



Emotional and Behavior Difficulties and the Mental Health of Caregivers of Adolescents Living with HIV

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Abstract

This study examined the relationship between child emotional and behavioral difficulties, parenting stress and the mental health of caregivers of adolescents living with HIV. Caregiver data from a two-year pilot study for adolescents and their caregivers (N = 89 dyads) in Uganda, were analyzed. Ordinary Least Square regression models were conducted to examine the association between child difficulties reported by caregivers using the Strengths and Difficulties Questionnaire on parenting stress (measured by Parenting Stress Index) and caregiver mental health (measured by the Brief Symptoms Inventory). Results indicate that 12.36% of caregivers reported child difficulty scores within the *borderline* range and 8.99% reported scores within the *abnormal* range. Child difficulties ($b = 0.52$, 95% CI: 0.18, 0.85) were associated with parenting stress. Similarly, the perceived impact of child difficulties was associated with both parenting stress ($b = 0.89$, 95% CI: 0.24, 1.54) and caregiver mental health ($b = 1.73$, 95% CI: 1.09, 2.37). Study findings have important implications for developing effective psychosocial interventions targeting children and adolescents living with HIV and their caregivers.

Keywords Emotional and behavioral difficulties · Parenting stress · Caregiver mental health · Adolescents living with HIV

Highlights

- Child emotional and behavioral difficulties (EBDs) have been documented to predict parental mental health distress.
- In our study, 12% of caregivers reported EBD scores within the *borderline* range and 9% reported scores within the *abnormal* range.
- EBDs were associated with both caregiver parenting stress and mental health distress.
- Findings point to the need for the development of effective psychosocial interventions targeting adolescents living with HIV and their caregivers.

Children and adolescents living with HIV are at a higher risk of emotional and behavioral difficulties (EBDs) (Dessauvagie et al., 2020; Vreeman et al., 2017). Increased risk of hyperactivity, impulsivity and attention deficit, as well as depression, anxiety, and conduct problems, have been observed among adolescents living with HIV (ALHIV)

(Pillay et al., 2021; Too et al., 2021). Among ALHIV in sub-Saharan Africa (SSA), a high prevalence of EBDs has been documented, with 24–27% of adolescents scoring positive for any psychiatric disorders and 30–50% exhibiting emotional, behavioral difficulties or significant psychological distress (Dessauvagie et al., 2020; Musisi & Kinyanda, 2009). Studies have documented correlates of EBDs among ALHIV, including older age, lower income, orphanhood, higher viral load, low level of family functioning, living with non-biological parents (Kalembo et al., 2019; Mellins & Malee, 2013; Ruiseñor-Escudero et al., 2015; Tadese et al., 2012), as well as caregiver factors, such as low education level, young age and lack of employment (Jantarabenjakul et al., 2020; Kefale et al., 2019; Kinyanda et al., 2019; Webster et al., 2019). If not addressed, children and adolescents with HIV and EBD comorbidities are at a higher

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risk of poorer health outcomes across the HIV care continuum, including non-engagement in care, non-adherence to medication, elevated viral load and increased opportunistic illnesses (Bucek et al., 2018; Remien et al., 2019).

In addition, caregiver mental health has been documented as a major predictor of child EBDs. For example, in non-HIV population studies, maternal depression was significantly related to higher levels of child internalizing and externalizing behaviors and general psychopathology for children (Alenko et al., 2020; Goodman et al., 2011). Caregiver anxiety and parenting stress were significantly associated with child behavioral problems in Kenya (Laurenzi et al., 2021). Among ALHIV, caregiver depression was associated with child EBDs (Jantarabenjakul et al., 2020; Louw et al., 2016; Webster et al., 2019). Similarly, studies have documented the bidirectional relationship between child EBDs and parental distress (Lin et al., 2021; Rodriguez et al., 2019). In particular, during early childhood (1–5 years), greater child externalizing behavior predicted greater parenting stress (McDaniel & Radesky, 2020), and internalizing behaviors from early to middle childhood (5–10 years) predicted later parenting stress (Woodman et al., 2015).

