

Associations Between Self-Stigma and Emotional Wellbeing Among Orphans

by

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An abstract of a thesis submitted in partial fulfillment
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ABSTRACT

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Abstract

Researchers have been searching for ways to improve outcomes for orphaned and separated children (OSC) worldwide. OSC have a particularly high rate of mental health disorders and experience lower emotional wellbeing. Stigma has been shown to be a predictor of mental health disorders and emotional wellbeing for people living with HIV and children in poverty. There are many different kinds of stigma that affect OSC, but self-stigma is one that is likely to have an impact on emotional wellbeing. No research has been conducted with OSC examining the relationship between self-stigma and emotional wellbeing. Using data from Round 10 of the Positive Outcomes for Orphans (POFO) study, a study of OSC from Kenya, Ethiopia, Tanzania, India, and Cambodia that, in Round 10, encompassed 2,013 OSC with a mean age of 16.3 years old, a linear model was implemented to examine the association between self-stigma and emotional wellbeing. Through the building of a linear regression model, self-stigma was shown to be associated with worse current emotional wellbeing as measured by the total difficulties score from the Strengths and Difficulties Questionnaire (SDQ) with a slope estimate of .56 in the adjusted model. This indicates that self-stigma may be a relevant factor to minimize when looking at ways to improve emotional wellbeing among orphans.

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1. Introduction

Children residing in low- and middle-income countries (LMICs), such as Kenya, Ethiopia, Tanzania, India, and Cambodia, face a variety of challenges compounded by the countries they reside in. For example, the populations of people living in LMICs suffer from higher rates of disease, particularly infectious disease, and also suffer from lack of access to methods of treatment such as Anti-Retroviral Therapy for HIV (Ismail, 2021). They also have higher rates of malnutrition due to lack of food (Fagbamigbe, 2020), unclean water and general low levels of sanitation (Ogunsola, 2020), higher exposure to infectious agents such as mosquitoes (Albers, 2020), and lack of access to proper medical care (Chattu, 2020). This lack of access to medical care is particularly pronounced when it comes to mental health care. The global average of psychiatrists per 100,000 people is 3.96; however, in China, the rate is 1.55, and in India, the rate is just 0.301 (Rathod, 2017). In Ethiopia, the rate of psychiatrists goes as low as just 0.04 psychiatrists per 100,000 people (Rathod, 2017). However, while LMICs experience this lack of available treatments, LMICs contain 80% of the burden of mental health disorders worldwide (Rathod, 2017).

One group that is particularly susceptible to facing mental health challenges is children, especially children that are orphaned or separated from their parents. The majority of OSC, approximately 113 million (World Bank, 2020) to 140 million (UNICEF, 2015), are concentrated in Asia and Africa (World Bank, 2020). More specifically, 55 million of these OSC children live in Sub-Saharan Africa (SSA) (Embleton, 2014). In a

four-year longitudinal study of 1,021 AIDS-orphaned, orphaned, and non-orphaned children in South Africa, researchers found that the AIDS-orphaned group had higher rates of PTSD, depression, and anxiety when compared to otherwise orphaned and non-orphaned children (Gardener, 2011). Similarly, Makame (2002) compared a group of Tanzanian orphans to a group of non-orphans and discovered significantly higher rates of internalizing problems and suicidal thoughts among the orphan group when compared to the non-orphan group.

Many researchers are working to discover optimal ways to support and improve the outcomes of OSC, including identifying vulnerabilities of these children and their families in order to address the vulnerabilities and intervene where necessary (UNICEF, 2021). Interventions that have been implemented with OSC in LMICs include nutritional curriculums to enhance caregiver understanding (Thomas, 2020), parenting classes and economic strengthening (Mebrahtu, 2019), unconditional and conditional cash transfers (Crea, 2015), and matched savings accounts (Ssewamala, 2018). Some mental health interventions have been conducted as well, such as task-shifted cognitive behavioral therapy (Dorsey, 2020) and community-based mental health counseling (Kaufman, 2012). Despite this, research is still sparse on these interventions, and there is still a need for further research to improve and update the knowledge base about orphans and their mental health in order to improve interventions to ensure the best outcomes for OSC.

One potential factor that has been shown to negatively affect the mental health of different marginalized groups is stigma. Stigma has been defined as negative judgments that are passed by others against a group someone else might belong to (Lucksted, 2015). There are many different types of stigma that have been defined by researchers, such as experienced (or enacted) stigma which is defined as episodes of discrimination against people with those stigmatized identities (Chung, 2018), perceived stigma which is defined as discrimination being felt by a person with a stigmatized identity (Chung, 2018), and internalized or self-stigma, which is defined as harmful stigmatizing beliefs about a group one identifies with that have been internalized by the person (Lucksted, 2015).

