

## **Psychosocial Stressors of Families Affected by HIV/AIDS: Implications for Social Work Practice**

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*This study identified the psychosocial stressors of low-income families who were affected by HIV/AIDS in Alabama. Methods consisted of personal interviews with 12 social workers at public agencies and a review of social work charts for 80 clients at an HIV clinic for mothers and children. The combined results indicated that families were likely to experience housing instability, family breakdown, mental illness, behavioral problems, and stigma. Younger children typically lived with their mothers, while older biological children often resided with relatives or in*

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*foster care. Social workers perceived mental health conditions such as depression and anxiety to be common among women caregivers. Behavioral problems and learning difficulties were frequently reported among children but children who were not living with HIV/AIDS did not have the same access to health care and social services as their siblings who were living with HIV/AIDS. This outcome is relevant to social workers because the children who were affected by HIV/AIDS outnumbered the children who were living with HIV/AIDS by a ratio of 3 to 1. Findings suggest that a model of care that involves funding for family-centered services for caregivers and children would provide a useful foundation for building stronger, more resilient families.*

*KEYWORDS families, HIV/AIDS, psychosocial stressors, social services*

## INTRODUCTION

HIV/AIDS in the United States increasingly affects women of childbearing age, most of whom are primary caregivers for their children. This trend is evident in clinics and AIDS Service Organizations (ASOs) around the nation. Whitmore, Zhang, & Taylor (2009) identified a 36% increase in U.S. women of childbearing age who were living with HIV/AIDS during a six year period from 2000 to 2006, with 8,000 pregnancies for these women in 2006 alone. As described by Lichtenstein (2008) and Schable et al. (1995), such women often live in low-income households with inadequate housing and social support, and they are likely to experience considerable stress from chronic illness or the prospect of death. These stressors are relevant to social work practice for three reasons: 1) HIV-affected families are an underserved population, 2) such women often do not relinquish their children regardless of the severity of disease (Schuster et al., 2000, and 3) social support from family or community is often lacking (Hughes & Caliandro, 1996; Lichtenstein, Laska, & Clair, 2002).

The term “family affected by HIV/AIDS” came into vogue in the United States in the 1990s when it was apparent that large numbers of women, particularly in low-income communities of color, were being diagnosed with HIV/AIDS (Centers for Disease Control and Prevention [CDC], 2007). At the same time, traditional (i.e., individualized) approaches to HIV care were being challenged by a simple fact—medical advances had enabled HIV-infected people to live longer and healthier lives. This shift was characterized by better reproductive health for women who were living with HIV/AIDS, as well as changes in how children were being affected by HIV/AIDS. For example, while fewer babies were being diagnosed HIV-positive once mothers received antiretroviral medicines during pregnancy, such gains were

offset by sharp increases in the number of children who live in families affected by HIV/AIDS (Nostlinger et al., 2004; Townsend et al., 2008; Whitmore et al., 2009). This outcome presented a conundrum for providers because care was available only to HIV-affected adults and children; children who were affected by HIV/AIDS comprised the large majority of dependents in such families but were excluded from receiving support services (Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007).

What happens if children who are affected by HIV/AIDS do not receive support services? Elkington, Bauermeister, Brackis-Cott, Dolezal, and Mellins (2009) noted that such children typically live in impoverished households in risky neighborhoods where life is burdened by the prospect of parental illness and death. Such children are likely to suffer from depression, anxiety, social withdrawal, learning difficulties, and attention deficits (Brackis-Cott et al., 2007). Lee, Gortmaker, McIntosh, Hughes, and Oleske (2006) reported that children aged 5–11 years who were affected by HIV/AIDS had lower psychological functioning compared to their peers who were living with HIV/AIDS. The authors hypothesized that differential access to health and social services was a causal factor; that is, children living with HIV/AIDS functioned at a higher level because they had greater access to services than children who were affected by HIV/AIDS. Gadow et al. (2010) and Forehand et al. (1999) also noted how children who were affected by HIV/AIDS experienced greater psychosocial difficulties than other children, especially in terms of academic or social functioning. The Interagency Coalition on AIDS and Development (2002) stated that it should not be surprising that children who are affected by HIV/AIDS experience these psychosocial stressors because: “[They] live with long periods of uncertainty and intermittent crises . . . Children who live through their parent’s pain and illness frequently suffer from depression, stress, and anxiety” (p. 2).

These outcomes are sobering for children who have yet to garner the public sympathy, political attention, social support, and medical services that are routinely provided to HIV-infected adults and children through The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. The Ryan White Act was passed to provide treatment and services to uninsured, low-income people with HIV/AIDS, and is the payer of last resort for most individuals who receive HIV care (Health Resources and Services Administration [HRSA], 2008). In 2006, The Ryan White Treatment Modernization Act (Part D) emphasized “family centered care” as a policy focus, so that family members who were affected by HIV/AIDS were eligible for some services (HRSA, 2008). However, the lack of adequate funding even for core services (i.e., medical treatment for clients with HIV/AIDS) meant that few family members who were affected by HIV/AIDS received these ancillary services (South Carolina Department of Health and Environmental Control, 2009). The Joint Learning Initiative on Children and HIV/AIDS (2009) has urged government officials to provide resources for such children in order to provide families with

a strong foundation for their future. This policy change calls for funding for a family systems approach to HIV/AIDS rather than the individual-based formula that has existed in the United States since 1990.

