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## An act of agency: people with albinism in Tanzania creating change

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### ABSTRACT

The contact strategy has proven to be effective in reducing stigma in relation a variety of disabilities and health-related conditions. This strategy requires people to be willing to present on their condition. This study explored what the considerations are of 'spokespersons' to do so. Semi-structured in-depth interviews were conducted. Informants (13) expressed how they felt about presenting, that it gave them the opportunity to develop themselves and to increase their status and confidence. Informants felt responsible for making a change in society and experienced their presentations as an effective strategy. The informants did not consider presenting themselves as a risk, as long as the necessary security arrangements are made, and proper training is provided. Recommendations are provided for the implementation and development of contact interventions in relation to health-related stigma.

### ARTICLE HISTORY

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### KEYWORDS

Health-related stigma; contact strategy; stigma-reduction intervention; spokespersons; albinism; Tanzania

### POINT OF INTEREST

- People with albinism in Tanzania experience a lot of discrimination.
- Discrimination and negative attitudes can be reduced when people with albinism give presentations about themselves, so that people can get to know them and learn more about albinism.
- In this research people with albinism explain they want to give presentations to improve people's attitudes towards people with albinism
- Giving presentations about albinism gives people with albinism more self-confidence
- The recommendations provided in this article can be used by organizations for the development of interventions in which people with lived experience present on their condition to create positive change.

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## Introduction

'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 quote above came from a person with albinism who raised awareness on albinism by presenting on his own condition. He referred to himself as a professor in albinism because he had the feeling that by learning about albinism and living with albinism, he had the necessary knowledge on albinism to teach others about it.

It is estimated that one in 2,673 people in Tanzania has albinism (Franklin et al. 2018). This number might be higher, as people with albinism and their family members possibly fear reporting those with albinism in the census due to the perceived risk of discrimination (Lund and Roberts, 2018). People with albinism have a partial or complete lack of pigment due to a shortage of melanin. They have pale-coloured skin, hair and eyes. They often suffer from skin cancer because their skin is highly vulnerable to ultraviolet radiation (Hong, Zeeb, and Repacholi 2006; Kromberg, Kromberg, and Manga 2018a). Additionally, hypopigmentation of the eyes causes them to have low vision, their eyes make unintentional movements (involuntary nystagmus), and are highly sensitive to light (Kromberg, Kromberg, and Manga 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. Among other things, albinism is perceived a curse and a sign of bad luck (Bucaro 2010), people with albinism are believed to have special powers and the belief exists that their body parts bring good fortune (Bryceson, Jønsson, and Sherrington 2010; Cruz-Inigo, Ladizinski, and Sethi 2011). People with albinism are believed to be ghosts (Baker et al. 2010; Brocco 2015) and it is believed that they do not die but just 'disappear' (Baker et al. 2010; Lund and Gaigher 2002). These beliefs and superstitions have contributed to the stigma towards people with albinism in Tanzania.

People with albinism in Tanzania as elsewhere in Africa (e.g. Malawi) 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, and Massah 2014). According to a report by Under The Same Sun (UTSS), an NGO that supports people with albinism in Tanzania, there have been 182 attacks on people with albinism, of which 76 were fatal, between 2000 and January 2019 (UTSS, 2019). It has been said that babies born with albinism have been murdered after birth (International Bar Association 2017) because of the belief that they are physically unable to support their families (Bryceson, Jønsson, and Sherrington

2010) or because they are believed to be evil spirits (Machoko 2013). The United Nations Human Rights Council (UNHCR) stated 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***

A wide range of stigma reduction interventions (SRI) have been developed and assessed for a variety of health-related stigmas such as HIV/AIDS, leprosy and mental illnesses (Brown, Macintyre, and Trujillo 2003; Heijnders and van der Meij 2006; Peters et al. 2015; van Brakel et al. 2019). Health-related stigma can be defined as 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, and 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, Macintyre, and Trujillo 2003; Cross et al. 2012). As a strategy, education involves providing knowledge about the condition to rectify the misconceptions about it. The contact strategy provides people with an opportunity to get to know someone with a stigmatizing condition (Corrigan and O'Shaughnessy 2007). Contact refers to:

All interactions between the public and persons affected, with the specific objective to reduce stigmatizing 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 and van der Meij 2006, p. 359)

Research in changing attitudes towards people with stigmatized conditions mostly focuses on the contact strategy (Allport 1954; Paluck, Green, and Green 2019; Zhou et al. 2018). 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, Macintyre, and Trujillo 2003; Zhou et al. 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 and implement effective SRI which in turn, can boost the morale of the stigmatized (Cook et al. 2014; Heijnders and van der Meij 2006; Lusli et al. 2015; Peters et al. 2016; UNAIDS 2000).

