ORIGINAL RESEARCH

The Cultural Validation of Two Scales assessing Albinism- related Social Stigma among High School Students in Tanzania

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ABSTRACT

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.*

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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 (Lund, 2001; Hong et al, 2006).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 (Braathen & Ingstad, 2006; Baker, 2010; Bryceson et al, 2010; Uromi, 2014; Brocco, 2015). 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 et al, 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 (Weiss, 1997; Brieger et al, 1998; Stienstra et al, 2002; Van Brakel et al, 2012; Stevelink & Van Brakel, 2013; Peters et al, 2014), and the Social Distance Scale or SDS (Bogardus, 1925; Link et al, 1987; Penn et al, 1994; Crandall & Moriarty, 1995; Leiker et al, 1995; Corrigan et al, 2002; Mak et al, 2014; 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 et al (1998), Terwee et al (2007) and Stevelink and Van Brakel (2013). Cultural equivalence was tested for the Scales by assessing five equivalences (Herdman et al, 1997,1998; Terwee et al, 2007; Stevelink & Van Brakel, 2013; Peters et al, 2014) (see Table 1).

Table 1: Equivalences

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

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).

Table 2: Steps of Scale Validation

Steps	Methods	Sample	Proceedings
Step 1 – Conceptual and item equivalence	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 stigmatisation of people with albinism in Tanzania.
	In-depth interviews	13 people with albinism	12 in-depth interviews were conducted to gain more insight into the experienced stigma of people with albinism, after which new items were formulated.
Step 2 – Semantic equivalence	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.
Step 3 – Conceptual, item, semantic and operational equivalence	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.
Step 4 – Measurement equivalence	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 re-took 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).
Step 5 – Conceptual and item equivalence	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, drawing visual vignettes were used.

Data Analysis

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

Table 3: Psychometric Properties and Corresponding Statistical Methods

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

*Due to the sensitivity of Cohen's 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).

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

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.

Table 4: Aspects of Stigmatisation and Supporting Quotes

Aspects of stigmatisation	Illustrating quotes
Process of discrediting	*"They think like we are maybe ghosts, or we are not human"* (interview with woman with albinism, adult).
Shame and embarrassment	*"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).
Avoidance/taking distance/isolation	*"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).
Problems with getting married or ongoing marriage	*"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 nobody"* (discussion with high school student, female).
Problems for family or other people	*"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).
Problems with work	*"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).

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 A).

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 A.

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 A). 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 A).

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 then an interviewer-administered Scale.

The first author and a school teacher 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%).

Table 5: Socio-demographic Characteristics of Participants

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

Item Characteristics

Most people scored low on the EMIC-CSS and ASDS-A. An extensive overview of item characteristics is presented in Appendix B - EMIC-CSS, and Appendix C - 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.

Table 6: Descriptive Statistics EMIC-CSS and ASDS-A

Nr.	Code	Item	Mean	SD
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 the 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 badly 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
A-SDS-A				
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

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 (α: 0.79) and item N-E3 could also be removed (α: 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.

Table 7: Main Statistical Findings for the total EMIC-CSS and ASDS-A and Individual Items

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

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.

Table 8: Interpretability Table

Variables		EMIC-CSS Total score means (SD)	ASDS-A total score means (SD)
Sex	Male	11.96 (6.18)	3.67 (5.25)
	Female	11.98 (5.82)	2.96 (4.37)
School	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)
Know PLWA	No	10.46 (6.23)	3.53 (5.7)
	Yes	12.24 (5.9)	3.23 (4.59)

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 peoples' attitude towards buying something from someone with albinism (μ: 0.17).

