Addressing the Needs of Parentified Children of HIV Positive Parents

The school social worker is concerned about Maria, a nine-year-old Latina third grader, who missed over 20 days of school in the first two months of the school year. Maria is currently repeating the third grade due to her poor attendance and incomplete school work last year. When she does show up at school, she is generally late, and commonly wears dirty clothing that appears to be too small. She doesn’t have a backpack, but rather carries her pencil and loose leaf paper in a plastic bag. During lunchtime, Maria sits by herself. The teacher has reported that Maria doesn’t have any friends, and seems painfully shy. When the school social worker speaks to Maria, she learns that Maria needs to stay home many days to help care for her 3-year-old sister and infant brother. When the social worker asks why, Maria reports that “Some days my mom is just really tired. It's my job to help her.” Maria states that she commonly wakes up in the middle of the night to feed the baby, and wakes up early to make sure her sister has breakfast in the morning. On the weekends, Maria takes her siblings to the park, and sells burned CDs to make some extra money for the family. The social worker offers to connect Maria with an outside agency that can offer home visiting. Maria adamantly refuses, becoming almost panicked at the thought of external support. The social worker feels she has no choice but to call Child Protective Services to file a general neglect report. It is only after working with Maria for over a month that the social worker learns that Maria’s mother is HIV positive. The family has attempted to keep the mother’s diagnosis a secret, which has severely limited the support and resources available to the affected children in the home.

HIV and AIDS in American Families

The Centers for Disease Control and Prevention estimated that in 2009, over one million people were living with HIV or AIDS in the United States. While men comprise nearly 75% of the affected population, there are approximately 280,000 HIV positive women living in America. Women of color are especially hard-hit by the AIDS epidemic. While
African American and Latina women constitute only 26% of the U.S. female population over the age of 13, they represent 82% of AIDS diagnoses among women (1). For many, HIV and poverty are intimately intertwined. An HIV diagnosis commonly brings with it increased medical expenses, loss in work productivity, and unemployment (2). HIV positive women are disproportionately low-income, with 64% reporting annual incomes of less than $10,000, compared to 41% of positive men (1). Since HIV tends to cluster in low-income neighborhoods, the diagnosis serves to generate and intensify poverty in already vulnerable populations.

Commonly overlooked is the fact that many of these women are also mothers struggling to raise a family (3). Nearly 76% of women with HIV/AIDS who are actively receiving medical care have children under the age of 18 in their homes (1). HIV positive mothers, who are often single parents with stressors and time constraints due to their health and healthcare appointments, may sometimes be limited in their ability to reduce environmental stressors and provide adequate supervision to their children (4).

With the introduction of highly active antiretroviral treatment (HAART), which typically includes a combination of three or more medications, the life expectancy of HIV positive individuals has increased dramatically for both men and women. In 1996, the average life expectancy after an HIV diagnosis was 12.6 years. By 2005, women were living an average of 23.6 years post diagnosis (5). Positive mothers and fathers are now able to parent their children much longer than previously expected, and children are able to spend more of their formative years in a home with their HIV positive parent.

What is Parentification?

Parentification is generally defined as a type of role reversal or blurring of boundaries between a parent and a child, where the child assumes developmentally inappropriate levels of responsibility due to the parent’s physical incapacity or absenteeism. More specifically, parentification occurs when children are charged with meeting either the physical or emotional needs of siblings and/or parents (11). This phenomenon is generally divided into two categories: instrumental and emotional. Instrumental parentification involves the child undertaking responsibility for physical household tasks, such as grocery shopping, cleaning the home, preparing meals for the family, caring for the ill parent, watching over younger siblings, or paying bills. Emotional parentification occurs when the child becomes the parent’s confidante or the family’s mediator.
HIV and Parentification of Children

Many parents with HIV will struggle with chronic symptoms including decreased energy, increasing amounts of fatigue, depression, and an overall compromised health status (6). In some homes, this may lead to a child taking on the role of caregiver of the positive parent and potentially of the other siblings living in the house. This phenomenon, known as parentification, is not unique to homes affected by HIV/AIDS; it has also been reported in homes with parents struggling with other chronic physical illnesses such as fibromyalgia and rheumatoid arthritis, as well as in families recently affected by divorce. It has been reported, though, that children whose mothers are HIV positive report more parentification than children of HIV negative mothers (7). The very drugs that serve to increase life expectancy of positive parents may also bring with them certain side effects, such as increased drowsiness, nausea, vomiting, and inflammatory syndromes, which can affect traditional role functioning in the home. The stigma and secrecy commonly associated with HIV-affected homes may decrease the availability of social supports, making it more likely that a child will fill the parental role when a parent is ill (7).

