa wanafunzi wa elimu ya sekondari. Njia zote zilifanikiwa kutoa maarifa kwa usahihi kuhusiana na ualbino. Njia ya elimu ilifanikiwa kuleta matokeo chanya ya mtazamo, wakati ambapo njia ya ushirikishwaji haikuweza. Matokeo ya kipimo cha ubora yalionesha matokeo chanya katika njia hii, na washiriki walihamasika katika njia ya ushirikishwaji. Sura ya 9, inaonesha mkakati wa elimu wenyewe kama wenyewe unaweza kupendekezwa kutumika kupunguza unyanyapaa unaohusiana na ualbino. Hata hivyo, inaweweza kusababishwa hali ya kupokea kwa maarifa na ukubwa wa maarifa wa wanafunzi ambao njia hizo zilijaribiwa. Kama tafiti za hapo awali zilivyopendekeza, tunapendekeza kutumika mikakati yote kwa pamoja. Tafiti zaidi zinahitajika katika uwezo wa kila mkakati katika kupunguza unyanyapaa unaohusiana na ualbino, hasa kwa makundi tofauti tofauti.

**Sura ya 10** inajikita katika uzoefu wa watu wenye ualbino katika mkakati wa ushirikishwaji. Katika Sura hii msemaji wa watu wenye ualbino, watu wanaowakilisha hali zao katika utafiti huu waliulizwa kwa heshima kubwa kutoa uzoefu wao katika majukumu hayo. Msemaji alielezea kuwa maranyingi wana uzoefu mzuri katika uwezo wa kuwa wasemaji. Msemaji anafurahia majukumu yake. Kingine inawapa nafasi ya ukuaji binafsi, kuongeza hali ya kujiamini, na inawapa hadhi katika jamii na kuwafanya wajisifie. Pia walikuwa wameshawishiwa kuwa kujieleza kwao hupunguza unyanyapaa katika ngazi ya jamii. Kwa mujibu wa msemaji, faida za kutumia njia ya ushirikishwaji ni kama ifutavyo: uwepo wao huwapa watu katika jamii kuwa na mfano mzuri wa watu wenye ualbino na msemaji ataonesha kuwa anaweza kuongea katika jumuiya na kuelezea mafanikio yao katika maisha, Mfano katika kazi, au elimu. Kwa mujibu wa washiriki msemaji anatakiwa awe na uwezo wa kujiamini, awe na ufahamu kuhusu ualbino na wawezekukubaliana na hali. Ni muhimu kwa msemaji kuwa na hadhi fulani, mfano kiwango kuzuri cha elimu na awe na uwezo wa kuwasoma washiriki. Sura hii imemaliza kuwa msemaji lazima aweze kufikia matarajio ya washiriki juu ya watu wenye ualbino. akiwa kama msemaji anakuwa na kazi ya uwakilishi na kuwawakilisha wengine. Katika Sura hii mapendekezo yaliyotolewa ni kuendeleza njia ya ushirikishwaji na ni kwa namna gani kutakua na maandalizi mazuri ya wasemaji kumudu majukumu yao.

#### HITIMISHO

Utafiti huu unahitimisha kwamba kupunguza unyanyapaa unaohusiana na ualbino Tanzania sio jambo la maramoja. Watu wenye ualbino wanachukuliwa kana kwamba sio watu, mtizamo huu wa dunia umejichimbia chini. Kuanza kupunguza unyanyapaa na kubadili mtizamo wa dunia, kuna umuhimu kwanza tutambue kwanza mitazamo ya namna watu wanavyoishi. Kubadili mitazamo na kuboresha uelewa inahitaji mikakati mbalimbali ambayo inatakiwa kutumika kwa uangalifu ili kuwafikia walengwa. Mikakati ya elimu na ushirikishwaji yote inaonesha ni mikakati yenye ufanisi katika kuongeza uelewa kuhusu ualbino na kuboresha mitazamo ya watu juu ya watu wenye ualbino. Mbinu ya pamoja inapendekezwa. Utafiti huu unaonesha itakuwa muhimu kuongeza vipengele vya mikakati ya maburudisho katika kupunguza unyanyapaa endapo itatumika kwa usahihi. Matokeo ya utafiti yalionesha kuwa mikakati ya elimu, ushirikishwa na maburudisho imeonesha ufanisi mkubwa katika kupunguza unyanyapaa, unaotokana na sababu nyingine zinazoendana na changamoto za kiafya katika ngazi ya jamii, pia mikakati hii ilitumika katika sababu nyingine zinazosababisha unyanyapaa kwa watu wenye ualbino nchini Tanzania.

Hata hivyo, matokeo ya njia za kupunguza na kuingilia unyanyapaa hayakutarajiwa hata kidogo. Hii inathibitisha umuhimu wa maandalizi sahihi na tathimini ya mbinu za kuingilia unyanyapaa. Hata hivyo kulifanyika kupitia maandalizi sahili na upimaji wa mikakati ya kuwavutia watu. Katika lengo la kuthibiti athari za kupunguza unyanyapaa na kuwa tayari kuboresha mazingira. Vipimo mbalimbali vya ubora vilizingatiwa: KMMUNJ na UKU. Mbinu hizi zilithibitika kuwa na ubora kutathimini hali ya unyanyapaa, hata hivyo utafiti wetu pia umethibitisha umuhimu wa mbinu mchanganyiko katika kufikia malengo sahihi, kwa mfano matumizi wa picha za kufikirisha.

Pia utafiti ulitonesha kuwa watu wenye ualbino wanaweza kuwa sehemu muhimu katika kupunguza na kuingilia unyanyapaa, kitu ambacho hakisaidii tuu maboresho bali kina wapa msukumo chanya wasemaji. Pia tunapenda kuisitiza unyanyapaa sio ugonjwa ulioshindikana na unaweza kusaidia mabadiliko ya kimtazamo: kupitia wachache walionyanyapaliwa wanaweza kubadili mataraji ya jamii hasa katika kuvunja miduara inayoonekana kama haina tija na kulazimisha kuishi katika mfumo mpya.



# Acknowledgements

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## ACKNOWLEDGEMENTS

Throughout my PhD research I have received a great deal of support and assistance.

First and foremost, I would like to thank my supervisors, Professor Pieter Meurs and Professor Wolfgang Jacquet. Without your assistance and dedicated involvement in every step throughout the process this thesis would never have been accomplished. I would like to thank you for your enthusiasm, positivity, and flexibility. I would also like to thank Dr. Ruth Peters, whose expertise in the field of health-related stigma was invaluable in the writing of this thesis and whose work has been an inspiration to me. Thank you, Professor Tom Vanwing, for motivating me to develop this research. Also, a big thanks to my colleagues at the VUB and all other colleagues working in this line of research who have assisted and accompanied me on this journey.