Nevertheless, the active involvement of people with a stigmatizing condition in an intervention also presents a difficulty for a contact intervention. This because people are needed who are willing to talk about their stigmatizing condition (Corrigan and O'Shaughnessy 2007; Stuart 2006). When people are

not willing to present on their condition it can be hard to roll out a contact intervention on a larger scale (Corrigan and O'Shaughnessy 2007). One can imagine that when people are fiercely stigmatized, it might be difficult for them to present themselves in unfamiliar circumstances or communities. There is the risk that when breaking down stereotypes new ones can arise (Howarth 2006; Macrae et al. 1994). This raises the question of how willing people with a stigmatizing condition are to present on their stigma?

Limited research has been carried out on experiences of presenting on personal stigmatizing conditions. Most research in this area has focused on the disclosure of, otherwise, invisible stigma (e.g. HIV/AIDS or a mental illness) (Muula and Mfutso-Bengo 2005; Paxton 2002a; Stutterheim et al. 2011). In cases of 'invisible stigma' it is necessary for people to be willing to disclose their conditions when presenting on it (Corrigan and O'Shaughnessy 2007). For visible health-related conditions such as: albinism, buruli ulcer and a variety of physical impairments, disclosure is unnecessary because people can see for themselves that one has a certain condition. Therefore, the experience of presenting on a visible stigma can differ from disclosing an invisible stigma. This makes it hard to generalize findings on disclosure to presenting on a visible condition.

Research on what people's considerations are to present on their condition is lacking. In the Tanzanian context people with albinism are fiercely stigmatized and little is known about the way in which people with albinism cope with the stigmatizing society around them (Kromberg, Kromberg, and Manga 2018b). Therefore, this paper aims to gain more insight into what the considerations are of people to present on their own visible condition by using albinism in Tanzania as a case. The research question is as follows: What are the considerations of people with albinism when deciding to present on their condition? Through this research we want make a start in researching the experience of people with visible stigma presenting in these interventions and provide recommendations for organisations implementing these interventions in the field.

## **Method**

To gain insight into the considerations of people with albinism to present on their own condition, individual in-depth interviews were conducted with spokespersons with albinism. From here on people with a stigmatizing condition who present themselves in a contact intervention will be referred to as 'spokespersons'. This term is not used by organizations in the field but was introduced by the first author for clarity purposes.

### ***Study population and selection***

The research was carried out with the help of two Tanzanian organizations: the Tanzanian Albinism Society (TAS) and Under the Same Sun (UTSS). These

organizations assist people with albinism in all aspects of life: education, information, health care and awareness raising in the community. The sample consisted of a convenience sample aimed at people with presenting experience. Therefore, the informants were found with the help of these organizations, who referred the researcher to members who functioned as spokespersons, whom these organisations expected to be willing to participate in an interview about their experiences as spokespersons. All spokespersons 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 into spokespersons' experiences. Semi-structured in-depth interviews were conducted with 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.

In total 13 spokespersons (three females, ten males) participated in this research. The informants' ages varied between 25 and 55. Some had recently started presenting as a spokesperson while others had been spokespersons for over 20 years. The informants lived in different regions of Tanzania (Dar es Salaam, Mbeya, Kilimanjaro, Kigoma, Mara and Mwanza) and had 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 informants 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 informants being a spokesperson was voluntary. Some participants were used to being interviewed, especially by the media.

The presentations that spokespersons with albinism in Tanzania provided have a large variety of formats. Part of these contact interventions were organized by TAS and UTSS themselves as part of a larger campaign on raising awareness on albinism or as separate interventions. Other presentations were initiated by the spokespersons themselves or were initiated by other parties. Presentations can take place in a large variety of locations, such as community halls, schools and churches. These awareness raising events can take place in rural and urban areas, and the audience groups addressed in the presentations can also vary largely in size and composition. These presentations were not necessarily supported by institutional authorities. Presentations exist out of people with albinism introducing themselves and telling about their lives, explaining about their condition, and giving the audience the opportunity to ask questions. However, there is no set format for these types of presentations. In this research we discussed real life presentations.