This article examines psychosocial stressors for family members who are affected by HIV/AIDS in Alabama. These families are often the largest single group of clients being served by social service agency personnel who often struggle to find the resources to help them (Southern AIDS Coalition, 2008). Alabama is primarily a rural state in which African American women represent the majority of caregivers who are living with HIV/AIDS (Lichtenstein, 2008). A defining characteristic of this population is that family circumstances in relation to poverty, housing, and access to health care and services are often dire regardless of HIV status. Adult unemployment in Alabama is among the highest in the nation (Bureau of Labor Statistics, 2010) with 16.6% of residents living below the poverty line (U.S. Census Bureau, 2008). Alabama also ranks 45th in the nation for children living in poverty, 46th in high school drop-out rates, and 48th respectively for infant mortality, percentage of low-birth-weight babies, infant mortality, and overall quality of life (Annie E. Casey Foundation, 2009).

The broader goal in collecting psychosocial data from ASOs and clinics was to generate information on the type of stressors affecting families with HIV/AIDS with a view to identifying the need for family-centered social services for this vulnerable population. The study used qualitative methods from multiple sources to identify psychosocial stressors as reported by both providers and recipients of HIV services in the state. We followed the example of Brackis-Cott et al. (2007) and Fair and Brackett (2008) in defining children affected by HIV/AIDS as minor dependents who reside with mothers living with HIV/AIDS. As the study progressed, we expanded the definition to include children residing with a sibling or a caregiver who was living with HIV/AIDS (e.g., mother, grandmother, or aunt) because these children were included in family assessments and in clinic reports to HRSA.

## METHODS

### Synopsis

The study was conducted at 10 agencies and two specialist HIV clinics for mothers, adolescents, and children in Alabama. The clinics are federally funded for social services and HIV care through Part D of The Ryan White Act. Twelve social workers were interviewed individually at these sites, followed by a chart review at one of the clinics. The social worker interviews provided narrative information on psychosocial stressors involving families affected by HIV/AIDS, while the chart review provided case histories of clients who were living with HIV/AIDS and their family members. This dual approach to data collection followed the Pope and Mays (2000)

recommendation for multiple sources and perspectives on health-related phenomena.

## Procedures

Approval for each aspect of the research was obtained from institutional review boards (IRBs) at The University of Alabama at Tuscaloosa and The University of Alabama at Birmingham. The study began with interviews of a convenience sample of social workers who were recruited primarily by the third author (A.M.), a member of the research team who was known to the social workers in this study through agency affiliations and pro-bono legal advocacy for clients at ASOs. AM was aware of IRB standards and was supervised by certified IRB personnel during the interviewing process. All three authors are members of the Governor of Alabama's AIDS Commission on Children, Youth, and Adults who have collaborated in AIDS-related advocacy, service, and research with personnel at ASOs and public HIV clinics in the state over a 15-year period.

Most of the social workers were employed at ASOs or public HIV clinics and everyone who was approached for the study was available for interview. The first and third authors conducted interviews with the social workers, either by telephone or in person, over a 3-month period. Phone interviews were conducted if schedules or the distance to rural clinics made face-to-face meetings impracticable. Semistructured schedules were developed for these interviews. Each schedule consisted of 4 items about caseloads and services, 8 items on demographic, family, and mental health status of clients and families, and 11 items specifically on the social demographics and circumstances of children who were affected by HIV/AIDS. All items were open-ended. Verbal consent was obtained and recorded on the participant's interview guide for the telephone interviews. Written consent was obtained prior to the individual interviews. Verbatim written notes were taken during both the telephone and in-person interviews and were typed up into interim reports. All written notes and typed reports were sent by fax or email to the first author (B.L.) for safe-keeping and data management. Notes for the typed reports were then transferred into a Word document in which responses were organized according to main categories from the interview guide for analysis at a later date.

For the chart reviews, a trained assistant collected information about clients and their families on a weekly basis over a 2-month period. Clients were defined as children, adolescents, and adults who were living with HIV/AIDS as well as infants who were awaiting diagnosis. The charts for these clients spanned an 8-year period from 1999 to 2006 inclusive. Each chart consisted of demographic information (e.g., name, gender, age, HIV status, and ethnicity) and psychosocial information from date of intake to the client's most recent visit. In the case of adults and adolescents, this information had been obtained by the social worker manager during face-to-face psychosocial

assessments with the client. In the case of infants and young children, the social worker manager had obtained relevant information from the primary caregiver in keeping with protocols for public HIV clinics in Alabama. Information about resident and nonresident children had also been obtained from caregivers.

The research assistant recorded client information on social demographics, mental health status, domestic violence, and other factors such as school progress or work and changes to family history since entering care at the clinic. Information about family members was collected from the primary client's file. This information included social demographics, family composition (e.g., household members living at the same address), HIV status of family members, number and age of siblings, behavioral issues, school performance, and home environment (e.g., caregiver's drug or alcohol use; domestic violence in the home). Systematic sampling was conducted by selecting every third chart from a list of clients who attended the weekly clinics. These data were then entered into an Excel Spreadsheet for data management. To protect the identity of this sensitive population, all names and addresses were replaced with unique identifiers. Both the typed interview notes and the chart review data were stored on a password-protected computer. Hard copies of the data were kept in a locked cabinet in the first author's office.

## Sampling

### SOCIAL WORKERS

The 12 social workers (all women) were experienced practitioners who had been employed for 5 or more years at the ASOs, clinics, and state agency in Alabama. With the exception of the family clinics and state agency, the mission of these organizations was to serve adults who were living with HIV/AIDS. However, the social workers had daily contact with young children who accompanied their parents to appointments and/or who attended social events at the agencies. Rural social workers ( $n = 5$ ) typically were responsible for managing staff and activities at small agencies, while the urban social workers ( $n = 7$ ) supervised social work units or provided client services such as health benefits, housing, and transportation. Job descriptions included case manager, social services coordinator, unit manager, and executive director.