Secondly, I am extremely grateful for all the governmental and non-governmental organisations and all the schools in Tanzania that cooperated with me in this research. Thanks to all the respondents who participated, this research could not have taken place without you. I would like to thank all the new friends I made in Tanzania who have supported me in the research.

Thirdly, my research would have been impossible without VLIR-UOS, who provided me with the opportunity to carry out this research by awarding me a VLADOC scholarship, for which I am very grateful.

I would like to thank all my friends and family who have supported me throughout this project. Doing research in Tanzania meant I was often not home, and I would like to thank everyone for their understanding. A special thanks for my parents and brother for always supporting me. Finally, thank you Niels, for never complaining about my fieldwork visits to Tanzania, for listening to my ideas, for being my colleague at home and for always being there for me.



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# Appendices

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# APPENDICES

## APPENDIX A: POWER-POINT PRESENTATION OF FINDINGS AND WORKSHOP ON INTERVENTION DEVELOPMENT (CHAPTER 3)

Slide 1

Presentation of findings  
and workshop on  
intervention development  
– Spring 2018

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TIJTSKE DE GROOT

**VUB** VRIJE  
UNIVERSITEIT  
BRUSSEL

Slide 2

Workshop overview

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- ❖ Introduction of research and researcher
- ❖ Goals of today's meeting
- ❖ Overview of findings last visit
  - ❖ Perceptions
  - ❖ Questions
- ❖ Possible interventions
- ❖ Brainstorm session

Slide 3

How to break the myth of albinism?

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*The development and assessment of albinism related stigma reduction interventions in local community and formal education in Tanzania.*

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graph LR; A[Stigma related to albinism] --> B[Discrimination]; B --> C[Need of effective stigma reduction interventions]
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Slide 4

## Today

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- ❖ Present the results and discussion
- ❖ Present possible interventions
- ❖ Discussion

Slide 5

## Results



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*Out there is some peoples who believed that if I will give the hand one who have albinism my hand I will change for I will be albinism or where I get a pregnancy or when I have a pregnancy when I will be birth I will birth a person who have what? Who have albinism, but that is not true.*



Slide 6

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*at what I see here it is an image of two people one is albino and the second one is a normal person, this one tries to greet her and someone, her neighbour but her neighbour she does not want to respond that shows that it is a crisis between them, that one, that normal person who thinks when I will respond, I will respond to her it is depending on customs, I will need a curse, it is the curse when I will be responding to her it will be bad to me that is why she wants to, she don't want to respond to her, that is why it shows crisis in the society, between normal person and albinism in.*

## Slide 7

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*what I see for me is that all people say that albino's is are not useful to ask that they are somehow helpful this to us so we this is this they are not supposed to discriminate them, yes.*



## Slide 8

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*long ago our fathers and our grandfathers and our grandmothers they believe that when you boring, when you boring a person with albinism that is about luck so that they take him or her to kill, and they killed them.*



## Slide 9

### Questions

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- ❖ What is the cause of albinism (and what not)?
  - ❖ Why do people get albinism?
  - ❖ How can people without albinism get a child with albinism?
  - ❖ What exactly is a lack of melanin (further explanation)?
  - ❖ Are there types of albinism?
- ❖ What are the physical effects of albinism (and what not)?
  - ❖ Skin
    - ❖ How to protect the skin? (how does sunscreen work? What exactly is a sunburn? Wounds? Smell? Pigmentation disorder? Why can PWA not be in the sun in the afternoon?)
  - ❖ Eyes (low vision, night vision)
  - ❖ Superstition
    - ❖ Do body parts of PWA bring good fortune?
    - ❖ Do PWA die or disappear?
- ❖ Can albinism be cured or prevented? (How do I know whether there is an albinism gene in the family?)
- ❖ What can we do to help/protect PWA?
  - ❖ What does the government do to help and protect PWA?
  - ❖ How can parents of PWA be helped?
- ❖ Is there albinism in other countries? (relation between white people and PWA?)

Slide 10

## Target group

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- High school youth
  - 'disadvantage': express low levels of stigma
  - 'advantage': teaching youth → change in the future
  - 'advantage': easily accessible through schools
- Community

Slide 11

## Ideas on interventions?

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Aspects:

- Contact
- Information
- Entertainment level of interventions

?

Slide 12

## Possible interventions

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1. Story telling/story finishing
2. Serious games
3. Picture book/book
4. Cartoon/Photo Novella
5. Presentation
6. Video
7. Religious intervention
8. Normal education
9. Theatre
10. Etc.

### Story telling/story finishing

*Mrembo is a girl with albinism, her family does not understand what albinism is and they were thinking Mrembo was not able to go to a normal school. However, one day a community development officer came to her house and explained her parents what albinism is, and that Mrembo is as capable as all the other children to go to a normal school. When Mrembo arrives at school the other students:*

1. Start yelling bad things to her
2. Ask her if she wants to play with them

1. They yell, zeruzeru! Mzungu! Mrembo is feeling very sad.

2. They start playing with a ball. However, the sun is shining fiercely and this causes the skin of Mrembo to turn red.

### Serious games




*Playing a game that explains albinism and genetics and the chance of getting a child with albinism.*

*-Cards with questions, can be about albinism: if you answer correctly you need to pick two little balls from a bag, every ball is a point, if you pick two white balls you get one bonus point, if you reach 10 points you win the game*

*-Memory game with pictures of animals and people with and without albinism.*

### Picture book/book



While the children find their way to school, one girl is left behind. She is sitting in the shadow of a big tree. She is not feeling well. Her skin itches and she is feeling lonely.

Old Mzee passes by and asks: "Why are you not in school?"

The girl is quiet for a while and says: "I am afraid to go because I am different." "Different?" Mzee frowns, "You are unique! Just like every child in the whole world."

Why does the girl think that she is different?  
 Why is the skin of the girl itchy?

