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Stigma by Association, Parenting Stress, and the Mental Health of Caregivers of Adolescents Living With HIV in Uganda

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Abstract

Purpose: This study examined the relationship between stigma by association—defined as prejudice and discrimination against individuals who are associated with stigmatized individuals, parenting stress, and the mental health of caregivers of adolescents living with HIV.

Methods: Multivariate regression analyses were conducted using baseline data from the Suubi4Stigma study (2020–2022), a pilot study addressing HIV-related stigma among adolescents and their caregivers in southern Uganda.

Results: The average age was 47 years, 77.5% were female, and 49% identified as the child's biological parent. Stigma by association was associated with poor caregiver mental health ($b = 1.346$, 95% confidence interval = 0.49, 2.21) and parenting stress ($b = 1.431$, 95% confidence interval = 0.79, 2.08). Caregiver's gender, biological relatedness, household composition, and family cohesion were uniquely associated with caregiver mental health and parenting stress.

Discussion: Findings point to the need to incorporate stigma reduction components, not only for adolescents living with HIV, but also their caregivers, to counteract the effects of stigma on their mental health.

Keywords

Parenting stress; Caregiver mental health; HIV stigma; Uganda

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Supplementary Data

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Stigma is a major health determinant associated with morbidity, mortality, and health disparities worldwide [1,2]. HIV is one of the most highly stigmatized infections, characterized by public blame and moral condemnation of contracting the infection [3,4]. HIV-related stigma has been documented as a major barrier to all aspects of HIV prevention, care, and treatment services, including delayed HIV testing and care enrollment [5], increased risk of nonretention in care [6,7], nonadherence to antiretroviral therapy (ART) [4,8,9], and status nondisclosure [10,11]. Moreover, studies have documented the adverse impact of HIV-related stigma on the physical and psychosocial well-being of people living with HIV (PLHIV), including depression and post-traumatic stress disorders [12], loneliness and social isolation [13], and overall negative impact on their quality of life [14].

Although family members of PLHIV, including children, may not be HIV positive, they experience the negative effects of stigma by association—defined as prejudice and discrimination against individuals who are associated with stigmatized individuals [15]. Family members are often condemned and stigmatized in similar ways by virtue of their association with an HIV infected family member, manifested through gossip, name calling, rejection and isolation, loss of social support, and harassment [16]. They are often held accountable for not preventing the perceived “immoral behaviors” of the HIV infected family member and/or believed to be “contaminated” by the disease, “harmful,” “dangerous,” and “unhealthy” [17]. In particular, biological parents of children living with HIV harbor feelings of guilt and self-recrimination and anticipate being blamed and despised by their children for having infected them with the virus [18]. These perceptions combine with other factors such as lack of correct HIV-related knowledge and disease management information, to further exacerbate feelings of failure, anger, guilt, and shame [16]. Moreover, such feelings negatively affect family caregiving roles and family functioning [19].

Studies have also documented the negative psychosocial impact of HIV-related stigma on caregivers of PLHIV, including depression and anxiety [20,21]. In sub-Saharan Africa (SSA), however, the majority of studies have explored caregivers’ experiences with PLHIV [22,23]. Very few studies have investigated how HIV-related stigma impacts caregivers’ mental health [24,25]. Yet, caregiver mental health directly impacts the well-being of children under their care, quality of care provided, and overall family functioning [26,27].

To address the gap in literature on studies focused on the mental health of caregivers of adolescents living with HIV (ALHIV), we utilize baseline data from a National Institute of Mental Health–funded pilot study focused on addressing HIV-related stigma among ALHIV ages 10–14 years and their caregivers in southern Uganda. Majority of adolescents in the study, if not all, acquired HIV perinatally. We examine the relationship between experienced stigma by association, parenting stress, and caregiver mental health, as well as potential factors associated with these challenges. In addition to contributing to the growing literature, study findings may inform the development of interventions that not only address HIV-related stigma but also the psychosocial and mental health impacts of stigma on families affected by HIV/AIDS, especially, caregivers of children and ALHIV in low resource settings.