Stigma applies to OSC as well, as orphan is a stigmatized identity. For example, Cluver and Orkin (1982) found that both poverty and experienced stigma were strong predictors of mental health disorders, and when both are present, likelihood of disorder rose from 19 to 83%. Hermenau (2015) confirmed this with a sample of orphans from Tanzania, reporting stigma to be a moderator for the link between neglect and depression. Caserta et al (2016) began to examine this with orphans in Rwanda, recognizing that the majority of research on stigma and mental health in orphans has revolved around HIV. In this study, 430 orphans between the ages of 10 and 25 were recruited from four different living environments, including orphans living both in residential care and in family-based settings. This study also included those living in child-headed households and on the street. Stigma in this study was operationalized as

stigma the child felt they experienced from the greater community, using a series of questions with responses ranging from 1 (agree) to 3 (disagree). Marginalization was also included in this study as a variable. It is important to note, though, that this study looked at stigma and marginalization experienced by the children from the outside community, and not internalized stigma. Therefore, despite the significant effects shown associating both marginalization and stigma with emotional wellbeing, there still exists a gap in understanding the association between internalized self-stigma as it relates to the mental health symptomology or wellbeing of orphans.

Although the link between self-stigma and mental health symptomology has not yet been studied with the independent variable of stigma experienced by orphans specifically, it has been examined within other stigmatized populations, such as children with HIV. Originally, studies mostly focused on the impact of HIV stigma on families with HIV (Hamra, 2005; Hamra, 2006) and on the experiences and impact of parental loss (Wood, 2006; Winston, 2003). A more recent study, Chi (2014), looked at a question involving stigma and mental health. The study sample was 272 orphaned children by AIDS and 249 children of HIV-positive parents in China. The results of the study indicated a cyclical effect, where enacted stigma leads to depressive symptoms which leads to perceived stigma and then back to enacted stigma. This indicates evidence for an interplay between stigma, including internalized stigma, and mental health difficulties. However, this study focused mainly on the stigma of being HIV positive or a child of parents that died of HIV/AIDS related causes instead of looking at the stigma of

being an orphan more generally. Still, this indicates a further need to examine the interplay between stigma and mental health.

Self-stigma is defined in Lillis (2010) as when people notice stigma directed towards others in their group and begin to internalize those same negative thoughts about themselves and the group that they belong to. Self-stigma has been researched among other marginalized groups. Many studies have attempted to measure this self-stigma among different populations. A scale was developed for weight self-stigma (Lillis, 2010) and for mental illness (Corrigan, 2012). Current interventions have been developed to increase empowerment and decrease self-stigma, such as being more open about mental illness (Corrigan, 2013). However, there are no current research studies that discuss the impact of self-stigma for orphans specifically on their mental health outcomes.

One study examining correlates of outcomes for orphans is the POFO (Positive Outcomes for Orphans) study, which has collected 12 rounds of data since its inception in 2006. The POFO study is a cohort of more than 3000 children, including orphans and non-orphans, in five different countries, and its current focus is on preventing HIV and addressing high-risk HIV-behaviors. Previous studies from the POFO team have examined potential factors affecting emotional wellbeing, such as care setting (Whetten, 2014), adverse childhood experiences (Escueta, 2014), and disruption of care (Gray, 2018). Data were also collected around the stigma that orphans have internalized towards themselves and other groups in one round of the POFO study. However, no

studies so far have examined stigma in relation to emotional wellbeing using the POFO database.

Therefore, the primary aim of this study is to examine the relationship between one's status as an orphan and perception of stigma towards this status and their emotional wellbeing. The main hypothesis is that higher levels of self-stigma would also be associated with higher rates of emotional difficulties. This is a gap that has yet to be filled in global mental health research, and a better understanding of self-stigma and emotional wellbeing among OSC can help with the prevention of emotional distress and to facilitate mental health treatment.

2. Methods

2.1 Participants

The sample population for this study consists of orphaned and separated children. The definition of orphaned and separated children for this study is having at least one parent who died or was separated from the child's life with no expectation of reunification (Whetten, 2009). At baseline, the children included were between the ages of 6-12. The representative sample consisted of 1,356 OSC from residential care, 1,481 OSC from family or community settings, and 300 non-OSC participants, for a total of 3,137 children in the POFO cohort. The data were collected from six study sites in five different low- and middle-income countries. The sites were chosen because of their diversity: cultural, historical, geographic, political, religious, and ethnic. The six sites are Battambang District, Cambodia; Addis Ababa, Ethiopia; Hyderabad, India; Nagaland, India; Bungoma District, Kenya; and Kilimanjaro Region, Tanzania.