### CLINIC CHARTS

The total clinic sample consisted of 141 adults, adolescents, children, and infants who were either living with HIV/AIDS or who were affected by HIV/AIDS. The clients with HIV/AIDS comprised 12 adults, 37 adolescents, and 12 children aged 2 years or older ( $N = 61$ ). A total of 19 infants were awaiting diagnosis; these children were primary clients who had their own charts and were eligible for all medical and social support services at the clinic until their

own HIV status could be finalized through antibody testing (typically between 12 and 24 months of age). Thus, a total of 80 clients in the sample received the full array of services at the clinic (hereafter known as “primary clients”). The family sample ( $N=61$ ) consisted of children aged two years or older who were not seropositive but who were residing in the same household as the primary clients living with HIV/AIDS (hereafter known as “family members”). Although they did not have their own charts or receive medical services, family members were included in clinic reports to HRSA. As noted, details of these children were recorded in family histories on the primary client’s chart. Details about non-residential caregivers, siblings, and children did not appear in these reports and were not included in totals for the clinic sample.

Clinic records for the primary clients (i.e., children and adults who were living with HIV/AIDS and infants who were awaiting diagnosis) defined adults as being 25 years and older, adolescents as between 13 and 24 years old, children as between 2 to 12 years old, and infants as between 0 and 2 years old. Distribution of the sample by age, gender, and ethnicity was representative of the clinic population as a whole. Most clients were African American (83%) and female (81%), with many women being referred to the clinic during pregnancy. Approximately one sixth of the HIV-infected sample (15.1%) consisted of male clients, with all of these clients being infants who were awaiting diagnosis, or children or adolescents who were living with HIV/AIDS.

#### ANALYSIS

The analyses were conducted after both the interviews and chart reviews had been completed. The Framework Approach was used to analyze the qualitative interview data according to the principles of applied qualitative research (Pope & Mays, 2000). This approach utilized the interview guides as a framework to identify a priori themes for the analysis. Initial coding for these data was based on the main topic areas in the interview guide (e.g., caseloads = 1, social demographics = 2, family circumstances = 3, maternal health = 4, impact on children = 5, children’s needs = 6). Then, subcodes were created for themes that emerged from responses for each main topic area (e.g., responses for “family circumstances” were subcoded as follows: single parent household = 3a, poverty = 3b, housing instability = 3c, domestic violence = 3d, stigma/discrimination = 3e). The coding was refined further by cross-matching all statements for each theme (e.g., stigma) with responses for each main topic area in the interview guide. This process yielded information on how the themes intersected in multiple ways in the lives of HIV-affected families (e.g., stigma was identified in relation to family circumstances, maternal health, and impact on children).

All coding, subcoding, and matched responses were reviewed by the first author and a trained research assistant for accuracy and to identify

patterns of convergence or divergence in the data. The responses were remarkably convergent, so for examples under “family circumstances,” most responses referred to single parenthood, poverty, housing instability and discrimination, and under “impact on children,” responses typically referred to poverty, mother’s ill-health, absence of fathers, housing problems, and stigma. Differences occurred mainly in relation to caseloads and the urban-rural context of client services or needs. At the end of this analytical process, the first and third authors reviewed each interview schedule for “thick description” (Geertz, 1973) that could be used to describe family composition and children’s circumstances in the results section of this article. All qualitative results were summarized in a report, which was then discussed by all members of the research team. This iterative process yielded five main themes in relation to children in HIV-affected families: poverty, stigma, mental health, physical health, and orphanhood. The themes are discussed and summarized in the qualitative results.

The chart data were tabulated for frequency distributions for sociodemographic variables such as age, ethnicity, gender, family composition, income, and housing. Cross-tabulations were performed for mental health status, home environment (e.g., family fights or family breakdown), school performance, and legal status (e.g., incarceration or probation). For each client and family member, a complete psychosocial history was compiled from social demographics and chart notations in the 15-column Excel spreadsheet. These histories were then organized into separate combinations or groupings (e.g., mothers and children in residence; mental health and behavior by age category, siblings by living arrangement) for more detailed information on psychosocial stressors by subgroup or variable. This process was repeated for each grouping or variable until the most important results had been identified with regard to psychosocial stressors for families affected by HIV/AIDS.

## RESULTS

The qualitative and chart results are presented sequentially. The results of the individual interviews are presented first, followed by descriptive data on all clients from the chart review. The themes for the qualitative section are illustrated by quotes from interview narratives, with a unique identifier assigned to each speaker (e.g., SW1 or SW2) for confidentiality. Tables and graphs are presented for results that are pertinent to social work practice.

### Interviews

#### POVERTY

Poverty was a theme evoked by all social workers in relation to daily struggles with HIV/AIDS, dangerous neighborhoods, discrimination, temporary



housing, or homelessness. Poverty, stigma, housing instability, and parental ill-health thus were interrelated stressors for children. Said one social worker; “The issues are the same even when the kids aren’t infected. There’s no money or child support. The kids’ fathers are often not involved, financially or otherwise. They’re in bad housing, they’re exposed to guns and violence, and the mom is often ill” (SW2). Said another; “Clothing is an issue. Kids may go to school with middleclass kids with nice clothes and these kids may have hand-me-downs” (SW5). The effects of deprivation were evident in a social worker’s description of how children in one family were taken to a restaurant and how they, “Complained about the food not being quick enough—the kids always ate fast food and hadn’t made the connection between food preparation and dining. We took them back to the kitchen to show them how the food is cooked” (SW3).