Theoretical framework

This study is situated within the stress-coping models, which posits in part that, stigma as a stressor does not affect the stigmatized individual as a passive recipient but whether stigma acts as a stressor or not depends on the individual's perceptions of stigma-related harm and availability of personal resources to cope with the harm [28]. Moreover, stress only occurs when perceived related harm exceeds the person's perceived coping resources [29]. Therefore, given that stigma reduction interventions, especially those targeting caregivers of ALHIV, that provide coping resources are limited, we hypothesize that high levels of stigma, in this case, experienced stigma by association, will be positively associated with parental distress and poor mental health functioning among caregivers.

Methods

Study sample and setting

We utilized baseline data from the Suubi4Stigma study (2020–2022). “Suubi” is a Luganda word meaning “hope.” The overall goal of this study is to pilot test the feasibility, acceptability, and preliminary impact of two evidence-based interventions on addressing HIV-related stigma among ALHIV and their caregivers in southern Uganda. A total of 89 child-caregiver dyads (N = 178) were recruited into the study. Adolescents were eligible to participate for the following reasons: (1) if they were living with HIV and aware of their status; (2) if they were between 10 and 14 years; (3) if they were enrolled on ART in participating clinics; and (4) if they were living within a family, including with extended family. Caregivers were eligible if they identified as the primary caregiver of the adolescent and were willing to complete study activities.

Study participants were recruited from nine health care clinics across four political districts of Masaka, Kyotera, Kalungu, and Lwengo located within the greater Masaka region of Uganda. This region has one of the highest prevalence of HIV in Uganda (i.e., 11.7% compared to 5.4% of the national average) [30]. All health care clinics were comparable in terms of number of adolescents (below 18 years) served, facility level (health center III and IV), and had to have adolescent clinic days.

Participant recruitment

Study participants were identified and recruited from HIV health clinics associated with the research team in the study region. At HIV clinics, patients are seen at least annually and each patient on ART must have prescriptions filled at least monthly at each clinic. Although appointment days (not times) are provided, most patients (children and their caregivers) arrive early in the morning on adolescent days and wait for several hours before they are seen, providing an opportunity for recruitment through medical staff. A clinic staff created a list of all eligible families from medical records, noting their eligibility to participate. Next, the clinic staff presented the project idea to adult caregivers of eligible children during appointments. If caregivers were interested, verbal consent to be contacted by research staff who was on site during the adolescent clinic days was requested. After speaking with the research staff one-on-one about the study, interested caregivers were taken through informed

consent after which they provide written consent for themselves and for their child to participate. Children were asked to provide written assent separately to avoid coercion.

Ethical considerations

Participation in the study was voluntary. Informed written consent and assent were obtained from caregivers and adolescents, respectively, prior to study participation. All study procedures were approved by the Washington University in St. Louis Institutional Review Board (IRB # 202,009,185), the Uganda Virus Research Institute (GC/127/20/10/792), and the Uganda National Council for Science and Technology (SS632ES).

Data collection

Data were collected using a 90-minute interviewer-administered questionnaire. All interviews were conducted in person while observing COVID-19 mitigating measures. All study related materials (including consent forms and data collection tools) were translated into Lugandad—the widely spoken language in the study region—and back translated into English to ensure consistency. A certificate of translation was obtained from Makerere University’s Center for Language and Communication Services. All interviewers received training in human subjects research and completed Good Clinical Practice trainings.