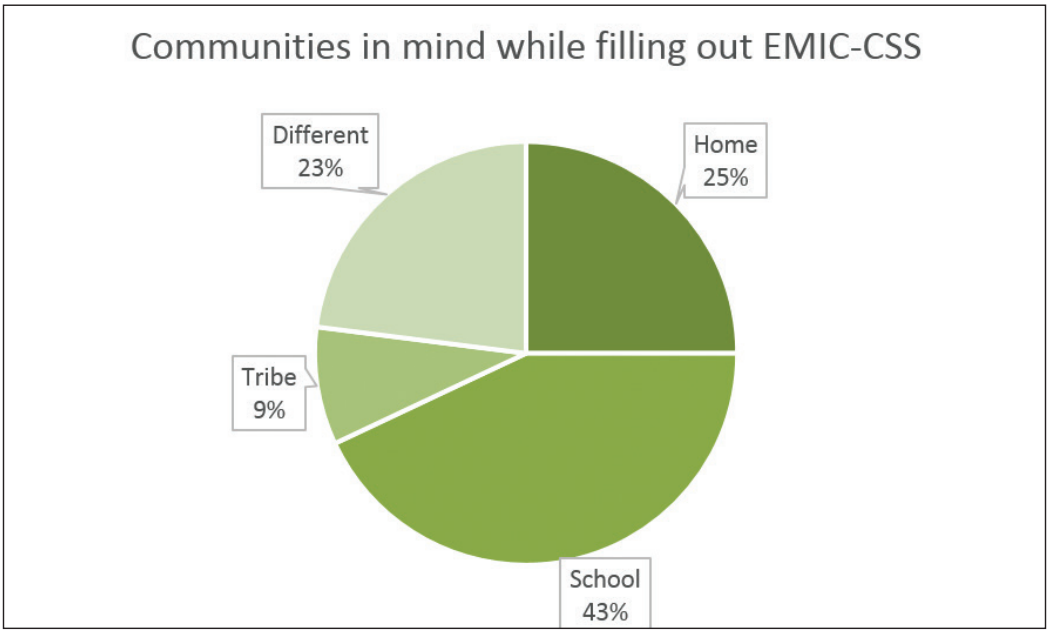
The ASDS-A showed that respondents felt uncomfortable about having a family member with albinism but were less uncomfortable having someone with albinism as a friend (Appendix C). Respondents had difficulty in explaining differences in feelings in different relationships. One respondent explained the 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; Stienstra et al, 2002; Stevelink & Van Brakel, 2013; Peters et al, 2014), 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 (Nyblade, 2006; Bos et al, 2008; Creel et al, 2011). 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 (μ: 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 D, 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 (α: 0.78) and ASDS-A (α: 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 (α: 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 et al, 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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Appendix A: Description Adaptation for Validation Items EMIC-CSS and ASDS-A

EMIC-CSS			
Original items	**New Items**	**Aspect of stigmatisation**	**Difference in equivalence**
O-E1 Would a person with leprosy keep others from knowing, if possible?	N-E1 Would family of someone with albinism keep this person hidden?	Concealment/Shame and embarrassment	Concept is not fitting
O-E2 If a member of your family had leprosy, would you think less of yourself?	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
O-E3 In your community, does leprosy cause shame or embarrassment?	N-E3 In your community, does albinism cause shame or embarrassment?	Shame and embarrassment	
O-E4 Would others think less of a person with leprosy?	N-E4 Would people think less of a person with albinism?	Discrediting	
O-E5 Would knowing that someone has leprosy have an adverse effect on others?	REMOVE	Concealment	Concept is not fitting
O-E6 Would other people in your community avoid a person affected by leprosy?	N-E6 Would people in your community avoid a person with albinism?	Avoidance and taking distance/isolation	
O-E7 Would others refuse to visit the home of a person affected by leprosy?	N-E7 Would others refuse to visit the home of a person with albinism?	Avoidance and taking distance/isolation	
O-E8 Would people in your community think less of the family of a person with leprosy?	N-E8 Would people in your community think less about the family of a person with albinism?	Discrediting/Problems for family	
O-E9 Would leprosy cause problems for the family?	N-E9 Would albinism cause any problems for the family in the community?	Problems for family	Semantic: question was unclear
O-E10 Would a family have concern about disclosure if one of their members had leprosy?	REMOVE	Concealment	Concept is not fitting
O-E11 Would leprosy be a problem for a person to get married?	N-E11 Is albinism a problem for a person to get married?	Problems with marriage	
O-E12 Would leprosy cause problems in an on-going marriage?	N-E12 Would getting a child with albinism cause problems in a marriage?	Problems with marriage	Concept is not fitting
O-E13 Would having leprosy cause a problem for a relative of that person to get married?	N-E13 Would having a relative with albinism cause problems for someone to get married?	Problems for family/ problems for marriage	

O-E14 Would having leprosy cause difficulty for a person to find work?	REMOVE	Work	Item is not fitting
O-E15 Would people dislike buying food from a person affected by leprosy?	N-E15 Would people buy goods or services from a person with albinism?	Work/Avoidance and taking distance/ isolation	Item is not fitting
New Items			
	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