Slide 16

## Cartoon/photo novella

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Slide 17

- 
1. Presentation
  2. Video
  3. Religious intervention
  4. Normal education
  5. Theatre
  6. Etc.
- 

Slide 18

## Brainstorm

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APPENDIX B: ADAPTATION FOR VALIDATION ITEMS EMIC-CSS AND ASDS-A  
(CHAPTER 4)

<b>EMIC-CSS</b>			
<b>Original items</b>	<b>New items</b>	<b>Aspect of stigmatisation</b>	<b>Difference in equivalence</b>
<i>O-E1 Would a person with leprosy keep others from knowing, if possible?</i>	N-E1 Would family of someone with albinism keep this person hidden?	Concealment/Shame and embarrassment	Concept is not fitting
<i>O-E2 If a member of your family had leprosy, would you think less of yourself?</i>	N-E2 Would the family of someone with albinism feel less worth?	Discrediting	Semantic change, EMIC-CSS questions are about what others think and this question was originally about what you think
<i>O-E3 In your community, does leprosy cause shame or embarrassment?</i>	N-E3 In your community, does albinism cause shame or embarrassment?	Shame and embarrassment	
<i>O-E4 Would others think less of a person with leprosy?</i>	N-E4 Would people think less of a person with albinism?	Discrediting	
<i>O-E5 Would knowing that someone has leprosy have an adverse effect on others?</i>	REMOVE	Concealment	Concept is not fitting
<i>O-E6 Would other people in your community avoid a person affected by leprosy?</i>	N-E6 Would people in your community avoid a person with albinism?	Avoidance and taking distance/isolation	
<i>O-E7 Would others refuse to visit the home of a person affected by leprosy?</i>	N-E7 Would others refuse to visit the home of a person with albinism?	Avoidance and taking distance/isolation	
<i>O-E8 Would people in your community think less of the family of a person with leprosy?</i>	N-E8 Would people in your community think less about the family of a person with albinism?	Discrediting/Problems for family	
<i>O-E9 Would leprosy cause problems for the family?</i>	N-E9 Would albinism cause any problems for the family in the community?	Problems for family	Semantic: question was unclear
<i>O-E10 Would a family have concern about disclosure if one of their members had leprosy?</i>	REMOVE	Concealment	Concept is not fitting

<i>O-E11 Would leprosy be a problem for a person to get married?</i>	N-E11 Is albinism a problem for a person to get married?	Problems with marriage	
<i>O-E12 Would leprosy cause problems in an on-going marriage?</i>	N-E12 Would getting a child with albinism cause problems in a marriage?	Problems with marriage	Concept is not fitting
<i>O-E13 Would having leprosy cause a problem for a relative of that person to get married?</i>	N-E13 Would having a relative with albinism cause problems for someone to get married?	Problems for family/problems for marriage	
<i>O-E14 Would having leprosy cause difficulty for a person to find work?</i>	REMOVE	Work	Item is not fitting
<i>O-E15 Would people dislike buying food from a person affected by leprosy?</i>	N-E15 Would people buy goods or services from a person with albinism?	Work/Avoidance and taking distance/isolation	Item is not fitting
<b>New items</b>			
	N-E16 Would people call people with albinism bad names?	Discrediting	
	N-E17 Would people in your community gossip/talk bad about a person with albinism?	Discrediting	
	N-E18 Do people in general fear people living with albinism?	Fear	Concept missing

<b>ASDS-A</b>		
<b>Original items</b>	<b>New items</b>	<b>Equivalence</b>
<i>O-S1 How would you feel about renting a room in your home to someone like Rahman/Rahmi?</i>	N-S1 How would you feel to visit a house of someone like John/Joyce?	Item is not fitting
<i>O-S2 How about being a worker on the same job with someone like Rahman/Rahmi?</i>	N-S2 How would you feel to be in the same class with someone like John/Joyce?	Item is not fitting
<i>O-S3 How would you feel having someone like Rahman/Rahmi as a neighbour?</i>	N-S3 How would you feel to sit next to someone like John/Joyce in class?	Item is not fitting
<i>O-S4 How about having someone like Rahman/Rahmi as caretaker of your children for a couple of hours?</i>	N-S4 How would you feel having someone like John/Joyce, who is older, as a teacher?	Item is not fitting
<i>O-S5 How about having one of your children marry someone like Rahman/Rahmi?</i>	N-S5 How would you feel to have someone like John/Joyce as a family member?	Item is not fitting
<i>O-S6 How would you feel about introducing Rahman/Rahmi to a young woman you are friendly with?</i>	N-S6 How would you feel to introduce John/Joyce to your friends?	Item is not fitting

<i>O-S7 How would you feel about recommending someone like Rahman/Rahmi for a job working for a friend of yours?</i>	N-S7 How would you feel helping someone like John/Joyce with a question about school work?	Item is not fitting
<b>New items</b>		
	N-S8 How would you feel to have John/Joyce as a friend?	Item is missing
	N-S9 How would you feel shaking hands with someone like John/Joyce?	Item is missing
	N-S10 How would you feel if your friend knew that you had someone like John/Joyce in your family?	Item is missing
	N-S11 How would you feel if someone like John/Joyce was your teammate when playing games/sports?	Item is missing
	N-S12 How would you feel being in the same school with someone like John/Joyce?	Item is missing

APPENDIX C: EMIC-CSS (CHAPTER 4)