Measures

Outcome variables.—*Caregiver mental health* was measured using 34 items from the Brief Symptom Inventory [31]. The scale measures symptoms of anxiety, somatization, and depression. Sample items include experiencing “feelings of nervousness or shakiness inside, uncontrollable temper outbursts, feeling lonely even when with other people, and feeling no interest in things.” Responses were rated on 5-point Likert scale with 1 = “Never” and 5 = “Always” (Cronbach’s alpha was 0.93). *Parenting stress* was measured by 33 items from the Parenting Stress Index [32]. Sample items include “feeling that you cannot handle things very well, feeling trapped by your responsibilities as a parent, and feeling that you are not very good at being a parent to the child.” Responses were rated on a 4-point Likert scale ranging from 1 = “Strongly disagree” and 4 = “Strongly agree” (Cronbach’s alpha = 0.83).

Independent variables.—*Stigma by association* was measured using 10 items from the Brief Stigma-by-Association Scale [33]. The scale measures experiences and consequences of associated stigma, rated on a 3-point scale with 0 = “Not at all,” 1 = “Sometimes,” and 2 = “All the time” (Cronbach’s alpha = 0.93). Sample items include “ever been teased, treated badly, or gossiped about,” because someone in the family is living with or died of HIV/AIDS. *HIV knowledge* was measured by 19 items that assess HIV transmission knowledge, with 3 response categories: 3 = “True,” 2 = “False,” and 1 = “Not sure.” Sample items include “you can get AIDS even if you have sex only once without using a condom, and a person can get HIV by sharing needles.” *Family cohesion* was assessed using 6 items that measure the degree of help, commitment, and support between family members, rated on a 5-point scale (1 = Never to 5 = Always). Sample items include “family members like to spend free time with each other, feel close to each other, and ask each other for help before asking non-family members.”

Sociodemographic and household characteristics included in the analysis as control variables were age, gender, relationship to the child, and household size.

Analysis procedures

Data analysis was performed using SPSS 27. We analyzed participants' sociodemographic and household characteristics, outcome, and predictor variables. Two multivariate regression analyses were conducted to ascertain the relationship between stigma by association and caregiver mental health, and stigma by association and parenting stress, controlling for sociodemographic and household characteristics, HIV knowledge, and family cohesion. For each model, we conducted diagnostic tests to check the distribution of residuals for non-normality and/or inequality of residuals over levels of predicted values. Histograms are provided in Supplementary Materials. We examined multicollinearity for each model using the variation inflation factors and dropped number of children in the family from all models. Statistical significance was set a priori at the 5% level.

Results

Sample characteristics

Sample characteristics are presented in Table 1. The average age was 47.4 years. Majority of caregivers (77.5%) were female, 49% identified as the biological parent of the child, and about 32% identified as the grandparent. On average, caregivers lived in a household with seven people and four children under 18 years. Caregivers reported moderate levels of family closeness, as measured by the family cohesion scale (mean = 26.6, minimum/maximum: 41–55). Caregivers also reported moderately high levels of parenting stress (mean = 72.08, minimum/maximum: 43–123), mental health distress (mean = 74.54, minimum/maximum: 34–125), and low levels of stigma by association (mean = 4.74, minimum/maximum: 0–20).

Regression analysis results

Bivariate correlation results are presented in Table 2 and results from regression analyses are presented in Table 3. Gender, family cohesion, and stigma by association were all associated with caregiver mental health. Specifically, being a female caregiver ($b = 10.46$, 95% confidence interval [CI] = 0.12–20.79) and stigma by association ($b = 1.346$, 95% CI = 0.49–2.21) were associated with poor caregiver mental health. On the other hand, family cohesion ($b = -1.143$, 95% CI = -1.99 to -0.29) was associated with better caregiver mental health.

Regarding parenting stress, caregiver type, household size, family cohesion, and stigma by association were associated with parenting distress. Specifically, being the child's biological parent ($b = 10.63$, 95% CI = 3.04–18.22), more people in the household $b = 0.031$, 95% CI = -1.16 to 1.23), and stigma by association ($b = 1.431$, 95% CI = 0.79–2.08) were associated with higher levels of parenting distress. As with caregiver mental health, family cohesion ($b = -0.930$, 95% CI = -1.57 to -0.29) was associated with lower levels of parenting distress.