### ***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 (example question: “In what kind of ways do you notice people treating you differently because you have albinism?”), b) the personal experience of being a spokesperson (example question: “When did you first talk about albinism in front of people? How did that feel?”), c) the experienced outcomes of the contact intervention (example question: “Did you notice changes in the way the community treated you after your presentation?”), d) characteristics of a spokesperson (example question: “Do you think everyone is able to be a spokesperson? Why?”). The first theme discussed in the interview 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 considerations of people to present in a contact intervention.

Although most of the spokespersons were fluent in English, two interviews were conducted in Swahili. One interview took place with two spokespersons simultaneously because the informants indicated feeling more at ease by doing so. Interviews lasted between 30 up to 98 min and took place at the informants’ house, workplace of the informant or at a café close to the informants’ house. The interviews were conducted by the first author who speaks Swahili.

### ***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 the first author 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 de Vrije Universiteit Brussel decided that the research was exempt from ethical approval since the informants 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). Informants 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

voluntary, no incentive was provided. Written consent was provided by all informants.

## Results

### *Personal experience of being a spokesperson*

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

Informants indicated that what motivated them to present as a spokesperson with albinism was a feeling of responsibility to change the way people think about people with albinism. Nine informants 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.

On an individual level being a spokesperson offered opportunities for personal development. Informants mentioned to have gained confidence from presenting about albinism to an audience, one of these informants described this process as follows:

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

When discussing whether informants occasionally felt afraid in their role as a spokespersons, 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 informants, in the beginning talking about albinism seemed a taboo and talking about one's own condition was hard. Another informant described the negative effect of not talking about one's condition and the relief that was caused by talking about it.

'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)

Only two individuals brought up their fear of something happening to spokespersons because of their presentation. Informants considered their security, as can be read in the quote below. However, they 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***

Informants expressed the experience that presenting about albinism by a person with albinism reduced stigmatizing attitudes in the community. Several mechanisms were named by the informants that they thought explained the effectiveness of a contact intervention: 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 that people with albinism are human, 4) knowledge from the experience of the spokesperson is provided, and misinformation can be corrected and 5) friendship and feelings of empathy can arise. Additionally, the informants also identified that these mechanisms could backfire because people might distrust them because they advocate for themselves.

Informants mentioned the importance of showing the audience an example of an educated person with albinism, since this counters people's stereotypical views that entail people with albinism not to be able to be educated or having a low level of education, as illustrated in the quote below, in which an informant expresses how people were surprised by meeting an educated person with albinism:

'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)

According to the informants it is necessary for spokespersons to have a certain level of education. It is not only necessary to demonstrate a 'good example' but also to grab people's attention, so their presentation will be taken seriously.

The importance of having status arose in many interviews. This was also represented by five informants who expressed interest in becoming members of parliament, which is a position with high status.

Besides educational level, the portrayal of the ability of people with albinism to speak in public also changed people perceptions according to the informants:

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

Through the spokespersons, the audience experienced that people with albinism are 'human beings' and the audience had the opportunity to physically touch them. From the informant's perspective, this was key to change the beliefs about people with albinism being ghosts:

'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)

Moreover, the informants expressed that they not only provided theoretical knowledge but also experiential knowledge making their presentations interesting as well as trustworthy. The audience has the opportunity to ask questions directly

and misinformation can be corrected. 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)

Finally, informants 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 wanted to reduce stigmatization. One informant mentioned the following:

'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)

On the negative side, informants noted that the mechanism of them presenting on their condition themselves could be a disadvantage in influencing people. They assumed that some people might not trust them and think that the spokespersons were advocating 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 informants were also asked what they thought were important characteristics for being a spokesperson. The characteristics the informants 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. Supposedly these are aspects they presumed to have themselves, which made them able spokespersons in their own eyes.

There is an overlap between the named mechanisms of the contact intervention discussed in the foregoing section, and the characteristics of spokespersons, discussed here. Specifically, the importance of a good level of education and status, which was already explained above, is a characteristic that is important for being a spokesperson according to the informants. The informants often noted that many people with albinism do not have these named characteristics. Besides the importance of certain characteristics, the informants 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 informants, many people with albinism lack the confidence to be a spokesperson because they often feel inferior and ashamed of their condition.