Our analytic sample included 2,190 OSC interviewed in the 10th round (2011-2012) of the POFO study, as that is the only round in which the stigma questionnaire was used. Therefore, the ages of the participants are older on average (6 years older) than during the baseline study, and most were now adolescents at the time of data collection. As this study only focused on the effects of self-stigma associated with being orphaned, all non-orphans were excluded from analysis.

2.2 Measures

The main exposure of interest in this study, self-stigma, is defined using a series of questions about attitudes toward stigmatized groups, consisting of 16 items for each

group that measure participants' feelings towards various stigmatized groups, designed by the POFO team. This questionnaire was exclusively used in this one round of the POFO study and was not used in any other round or POFO study. The stigma instrument, along with all other measures, was translated and then back-translated by the study staff into each of the different languages for each region in order to ensure that items would be culturally relevant.

Self-stigma was operationalized by summing the items in which the participant endorsed propagating stigma due to their orphan status. This questionnaire has the potential to measure levels of stigma toward a lot of stigmatized groups (e.g., HIV positive persons, sexual minorities, orphans), but for the purposes of this paper, we will only be looking at orphan self-stigma. There are 16 items included in this instrument, all of which are questions such as "Do you think children who are (stigmatized group) are naughtier than other children?" or "Do you think it is okay to bully or tease (stigmatized group)?". The interviewer would read each question multiple times to specify each of the stigmatized groups (e.g., HIV-positive people, sexual minorities, orphans) separately for each of the 16 items. If the participant indicated that a particular item did not apply to any of the stigmatized groups, the interviewer marked down that none of the stigmatized groups were endorsed for that item. The self-stigma score assigned to each participant consists of the total number of items on which a participant affirms stigmatizing orphans. Using this method, the maximum self-stigma score is 16 and the

lowest is 0. Higher scores indicate greater amounts of self-stigma, whereas lower scores indicate low amounts of self-stigma. This variable is examined as a continuous variable.

The dependent variable is emotional wellbeing, as defined by the Strengths and Difficulties Questionnaire (SDQ). The SDQ is a self-report screening questionnaire for children aged 2 to 17 that was developed by Robert N. Goodman, a child psychologist from the UK (Goodman, 2004). It has been tested in a variety of settings and translated into over 80 languages for use in different settings. For example, Vugteveen et al (2019) tested the SDQ with Dutch adolescents and found it to be useful in screening for mood disorders, anxiety disorders, conduct disorders, and attention deficit/hyperactivity disorders. The SDQ has been validated in LMICs as well as high income countries (HICs). For example, Samad et al (2006) tested the Urdu version among 212 children aged 4 to 16 years old in Pakistan who presented to both psychiatry and pediatric wards of the hospital. It has also been validated in populations of Swedish children (Gustafsson, 2016), deaf children using Norwegian Sign Language (Aanondsen, 2020), and South African children (Mellins, 2008), among others. Using these two groups as case and comparison, the SDQ was able to discriminate between the two groups and identify children in need of intervention, demonstrating its efficacy at identifying children in need of psychiatric attention.

In order to look at the emotional well-being challenges experienced by the participants, only the difficulties portion of the SDQ will be examined. The difficulties portion consists of 20 items. There are four different difficulties subscales within the

SDQ: conduct problems, hyperactivity and inattention, peer relationships, and emotional symptoms. Each subscale contains five questions, and each question has a score that ranges from 0 (not at all true) to 2 (completely true). The total difficulties score is a sum of the 20 items, such that each participant can have a score from 0-40, and higher scores indicate more difficulties. The clinical cutoff for the purpose of this analysis was set at 18, which has been demonstrated to be the beginning of the clinically significant range for the difficulties portion of the SDQ (Goodman, 1997). However, this cutoff was not used for the purposes of this study as SDQ was examined as a continuous variable. Additionally, all participants were required to be over the age of 10 when given the SDQ.

Other covariates included were from the questions regarding demographics from the initial questionnaire. These covariates were thought to potentially have an impact on the relationship between emotional wellbeing and stigma. First, gender was included due to the potential of stigma possibly differing by gender. Gender was dichotomized into 0 (male) and 1 (female). Second, age was included, since stigma may be more likely to be internalized by older children due to the fact that older children are more likely to internalize rejection and stigma based on their own experiences (Kang, 2011). Age was a numeric variable of number of years lived. This was also a continuous variable for maximum accuracy in age. Care setting was also included due to its potential to have an impact on both stigma and emotional wellbeing. This variable was also dichotomized into two levels: residential care settings and family-based care settings. Finally, site was

included as a proxy for culture to control for cross-country cultural differences. There is certainly variability within these geographic areas. However, as culture is difficult to measure as a true variable, site may be the closest proxy due to shared experiences of living in the same area and sharing country-level values.