Very few studies have investigated the mental health of caregivers of ALHIV (Goodrum et al., 2021), especially in SSA settings. However, most studies have focused on young children from early to middle childhood –despite significant changes during early and middle adolescence (McDaniel & Radesky, 2020; Lin et al., 2021; Rodriguez et al., 2019; Woodman et al., 2015). Yet, distressed caregivers may be less responsive to and engaging with their children, more authoritarian and neglectful in their parenting behaviors, and demonstrate poor parent-child communication. In the context of HIV, this may negatively impact child self-regulation, coping strategies, social and behavioral competence (Baumrind, 2013), potentially increasing the risk of non-adherence to medication and overall poor health functioning (Murphy et al., 2010; Rousseau et al., 2013; Schulte et al., 2017). Moreover, given that ALHIV experience unique challenges, the stressors associated with prolonged caregiving can exert an emotional burden on their caregivers. Thus, understanding caregivers' mental health needs is critical to providing appropriate mental health resources and ensuring that ALHIV receive appropriate support and care from their caregivers in return. To address this gap in the literature, this study examined the relationship between child EBDs and the mental health functioning of caregivers of ALHIV in Uganda.

Theoretical Framework

This study is guided by the stress process model (Pearlin et al., 1990). Within the caregiving context, stressors refer

to the problematic conditions and difficult circumstances experienced by caregivers, such as demands and obstacles that exceed an individual's capacity to adapt (Pearlin et al., 1981; Raina et al., 2004). These stressors arise when demands imposed by a patient's condition (such as a chronic illness that requires long duration for caregiving) conflict with the caregiver's ability to respond (Sisk, 2000). Within the context of HIV, prolonged caregiving for children living with a highly stigmatized chronic illness, as well as managing their social and treatment needs, may place a significant strain on family resources, prevent caregivers from attending to their own health needs, negatively impacting their physical and mental health functioning. As such, we hypothesize that high levels of child EBDs as reported by caregivers will be positively associated with parenting stress and poor mental health functioning.

Methods

Study Sample and Setting

Caregiver data from a pilot study for adolescents and their caregivers (N = 89 dyads) in Uganda, were analyzed. Study participants were identified and recruited from 9 comparable health care clinics across four political districts within the greater Masaka region of Uganda –a region with a high HIV prevalence compared to the national average (Uganda Ministry of Health, 2021). Adolescent inclusion criteria include: 1) living with HIV and aware of their status; 2) between 10–14 years; 3) taking prescribed antiretroviral therapy (ART) and receiving care from participating health clinics; and 4) 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. Detailed study procedures are provided in the study protocol (Nabunya et al., 2022).

Participant Screening and Recruitment

Screening and recruitment of participants took place between November 2020 and May 2021. Clinics were comparable in terms of the number of adolescents served, facility level and having adolescent clinic days. A clinic staff presented the project idea to adult caregivers of eligible children –per the inclusion criteria –during appointment days. Verbal consent to be contacted by a research staff member was obtained from interested caregivers. A total of 147 dyads were screened; among these, 89 dyads met the inclusion criteria. During a one-on-one meeting with the research staff, caregivers were taken through an informed consent process, after which they provided written consent for themselves and their children to participate. Children

provided assent separately from their caregivers to avoid coercion.

Data Collection and Measures

Measures utilized in this study have been tested in the study region among caregivers of ALHIV (Kagotho & Ssewamala, 2012; Nabunya et al., 2014; Wang et al., 2014). Data were collected between January and May 2021 during the COVID-19 lockdown, using a 90-minute interviewer-administered questionnaire. Interviews were conducted based on the participant's preference in a private space at the health clinics or at the participant's home. Caregivers reported on all measures. All study procedures, including the study measures, were translated into Luganda (the widely spoken local language), and back-translated into English to ensure consistency. The translation was certified by experts from Makerere University's Center for Language and Communication Services.

Outcome Variables

Caregiver mental health was measured using 34 items from the Brief Symptom Inventory that measures symptoms of anxiety, somatization and depression (Derogatis, 1993). Respondents were asked to rate how they felt emotionally, on a 5-point Likert scale, with 1 = Never true, 2 = rarely true, 3 = true sometimes, 4 = true most of the time and 5 = always true. Sample items include: *Feeling that people are unfriendly or dislike you. Feeling inferior to others. The idea that someone else can control your thoughts.* Summated scores were created with higher scores representing higher levels of mental health distress (Cronbach's alpha = 0.83).