All of the social workers spoke about poverty in relation to housing instability. In one case, “A child lived in a storage room at a house of another family. The shelter had holes in the floor and the family stole from her” (SW9). For some families, “They don’t have anything except donations. They go from place to place, or they go to a shelter where kids aren’t allowed” (SW4). A consensus opinion was that, “All clients live below the poverty line” (SW2), and that poverty was a more pressing issue than HIV/AIDS for vulnerable families. Poverty even followed clients into death so that, “We have helped to pay for the mom’s burial because the funeral home threatened to dump the body” (SW1).

## STIGMA

HIV stigma was commonplace (“the public isn’t educated about HIV/AIDS”), and affected the children even if they were unaware of their caregiver’s HIV diagnosis. Again, the social workers all spoke about the myriad problems of HIV stigma which, in the case of children, meant trying to avoid being singled out at school or where they lived. One social worker referred to the pervasiveness of stigma by stating that, “The stigma of HIV/AIDS is one of the biggest effects on kids. There’s still a lot of discrimination that impacts the whole family” (SW1). The effects of HIV stigma were twofold. First, caregivers were likely to withhold information about their diagnosis from children, family, and outsiders. In this case, the family was in danger of being socially isolated because, “Mom doesn’t want anyone to see her HIV medicine or to know why she’s fatigued or ill” (SW4). Nondisclosure about a child’s diagnosis to adult family members was potentially hazardous because, “If the child goes to stay with the grandparents, mom doesn’t send his medicines along in case they find out about his diagnosis” (SW7). HIV stigma prevented seeking help for behavioral or educational problems because: “Some of the kids need to be in counseling in the school system, but the parents are afraid that system will react negatively if they reveal their HIV status” (SW8).

Second, stigma could result in discrimination so that, “The children aren’t invited to play at someone’s home or for sleepovers” (SW11). Being labeled HIV-infected and poor was doubly stigmatizing for children because, “These kids can be identified as coming from AIDS housing” (SW6) and, “They are taunted at school because they’re poor or because mom’s got AIDS. The kids get into a lot of fights at school from being labeled ‘those AIDS kids’” (SW4). Being labeled “an AIDS kid” thus occurred if children were HIV-infected or if their primary caregiver’s HIV-infected status was known, but also if they lived in public housing that had dedicated units for people with HIV/AIDS.

#### MENTAL HEALTH

The struggle of being poor, ill, and stigmatized could leave HIV-positive women feeling overwhelmed. A total of eight social workers specified mental health issues for impoverished and overburdened mothers who were struggling with HIV/AIDS. A social worker at a busy urban clinic stated that, “The moms are all stressed out and depressed. They have low self-esteem and their kids are acting out and they are getting into trouble at school” (SW3). These children were at risk for learning and behavioral problems, so that “Many of the kids get into trouble because they have learning difficulties or ADHD. Most of the kids are a grade or two behind at school” (SW5). A particularly poor outcome involved, “A mother who was diagnosed with bipolar disorder. Her kids were all put in different homes, all different schools, and are so out of control that she can’t take them back” (SW2). Maternal depression did not always mean that the children’s needs were neglected, however. Said one interviewee: “There are mothers who are depressed and who neglect their own needs, but they take better care of their kids than they do themselves” (SW6). This statement was supported by a rural social worker who observed that, “The children are a bright spot in the lives of clients, and the kids are well taken care of” (SW1).

#### PHYSICAL HEALTH

The burden of HIV-related illness could be considerable. Nine social workers spoke about the effects of physical illness on caregivers and their children. For example, if caregivers were symptomatic and could no longer work, “The parent’s status makes everyday issues twice as hard to deal with and this really affects the children. By the time most parents are approved for social security, they’re knocking at death’s door” (SW4). One social worker remarked that, “The kids’ lives are dismal. They don’t get a lot of affirmation when mom’s ill and all stressed out” (SW7). Another social worker stated that, “Some kids have told me that they can’t focus in school because of their mom’s illness” (SW 10). The progression of HIV-related illness for primary caregivers could

also mean, "Being unable to care for the children or themselves. Then the kids are sent to live with someone else or they go into foster care" (SW6). The trauma of having an acutely-ill caregiver was also reflected in this statement, "In one case, the mom was taken away in an ambulance and I guess they thought she was having a heart attack. That's the last time they saw their mom. The kids only talked to her one time before she passed away" (SW3).

## ORPHANHOOD

All except one social worker reported knowing about children who had lost one or both parents to HIV/AIDS. However, being orphaned by HIV/AIDS often occurred in a context of silence. Recalled one social worker; "The family doesn't get involved until the caregiver is on their deathbed. Then all of a sudden the family assumes responsibility for the children and the child finds out for the first time what is wrong with their parent" (SW7). This anecdote from a social worker at a rural clinic was especially poignant; "We brought the AIDS quilt to the high school. Afterwards, the kids wrote about their thoughts. Fourteen kids wrote about losing a family member to AIDS. One child was crying as he wrote comments and said his father had died the previous week. None of the child's teachers even knew" (SW6). In summarizing the effects of trauma among at-risk and orphaned children, this social worker concluded that, "One hundred percent of the children could do with counseling. There's a lot of issues around anger management after a parent's death, or even if a parent is too ill to look after them properly. They need to be included in family assessments to make sure that their mental health, behavioral, school and other needs are being met" (SW6).

Table 1 summarizes the social workers' comments about mothers and children in HIV-affected families for each of the five themes in the qualitative results.