2.3 Procedures

The POFO study utilized in-person interviews, both interviews of the children and of the caregivers – whether they be family-based caregivers or residential care center caregivers. Consent was given by caregivers for all caregiver interviews, and caregivers gave consent for children under the age of 18 to participate. All measures were translated and then back-translated into the local language of interviews to ensure maximum validity. For the POFO study at large, one male local interviewer and one female local interviewer were trained in the interview procedures. During training, the interviewers were observed through video or in person to ensure fidelity of the interviews. All interviews were conducted under supervision, mostly in the children’s homes in the child’s native language. Typically, interviews lasted anywhere from two to two and a half hours and participants were allowed breaks over the course of the interview.

Only a portion of the data were used in this study. The data used in this analysis were stored in three separate files, and R Studio was used to combine all three of the datasets (demographic information, SDQ scores, and stigma scale responses) into one

file by the unique participant ID. After this, the data were examined to look for outliers in each of the variables.

2.4 Analysis

The statistical analysis used for this project is the building of a regression model, with the predicted outcome variable being the SDQ score. The primary independent variable (exposure of interest) is the self-stigma score from the orphan stigma scale. Other variables, such as gender and site in which the child was interviewed, were also added into the model to control for confounding.

Therefore, two regression models were developed with stigma score as the exposure variable of interest and SDQ score as the outcome variable. The first model was a simple linear regression model, with the SDQ score regressed on stigma score. The second model added in potential confounders along with the interaction terms in order to provide an adjusted estimate with higher accuracy.

Figure 1, below, is a directed acyclic graph (DAG) of the relationship between self-stigma and emotional wellbeing. To cut off as many pathways as possible, culture, age, and gender were included in the full model. However, other variables such as experienced stigma were unmeasured and unable to be included in the model.

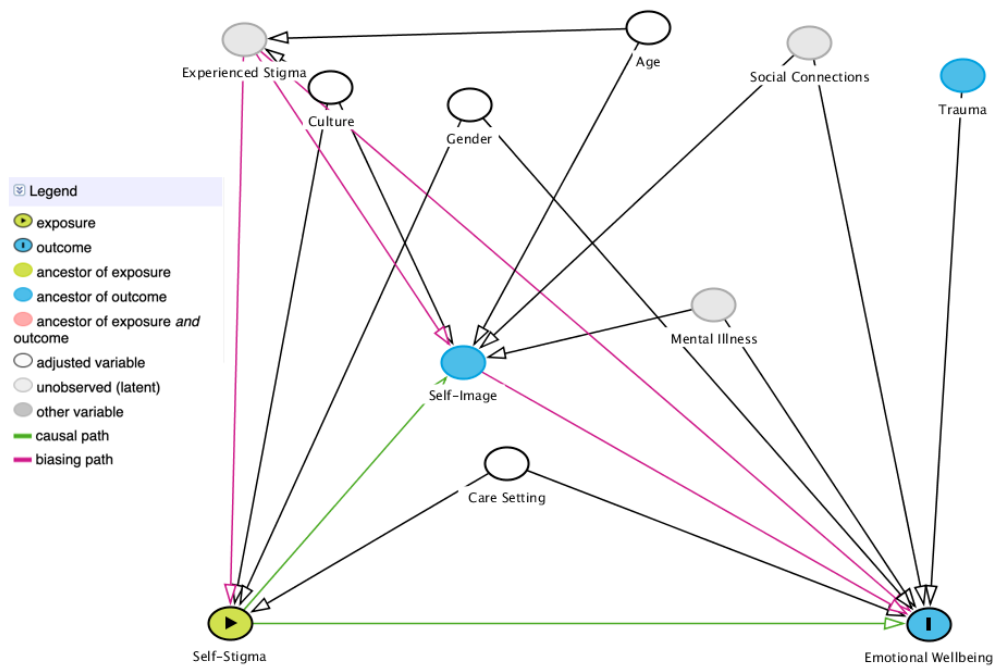


Figure 1: Primary DAG

3. Results

Table 1 below summarizes the participants included in analysis. There were 2190 participants included in analysis, 46% were female. There were participants from all six sites and from both residential and family-based care.

