What’s New in Research?

A review and analysis of recent publications on children affected by HIV and AIDS

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In this issue we review four papers on disclosure: one on the social circumstances affecting child HIV disclosure in Kenya, a review of the investments made by NIH in studies of disclosure to children, and two intervention studies, one in Namibia and one in South Africa. We also introduce two papers on sex work in the context of HIV prevention, treatment and support. The first, a Lancet commentary on sexually exploited children and adolescents who sell sex and, the second, a study recommending integrated services for women, who are mothers, who sell sex in Burkina Faso.

Reviewed in this edition of What’s New in Research?

- 'Why did you not tell me?': perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya
- National Institutes of Health investment in studies of HIV disclosure to children
- Growing-up just like everyone else: key components of a successful pediatric HIV disclosure intervention in Namibia
- Maternal and child psychological outcomes of HIV disclosure to young children in rural South Africa: the Amagugu intervention
- Responses to HIV in sexually exploited children or adolescents who sell sex
- Mothers who sell sex: a potential paradigm for integrated HIV, sexual, and reproductive health interventions among women at high risk of HIV in Burkina Faso
'Why did you not tell me?': perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya


Published Abstract

Objective: We sought to better understand how social factors shape HIV disclosure to children from the perspective of caregivers and HIV-infected children in Kenya.

Design: We conducted a qualitative study using focus group discussions (FGDs) to gain perspectives of caregivers and children on the social environment for HIV disclosure to children in western Kenya. FGDs were held with caregivers who had disclosed the HIV status to their child and those who had not, and with HIV-infected children who knew their HIV status.

Methods: FGD transcripts were translated into English, transcribed, and analyzed using constant comparison, progressive coding, and triangulation to arrive at a contextualized understanding of social factors influencing HIV disclosure.

Results: Sixty-one caregivers of HIV-infected children participated in eight FGDs, and 23 HIV-infected children participated in three FGDs. Decisions around disclosure were shaped by a complex social environment that included the caregiver-child dyad, family members, neighbors, friends, schools, churches, and media. Whether social actors demonstrated support or espoused negative beliefs influenced caregiver decisions to disclose. Caregivers reported that HIV-related stigma was prominent across these domains, including stereotypes associating HIV with sexual promiscuity, immorality, and death, which were tied to caregiver fears about disclosure. Children also recognized stigma as a barrier to disclosure, but were less specific about the social and cultural stereotypes cited by the caregivers.

Conclusion: In this setting, caregivers and children described multiple actors who influenced disclosure, mostly due to stigmatizing beliefs about HIV. Better understanding the social factors impacting disclosure may improve the design of support services for children and caregivers.

Availability: Subscription or pay for access.

Comment and implications for Policy and Practice

It is well to remember the size and nature of the problem addressed by studies on disclosure of HIV status. More than 3.4 million children under 15 years of age are living with HIV, of which 90% are in sub-Saharan Africa. Knowledge of children’s status is critical to their lifelong adjustment to living with HIV. However, in low- and middle-income countries, the issue does not receive the attention it deserves, and children in these settings are less likely to know their status and when they do, they learn it later. In all circumstances, caregivers face difficult decisions about when and how to tell a child that they are HIV-positive. On the one hand, children's knowledge of their
status helps to normalize their situation and supports adherence; on the other hand, caregivers fear that the child will tell others and face stigma and cruel discrimination. It is important to realize that, in this study, children and caregivers who participated in the focus groups were recruited separately and are not necessarily paired. They could have been paired as the legal guardians, presumably also the child’s main caregivers, gave written consent for child participation. But participating caregivers included those who had disclosed and those who had not disclosed to a child (the majority, 62%), and this created variability and a test of the commonality of experience across the two groups. Caregivers were mostly biological mothers. The children were between 10 and 16 years of age, and knew their HIV status. The average age of disclosure to a child was 11 years. Pervasive themes emerging from the analyses included the following: 1) the fear that immorality associated with HIV would be hurtful for the child and caregiver, as would 2) the notion that HIV led to terminal disease and eventual death. Also of concern was: 3) fear of a strong negative, even suicidal, emotional reaction by the child (although no child participant expressed suicidal thoughts in response to disclosure), and 4) fear of rejection by the child, who might blame the parent for their infection and/or judge them negatively for the immorality associated with HIV. Both caregivers and children 5) shared the fear of onward disclosure and resulting rejection and discrimination. Beyond these, major caregiver-child factors were was fear of rejection, negative judgement and discrimination from close family, friends and neighbors. However, attempts to keep a child’s HIV status secret from these groups impacted adversely on HIV management and adherence. These fears, though, were seldom realized, with most disclosing caregivers and children reporting psychological and HIV management support offered by these close communities. Both church and school were also important social contexts for disclosure, with both negative and positive experiences reported. The authors conclude that there are as yet, few studies evaluating disclosure protocols and interventions, which provides a fitting introduction to the two later papers on intervention results.