Discussion

In this study, we sought to examine the relationship between HIV stigma by association, parenting stress, and the mental health of caregivers of ALHIV. Guided by the stress-coping model [28], we hypothesized that high levels of stigma by association would be associated with poor mental health functioning and parenting stress. Study results support this hypothesis. Given the lack of stigma reduction interventions and programs to provide coping resources for families, and specifically caregivers of children and ALHIV, it is possible that caregivers end up suffering in silenced—negatively impacting their mental health functioning. These findings are consistent with other studies in SSA, including in Uganda [24] and South Africa [25,34] that have investigated HIV-related stigma and caregiver’s mental health. Similar mental health outcomes have been documented among caregivers of children orphaned by HIV/AIDS in Uganda [35,36]. Collectively, these studies have documented feelings of helplessness and hopelessness, parenting stress, and mental distress, including struggling with lack of energy, sad mood, social isolation, as well as continued fear of rejection, among caregivers of children affected by HIV.

Among sociodemographic characteristics, household size (i.e., high number of people in the household) was associated with parenting distress. This finding is consistent with studies documenting the caregiving burden in HIV-affected communities, including high levels of economic, emotional, and physical stress [37,38]. In addition, being the biological parent was associated with parenting stress. Given that the study focuses on ALHIV between the ages 10 and 14 years old, it is likely that most children, if not all, are perinatally infected. Hence, it is possible that biological parents may suffer from stress related to self-blame and hold themselves responsible for passing on the infection to their child. Indeed, family members of individuals living with HIV are often held accountable for not preventing the perceived “immoral behaviors” related to HIV transmission [17,39], and may anticipate being blamed and despised by their children for having infected them with the virus [18]. Once internalized, these feelings further exacerbate feelings of failure, anger, guilt, and shame [16].

Finally, family cohesion was associated with better mental health functioning and reduced parenting stress. This is consistent with other studies that have documented that availability of social support, in this case, family closeness and feeling accepted, has been shown to reduce stressors, enhance resilience, and ultimately improve mental health functioning [40,41]. Indeed, findings from our previous studies have documented the positive impact of better family relations on the mental health functioning among caregivers of children affected by HIV [35]. Thus, supporting and improving family functioning caregiving families is critical to elevate the mental health functioning of caregivers themselves.

Limitations

These findings should be cautiously interpreted considering the following limitations. First, we report cross-sectional data from a small pilot sample. Second, the measure of stigma by association has been utilized among youth and has not been validated for use among adult populations. Moreover, given that we did not assess caregivers’ HIV status, it is not possible to conclude whether the measured stigma is associated with the child’s or

caregiver's positive HIV status. Third, the data were self-reported and therefore our findings may be affected by social desirability bias. Finally, data collection was conducted during the COVID-19 pandemic when the country was on a lockdown. We do not know how this impacted the responses or how participants would have responded without the pandemic. Moreover, it is possible that the pandemic and related social distancing measures could have negatively impacted their mental health and increased parenting stress.

Even with these limitations, study findings point to a few important implications. Stigma by association and family cohesion were the strongest factors associated with parenting stress and caregiver mental health. This finding points to the need to incorporate stigma reduction components within the care and support programs for families affected by HIV. Similarly, family-level interventions that incorporate family strengthening components focused on building relationships, communication, and problem solving, may be critical in improving both HIV- and health-related outcomes, as well as family cohesion and functioning, as family members work together to address the associated challenges. Finally, given the limited literature focused on stigma by association, future research could focus on testing and validating assessment tools among adult populations, as well as ascertaining the extent to which this kind of stigma is associated with either the child or caregiver's own HIV serostatus.