Parenting stress was measured using 33 items from the Parenting Stress Index that assesses parental distress, difficult child and caregiver-child dysfunctional relationships (Abidin, 1990). Respondents were asked to rate their parenting stress, on a 4-point Likert scale, with 1 = strongly disagree, 2 = somewhat disagree, 3 = somewhat agree and 4 = strongly agree. Sample items include: *You find yourself giving up more of your life to meet your child's needs than you ever expected. You feel trapped by your responsibilities as a parent. Since you started taking care of this child you have been unable to do new and different things.* Summary scores were created, with higher scores indicating higher levels of parenting stress (Cronbach's alpha = 0.83).

Independent Variables

Emotional and behavioral difficulties were measured using the Child Strengths and Difficulties Questionnaire (SDQ) (Goodman, 2001). The 25-item brief behavioral screening

questionnaire includes five subscales related to emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behavior. The scale has been validated in the study region (Nakigudde et al., 2016; Thumann et al., 2016). Responses were rated on a 5-point Likert scale, with 1 = Never, 2 = rarely, 3 = sometimes, 4 = most of the time and 5 = always. Sample items include: *Your child has many worries or often seems worried. Your child steals from home, school or elsewhere Your child is easily distracted, concentration wanders.* All subscales (excluding prosocial behavior) are summated to create the total difficulties score, with higher scores indicating elevated child difficulties (Cronbach's alpha = 0.78). Percentiles were created for each of the four subscales and the total difficulties score. Scores above the 90th percentile were considered *abnormal*, scores between 80–90th percentile were considered *borderline*, and scores below 80th percentile were considered *normal* (Hoofs et al., 2015).

The SDQ was supplemented with a 7-item *brief impact scale* which assesses the perceived impact of the child's difficulties in terms of distress, social impairment, burden and chronicity on their life, including interfering with their family life, friendships, classroom learning leisure activities, and home life (Goodman, 1999). Responses were rated on a 5-point Likert scale, with 1 = Never, 2 = rarely, 3 = sometimes, 4 = most of the time and 5 = always. Sample items include: *“Do the difficulties interfere with your child's family life? Do the difficulties interfere with your child's friendships? Do the difficulties interfere with your child's classroom learning?”* Higher scores indicate negative impact (Cronbach's alpha = 0.91).

Finally, caregiver and family-level characteristics included in the analysis as control variables were age, gender, relationship to the child, family cohesion and household asset index. Family cohesion was measured using items adapted from the Family Environment Scale (Moos and Moos, 1994) and the Family Assessment Measure (Skinner et al., 1983), all previously used in the study region (Damulira et al., 2019; Osuji et al., 2018). The 7-item scale assesses the degree of commitment, help, and support that family members provide for one another, on a 5-point Likert scale, with 1 = never, 2 = sometimes, 3 = about half of the time, 4 = most of the time, and 5 = always. Sample items include: *Do your family members ask each other for help before asking non-family members for help? Do your family members like to spend free time with each other? Do your family members feel close to each other?* High scores indicate high levels of family cohesion (Cronbach alpha = 0.72). The household asset index was calculated by summing 17-items assessing the availability of assets, including land, a house, means of transportation, livestock and gardens).

Analytical Procedures

All analyses were performed using Stata version 17. Effects that were significant at $p < 0.05$ were interpreted. Model diagnostic tests were performed. Multicollinearity was examined using variation inflation factors. All values fell into the acceptable range (< 10), indicating that variables were not highly correlated. The normality of residuals was examined with kernel density plot and standardized normal probability plot with slight deviations from normal at the upper tail. The OLS model is robust to handle these minor violations. Using descriptive statistics, means and standard deviations, as well as frequencies and measures of central tendency, were generated to describe caregiver characteristics. Caregiver reports were used to examine the prevalence of child EBDs. Ordinary Least Square (OLS) regression models were conducted to examine the association between caregiver reported EBDs and perceived EBD impact on parenting stress and caregiver mental health. Standard errors and test statistics were adjusted for within-clinic correlation using robust Huber–Whiter sandwich variance estimation (White, 1980).