## Charts

### MOTHERS WITH HIV/AIDS

Information provided by social workers in the qualitative interviews was confirmed by descriptions in the chart review. Here, family situations were characterized by ill-health, poverty, housing instability and, sometimes, by a pervasive sense of hopelessness. Notations such as, "has crying spells," "utilities disconnected," "has warrants for arrest for unpaid traffic fines," "has not disclosed diagnosis to anyone," "boyfriend uses client's money for drugs," "father of baby is abusive," and "client needs safe housing" indicated the often stressful, violent, and impoverished circumstances of HIV-affected families. Further, follow-up assessments indicated that circumstances might not improve between visits, with hopeful statements such as "is working

**TABLE 1** Summary of Qualitative Responses by Theme for Mothers and Children in Families Affected by HIV/AIDS

Theme	Sub-theme	Impact on children's lives
1. Poverty	Housing	"The kids are in bad housing." "They're in places where there is a lot of shooting."
	Transience	"They get housing but can't maintain it, especially when they're poor or there's domestic violence."
2. Stigma	HIV+ Children	"They don't want to be labeled as different so they have compliance issues."
	HIV- Children	"These kids get into fights because other kids pick on them. They get called "those AIDS kids."
3. Mental Health	Mothers	"Most moms have low self-esteem. There's depression, anxiety, and post-traumatic distress."
	Children	"They have low self-esteem, act out, and get into trouble at school."
4. Physical Health	Mothers	"The moms get to a point where they can't care for children or themselves."
	Children	(HIV-infected): "Most don't look much different from other kids except being smaller in size." (HIV-affected): "Most kids are in pretty good physical health but they don't get evaluated."
5. Orphans	Grief	"They find out what is wrong after their parent has died. They all need counseling."
	Care	"They end up with grandparents who have health problems of their own."

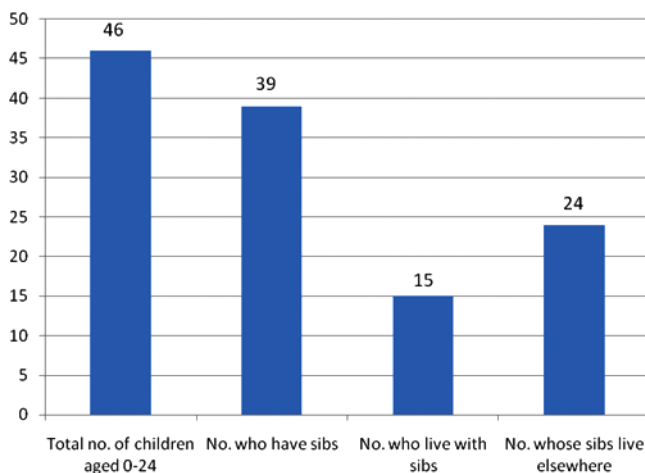
toward better life for self and children" turning into, "client feels completely overwhelmed. She has stopped taking meds because they make her feel ill," and "Overwhelmed at this time. Husband wants her to leave with her son, but not his three biological daughters. She said he monitors her calls and comings and goings and will not let her leave. She has stopped Rx for bipolar disorder; doesn't take meds for HIV." In the best case scenario, mothers who were living with HIV/AIDS took prescribed medications, kept appointments at the clinic, and had steady employment, family situations, and/or educational goals. In other cases, fatalism ("I put my trust in God"), mental illness, addiction, or adverse life events led to nonadherence to HIV regimens and to family disintegration as marked by notations such as "[name of child] placed into DHR foster care."

LIVING SITUATIONS

Two factors were particularly noteworthy in terms of residence for children who were living with HIV/AIDS or who were affected by HIV/AIDS. First, families were often dispersed in terms of caregivers and geographic location.

This relocation occurred for 15 children and adolescents whose mothers had died of HIV/AIDS. Three of these minor dependents had gone to live with their fathers, while the other 12 children were living with other relatives or were in foster care. Second, the 66 children with living parents did not always reside with them. For example, less than one third of these children (27%) lived with one or both biological parents and most were their mothers. In these kin units, dependent minors tended to be preschoolers rather than school-aged children, (e.g., the 19 infants all lived with their biological mothers). Nine of the children with living parents (14%) were residing with extended family members such as grandparents or aunts, while six children (9%) were in foster care or had been adopted. Life transitions provided a partial explanation for relocation in the case of adolescents. For example, a total of 22 adolescents (33%) were living independently. These children were described as female adolescents who were pregnant or had recently given birth. This subgroup generally formed their own family units after moving to public housing, usually in single-parent households, or, in a few cases, with an intimate partner. The remaining 17% of children in this category were lost to contact.

The living arrangements of children with HIV/AIDS in relation to their biological siblings are described in Figure 1. This subsample of 46 dependent children includes the 19 infants who were categorized as primary clients but excludes the 22 adolescent mothers described above. The biological families of these children consisted of one caregiver and between 2 to 10 siblings, with a mean size of 3.2 children per family unit. Most of the children and



**FIGURE 1** Infants, children, and adolescents with HIV/AIDS: residence in relation to their siblings. This category excludes 22 adolescent mothers who lived independently. The mean age of the children with HIV/AIDS was 12.2 years. The ages of siblings were not always recorded, especially if they did not reside with the client.

infants (85%) in these families had biological siblings, and most of these siblings were not living with HIV/AIDS. Almost two-thirds of the infants/children with HIV/AIDS (62%) had siblings who did not live with them, either because they were older and had moved away or, more commonly, because of family dislocation following domestic violence or divorce, termination of parental rights (e.g., after a mother's incarceration) or maternal illness. In these cases, the siblings were being raised by other relatives, often in another state, or they were in foster care or their whereabouts were unknown. As noted, the siblings who did not live with biological parents tended to be older than those children who did. These older children were usually from prior relationships while children in residence were part of "second" families for women with HIV/AIDS who attended the clinic.