EMIC-CSS items	N	No	Perhaps	Yes	Mean	SE	Median	N	Reliability test-retest							Answers Unequal	Equal	N	p
									Kappa	Linear Weighted	Gwet's AC1	SE	Kendall's t						
N-E3 In your community does albinism cause shame or embarrassment?	322	90.10%	4.30%	5.60%	0.16	0.03	0	132	0.29	0.34	0.79	0.04	0.36	19.10%	80.90%	-2.49	0.013		
N-E15 Would people buy goods or services from a person with albinism?	324	87.30%	8.60%	4.00%	0.17	0.03	0	129	0.23	0.22	0.78	0.04	0.24	20.30%	79.70%	-0.277	0.813		
N-E11 Is albinism a problem for a person to get married?	324	65.10%	13.30%	21.60%	0.56	0.05	0	132	0.37	0.42	0.61	0.05	0.43	35.10%	64.90%	-0.811	0.442		
N-E6 Would people in your community avoid a person with albinism?	322	63.00%	12.10%	24.80%	0.62	0.05	0	132	0.24	0.3	0.50	0.05	0.31	41.70%	58.30%	-0.312	0.777		
N-E8 Would people in your community think less about the family of a person with albinism?	323	56.00%	19.20%	24.80%	0.69	0.05	0	132	0.26	0.3	0.48	0.05	0.30	44.60%	55.40%	-2.098	0.038		
N-E1 Would the family of someone with albinism keep this person hidden?	324	51.20%	27.20%	21.60%	0.7	0.05	0	132	0.40	0.45	0.54	0.05	0.48	39.40%	60.60%	-2.341	0.021		
N-E2 Would the family of someone with albinism feel less worth?	320	49.10%	29.10%	21.90%	0.73	0.05	1	132	0.44	0.46	0.55	0.05	0.45	36.40%	63.60%	-1.892	0.061		
N-E9 Would albinism cause any problems for the family in the community?	322	55.30%	11.20%	33.50%	0.78	0.05	0	131	0.39	0.42	0.56	0.05	0.40	37.20%	62.80%	-0.032	0.974		
N-E18 Do people in general fear people living with albinism?	325	47.40%	24.00%	28.60%	0.81	0.05	1	129	0.29	0.34	0.45	0.05	0.35	46.50%	53.50%	-1.385	0.166		
N-E13 Would having a relative with albinism cause problems for someone to get married?	325	39.70%	26.20%	34.20%	0.94	0.05	1	131	0.37	0.39	0.49	0.05	0.39	42.00%	58.00%	-1.498	0.144		
N-E16 Would people call people with albinism bad names?	322	41.60%	18.60%	39.80%	0.98	0.05	1	129	0.41	0.43	0.53	0.05	0.42	38.30%	61.70%	-1.45	0.155		
N-E7 Would others refuse to visit the home of a person with albinism?	324	33.60%	28.10%	38.30%	1.05	0.05	1	131	0.38	0.43	0.50	0.05	0.47	42.00%	58.00%	-3.043	0.002		
N-E17 Would people in your community gossip/talk bad about a person with albinism?	323	34.10%	25.10%	40.90%	1.07	0.05	1	131	0.35	0.38	0.47	0.05	0.39	43.80%	56.20%	-2.858	0.004		
N-E12 Would getting a child with albinism cause problems in a marriage?	324	18.50%	25.30%	56.20%	1.38	0.04	2	132	0.39	0.44	0.55	0.05	0.46	36.40%	63.60%	-1.013	0.331		
N-E4 Would people think less of a person with albinism?	323	21.40%	14.60%	64.10%	1.43	0.05	2	132	0.50	0.55	0.68	0.05	0.55	26.20%	73.80%	-1.043	0.314		

APPENDIX D: ASDS-A (CHAPTER 4)

ASDS-A Items	N	Reliability test-retest										Wilcoxon						
		I do not have a big problem	I do not have a problem	I do have a problem	I do have a big problem	Mean	SE	Median	N	Kappa	Linear Weighted Kappa	SE	Gwet's AC1	SE	Answer Unequal	Equal	Z	p
N-S12 How would you feel being in the same school with someone like John/Joyce?	320	83.10%	15.30%	1.30%	0.30%	0.19	0.03	0	131	0.37	0.39	0.1	0.81	0.04	25.2%	74.8%	-1.509	0.164
N-S7 How would you feel helping someone like John/Joyce with a question about school work?	319	79.90%	18.50%	0.90%	0.60%	0.22	0.03	0	131	0.29	0.28	0.1	0.75	0.04	22.3%	77.7%	-1.166	0.312
N-S2 How would you feel to be in the same class with someone like John/Joyce?	324	77.80%	21.00%	1.20%	0.00%	0.23	0.03	0	130	0.37	0.33	0.09	0.76	0.04	23.7%	76.3%	-1.136	0.326
N-S4 How would you feel having someone like John/Joyce, who is older, as a teacher?	326	78.80%	19.30%	1.20%	0.60%	0.24	0.03	0	131	0.36	0.47	0.09	0.77	0.04	21.4%	78.6%	-.898	0.474
N-S8 How would you feel to have John/Joyce as a friend?	320	79.40%	18.40%	0.90%	1.30%	0.24	0.03	0	131	0.34	0.33	0.09	0.73	0.04	31.3%	68.7%	-2.430	0.013
N-S9 How would you feel shaking hands with someone like John/Joyce?	319	79.00%	18.80%	1.30%	0.90%	0.24	0.03	0	131	0.27	0.30	0.09	0.71	0.04	26.9%	73.1%	-2.075	0.048
N-S3 How would you feel to sit next to someone like John/Joyce in class?	326	75.50%	23.00%	1.50%	0.00%	0.26	0.03	0	131	0.38	0.39	0.09	0.74	0.04	23.7%	76.3%	-.819	0.494
N-S11 How would you feel if someone like John/Joyce was your teammate when playing games/sports?	319	77.40%	19.40%	3.10%	0.00%	0.26	0.03	0	130	0.26	0.30	0.08	0.68	0.04	25.2%	74.8%	-1.411	0.185
N-S1 How would you feel to visit a house of someone like John/Joyce?	326	75.20%	22.40%	1.50%	0.90%	0.28	0.03	0	131	0.36	0.37	0.09	0.73	0.04	26.7%	73.3%	-1.866	0.075

N-S6 How would you feel to introduce John/Joyce to your friends?	320	70.60%	25.60%	2.80%	0.90%	0.34	0.03	0	130	0.42	0.46	0.08	0.70	0.04	33.1%	66.9%	-2.166	0.034
N-S10 How would you feel if your friend knew that you had someone like John/Joyce in your family?	319	67.40%	24.10%	6.90%	1.60%	0.43	0.04	0	130	0.34	0.40	0.07	0.63	0.05	30.0%	70.0%	-2.294	0.786
N-S5 How would you feel to have someone like John/Joyce as a family member?	320	64.40%	28.80%	5.30%	1.60%	0.44	0.04	0	131	0.37	0.42	0.08	0.65	0.05	18.3%	81.7%	-0.016	1.000

APPENDIX E: RECOMMENDED EMIC-CSS AND ASDS-A (CHAPTER 4)

EMIC-CSS Item	Swahili Translation
<i>N-E6 Would people in your community avoid a person with albinism?</i>	Je, katika jamii yako kuna watu ambao wanamtenga mtu mwenye ualbino?
<i>N-E8 Would people in your community think less about the family of a person with albinism?</i>	Je, katika jamii yako kuna watu wanadharau familia ya mtu mwenye ualbino?
<i>N-E1 Would the family of someone with albinism keep this person hidden?</i>	Je, familia yenye mtu mwenye ualbino inaweza kumficha ndani kwa sababu inaona aibu?
<i>N-E2 Would the family of someone with albinism feel less worth?</i>	Je, familia yenye mtu mwenye ualbino hujiona haina thamani mbele ya jamii?
<i>N-E18 Do people in general fear people living with albinism?</i>	Je, kwa ujumla watu wanaogopa watu wenye ualbino?
<i>N-E13 Would having a relative with albinism cause problems for someone to get married?</i>	Je, kuwa na mtu mwenye ualbino katika familia kunaweza kuwa kikwazo kwa mtu kuoa au kuolewa?
<i>N-E16 Would people call people with albinism bad names?</i>	Je, watu wanawaita majina mabaya watu wenye ualbino?
<i>N-E7 Would others refuse to visit the home of a person with albinism?</i>	Je, kuna watu wanaokataa kutembelea nyumba ya mtu mwenye ualbino?
<i>N-E17 Would people in your community gossip/talk bad about a person with albinism?</i>	Je, watu katika jamii huwateta/huwasema vibaya watu wenye ualbino?
<i>N-E12 Would getting a child with albinism cause problems in a marriage?</i>	Je, kupata mtoto mwenye ualbino kunaweza kuleta mgogoro kati ya wanandoa?
<i>N-E4 Would people think less of a person with albinism?</i>	Je, watu wanaweza kumdharau mtu mwenye ualbino?