Results

Sample Characteristics

Caregiver characteristics are summarized in Table 1. The average age for caregivers was 47.3 years, and about three quarters (77.5%) were female. Of the total sample, 49% indicated they were the child's biological parent and 35% were grandparents. The average score on the family cohesion measure was 26.6 (SD = 5.2). Caregivers reported moderate levels of child EBDs (mean = 41.2, SD = 10.39) and perceived EBD impact (mean = 14.90, SD = 6.95). Similarly, caregivers reported moderate levels of parenting distress (mean = 72.08, SD = 18.47) and mental health distress (mean = 74.54, SD = 22.42).

Prevalence of Emotional and Behavioral Difficulties

The current study focuses on child EBDs, as such, the pro-social subscale was excluded from the analysis. Following Hoofs et al. (2015) approach, we calculated cut-offs for the whole sample and each of the four subscales (Table 2). On the total difficulties score, 12.36% of caregivers reported scores within the *borderline* range and 8.99% reported scores within the *abnormal* range. Across subscales, the percentage of caregivers reporting scores in the *borderline* category ranged between 15.75% (emotional symptoms) to 23.6% (peer problems). Within the *abnormal* category, the percentage of caregiver reports ranged between 4.49% (peer

Table 1 Description of study variables (N = 89)

Variables	M (SD) or N (%)
Gender	
Male	20 (22.47)
Female	69 (77.53)
Caregiver age (range 22–90)	47.35 (14.12)
Caregiver type	
Biological parents	44 (49.44)
Grand parents	28 (31.46)
Other parents	17 (19.10)
Family cohesion (range 14–35)	26.61 (5.20)
Asset index (range 0–16)	7.88 (3.04)
Parenting stress (range 43–123)	72.08 (18.47)
Caregiver mental health (range 34–125)	74.54 (22.42)
Total difficulties score (range 23–68)	41.21 (10.39)
Perceived EBD impact (range 7–35)	14.90 (6.95)

problems) and 6.74% (emotional symptoms, conduct problems and hyperactivity).

Regression on Parenting Stress and Caregiver Mental Health

Results from regression analysis assessing the association between caregiver reported EBDs, perceived EBD impact on parenting stress and caregiver mental health are presented in Table 3. In model 1, adjusting for caregiver characteristics, child EBDs ($b = 0.52$, 95% CI: 0.18, 0.85), and perceived EBD impact ($b = 0.89$, 95% CI: 0.24, 1.54), were associated with parenting stress. Specifically, every unit increase in child EBDs and perceived EBD impact score was associated with higher levels of parenting stress. On the other hand, being the child's grandparent ($b = -12.84$, 95% CI: -23.28 , -2.40) or other caregiver (aunt, uncle, etc.) ($b = -10.14$, 95% CI: -18.13 , -2.15) were both associated with lower levels of parenting stress.

In model 2, perceived child EBD impact was associated with poorer caregiver mental health ($b = 1.73$, 95% CI: 1.09, 2.37). On the other hand, household asset index ($b = -1.54$, 95% CI: -2.72 , -0.37), and being the child's other caregiver ($b = -12.36$, 95% CI: -19.49 , -5.24) were associated with better caregiver mental health. Other predictors were not associated with the outcomes.

Discussion

This study examined the relationship between child EBDs, parenting stress and the mental health functioning of caregivers of ALHIV in Uganda. In our sample, 12% of caregivers reported child EBD scores within the *borderline*

Table 2 Prevalence of caregiver reported EBDs

Child EBDs	Normal: <80 percentile		Borderline: 80–90 percentile		Abnormal: >90 percentile	
	Cut-off	Total %	Cut-off	Total %	Cut-off	Total %
Total difficulties score	23–48	78.65	49–56	12.36	57–68	8.99
Emotional symptoms	5–14	77.53	15–16	15.73	17–23	6.74
Conduct problems	5–11	75.28	12–13	17.98	14–17	6.74
Hyperactivity	5–13	75.28	14–15	17.98	16–21	6.74
Peer problems	5–12	71.91	13–15	23.60	16–21	4.49