Conclusion

This study contributed to the growing literature in SSA focused on HIV-related and the mental health of caregivers of ALHIV. Our study findings indicate that stigma by association is associated with poor mental health and parenting stress. However, family cohesion and having children in the household may help mitigate some of these risks. Taken together, these findings point to the need to incorporate stigma reduction components, not only for ALHIV, but also their caregivers, to counteract the effects of stigma on their mental health.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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IMPLICATIONS AND CONTRIBUTION

This study contributes to our understanding of the relationship between HIV stigma and the mental health of caregivers of children living with HIV. Care and support programs should integrate stigma-coping strategies targeting both individuals and their caregiving families, which will ultimately improve their mental health well-being.

Table 1

Sample characteristics (N = 89)

Variable	Mean(standard deviation)
Age (minimum/maximum: 22–90)	47.4 (14.1)
Gender: % (n)	
Female	77.5 (69)
Male	22.5 (20)
Relationship to the child: % (n)	
Biological parent	49 (44)
Grandparent(s)	32 (28)
Other relative	19 (17)
Household size (minimum/maximum: 2–17)	6.8 (2.79)
Family relationships	
Family cohesion (minimum/maximum: 14–35)	26.6 (5.2)
Caregiver HIV knowledge (minimum/maximum: 41 –55)	49.6 (2.99)
Parenting stress (minimum/maximum: 43–123)	72.08 (18.5)
Stigma by association (minimum/maximum: 0–20)	4.74 (5.17)
Caregiver mental health (minimum/maximum: 34–125)	74.54 (22.4)

Table 2

Bivariate correlation analysis

	Age	Gender	Number of people in the household	Primary caregiver	Family cohesion	Caregiver HIV knowledge	Stigma by association	Caregiver mental health	Parenting stress
Age	1								
Gender	-0.027	1							
Number of people in the household	0.189	-0.078	1						
Primary caregiver	-0.486 ^{**}	-0.114	-0.163	1					
Family cohesion	0.089	-0.005	-0.076	0.052	1				
Caregiver HIV knowledge	-0.065	-0.031	-0.017	0.048	0.187	1			
Stigma by association	-0.080	-0.058	0.121	0.203	-0.097	0.039	1		
Caregiver mental health	0.065	0.148	0.102	0.118	-0.282 ^{**}	-0.077	0.353 ^{**}	1	
Parenting stress	-0.116	0.101	0.030	0.302 ^{**}	-0.311 ^{**}	-0.162	0.465 ^{**}	0.435 ^{**}	1

^{**} $p < .01$.

Table 3
 Regression analysis results: stigma by association, parenting stress, and caregiver mental health

Variables	Caregiver mental health		Parenting stress	
	<i>b</i> (95% CI)	<i>p</i> -value	<i>b</i> (95% CI)	<i>p</i> -value
Age	0.318 (-0.04 to 0.67)	.078	0.097 (-0.17 to 0.36)	.471
Female caregiver	10.46 (0.12–20.79)	.047	6.772 (-0.98 to 14.53)	.086
Biological parent	8.612 (-1.50 to 18.73)	.094	10.63 (3.04–18.22)	.007
Number of people in the household	0.419 (-1.17 to 2.01)	.602	0.031 (-1.16 to 1.23)	.052
Family cohesion	-1.143 (-1.99 to -0.29)	.009	-0.930 (-1.57 to -0.29)	.005
Caregiver HIV knowledge	-0.214 (-1.68 to 1.25)	.772	-0.821 (-1.92 to 0.28)	.141
Stigma by association	1.346 (0.49–2.21)	.003	1.431 (0.79–2.08)	<.001
Constant	78.91 (2.39–155.43)	.043	115.48 (58.07–172.88)	<.001
<i>R</i> ²	0.257		0.384	
Adjusted <i>R</i> ²	0.193		0.330	
<i>F</i> -value (df)	3.998 (7)	.001	7.206 (7)	<.001
<i>N</i>	89		89	

Bolded numbers represent statistically significant results.

CI = confidence interval.