ASDS-A Item	Swahili Translation
<i>N-S12 How would you feel being in the same school with someone like John/Joyce?</i>	Je, ungejisikiaje kuwa shule moja na mtu kama John?
<i>N-S7 How would you feel helping someone like John/Joyce with a question about school work?</i>	Je, ungejisikiaje kumsaidia mtu kama John kufanya kazi ya darasani?
<i>N-S2 How would you feel to be in the same class with someone like John/Joyce?</i>	Je, ungejisikiaje kuwa darasa moja na mtu kama John?
<i>N-S4 How would you feel having someone like John/Joyce, as a teacher?</i>	Je, ungejisikiaje kuwa na mtu kama John kama mwalimu wako?
<i>N-S8 How would you feel to have John/Joyce as a friend?</i>	Je, unajisikiaje kama ungekuwa na rafiki kama John?
<i>N-S9 How would you feel shaking hands with someone like John/Joyce?</i>	Je, unajisikiaje ukimpa mkono mtu kama John?
<i>N-S3 How would you feel to sit next to someone like John/Joyce in class?</i>	Je, ungejisikiaje kukaa karibu na mtu kama John darasani?
<i>N-S11 How would you feel if someone like John/Joyce was your teammate when playing games/sports?</i>	Je, ungejisikiaje kuwa na mtu kama John kwenye timu yako wakati wa michezo?
<i>N-S1 How would you feel to visit a house of someone like John/Joyce?</i>	Je, ungejisikiaje kumtembelea nyumbani mtu kama John?
<i>N-S6 How would you feel to introduce John/Joyce to your friends?</i>	Je, ungejisikiaje kumtambulisha mtu kama John kwa marafiki zako?
<i>N-S10 How would you feel if your friend knew that you had someone like John/Joyce in your family?</i>	Je, ungejisikiaje kama marafiki wangepahamu kuwa mna mtu kama John kwenye familia yenu?
<i>N-S5 How would you feel to have someone like John/Joyce as a family member?</i>	Je, ungejisikiaje kama ungekuwa na mtu kama John katika familia yako?

APPENDIX F: OVERVIEW (CHAPTER 5)

A-EMIC-CSS Items	N	Mean	Std. Deviation	Skewness	Kurtosis	Reliability test-retest					Wilcoxon		
						N	Kappa	Linear Weighted Kappa	Gwet's AC1	SE	Kendall t	Z	p
A-E1 Would family of someone with albinism keep this person hidden out of shame?	101	2.22	1.03	0.80	-0.04	79	0.29	0.39	0.42		0.36	-0.562	0.574
A-E2 Would the family of someone with albinism feel less worth?	101	2.22	1.05	0.73	-0.42	79	0.42	0.47	0.53		0.48	-0.267	0.790
A-E3 In your community, does albinism cause shame or embarrassment?	101	1.64	0.82	1.30	1.32	78	0.28	0.24	0.45		0.41	-1.657	0.098
A-E4 Would people think less of a person with albinism?	100	2.25	1.11	0.74	-0.36	78	0.33	0.38	0.44		0.39	-0.131	0.896
A-E5 Would people in your community avoid a person with albinism?	100	1.87	1.00	1.31	1.27	77	0.21	0.26	0.36		0.36	-1.054	0.292
A-E6 Would others refuse to visit the home of a person with albinism?	99	1.77	0.95	1.37	1.78	78	0.26	0.26	0.42		0.24	-0.765	0.444
A-E7 Would people in your community think less about the family of a person with albinism?	100	1.86	1.04	1.26	0.87	78	0.16	0.09	0.32		0.23	-0.975	0.329
A-E8 Would albinism cause any problems for the family in the community?	101	1.61	0.92	1.65	2.29	79	0.21	0.21	0.41		0.29	-0.805	0.421
A-E9 Is albinism a problem for a person to get married?	101	2.14	1.14	0.80	-0.50	79	0.21	0.24	0.33		0.26	-0.680	0.496
A-E10 Would getting a child with albinism cause problems in a marriage?	101	2.33	1.14	0.69	-0.78	79	0.33	0.31	0.45		0.41	-1.184	0.236
A-E11 Would having a relative with albinism cause problems for someone to get married?	101	2.16	1.10	0.87	-0.26	79	0.10	0.14	0.25		0.22	-0.166	0.868
A-E12 Would people buy goods or services from a person with albinism?	100	2.64	1.30	0.56	-0.86	78	0.07	0.10	0.17		0.13	-0.668	0.504
A-E13 Would people call people with albinism bad names?	101	2.30	1.19	0.57	-0.98	79	0.13	0.09	0.23		0.04	-0.673	0.501
A-E14 Would people in your community gossip/talk bad about a person with albinism?	98	2.38	1.12	0.43	-1.04	76	0.26	0.30	0.36		0.29	-0.752	0.452
A-E15 Do people in general fear people living with albinism?	100	2.19	1.10	0.69	-0.66	79	0.11	0.10	0.25		0.14	-0.824	0.410