Over the years, there has been much research examining the effects of parentification on children. Early on, it was assumed that parentification would consistently lead to poor outcomes including maladaptive behaviors and difficulties later in life; more recent studies have shown that this isn’t always the case. Mitigating factors including the resiliency of the child, the available social support network, the age of the parentified child, the closeness of the parent-child relationship, and the perceived fairness of the parentification may contribute to how a child will respond to the undertaking of adult tasks. Cross-sectional and, more recently, longitudinal studies have examined outcomes associated with parentification over time.
Positive Outcomes Associated with Parentification

In the last decade, a multitude of studies have shown that not all children who experience parentification will have long-term negative consequences. As in most social phenomena, the resiliency of the child greatly determines the child’s outcomes. Research shows that in some families, parentification is associated with:

- stability in a stressed family (7);
- a venue for developing coping skills, independent living skills, and self-esteem (3,7,9,10);
- better adaptive coping skills and less alcohol and tobacco use 6 years after initial parentification (10);
- a highly-valued, culturally-supported role in Latino and African American families (6,10);
- lower depression scores when the parent-child relationship is strong, the parentification is perceived as fair, and the child is an adolescent (7,8).

Despite the mixed outcomes, most children taking on adult responsibilities and tasks in light of their parents’ illness could benefit from outside resources and supports.

Negative Outcomes Associated with Parentification

Parentified children, especially those who are prepubescent or have few social supports, may be at a disadvantage in several ways. Parentified children have reported:

- feelings of being overburdened with responsibilities (3);
- limited time for age-appropriate social and leisure activities (8);
- education difficulties due to limited time for schoolwork and a high number of absences due to caregiving responsibilities (8);
- feelings of isolation (9);
- trouble forming new friendships due to lack of time, stigma of HIV, and the feeling of being different from peers due to the caregiving role (9); and
- a greater number of externalizing behaviors, e.g.,
  - The undertaking of parental role behaviors was consistently correlated with risky sexual behavior, substance abuse, emotional distress, and conduct problems (3, 10). The younger the parentified child, the more highly correlated the outcomes.

- Parents with HIV are largely ethnic minorities. Latino and African American cultures are generally more family-and group-oriented than Caucasian cultures. Behaviors that are labeled as parentification in some cultures may be considered normative and culturally appropriate in others, reflecting interdependent and collectivist cultural values rather than pathology (10).
- lower depression scores when the parent-child relationship is strong, the parentification is perceived as fair, and the child is an adolescent (7,8).

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Interventions

The way the HIV treatment system is currently structured, there are few resources available for HIV negative children living in homes with a positive parent. Support is available for HIV-infected individuals, but rarely funded for those affected by the disease. Even though HIV negative children face many of the same social issues as HIV positive children, including poverty, stigma, and isolation, they are commonly excluded from receiving supportive services. (12). HIV positive children have actually reported a higher level of functioning than HIV negative children living in positive homes, and attribute this advantage to their ability to access supportive services (12).

Current research recommends that there is a need in all countries for minor caregivers to be recognized, identified, analyzed and supported as a distinct group of vulnerable children (13). Regardless of whether parentified children display any of the negative outcomes listed above, they, at the very least, will experience much higher levels of stress than the typical child. The following is a list of interventions shown to improve outcomes for HIV negative children who take on a parental role while living with an HIV positive parent.

Recommendations

The Hooper Research Lab at the University of Alabama offers ten recommendations for clinicians working with parentified youth (11).

1. Don’t assume parentified clients are having a negative experience.

2. Consider the length of parentification. Short-term parentification may foster competency and self-efficacy. The longer a child is parentified, the higher the probability of poor outcomes.

3. Consider the age of the child. The younger a child is when parentified, the more likely it is that the child will experience negative outcomes.

4. Consider the type of parentification. Emotional parentification has been to shown to result in more negative effects than instrumental parentification.

5. Consider the culture of the family. Some cultures value interconnectedness and see parentification as strength.

6. “Use the Parentification Questionnaire-Youth for pre-adolescent and adolescent children to assess the level, type, and perceived fairness of parentification. (Available from G. J.Jurkovic, Department of Psychology, Georgia State University, University Plaza, Atlanta, GA 30303)

7. Assess if the client feels the parentification is “fair.” Fairness has been associated with fewer negative outcomes.

8. Explore the positive aspects of the parentification to assess the strengths of the experience.

9. Involve the entire family in the evaluation. Education and awareness may help balance the household tasks. In the literature, parents generally reported less parentification than the child did, insinuating that the parent may not realize the full extent of the child’s duties.