Table 1: Sample Characteristics

	FEMALE	MALE
TOTAL	1015	1175
SITE		
CAMBODIA	131	133
ETHIOPIA	166	210
HYDERABAD	221	204
KENYA	186	260
NAGALAND	160	178
TANZANIA	151	190
TYPE		
RESIDENTIAL	439	527
FAMILY BASED	576	648
AGE AT ROUND 10 (MEAN)	16.04	16.15
AGE AT FIRST INTERVIEW (MEAN)	9.15	9.25

First, graphs were created to display the distributions of both the SDQ and the stigma scores by each of the potential effect modifiers. Figure 2 displays the distribution of self-stigma scores among all participants analyzed in this sample. The majority of the self-stigma scores are skewed to the right with most of the scores falling in between the scores of 0-5.

Figure 3 displays the self-stigma scores when the scores have been stratified for gender. This chart shows that this right skew seems to be more intense for females than for males. Additionally, the mean for the male participants is higher than for female participants (2.573 vs 1.951), and higher than the overall mean (2.284).

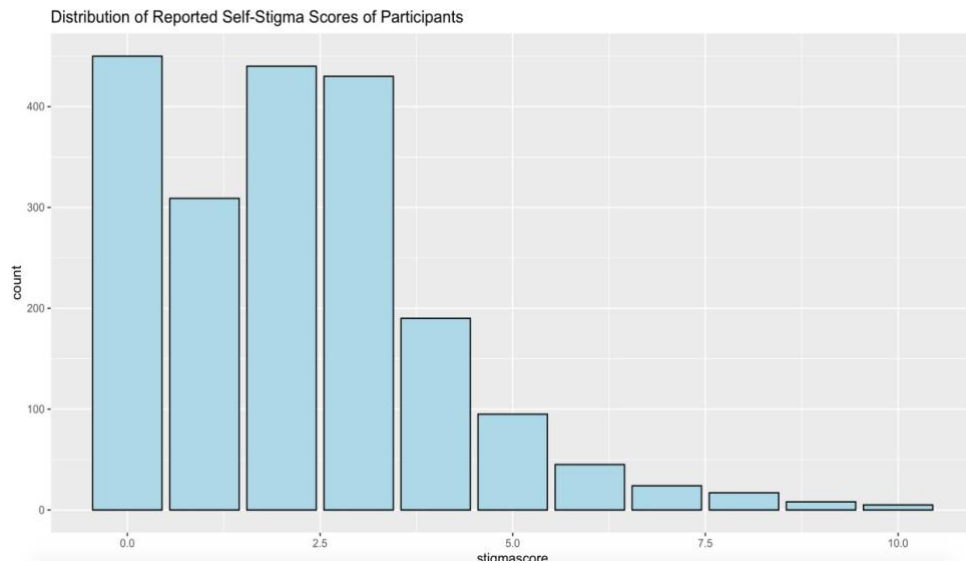


Figure 2: Distribution of Reported Self-Stigma Scores of Participants

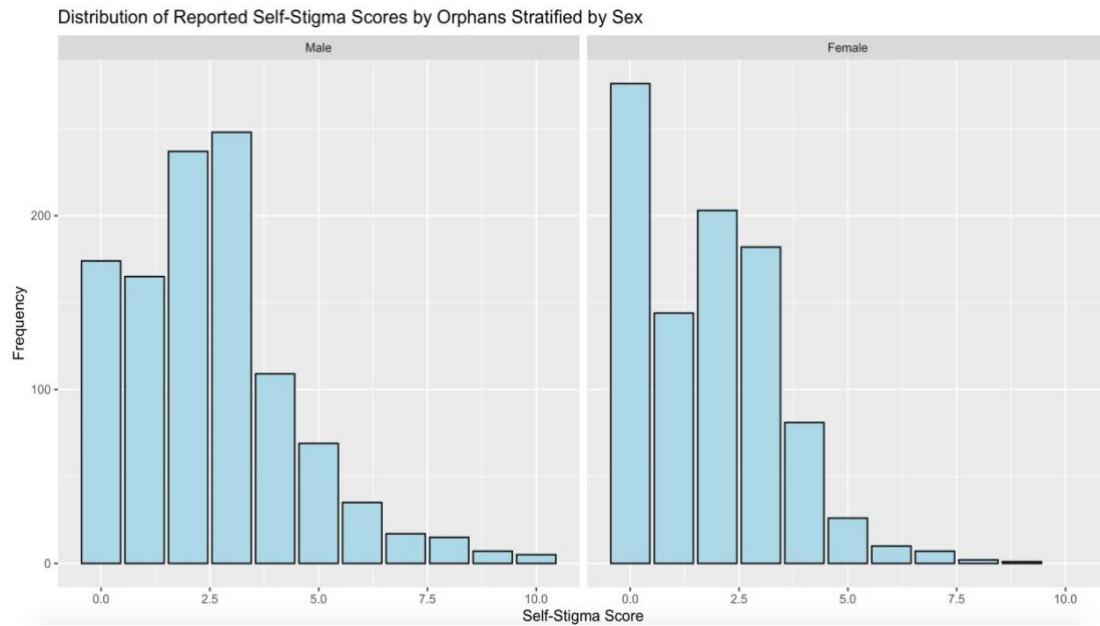


Figure 3: Distribution of Reported Self-Stigma Scores of Participants Stratified by Sex

Figure 4 below displays the distribution of total SDQ difficulties scores for orphans. The red dotted line demonstrates the proposed cutoff for clinical significance, which is approximately 18. Therefore, as demonstrated by Figure 4, the majority of total SDQ difficulties scores are below the clinical cutoff, meaning that the majority of participants do not experience clinically significant levels of emotional distress. Total SDQ difficulties scores are also skewed heavily to the right, with most of the respondents having a score between 0-10 and relatively few participants in the highest score categories (20+).

Figure 5 demonstrates, however, that SDQ scores seem to vary by gender. For the population included in this study, males seemed to have a relatively larger spread in terms of having more of the lowest and highest SDQ scores while female participants had more of an even spread throughout the distribution. The mean total SDQ difficulty

score for male participants is 7.945, whereas for female participants it is lower at 6.451, demonstrating the variation between gender groups. Overall, the mean SDQ score is 7.252.