#### MENTAL HEALTH AND COPING

Information on primary clients' mental health and related conditions was described in their charts. Children and adolescents with HIV/AIDS were psychologically assessed by a pediatric and adolescent psychologist at the Children's Hospital of Birmingham Complex on a periodic basis. For adults with HIV/AIDS, either a mental health professional at the study clinic or prior medical records were used for identification of mental health conditions. By these measures, two-thirds of adults (66.6%) and almost three-fourths of adolescents (70.3%) had at least one identified condition, with 18 of these clients reporting multiple conditions. Both adolescents and adults who were living with HIV/AIDS commonly experienced depression and suicidal ideation, and 16 clients were also victims of domestic violence. Learning disabilities and conduct disorders were recorded for almost one third of the school-aged children (32.0%). These deficits often impaired children's ability to get along at school and sometimes led to school suspensions and involvement with the criminal justice system as indicated in notations such as "teachers get on her nerves, currently in jail," and "limited reading and language skills, no longer at school, gang activity, arrested for assault." As a side note, mental health and behavior appeared to improve for children with HIV/AIDS who went to live with other relatives in more stable environments, especially in the case of three children whose new families enjoyed a higher standard of living.

Table 2 describes the psychosocial characteristics of primary clients in the sample. Comparative information for the children and adolescents who were affected by HIV/AIDS was partial or incomplete and is not presented here. Domestic violence is included for this sample of adults, adolescents, children, and infants if violence was present in the household (e.g., between mother and boyfriend or between mother and grandparent). These data were included because mothers who were abused by an intimate partner or family member also reported being depressed and because the abuse had a major impact on all aspects of family life including adherence to treatment, financial

**TABLE 2** Identified Mental Health and Other Conditions for Primary Clients by Age Category (N = 80)

Age category	No. of clients	% Identified <sup>a</sup>	Type of condition (by frequency) <sup>b</sup>
1) Adults (>25)	12	66.6%	Depression (6), Domestic Violence (4), Addiction (2), Schizophrenia (1) Suicide Attempt (1)
2) Adolescents (13–24)	37	70.3%	Depression (9), Behavioral/Jail (9), Domestic Violence (8), Suicide Ideation (6), Learning Disabilities (5), Bipolar Disorder (4), Sexual Abuse/Rape (3), Addiction (2), Anxiety Disorder (2), Self-Mutilation (1)
3) Children <sup>c</sup> (0–12)	31	25.8%	Domestic Violence (4), Developmental (2) ADHD (2), Depression (1), Behavioral (1)

<sup>a</sup>This column refers to the percentage of clients in each age group with one or more identified conditions.

<sup>b</sup>Includes multiple conditions for 5 adults and 15 adolescents as identified by a mental health professional.

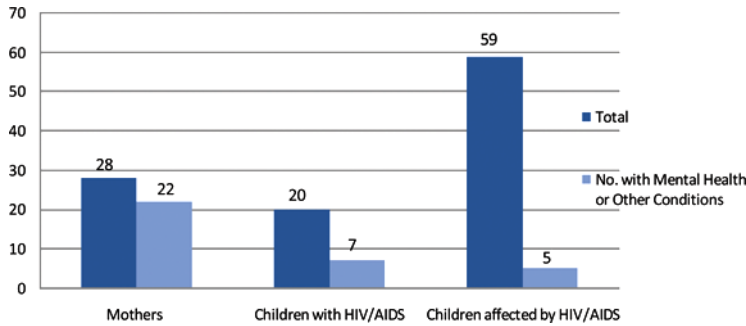
Domestic violence refers to incidents that occurred in the caregiver's residence.

<sup>c</sup>Domestic violence refers to violent episodes involving mothers and their relatives or intimate partners.

and housing stability, child behavior, school performance, and adverse effects on children. Mental health conditions and developmental delays are listed as they appeared in the clinic charts under the category of "Mental Health History."

Not surprisingly, depression was a common complaint among the adults and adolescents. Chart entries indicated that depressed caregivers neglected to take HIV medicines on a regular basis, or to administer children's HIV medicines, and to provide meals and general supervision for children. Nonadherence was measured by viral loads during clinic visits and by staff notations on reassessment forms. Entries included, "Mom is tired and forgetful, quit job, has not been consistent with medical care for son," and "History of depression; there have been concerns about medication adherence for her infant [and] she is even less adherent with her own personal care." Similar problems were recorded for depressed adolescents so that, "Client refuses to take meds; adherence is being encouraged," and, "Says he doesn't care about HIV; seemed bored; misses medical appointments." In one notable case, a fatalistic stance toward HIV/AIDS was expressed as "family opposes HIV medicines." Follow-up assessments at the clinic indicated that the health of depressed caregivers and adolescents with HIV/AIDS tended to deteriorate, leading to hospitalizations and, in some cases, children being sent to live with relatives or being placed into foster care as a temporary or permanent measure.