Table 3 Association of EBDs and perceived EBD impact on parenting stress and caregiver mental health

Variables	Model 1: Parenting stress		Model 2: Caregiver mental health	
	Coefficient (Robust SE)	95% CIs	Coefficient (Robust SE)	95% CIs
Total difficulties score	0.52 (0.17)***	0.18, 0.85	0.36 (0.21)	−0.05, 0.72
Perceived EBD impact	0.89 (0.33)**	0.24, 1.55	1.73 (0.32)***	1.09, 2.37
Gender (ref: male)				
Female	6.21 (3.89)	−1.54, 13.95	3.44 (4.66)	−5.84, 12.72
Caregiver age	0.25 (0.18)	−0.11, 0.61	0.15 (0.20)	−0.24, 0.54
Family cohesion	−0.31 (0.29)	−0.88, 0.26	−0.20 (0.36)	−0.93, 0.52
Asset index	0.49 (0.53)	−0.55, 1.54	−1.54 (0.59)**	−2.72, −0.37
Caregiver type (ref: Biological parents)				
Grand parents	−12.84 (5.25)*	−23.28, −2.40	2.27 (5.47)	−8.62, 13.56
Other parents	−10.14 (4.02)**	−18.13, −2.15	−12.36 (3.58)***	−19.49, −5.24
Constant	31.19 (16.20)	−1.04, 63.42	43.06 (19.12)*	5.00, 81.12
N	89		89	
R-Squared	0.46		0.56	

SE Standard Error, CIs Confidence Intervals, ref Reference categories

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

range and 9% reported scores within the *abnormal* range. This prevalence is lower compared to previous studies that have utilized the SDQ among children and ALHIV in SSA (Kalembo et al., 2019; Kefale et al., 2019; Tadesse et al., 2012). The prevalence is also lower compared to previous studies conducted in Uganda (Kinyanda et al., 2019; Ruiseñor-Escudero et al., 2015), although this might be attributed to the difference in the assessment tools used.

Based on previous studies that have documented the correlates of EBDs among ALHIV (Kalembo et al., 2019; Mellins & Malee 2013; Ruiseñor-Escudero et al., 2015; Tadesee et al., 2012), the low prevalence could be due to the study sample. Specifically, participants were younger (10–14 years), the majority (55%) were non orphans, and almost half of the sample (49%) lived with their biological parents, and reported moderate levels of family closeness (Nabunya and Namuwonge, 2022). Moreover, caregivers were older, with an average of 47 years. As such, it could be that these individual and household-level characteristics could potentially act as protective factors mitigating the risk of EBDs. Taken together, given that children and adolescents living with HIV

are at a higher risk of EBDs, resulting in negative developmental outcomes (Dessauvague et al., 2020), interventions to ensure early screening and detection, and enrollment in treatment programs are critical among ALHIV.

It is critical to point out that while the percentage of caregivers reporting *abnormal* scores within the peer problems subscale was the lowest across all subscales, it also received the highest percentage of caregivers (23.6%) reporting scores in the *borderline* category. While peers can potentially be a unique and powerful source of support (Mark et al., 2019), this finding points to peer support challenges among ALHIV. Indeed, items in this subscale were related to having at least one good friend, being liked by peers, getting along with peers, being picked or bullied by peers, and preference to spend time alone rather than with peers. It could be that HIV-related shame, non-disclosure, fear of stigma and peer violence, prohibits adolescents from engaging in supportive peer relationships (Nabunya and Namuwonge, 2022; Kip et al., 2022). Yet, in our previous study with ALHIV, support from peers (friends and classmates) was associated with lower levels of

HIV-related stigma (Nabunya et al., 2020). This finding supports the calls for peer support programs for ALHIV that can help strengthen their peer networks to address the multifaceted challenges of living with HIV, including reducing social isolation, and improving health and mental health outcomes on the HIV care continuum (Abrams et al 2021; Casale et al., 2019; Rencken et al., 2021).