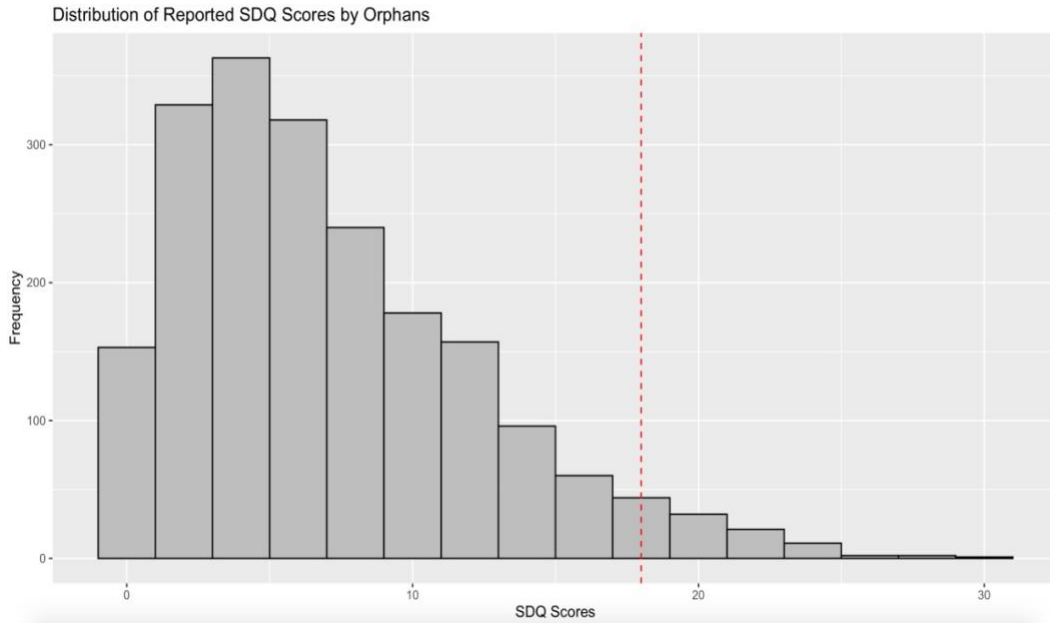


Figure 4: Distribution of Reported SDQ Scores by Orphans

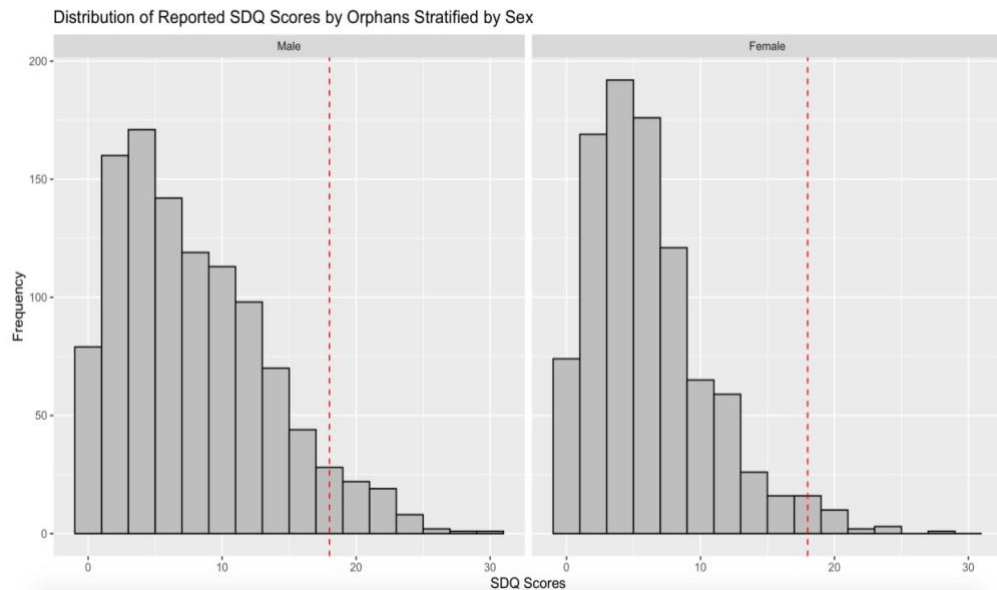


Figure 5: Distribution of Reported SDQ Scores by Orphans Stratified by Sex

Correlation Analysis

The correlation between SDQ score and self-stigma score is .317, indicating a slight positive correlation between the two variables, which means that as the level of internalized self-stigma increases, level of mental health difficulty also increases. This correlation can be seen in Figure 6 below, which shows a positive trend between SDQ and stigma score.

This correlation only includes complete sets of pairwise observations. Therefore, participants that only had an SDQ score or a stigma score or participants who had neither score were not included in the correlation analysis or the regression analysis.

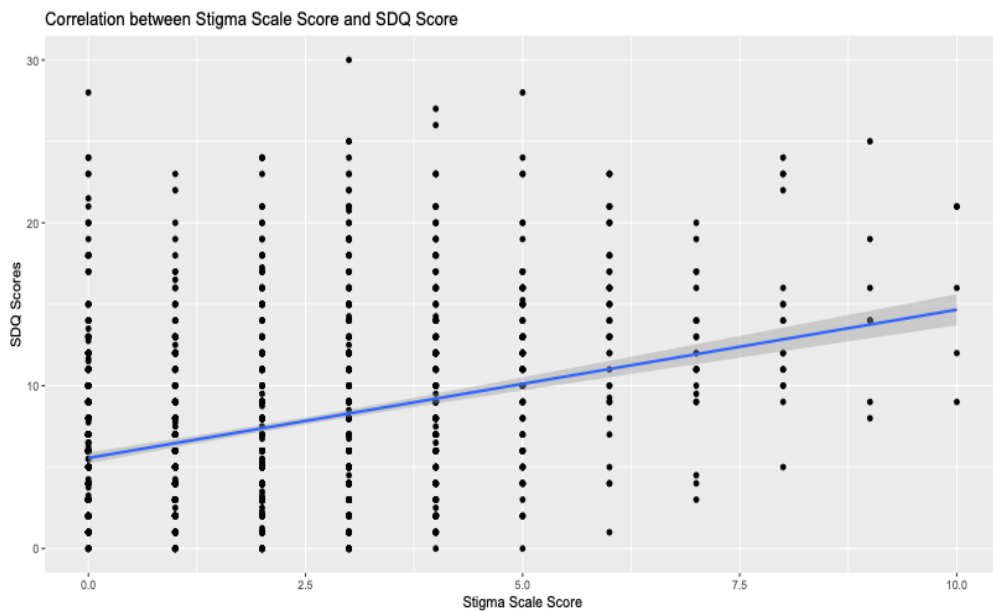


Figure 6: Correlation between Stigma Scale Score and SDQ Score

Multivariable Regression Model

Two models were developed to investigate the research question. The first model included only SDQ scores and orphan self-stigma scores and is shown below in Table 2.

The intercept and coefficient are shown to be significant at an alpha value of .05.

Table 2: Initial Model

Coefficients	Estimate	95% CI	Standard Error	T Value	P
Intercept	5.53	5.20, 5.87	.170	32.46	2e-16**
Stigma Score	.752	0.64, 0.87	.06	12.95	2e-16**

The full model, incorporating gender, care setting (whether it be a residential care setting or a family-based care setting), site (as a proxy for culture, since mental health and stigma can be affected greatly by culture), and age as potential confounders and interaction terms for each variable thought to have a relationship are shown below in Table 9. For this model, the referent group for site is Cambodia. In the full model, stigma score is once again shown to be significant at an alpha level of .05. The coefficient is 0.56 (95% CI: 0.18, 0.94) indicating that as the stigma score increases by one point, SDQ scores increase by over half of a point. This indicates that stigma scores and SDQ scores are positively associated, supporting the hypothesis.