A-SDS Items	N	Mean	Std. Deviation	Skewness	Kurtosis	Reliability test-retest					Wilcoxon		
						N	Kappa	Linear Weighted Kappa	Gwet's AC1	SE	Kendall t	Z	p
A-S1 How would you feel to visit a house of someone like John/Joyce?	100	1.18	0.54	3.68	14.97	79	0.08	0.06	0.71		0.08	-1.218	0.223
A-S2 How would you feel working together with someone like John/Joyce?	99	1.27	0.71	2.67	6.27	78	0.14	0.18	0.65		0.22	-0.706	0.480
A-S3 How would you feel having someone like John/Joyce as a neighbour?	99	1.21	0.52	2.89	9.68	78	0.17	0.21	0.66		0.13	-1.733	0.083
A-S4 How about having someone like John/Joyce taking care of your children for a couple of hours?	99	1.27	0.57	2.33	6.01	77	0.25	0.30	0.65		0.19	-1.733	0.083
A-S5 Would you permit your child to marry someone like John/Joyce?	95	1.47	0.77	1.66	2.24	73	0.23	0.25	0.54		0.20	-0.828	0.408
A-S6 How would you feel about introducing John/Joyce to a young woman you are friendly with?	99	1.28	0.62	2.56	6.95	77	0.07	0.11	0.57		0.01	-0.832	0.405
A-S7 How would you feel about recommending someone like John/Joyce for a job working for a friend of yours?	99	1.20	0.47	2.93	11.67	78	0.01	0.02	0.59		-0.03	-1.75	0.080
A-S8 How would you feel to sit next to John/Joyce in the bus?	99	1.18	0.46	3.22	13.86	77	0.10	0.12	0.63		0.05	-2.077	0.038
A-S9 How would you feel to have John/Joyce as a friend?	99	1.19	0.47	3.07	12.70	78	0.18	0.20	0.63		0.11	-2.462	0.014
A-S10 How would you feel shaking hands with someone like John/Joyce?	99	1.16	0.45	3.56	16.64	78	0.12	0.14	0.65		0.07	-2.253	0.024

APPENDIX G: KNOWLEDGE ITEMS (CHAPTER 7)

Nr.	Item	Baseline - all respondents				Baseline – Respondents that completed post-test				Post-test				McNemar				
		N	Yes	No	Don't Know	N	Yes	No	Don't Know	N	Yes	No	Don't Know	Nr correct in baseline - incorrect in post-test	Nr incorrect in baseline - correct in post-test	N	Chi <sup>2</sup>	Asymp. Sig.
K-01	Do you know the reason for albinism?	183	27.9	72.1		153	30.7	69.3		157	59.2	40.8		8	45	141	24.453	0.000
K-02	Do you think albinism is inherited?	195	29.7	70.3		165	33.3	66.7		163	59.5	40.5		10	49	156	24.475	0.000
K-03	Do you know what to do to help someone with albinism?	184	56.0	44.0		154	61.0	39.0		138	80.4	19.6		6	27	126	12.121	0.000
K-04	Do you think albinism is contagious?	206	66.5	11.2	22.3	172	65.7	11.0	23.3	169	83.4	14.8	1.8	15	46	166	14.754	0.000
K-05	Do you think a person with albinism will turn blind?	200	37.5	41.0	21.5	167	39.5	40.1	20.4	168	32.7	58.3	8.9	33	21	161	2.241	0.134
K-06	A person with albinism can get a child without albinism?	204	70.6	14.2	15.2	173	71.7	13.3	15.0	167	83.8	13.8	2.4	13	33	165	7.848	0.005
K-07	Persons with albinism can learn	202	95.5	3.5	1.0	170	95.9	2.9	1.2	172	97.1	2.3	0.6	5	7	167	-	.774b



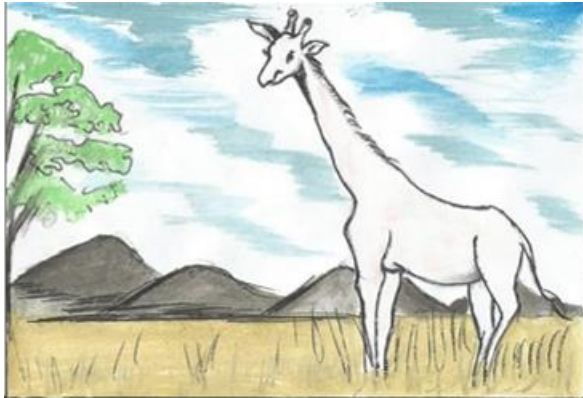
APPENDIX H: ASDS-A (CHAPTER 7)

Nr.	Item	Original ASDS-A										
		Baseline - all respondents		Baseline - Respondents that completed post-test		Post-test		Wilcoxon Signed-Rank Test			Lower score baseline - Higher score post-test	Higher score baseline - Lower score post-test
		N	Mean	N	Mean	N	Mean	N	Z	p	n	n
S-01	How would you feel to visit a house of someone like John/Joyce?	208	1.41	174	1.36	168	1.32	167	-.625b	0.532	24	27
S-02	How would you feel to be in the same class with someone like John/Joyce?	209	1.46	175	1.42	170	1.39	170	-.349b	0.727	28	27
S-03	How would you feel to sit next to someone like John/Joyce in class?	209	1.44	175	1.41	170	1.35	170	-.868b	0.385	20	26
S-04	How would you feel having someone like John/Joyce, who is older, as a teacher?	209	1.51	175	1.47	172	1.28	172	-2.984b	0.003	16	32
S-05	How would you feel to have someone like John/Joyce as a family member?	208	1.46	174	1.44	164	1.35	163	-1.441b	0.149	15	23
S-06	How would you feel to introduce someone like John/Joyce to you friends?	207	1.49	173	1.47	171	1.27	169	-3.438b	0.001	8	33
S-07	How would you feel helping someone like John/Joyce with questions about school work?	209	1.42	175	1.40	171	1.37	171	-.789b	0.430	20	24
S-08	How would you feel to have John/Joyce as a friend?	209	1.39	175	1.35	172	1.34	172	-.125b	0.901	26	21
S-09	How would you feel shaking hands with someone like John/Joyce?	206	1.43	174	1.40	172	1.30	171	-1.973b	0.049	13	25
S-10	How would you feel if your friend knew that you had someone like John/Joyce in your family?	208	1.43	174	1.41	171	1.29	170	-2.794b	0.005	12	26
S-11	How would you feel if someone like John/Joyce was your teammate when playing games/sports?	209	1.50	175	1.50	172	1.38	172	-2.416b	0.016	11	24
S-12	How would you feel being in the same school with someone like John/Joyce?	209	1.36	175	1.33	171	1.30	171	-.844b	0.399	17	22

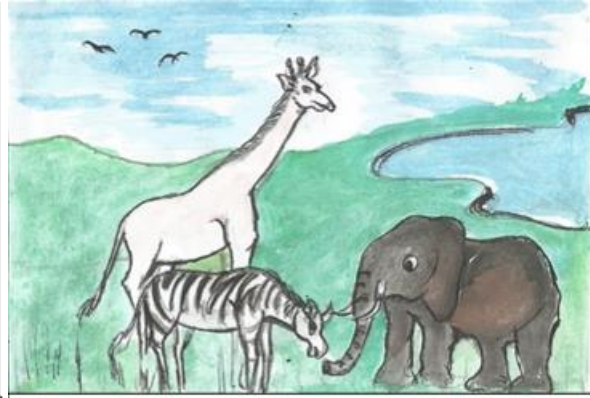
APPENDIX I: RESPONDENT CHARACTERISTICS (CHAPTER 8)