Guided by the stress process model (Pearlin et al., 1990, 1981), we hypothesized that high levels of child EBDs as reported by caregivers would be positively associated with parenting stress and poor mental health functioning. Study results support this hypothesis. Specifically, child difficulties and the perceived impact of these difficulties on children's wellbeing (including interference with family life, friendships, classroom learning, leisure activities, and home life), was associated with parenting stress. On the other hand, only perceived impact of child difficulties was associated with caregiver mental health. These findings align with previous studies in SSA that have documented the HIV burden on families, including the financial, physical and psychological hardships (Atanuriba et al., 2021; Osafo et al., 2017; Sherr et al., 2016). Moreover, caregivers must meet their children's medical, nutritional needs and overall health wellbeing –which tend to be costly (Lentoor, 2017; Osafo et al., 2017). These demands, combined with child difficulties and HIV-related stigma, further exacerbate caregiver anxiety and mental distress. Taken together, these findings are consistent with previous studies among caregivers of children living with HIV (Goodrum et al., 2021), and other behavioral challenges (Lin et al., 2021; Rodriguez et al., 2019).

Finally, being the child's non-biological caregiver was associated with lower levels of parenting stress and mental health distress. It could be that other caregivers (grandparents, aunts and uncle) do not have to bear the burden and guilt of transmitting the disease to the child, as opposed to the biological parent – potentially reducing the burden of mental health distress. In addition, ownership of household assets (e.g., a house, land, means of transportation etc.) was associated with lower levels of caregiver mental health. This finding is consistent with previous studies that have documented the importance of family economic stability in reducing mental health distress among caregivers of children affected by HIV (Nabunya et al., 2014; Wang et al., 2014).

Findings should be interpreted in light of the following limitations. First, we analyzed cross-sectional data from a small pilot sample and could not make causal inferences. This is also likely to impact the strength of the association. Therefore, there is a need for longitudinal well-powered studies to examine the association between child behavioral challenges and caregiver mental health. Second, emotional and behavioral difficulties were reported by caregivers and may suffer from social desirability. Adolescents were not

assessed on this measure to report on their own functioning. Third, assessments were conducted during the COVID-19 pandemic. The associated challenges may have worsened the mental health functioning of caregivers.

Even with these limitations, study findings have important implications for the development of effective psychosocial interventions targeting ALHIV and their caregivers. Family-related stress tied to HIV and poverty, may undermine parenting, including family organization, discipline practices, family connectedness, support, communication, and contribute to serious child EBDs (Kazdin & Whitley, 2003). Evidence based interventions, such as those focused on family economic stability, can potentially reduce financial, parenting and caregiver mental distress (Nabunya et al., 2014; Ssewamala et al., 2016; Wang et al., 2014). Similarly, group-based family strengthening interventions targeting family processes, including positive behavioral supports, effective behavioral management, parent-child relationships and parent involvements, problem solving, as well as coping, have been tested both in SSA among families impacted by HIV and poverty (Bhana et al., 2014; McKay et al., Sensoy Bahar et al., 2020; Ssewamala et al., 2018), and have proved efficacious in reducing child behavioral health (Brathwaite et al., 2022). A combination of such interventions may potentially address child EBDs and reduce the risk of caregiver mental distress.

Overall, study findings contribute to the limited literature examining the relationship between child emotional and behavioral difficulties and the mental health of caregivers of ALHIV. Future research is needed to understand the mechanisms through which child EBDs impact caregiver mental health. These findings point to the need for interventions to support caregivers of ALHIV to mitigate the burden of caregiving and the impact on their health and wellbeing.

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Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

Ethical Approval All study procedures were approved by Washington University in St. Louis Institutional Review Board (IRB #

202009185), the Uganda Virus Research Institute (GC/127/20/10/792), and the Uganda National Council for Science and Technology (SS632ES). Participation in the study was voluntary.

Informed Consent Informed written consent and assent were obtained from caregivers and adolescents respectively, prior to study participation. Children were asked to provide written assent separately to avoid coercion. The study is registered in ClinicalTrials.gov # NCT04528732.

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