The informants considered it crucial that a convincing spokesperson should have sufficient knowledge about albinism because according to them it is important to explain in an intervention what causes albinism. Often people with albinism do not understand their own condition, which some informants expressed as 'not knowing yourself'. Understanding and accepting the condition of albinism is therefore important to be 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 of the presentation and reduce the risk for the spokespersons themselves. Informants stressed that the presentation should 'fit' the audience, so it does not create unnecessary risks for the spokesperson to present:

'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 informants recommended that future spokespersons are being well-trained: they need to have knowledge on albinism and need to learn how to deliver a presentation. Being familiar with talking to crowds also provides some informants with confidence but this is intertwined with education levels and status.

## Discussion

The contact strategy has proven to be an effective strategy in reducing stigma in relation a variety of health-related conditions (e.g. Brown, Macintyre, and Trujillo 2003, Heijnders and van der Meij 2006) and this has also been the case for albinism (de Groot et al. 2021a, 2021b). A contact intervention requires people with a stigmatizing condition to be willing to present on their condition as spokespersons. To gain more insight into why spokespersons are willing to do so this study aimed to explore what the considerations are of people to present on their own visible stigma. For this study 13 people with albinism who presented in these types of interventions were interviewed about their experiences of being a spokesperson.

As a first consideration to be a spokesperson, the informants expressed that they felt very positive about being a spokesperson: they liked the work and it caused them to feel satisfied and proud. Besides enjoying the experience the spokespersons also personally gained something for being a spokesperson: being a capable spokesperson also raised the status and confidence of the spokespersons themselves. In the interviews, the concepts of confidence, education and status were mentioned and connected frequently. The spokespersons' presentations showed the audience that the spokespersons, were confident, educated and able to present which gave them a certain status. Which in turn increased the status and confidence of the stigmatized even further. Status, education and confidence increase the effectiveness of the intervention because, according to the spokespersons, this will make the audience trust them more and pay more attention. This process of gaining status and confidence through being a spokesperson can counteract the status loss as a result of stigmatization (Link and Phelan 2001).

The above probably goes hand in hand with the second consideration of people to be spokespersons. Spokespersons often expressed they felt responsible for making a change in society and with that to improve the lives of people with albinism. This was also found in research with counsellors with leprosy who felt it as their responsibility to share their knowledge which they gained from experience and therefore they felt trusted by others when explaining about leprosy (Lusli et al. 2015). The spokespersons were motivated to be spokespersons because they noticed that because of them presenting as a spokesperson stigma reduced in the society. The informants endorsed the effective outcomes of a contact strategy that are also named in the general literature on the contact strategy, including demystification, correcting misinformation and generating empathy. For the effectiveness of the contact strategy the spokespersons named several mechanisms. Mainly, being a spokesperson seemed to completely counteracts people's expectations of those with albinism. People with albinism are looked down on (Franklin et al. 2018), and there are those who expect them to lack education, abilities, status and confidence, and believe them not to be human. Spokespersons mentioned that because of their presentations, they showed the audience an example that people with albinism can be educated, successful and confident. They are capable of doing things people without albinism can also do, with this showing/proving their humanity. This is in line with findings of Bradbury-Jones et al. (2018, 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. By presenting, spokespersons become agents of change. This counteracts the stigmatizing process, in which the stigmatized is denied agency (Howarth 2006; Taylor, Bradbury-Jones, and Lund 2019). Being a spokesperson is 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.

The informants did not seem to have consideration for not presenting as a spokesperson. Spokesperson did not consider their personal safety to be at risk by being a spokesperson. Due to the discrimination and violence experienced by people with albinism (Bradbury-Jones et al. 2018; Bryceson, Jønsson, and Sherrington 2010), it was expected that spokespersons with albinism might be afraid of the consequences of presenting, as is the case with presenters on other health-related stigma (Boevink, in Heijnders and van der Meij 2006; Corrigan and Matthews 2003). However, only two informants raised the risk of being attacked and even they saw it as something that could be overcome by making the necessary security arrangements and by being properly trained/prepared, so that they could provide information about albinism to the audience in a way that does not put spokespersons at risk. The only reason that was named for not using spokespersons in contact intervention was that some people might not trust them and think that the spokespersons are advocates for themselves.