Variables		Radio drama		Radio Interview	
		Baseline (N=111)	Post-test (N=65)	Baseline (N=123)	Post-test (N=77)
		n (%)	n (%)	n (%)	n (%)
Gender	Men	50 (45%)	31 (47.7%)	59 (48%)	30 (39%)
	Women	61 (55%)	34 (52.3%)	64 (52%)	47 (61%)
Level of education	I cannot read or write	30 (33.7%)	20 (35.1%)	21 (19.4%)	15 (21.7%)
	I can read and write	11 (12.4%)	5 (8.8%)	17 (15.7%)	10 (14.5%)
	I finished primary school	37 (41.6%)	24 (42.1%)	55 (50.9%)	33 (47.8%)
	I finished ordinary level (high school)	9 (10.1%)	6 (10.5%)	11 (10.2%)	7 (10.1%)
	I finished advanced level (high school)	0	0	2 (1.9%)	2 (2.9%)
	I finished higher education/university	2 (2.2%)	2 (3.5%)	2 (1.9%)	2 (2.9%)
Religion	Christian	41 (37.6%)	22 (34.4%)	36 (29.3%)	22 (28.6%)
	Muslim	68 (62.4%)	42 (65.6%)	87 (70.7%)	55 (71.4%)
Profession	Paid Job	5 (4.8%)	3 (4.9%)	9 (8.7%)	7 (10.9%)
	Own business/farmer	98 (94.2%)	58 (95.1%)	91 (88.3%)	56 (87.5%)
	Student	1 (1.0%)	0 (0%)	3 (2.9%)	1 (1.6%)
Know person with albinism	No	26 (23.4%)	17 (26.2%)	16 (13.6%)	11 (14.9%)
	Yes	85 (76.6%)	48 (73.8%)	102 (86.4%)	63 (85.1%)
Family with albinism	No	98 (88.3%)	56 (86.2%)	97 (82.9%)	59 (78.7%)
	Yes	13 (11.7%)	9 (13.8%)	20 (17.1%)	16 (21.3%)

APPENDIX J: EDUCATIVE GAME (CHAPTER 12)



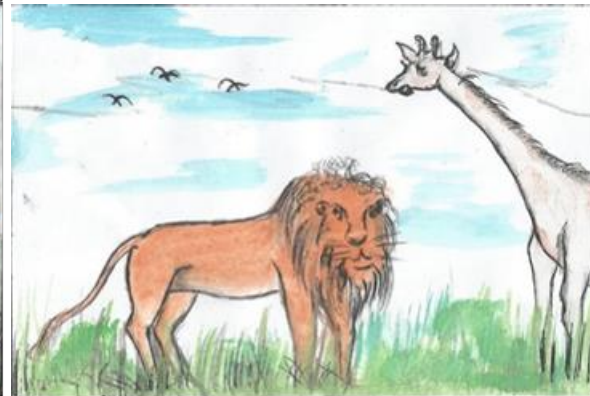
1. Kulikuwa na Twiga mpweke mwenye ualbino. Ngozi zake zilikuwa nangaa, hasa wakati jua lilipoangaza alipotembea mbugani. Siku moja Twiga aliamua hataki kuendelea kuwa mpweke na akaenda kutafuta marafiki.



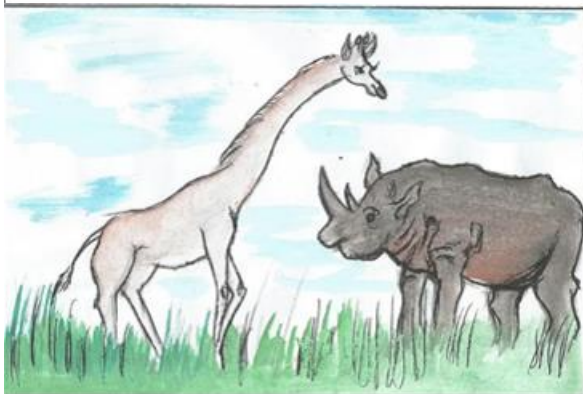
2. Akiwa njiani alikutana na wanyama wa aina mbalimbali.



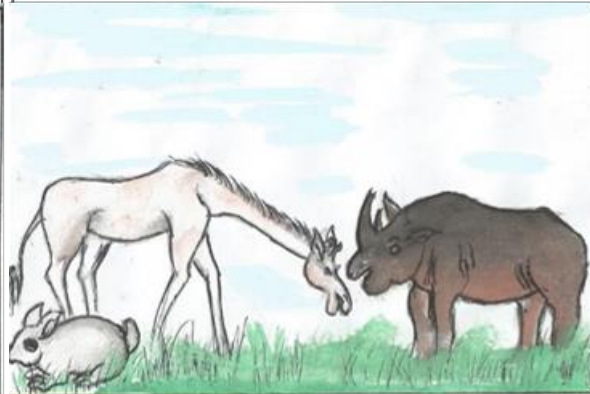
3. Kwanza Twiga akakutana na Tembo, naye akasema: 'Sijawahi kuona twiga kama wewe. Una tatizo gani?'.



4. Baadaye Twiga akakutana na Simba, naye akasema: 'Sijawahi kuona Twiga kama wewe. Una tatizo gani?'.



5. Baadaye Twiga akakutana Kifaru, naye akasema: 'Sijawahi kuona twiga kama wewe. Una tatizo gani?'. Twiga alijibu: 'Kila mmoja alisema kitu kama hicho na sijui nifanya nini?'.



6. Kifaru alitaka kumsaidia Twiga na akasema: 'Nenda kumtafuta Sungura. Anajua kila kitu'.



7. Twiga akaendana kwa Sungura, na akasema: 'Kila mnyama niliyekutana njiani ameniambia kuna kitu tofauti kwangu. Unaonaje?'



8. Sungura akasema: 'Usijali. Sababu ya kwamba una tofauti kidogo na twiga wengine ni kwa sababu una ualbino. Wewe siyo peke yako. Ualbino upo katika vitu mbalimbali, yaani wanyama, watu na mimea.'