10. Consider a referral for mental health services for the child.
1. Offer parenting resources

If HIV positive mothers are relying on their young children to perform tasks typically reserved for adults, it is critical that there be a strong attachment between the mother and child, as well as solid parenting skills in place for the child to emulate (10,14). Specifically, clinicians can assist mothers to:
• build structure in the home (15);
• create a positive relationship with their child(ren), as stronger parent-child relationships have been found to predict better mental health outcomes for the child, as well as decreased sexual behavior and emotional distress (8,16);
  ◦ Key components to a positive relationship, as reported by HIV-affected children, include positive conversations, mutual understanding, and a source of reliable support for the child (15).
  ◦ See Parenting Education Matrix under “Resources for Providers” for a list of evidence-based parenting curricula.
• understand the importance of monitoring their child(ren)’s friends and activities outside of the home (15);
  ◦ High levels of parental monitoring have led to declines in anxiety, depression, conduct disorder, and binge drinking (17).
• develop simple family routines that can be maintained stably even when a parent is symptomatic (17).
  ◦ Family routines, especially around meals, are related to lower alcohol use, depressive symptoms, suicide involvement, and a higher grade point average of the child (17).

Parenting Interventions Recommended by the Promising Practices Network and/or DEBI:
• Informed Parents and Children Together http://www.childtrends.org/lifecourse/programs/impact.htm
• Triple P, Positive Parenting Program (http://www5.triplep.net/)
• The Incredible Years (http://www.incredibleyears.com/)
• Project Teens and Adults Learning to Communicate (http://chipts.cch.ucla.edu/TALC-LA)
2. Provide economic supports

In Lichtenstein, Sturdevant, and Mujumdar’s 2010 study, HIV positive families reported that, on most days, poverty was a more pressing issue than HIV (12). Basic economic security would help to relieve some of the worst distress experienced by HIV-affected families, enabling parents to both support their children and afford medical costs for their treatment. Specific helpful economic supports include:

• transportation and school supplies to assist children in attending school (6);
• subsidized child care so older children do not feel obligated to care for their siblings during school hours (2);
• food acquisition, as many HIV-affected children live in food-insecure homes (2); and
• assistance applying for public benefits so the child does not have to work to support the family (2).

3. Link child to peer support and social/developmental activities

Parentified children commonly report difficulty forming friendships due to the combination of social isolation stemming from the stigma surrounding HIV and a feeling of being different from peers as a result of their unique set of responsibilities. These children also commonly miss out on social and developmental activities due to their family obligations. HIV-affected children have voiced the desire to talk about parental HIV openly with a child or adult who understands (18). Clinicians working with these children can help by:

• connecting the child to peer support groups with other HIV-affected children (6,8);
• providing the child with social support by referring to Big Brother/Big Sister, a church group, or other mentoring programs in the community (19).

It has been found that having at least 3 supports is related to significantly lower levels of depression and fewer conduct problems for adolescents (20).

Interventions Recommended by the Coalition for Evidence-Based Policy:

• Big Brother/Big Sister

4. Provide mental health screenings and assessments

Since few programs utilize a family-centered model of care, HIV negative children rarely receive the assessment services that may routinely be coupled with the treatment that their HIV positive parents and/or siblings are offered. While some children may not need additional services, the combined stress of undertaking adult responsibilities and having a parent with a chronic stigmatized illness warrants assessment. Clinicians are advised to:

• routinely screen the HIV-affected child for psychiatric concerns using multiple measures and sources to avoid under-identification (21).

Using two sources to obtain information, such as the child and a parent or the child and a teacher, provides a more complete screen. The Behavioral and Emotional Screening System (for children 3 through 18 years of age) is a valid and reliable screening tool that utilizes information from three sources. See http://www.pearsonassessments.com/ HAIWEB/Cultures/enus/Productdetail.htm?Pid=PAaBASC2bess for tool.
• familiarize themselves with the child-centered Parentification Questionnaire, as it has been shown to be a valid and reliable tool for assessing the extent of parentification and the child’s perception of fairness (22).
• obtain releases to speak with the child’s pediatrician.
  - Pediatricians are in a strategic position to assist children of mothers with HIV, as they often know the maternal health history, see the children over a prolonged period of time, and can identify and refer children with mental health concerns to appropriate resources (21).