Information for mental health and coping was also available for the functioning of a subsample of 28 mothers with HIV/AIDS and their children in residence (Figure 2). This subsample included the 22 adolescent mothers mentioned above who were living independently. In these families, the



**FIGURE 2** Identified mental health and other conditions for mothers with HIV/AIDS and their children in residence. This total is likely to be underreported. Compared to children with HIV/AIDS, few children affected by HIV/AIDS were evaluated for mental health and other conditions.

children affected by HIV/AIDS outnumbered the children who were living with HIV/AIDS by almost 3:1. A total of 22 (79%) of the mothers had mental health conditions that adversely affected personal functioning. Most of these caregivers reported being depressed (70%), although anxiety, bipolar disorder, addiction, and schizophrenia were also reported. Thirteen women (46%) reported being abused by nonresident intimate partners (or, occasionally, their mother), although their lifetime experience of domestic and sexual violence was much higher. More than one-third of the children who were living with HIV/AIDS (35%) were identified as being depressed or troubled, with criminal justice involvement and school suspensions being recorded for some children. Fewer emotional or behavioral problems were recorded for children who were affected by HIV/AIDS compared to their mothers and siblings who were living with HIV/AIDS. However, funding constraints meant that these children typically were not assessed for psychosocial functioning or behavioral problems at the study clinic.

## DISCUSSION

The qualitative and chart results of this study yielded corroborative information on the psychosocial stressors of families affected by HIV/AIDS. The three main findings were that such families experienced multiple stressors and mental health conditions; that children were often dispersed between different relatives and geographical locations; and that the children experienced significant psychosocial challenges regardless of their HIV status. The impact of these interrelated factors was considerable. In the face of chronic health and financial pressures, families affected by HIV/AIDS faced dislocation when caregivers were overwhelmed, when intimate relationships failed or became abusive, and when caregivers or children had criminal justice involvement because of



unpaid fines, domestic violence, or addiction. In relation to children's well-being, these problems were exacerbated by learning disabilities or stigma, and sometimes led to acting out at school and home.

The qualitative results alone offered a bleak picture of client families living with poverty, stigma, and multiple stressors relating to a caregiver's illness. Even when caregivers were classified as loving parents (as they were reported to be in most cases) children who were affected by HIV/AIDS were often stigmatized at school and were exposed to violence, inadequate housing, and the energy-sapping effects of maternal depression and chronic illness. The social workers in this study asserted that children affected by HIV/AIDS often had significant behavioral or learning problems that needed to be addressed on an urgent basis. Fair and Brackett (2008) noted that few studies have addressed the effects of HIV stigma on such children's emotional and educational functioning. Our study suggests that stigma affects children's functioning through overt discrimination such as finger-pointing and name-calling when they are identified as "those AIDS kids," as well as through more subtle indicators such as social distancing. These difficulties were apparent regardless of the child's own HIV status. It is important to identify whether or not a differential psychosocial effect is present if children believe that social problems and stigma are due to HIV/AIDS. Future research could identify the extent to which children are aware of the stigma or if they attribute exclusion or teasing to poverty or other factors that have yet to be identified.

The chart histories provided more detailed information on the psychosocial stressors of HIV-affected families over an eight-year period. These charts indicated that many mothers with HIV/AIDS were chronically depressed and that their children often suffered from behavioral and learning problems. The reports of maternal depression and other conditions were alarmingly high, with two thirds of adults experiencing mental health problems during the review period. It is likely that the adult rate of depression was even higher than appears from the data in Table 2, because the adolescent category (three-fourths of these clients had an identified condition) included adults over 21 years old. Furthermore, three fourths of mothers in Figure 2 had an identified mental health condition. These maternal rates of depression and other disorders exceed the reports of other researchers who found that approximately 50% of mothers with HIV/AIDS have identified emotional conditions and mental illness (Galvan, Byrnam, & Bing, 2003; Schuster et al., 2000; Wood & Tobias, 2004).

The chart review also identified that infants and young children usually lived with their mothers, while older children tended to reside with other relatives (e.g., aunts or grandparents) or in foster care. Thus, it was difficult to assess the long-term impact of living in families affected by HIV/AIDS except to note high rates of maternal depression and financial deprivation, and the family dislocation that resulted in older children living with relatives or in foster care. More relevant in relation to the present study, perhaps, was

the finding that older children are often an invisible population in terms of assessing their health and well-being. This factor suggests that family cohesion is a tenuous concept for children whose long-term experience may include the temporal loss of a parent through adversity (e.g., failed relationships, housing problems, and incarceration), the chronicity of maternal depression and HIV/AIDS or, perhaps, the death of their parents. The chart results indicated the urgent need for funding for family-centered care, not only to support chronically ill or depressed mothers, but also as a means of reducing HIV risk for seronegative children and for building resiliency in the future.

The children who were living with HIV/AIDS in our study were likely to have a learning deficit, depression, and conduct or hyperactivity disorders, especially in adolescence. This result is consistent with prior research that reported higher rates of behavioral and learning disorders among children in families affected with HIV/AIDS compared to age peers in families not affected by HIV/AIDS (e.g., Brown, Lourie, & Pao, 2000; Gadow et al., 2010; Lee et al., 2006). In our chart review, these conditions could not always be attributed directly to living in a family affected by HIV/AIDS. The clinic notes revealed instances of girls being sexually abused by family members or acquaintances and both the charts and social work interviews indicated that community-based factors such as poverty, incarceration, and housing instability played a major role in destabilizing families regardless of HIV status. This finding makes it difficult to determine whether these stressors are unique to families affected by HIV/AIDS or, as suggested by Elkington et al. (2009), if they are typical of high-risk communities more generally. In commenting on these multiple traumas, the social workers expressed concern about how children with persistent psychological problems in families affected by HIV/AIDS were being neglected by school and mental health systems. While the psychological and physiological needs of the children with HIV/AIDS were being met, in part, by dedicated services at the HIV family clinics, the results of this study suggest that children affected by HIV/AIDS might face the same psychological challenges if they live with impoverished families headed by chronically-ill and often depressed caregivers. However, similar interventions were unavailable for these children.