ASDS-A		
Original items	New items	Equivalence
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?	Item is not fitting
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?	Item is not fitting
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?	Item is not fitting
O-S4 How 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?	Item is not fitting
O-S5 How 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?	Item is not fitting
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?	Item is not fitting
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?	Item is not fitting
New items		
	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 B: EMIC-CSS

									Reliability test-retest								
	N	No	Perhaps	Yes	Mean	SE	Median	N	Kappa	Linear Weighted Kappa	Gwet's AC1	SE	Kendall's t	Answers Unequal	Equal	Z	P
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 C: ASDS-A

										Reliability test-retest							Wilcoxon	
	N	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%	-.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%	-.016	1.000

Appendix D: Recommended EMIC-CSS and ASDS-A

EMIC-CSS with Swahili Translation

N-E6 Would people in your community avoid a person with albinism?	*Je, katika jamii yako kuna watu ambao wanamtenga mtu mwenye ualbino?*
N-E8 Would people in your community think less about the family of a person with albinism?	*Je, katika jamii yako kuna watu wanadharau familia ya mtu mwenye ualbino?*
N-E1 Would the family of someone with albinism keep this person hidden?	*Je, familia yenye mtu mwenye ualbino inaweza kumficha ndani kwa sababu inaona aibu?*
N-E2 Would the family of someone with albinism feel less worth?	*Je, familia yenye mtu mwenye ualbino hujiona haina thamani mbele ya jamii?*
N-E18 Do people in general fear people living with albinism?	*Je, kwa ujumla watu wanaogopa watu wenye ualbino?*
N-E13 Would having a relative with albinism cause problems for someone to get married?	*Je, kuwa na mtu mwenye ualbino katika familia kunaweza kuwa kikwazo kwa mtu kuoa au kuolewa?*
N-E16 Would people call people with albinism bad names?	*Je, watu wanawaita majina mabaya watu wenye ualbino?*
N-E7 Would others refuse to visit the home of a person with albinism?	*Je, kuna watu wanaokataa kutembelea nyumba ya mtu mwenye ualbino?*
N-E17 Would people in your community gossip/talk bad about a person with albinism?	*Je, watu katika jamii huwateta/huwasema vibaya watu wenye ualbino?*
N-E12 Would getting a child with albinism cause problems in a marriage?	*Je, kupata mtoto mwenye ualbino kunaweza kuleta mgogoro kati ya wanandoa?*
N-E4 Would people think less of a person with albinism?	*Je, watu wanaweza kumdharau mtu mwenye ualbino?*

ASDS-A with Swahili Translation

N-S12 How would you feel being in the same school with someone like John/ Joyce?	*Je, ungejisikiaje kuwa shule moja na mtu kama John?*
N-S7 How would you feel helping someone like John/Joyce with a question about school work?	*Je, ungejisikiaje kumsaidia mtu kama John kufanya kazi ya darasani?*
N-S2 How would you feel to be in the same class with someone like John/Joyce?	*Je, ungejisikiaje kuwa darasa moja na mtu kama John?*
N-S4 How would you feel having someone like John/Joyce, as a teacher?	*Je, ungejisikiaje kuwa na mtu kama John kama mwalimu wako?*
N-S8 How would you feel to have John/ Joyce as a friend?	*Je, unajisikiaje kama ungekuwa na rafiki kama John?*
N-S9 How would you feel shaking hands with someone like John/Joyce?	*Je, unajisikiaje ukimpa mkono mtu kama John?*
N-S3 How would you feel to sit next to someone like John/Joyce in class?	*Je, ungejisikiaje kukaa karibu na mtu kama John darasani?*
N-S11 How would you feel if someone like John/Joyce was your teammate when playing games/sports?	*Je, ungejisikiaje kuwa na mtu kama John kwenye timu yako wakati wa michezo?*
N-S1 How would you feel to visit a house of someone like John/Joyce?	*Je, ungejisikiaje kumtembelea nyumbani mtu kama John?*
N-S6 How would you feel to introduce John/Joyce to your friends?	*Je, ungejisikiaje kumtambulisha mtu kama John kwa marafiki zako?*
N-S10 How would you feel if your friend knew that you had someone like John/ Joyce in your family?	*Je, ungejisikiaje kama marafiki wangefahamu kuwa mna mtu kama John kwenye familia yenu?*
N-S5 How would you feel to have someone like John/Joyce as a family member?	*Je, ungejisikiaje kama ungekuwa na mtu kama John katika familia yako?*