5. Implement a family-centered care model
Research consistently indicates that a model of care involving funding for family-centered services for caregivers and children provides a foundation for stronger, more resilient families (9,12,16,23). A family-centered model of care could provide:
• routine screenings for mental and physical health conditions for all members of the family unit (12);
• comprehensive medical care for children affected by HIV to promote the health and functioning of the entire family (12);
• family-focused coping skills interventions (16);
• a holistic approach to treatment that supports the parentified child, but doesn’t take away the child’s role, which commonly becomes integrated into his or her identity (9); and
• education and support to all members of a family to minimize the common intergenerational experience of HIV (23).

6. Ensure recognition and validation of young caregivers
Service providers who enter the lives and homes of HIV-affected children and youth most commonly direct their attention to the HIV positive individual in the house, leaving the child who is serving this important family function feeling invisible. Explicit support and recognition for the child’s adult responsibilities may influence the child’s perception of equity and fairness resulting in healthier long-term adjustment (7). It is important that both the service provider and the parent validate the child’s role in the family by speaking directly about it with the child, and acknowledging the importance and potentially difficult role the child is filling (9). Asking the child if they need assistance with their tasks may be an efficient engagement route for the clinician.
7. Provide ancillary support for children

In addition to the above interventions, providers can assist the parentified child by offering or referring the child to the following supportive services:

- stress reduction programs to increase the child’s resiliency;
  - *Children can be taught to label feelings, develop self-control, learn problem-solving skills, and apply anger management techniques (19).*
- respite care for caretaking duties, plus assistance with tasks, so children can attend school and participate in age-appropriate activities (3,6);
- counseling programs for identified mental health needs;
  - *Parentified children may benefit from a trauma-informed counseling program tailored to overcome feelings of guilt, shame, and stigma (3).*
- permanency planning to solidify linkages to support people, such as friends or relatives, as well as reduce potential anxiety for the child; and
- safe sex and drug abuse prevention education since youth are at high risk, and may not be attending school regularly (3).
  - *HIV negative inner city adolescents with HIV positive parents are considered to be one of the highest at-risk groups for acquiring HIV (4).*

**Interventions Recommended by SAMHSA and/or DEBI:**

8. Advocate for policy initiatives

Whereas the above recommended interventions are ideal supports for parentified children and youth living in HIV-affected homes, there are many policy issues that need to be addressed as well. In particular, we need the following:

• dedicated funding to help provide services to HIV negative children;
• education, awareness, and advocacy about HIV and young caregiving in mainstream culture to decrease social isolation and stigma;
• capacity building of professionals to support this group;
• greater coordination of services;
• more accessible and culturally appropriate services;
• safe sex and substance abuse prevention programs earlier! Ages 13-14 years is the critical period for initiating prevention programs for sexual behavior and substance abuse. Many programs target high school kids, and miss a critical period for effective intervention. Prevention programs are needed prior to high school (4); and
• policies that ensure that everything will be done to keep siblings together whenever possible and appropriate. Sibling bonds are protective, provide strong relationships, and are a source of continuity in the face of family challenge (2).

Given the financial times, and the general lack of funding available to intervene with HIV-affected children, it is unrealistic and unnecessary to think that any one program will be able to implement the spectrum of recommendations listed above. To provide the needed services for these families, a true community effort should be considered. The first step an agency can take to assist this population is to assess if parentification is indeed an issue for its families. If families and children are affected, the agency can then evaluate which of the above recommendations are reasonable within the context of its scope of work and finances. An assessment of the role of outside agencies in this regard would also be helpful to reduce duplication of services and effort. So, for example, partner providers and the broader community may already be providing certain services, such as parenting classes, sexual education, or respite care that can help fill in the gaps. Each parentified child may not require or benefit from all of the services listed above. As is the case with most social service programs, a detailed, individualized family assessment will help craft the roadmap of needed services for each family and child.
Resources for Providers

1. Parenting education matrix (programs that work and don’t work):
   http://archive.constantcontact.com/fs008/1101701160827/archive/1102882009771.html
2. Interventions and assessment tools available online at: http://chipts.ch.ucla.edu/manuals
3. The Diffusion of Effective Behavioral Interventions (DEBI), evidence-based HIV prevention/risk reduction programs:
   http://www.effectiveinterventions.org
4. Samsam National Registry of Evidence-based Programs and Practices:
   http://nrepp.samhsa.gov/Search.aspx

References

The National Abandoned Infants Assistance Resource Center’s mission is to enhance the quality of social and health services delivered to children who are abandoned or at risk of abandonment due to the presence of drugs and/or HIV in the family by providing training, information, support, and resources to service providers who assist these children and their families. The Resource Center is located at the University of California at Berkeley, and is a service of the Children’s Bureau.

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