### ***Recommendations***

Below recommendations are provided for organizations who are (considering) cooperating with spokespersons in a contact-based intervention to reduce health-related stigma.

#### ***The necessary security arrangements***

Information about the stigmatizing condition should be presented to the audience in a way that does not put spokespersons at risk. When organizing a contact strategy, organizations are obliged to ensure the spokespersons' safety, as there is a reasonable possibility of negative outcomes for spokespersons in the society and for the spokesperson at a personal level. In the case of albinism in Tanzania, 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 illegal trade of body parts of people with albinism.

#### ***Proper training of spokespersons***

An effective contact intervention requires training of the spokespersons (Corrigan and O'Shaughnessy 2007; Stuart 2006). Spokespersons should be trained on how to present themselves and what to disclose about their condition (Heijnders and van der Meij 2006; Paxton 2002a; Paxton 2002b). This was also pointed out by the informants in this research and was among others discussed by asking them what they thought were important characteristics of a spokesperson. Informants pointed out that future spokespersons should be trained on albinism knowledge and in how to deliver a presentation. This because being confident in presenting and possessing the right knowledge is according to them important to be a good spokesperson. Especially because people with albinism can feel ashamed of their condition and therefore need to become more knowledgeable about their condition

to understand that they are not cursed (Bucaro 2010) before presenting themselves to an audience. Training is also necessary to overcome possible risks for the spokespersons, as also described under security arrangements in the paragraph above.

### *Scaling for impact*

Presentations in which spokespersons need to be present are costly and time-consuming. Moreover, it is difficult to reach everyone in the country through these type of presentations, let alone recurrently, which requires the participation of many spokespersons. To explore an alternative for presentation in which a spokesperson needs to be present, research has been carried out on the effectiveness of video presentations in contact interventions. A video intervention can be easier to distribute and does not depend on the willingness, ability or time of spokespersons (Corrigan and 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). Additionally, distributing a video intervention 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 et al. 2011; Nambiar et al. 2011). In the case of Tanzania, the majority of people have access to radio (Kuhlmann et al. 2008) and a radio intervention was also found to be an effective way to improve people attitudes towards people with albinism in Tanzania (de Groot et al. 2021b). Additionally, considering reducing albinism related stigma structurally and on a larger scale there is the need of organizations like UTSS and TAS to convince the national government to roll out a country wide campaign against the discrimination of people with albinism

### *Ethical aspects*

One could ask whether being paid to be a spokesperson as part of a job is entirely voluntary and therefore ethically sound. The 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). Organizations should therefore ask themselves if spokespersons who are presenting are doing so on a voluntary basis.

Despite the drawbacks, direct contact strategies are recommendable, especially in relation to albinism in Tanzania. This because interaction in a direct contact intervention can include the opportunity to physically touch a person with albinism. According to the informants this is important for some people to understand the 'humanness' of the stigmatized. In relation to other stigmatizing conditions touching someone with is often dreaded out of fear for contagion, such as with onchocerciasis (Brieger, Oshiname, and Ososanya 1998), leprosy (Brieger, Oshiname, and Ososanya 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 and Lund 2017; Cruz-Inigo, Ladizinski, and Sethi 2011). 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. This could also be the case with albinism, showing you can touch someone with albinism can reduce stigmatization in the community.

### **Limitations and recommendations for further research**

The potential informants were limited. The spokespersons participating in the research could express their considerations to become a spokesperson, but additional research should be carried out to gain insight into why others are not willing to become spokespersons.

In addition, it should be noted that the considerations discussed by the informants in this study are all discussed from their own experience. It would be relevant to ask whether the public's experience and recommendations match those of the spokespersons in terms of the effective mechanisms of a contact intervention.

### **In conclusion**

- People feel good about being a spokesperson and personally gained the opportunity to develop themselves and gain more status and confidence,
- Spokespersons felt responsible for making a change in society and experienced presenting themselves as spokespersons as an effective way to do so.
- The spokespersons did not consider presenting themselves as spokespersons as a risk as long as the necessary security arrangements were made, and proper training is provided.
- A variety of recommendations are made for the implementation and development of contact interventions in relation to health-related stigma.

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