9. 'Ualbino unasababishwa na kurithi chembechembe za uzazi za ualbino kama wazazi wote wawili wanazo. Kama chembechembe zikikutana, basi mtoto mwenye ualbino anaweza kuzaliwa.'



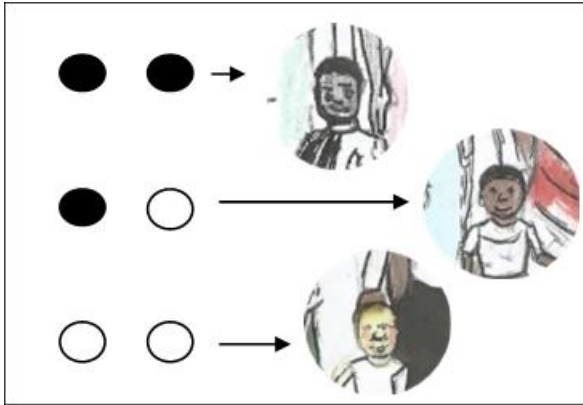
10. 'Kama chembechembe za uzazi hazikutani, basi mtoto hawezi kuzaliwa mwenye ualbino.'



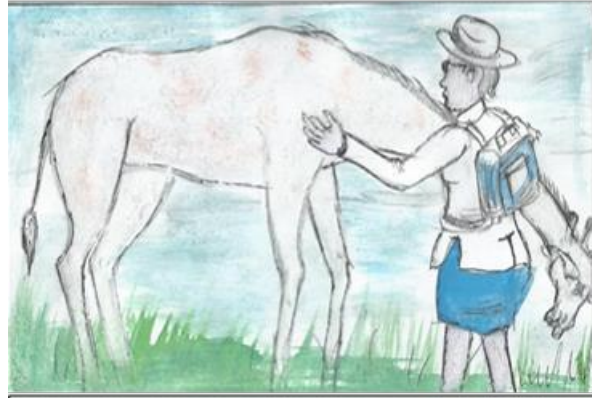
11. 'Kila mtu mwenye ualbino anaweza akawa na chembechembe za uzazi za ualbino lakini labda mtoto wake hatarithi ualbino.'



12. 'Fikiri kuhusu hili. Kuna begi kubwa: hivyo mipira nayo wakilisha chembechembe zenye uzazi za ualbino. Bila kuangaliwa unaweza kuchukua mipira na ina maana kuwa urithi, kila mipira kutoka mzazi mmoja.'



13. 'Kama ukichukua mipira miwili yote mweusi, basi mtoto hana ualbino. Kama ukichukua mipira mmoja mweusi na mmoja mweupe, basi mtoto hana ualbino. Lakini kama ukichukua mipira miwili yote mweupe, basi mtoto anao ualbino.'



14. Akiwa njiani alikutana na Sandra mwanamke mwenye ualbino anayefanya kazi za udaktari wa wanayama huko mbugani. Twiga akauliza: 'Kama mimi, je wewe uko sawa na binadamu wengine?'



15. Sandra akaelezea: 'Naweza kufanya vitu sawa na binadamu wengine kama kusomea udaktari wa wanyama. Njoo nami ili ukutane na familia yangu.'



16. Sandra akasema: "Huyu ni bwana wangu na mtoto wangu. Naona mwanangu hana ualbino, kwa hiyo labda mwanangu hana chembechembe za uzazi za ualbino au labda chembechembe hazifanani.'



17. Sandra na familia yake walimwonyesha ramani ya dunia. 'Ulijua kwamba nchi zote duniani wana watu wenye ualbino? Kuna Wachina, Waingereza, na Waamerikani wenye ualbino.'



18. Twiga aliuliza kwa nini daktari wa wanyama anavaa kofia. Sandra akaelezea: 'Ngozi za watu wenye ualbino zina akisi mwanga kwa hiyo inabidhi tukinge na jua kwa kuvaa nguo ndefu na kofia. Kama tusipofanya hivi, ngozi zetu zitachubuka na kupata saratani ya ngozi.'





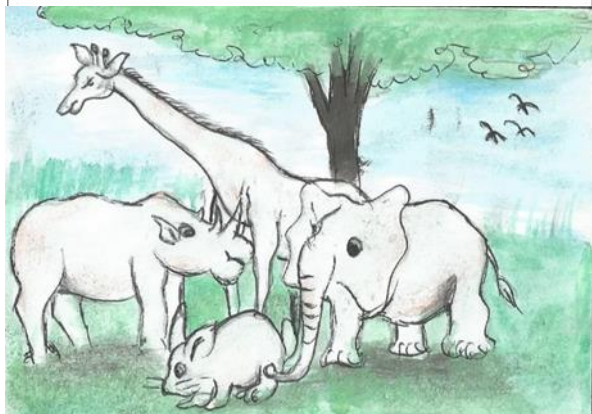
19. 'Pia watu wenye ualbino wana uoni hafifu. Wanaweza kuhitaji miwani yeney lezi. Wanafunzi wanaweza kusaidiwa kwa kuweka kitabu karibu na macho yao na kukaa mbele ya darasa ili kuona ubao vizuri zaidi.'



20. Twiga alifurahi sana kujifunza mambo hayo. Aliendelea na safari zake na akaelezea kuhusu wanyama wenye ualbino na wale bila ualbino.



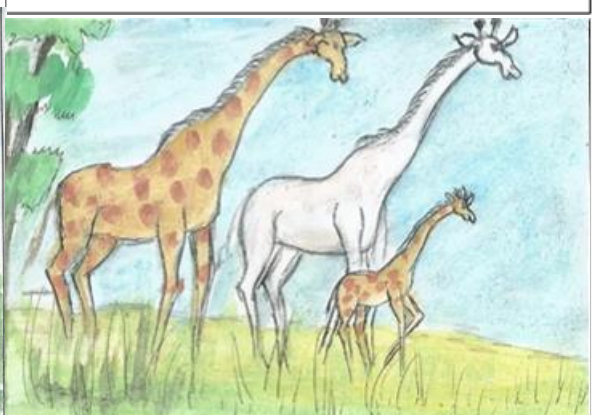
21. Akakutana na Twiga wa kike. Naye akauliza maswali mengi: 'Kwa nini una rangi hizi? Wewe ni mzimu wa twiga? Ni kweli siku moja inaweza kutokea?'



22. Twiga akaelezea kwamba kuna wanyama na watu wengi wenye ualbino kama yeye.



23. Twiga wa kike alimwona Twiga kama mayania anayebutia kama Twiga alibutiwa naye sana. Na nakapendana.



24. Wakaishi kwa furaha maisha yao mzima.