

## ORIGINAL RESEARCH

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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

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### ABSTRACT

**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.*

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## 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 (Bryceson et al, 2010; Brocco, 2016). 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 (Hong et al, 2006; Grønskov et al, 2007).

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 et al, 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 et al, 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 (Bryceson et al, 2010; Cruz-Inigo et al, 2011; Brocco, 2015). The various beliefs about albinism in Tanzania influence the way society perceives and acts towards people with albinism (de Groot et al, 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.

## Objective

The objective 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 et al, 1995), mental illness (Corrigan et al, 2002), and leprosy (Peters et al, 2014). The SDS version used by Link et al (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 et al, 1998), Indonesia (Peters et al, 2014) and Ghana (Stienstra et al, 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).

## METHOD

### 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 et al (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.

**Table 1: Equivalences and Methods** (Herdman et al, 1997; Herdman et al, 1998; Terwee et al, 2007; Stevelink & Van Brakel, 2013; Peters et al, 2014)

Equivalences	Methods
<p><b>Conceptual</b> The correspondence of conceptual meaning between cultures in relation to the measured stigmatising attitude.</p>	<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 et al, 2020)</li> </ul>
<p><b>Item</b> The equivalency of items between cultures in usefulness, relevancy and acceptability.</p>	
<p><b>Semantic</b> The correspondence in linguistic meaning.</p>	<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>
<p><b>Operational</b> The suitability of the practical implementation of the research in the specific culture.</p>	<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>

<b>Measurement</b> The psychometric properties: test-retest reliability and scale consistency.	<ul style="list-style-type: none"> <li>• Test and re-test (n=101)</li> </ul>
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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 et al, 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).

**Table 2: Changes in the Items of the SDS to achieve Item and Semantic Equivalence**

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?



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).

**Table 3: Demographics of the Participants**

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

## 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').

**Table 4: Descriptive Statistics A-SDS**

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 5: Descriptive Statistics A-EMIC-CSS**

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

## 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).

**Table 6: Rotated Component Matrix A-EMIC-CSS**

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

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 A).

### 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).

**Table 7: Interpretability**

Variables		A-SDS Total score mean (SD)	A-EMIC-CSS Total score mean (SD)
<b>Gender</b>	Male	1.27 (0.53)	2.14 (0.13)
	Female	1.22 (0.33)	1.99 (0.60)
<b>Profession</b>	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)
<b>Urban/Rural</b>	Urban	1.15 (0.29)	2.03 (0.66)
	Rural	1.43 (0.61)	2.12 (0.73)

## 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; Bryceson, et al, 2010; Cruz-Inigo et al, 2011; Brocco, 2015), 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 et al, 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 (Crowne & Marlowe, 1960; Beretvas et al, 2002; Perry et al, 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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<b>Appendix A: Overview</b>		<b>Reliability test-retest</b>										<b>Wilcoxon</b>		
		N	Mean	Std. Deviation	Skewness	Kurtosis	N	Kappa	LinearWeightedKappa	Gwet's AC1	SE	Kendall's t	Z	p
<u>A-EMIC-CSS</u>														
A-E1	Would the 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

<b>A-E12</b>	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
<b>A-E13</b>	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
<b>A-E14</b>	Would people in your community gossip/talk badly 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
<b>A-E15</b>	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
<b><u>A-SDS</u></b>														
<b>A-S1</b>	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
<b>A-S2</b>	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
<b>A-S3</b>	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
<b>A-S4</b>	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
<b>A-S5</b>	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
<b>A-S6</b>	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
<b>A-S7</b>	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
<b>A-S8</b>	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
<b>A-S9</b>	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
<b>A-S10</b>	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