Table 3: Full Model with Confounders

Coefficients	Estimate	95% CI	Standard Error	T Value	P Value
Intercept	7.54	5.37, 9.71	1.11	6.80	1.38e-11**
Stigma Score	.56	0.18, 0.94	.19	2.86	.004**
Gender (Female)	-1.14	-1.83, -0.45	.35	-3.26	.001**
Age (in years)	.10	0.01, 0.21	.06	1.75	.08*
Site (Ethiopia)	-3.28	-4.74, -1.81	.75	-4.39	1.19e-05**
Site (Hyderabad)	-.07	-1.49, 1.32	.71	-.10	.918
Site (Kenya)	-1.64	-3.10, -0.18	.74	-2.20	.028*
Site (Nagaland)	-3.10	-4.57, -1.64	.75	-4.15	3.52e-05**
Site (Tanzania)	-4.84	-6.52, -3.16	.86	-5.65	1.84e-08**
Type	-.08	-0.49, 0.33	.21	-.37	.707
Stigma*Gender	.004	-0.26, 0.27	.14	.028	.978
Stigma*Site (Ethiopia)	-.41	-0.91, 0.09	.25	-1.62	.105
Stigma*Site (Hyderabad)	-.46	0.06, 0.86	.20	2.26	.024**
Stigma*Site (Kenya)	-.26	-0.72, 0.19	.23	-1.12	.259
Stigma*Site (Nagaland)	-.60	-1.15, -0.04	.28	-2.20	.034**
Stigma*Site (Tanzania)	-.39	-0.90, 0.12	.27	-1.48	.140

4. Discussion

This study supports the hypothesis that orphan self-stigma is associated with emotional wellbeing among OSC in an unadjusted model. This effect is maintained even when potential confounding variables are added to the model. Therefore, in efforts to improve emotional wellbeing of OSC, it may be helpful to consider self-stigma and address self-stigma in interventions developed specifically for orphans. For example, an intervention may work by addressing experiences of stigma faced by orphans, emphasizing that these experiences are not reflective of their worth as people.

Other variables that were included in the model that were shown to be significant include age, gender, and certain sites. Therefore, these other variables may also be related to emotional wellbeing and may be important to measure more specifically and examine in future studies. There were also numerous variables that have been demonstrated to affect emotional wellbeing, such as trauma and mental illness diagnoses, that were unmeasured and could create residual confounding.

This study has implications for a variety of other areas as well, including mental health treatment and mental health policy, informing stakeholders on potential areas of focus. However, as this is the first study to examine self-stigma in orphans and its association with emotional wellbeing, further research may be needed to confirm this association.

This study has many strengths, such as the large sample size, the inclusion of six sites with a variety of cultures, and the sampling method that yielded a sample of OSC from differing care settings.

However, this study also has several limitations. As mentioned above, this estimate may also include residual confounding from unmeasured variables. There may also be the potential for self-report bias given that participants answered the questions themselves about themselves, but the potential for bias was mitigated as much as possible through highly trained interviewers that built rapport with participants. The data were also examined cross-sectionally, which means the data were only drawn from one point in time and are not as strong as longitudinal data. This study includes LMICs in Africa and Asia but does not include LMICs in South America and Europe, so caution is warranted in generalizing beyond the study sites. Finally, there may have been some instances of non-response bias. This was a complete-case analysis; anyone who had missing information on a variable in the model was excluded from analysis. There were 2 participants excluded from analysis (less than .01%), meaning that missing data among the OSC who participated in the round of data in which stigma was assessed was a minimal problem for the purposes of this analysis.

5. Conclusion

The number of OSC worldwide is high and they face multiple challenges to their mental health. Researchers have been seeking ways to prevent poor mental health among OSCs. This study found that higher levels of orphan self-stigma are associated with worse emotional wellbeing, defined by total difficulties from SDQ. Further research from additional studies would be useful to confirm this association and examine other potential confounding variables that are unmeasured in this study, as well as searching for ways to incorporate self-stigma into existing interventions for OSC. However, this new insight into a specific kind of stigma – self-stigma – is important to consider as communities continue to seek ways to improve mental health outcomes for OSC and support the large number of OSC worldwide.

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