Finally, both the qualitative results and the chart review suggested that two types of trauma may occur among children in families affected by HIV/AIDS. The first trauma relates to living with caregivers with HIV/AIDS in stigmatizing and straitened circumstances. The second trauma relates to family disintegration, which includes being separated from siblings who potentially could buffer the worst effects of losing contact with parents. A particularly striking result was that resident children of mothers with HIV/AIDS were often part of "second families," with older children being likely to relocate with relatives or foster parents. We noted that circumstances sometimes (but not always) improved for children with HIV/AIDS after their mother's death if they lived with other relatives (e.g., aunts or grandparents) in more

stable environments. This finding is supported by Forehand et al. (1999) who reported that orphans of HIV/AIDS who moved in with close relatives in stable environments experienced fewer adjustment problems than expected. The author concluded that trauma from losing a parent to HIV/AIDS was offset by this newly-found stability. A question for future research is how children experience this transition when the biological parent is still alive but is no longer able to care for them. This was a regular occurrence for young people in our study, and the lack of information about such children's whereabouts and circumstances calls to mind Dansky's (1997) label of "nobody's children" who receive little formal acknowledgement, and indeed, who may not know why they have been separated from their mothers because HIV stigma has resulted in reluctance by caregivers to disclose HIV status to children and other kin (Lichtenstein, 2008).

### Limitations

We should note several limitations in the research. First, the psychosocial contexts and challenges of these families in a low-income southern state may not be representative of families who are affected by HIV/AIDS in the nation as whole. Second, the presence of a clinical pediatric and adolescent psychologist at the family clinic may have led to more mental health or behavioral diagnoses for children with HIV/AIDS than typically is the case at other HIV clinics. Third, while social workers elicited information from caregivers about their nonadolescent children as standard clinical practice, first-hand accounts or direct assessments are needed to identify the needs and well-being of young children on a more definitive basis. In the best case scenario, information about young children and siblings was provided by the caregiver (e.g., a biological parent or foster parent). In the worst case, information about nonresident children was missing from family charts. The high rates of mental illness and conduct disorders among children affected by HIV/AIDS as described in Bauman, Silver, Draimin, and Hudis (2008) and missing information about children who were not in residence suggests that we have probably underestimated both the size and mental health needs of this population. The family-centered social work assessment in clinic charts nevertheless provided information on the psychosocial contexts of a sizeable number of children with HIV/AIDS and their siblings, including family histories over an extended period of time. However, we wish to emphasize the preliminary nature of our findings and the need for replication, including prospective studies of children and youth who live in families affected by HIV/AIDS.

The insights from this study on the mental health and functioning of mothers and children in HIV-affected families are only a beginning point for definitive research on the topic. Future research could identify more reliable methods for eliciting information about children who are affected by HIV/AIDS, including objective measures to assess psychosocial

adjustment and stressors. This research plan could focus on the children themselves who would serve as primary sources of information, although caution would need to be taken to satisfy IRB requirements for interviewing minor children. In this case, professionals (e.g., social workers with expertise in dealing with children) could help execute a study to obtain valid data on children and siblings in families affected by HIV/AIDS. A longitudinal study of such families that utilized the most compelling results of this study could identify how mothers and children fare over the long term, especially if a comparison group of families not affected by HIV/AIDS were included in the study design. This comparison study could help to identify the extent to which poverty, HIV-related illness, or other factors contribute to psychosocial stressors among families affected by HIV/AIDS either individually or in combination.

### IMPLICATIONS FOR SOCIAL WORK PRACTICE

The narratives of social workers and the client histories in this study demonstrate the need for family-centered services for children who are affected by HIV/AIDS. We conclude that these services are desirable, not only to provide support for chronically ill or depressed mothers, but also as a means of reducing psychosocial risk for children and of building more stable and resilient families. As noted in the Introduction, Part D of the Ryan White Act technically provides access to some services for HIV-affected family members. However, although family members who are affected by HIV/AIDS can benefit indirectly from case management under the rubric of family-centered care, grantees such as the family clinic have been compelled to limit their services to primary clients because of funding shortfalls. Additional resources for family members who are affected by HIV/AIDS could fulfill the mandate of family-centered care and take account of the exponential growth in HIV-affected children and family members as described in this article.

How would family-centered care be different from the individualized social services already being provided? This expansion would be based on the model proposed by the Joint Learning Initiative on Children and HIV/AIDS (2009) which recognized that HIV/AIDS affects the entire family, reduces the life-chances of seronegative children in such families, and compels family members—including children—to provide support for the afflicted or to cope with extreme adversity on their own. Family-centered care treats the family as the client, understanding that the health of each family member has substantial effects on the entire family unit. To specify, family-centered care involves: 1) routine screening for mental and physical health conditions with all members of the family unit, 2) routine mental health and psychosocial assessments for all members of the HIV-affected family rather than just for the family member who is living with HIV/AIDS, and

3) comprehensive medical care for children affected by HIV/AIDS in order to promote the health and functioning of the whole family. These steps would be undertaken in the understanding that a healthy family is better equipped to demonstrate resiliency when faced with ongoing stressors of chronic illness, poverty, and disadvantage. The model would involve developing partnerships between families and professionals and prioritizing levels of treatment for families that are deemed most in need. The lack of funding for such measures was a source of frustration for social workers in this study who reported that the present model of HIV care did not meet the needs of underserved families who comprised the majority of clients in this resource-poor state. As a final point, we would like to reiterate that children who are affected by HIV/AIDS experience the same stigma, poverty, transience, and parental loss as children with HIV/AIDS; that their needs have been neglected in both funding and services; and that a fully-funded family systems approach to services would help to alleviate the impact of the “secondary epidemic” on the future health and well-being of this vulnerable population.

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