**BOX 1 – Triangulation in research**

Triangulation is often reported as a validation procedure in qualitative studies, sometimes seemingly as a way to make the findings seem more solid and credible. But what does it mean in practice? Triangulation is a mathematical term used in land surveying to describe the process of deducing the location of a point by measuring angles to it from known points at either end of a fixed baseline, rather than having to measure the distances to the point directly. In social science research it refers to the use of two or more approaches to check results. It can be used in either qualitative or quantitative studies and may involve the comparison of findings from both kinds of studies. But it can also involve comparison of observations from different observers or interviewers, the use of different theoretical approaches, different methods, different instruments, and so on. At its heart, efforts to triangulate findings reflect a basic tenet of the scientific method – the importance of excluding false results or results attributable to unrelated factors, or factors related to, but not, the hypothesized cause. It is important, when describing the use of triangulation, to indicate what was triangulated and what findings emanated from the procedure. In the study by Vreeman et al (2015), views on disclosure by children and caregivers, and by caregivers who had and had not disclosed HIV status to children, were triangulated to draw conclusions about community and interpersonal factors that affect caregiver to child disclosure.
Published Abstract

The goals of this manuscript will be to review current and past National Institutes of Health (NIH) funding on maternal and child HIV disclosure research and lay out current research gaps in these areas. Examples of work funded by NIH will highlight how the disclosure needs of families affected by HIV have changed over the past 30 years as well as highlight what we have learned. The review will include the recent NICHD RFA that focused specifically on disclosure of HIV status to children in low and middle-income country settings. A brief description of findings from these NIH-funded grants will be provided. The authors will then describe current research gaps and challenges as they relate to research on HIV disclosure both in the U.S. and internationally.

Availability: Subscription or pay for access.

Comment and Implications for Policy and Practice

Mortality of children and adults with HIV has dropped and increasing numbers of people are living with HIV infection as a chronic disease. Recognizing the importance of disclosure, the National Institutes of Health (NIH) began investing in research on the topic in the 1990s, funding studies that examined 1) disclosure of adult HIV to children and 2) disclosure of children’s HIV status to them. From the earliest studies, some of which were longitudinal in nature, and even with limited treatment and uncertainty of disease outcome, trends began to emerge. Among these are: 1) the need to support families with this difficult process; 2) the mental health relief experienced by parents (mostly mothers) and children on successful disclosure and consequent improved coping over time; 3) the fear of rejection and discrimination by wider networks, and 4) the need to identify “safe people” to whom HIV status could be disclosed so as to increase support for a mother and her children. In 1999, the American Academy of Pediatrics published guidelines stating that all adolescents should know their HIV status and that disclosure should be considered for school-aged children; the guidelines were re-affirmed in 2012. Reviews published in 2004 laid out what was known at the time and remain applicable today. Details of these landmark publications are given below. In 2005, international work (in Uganda) and in 2007, intervention studies started to be funded by NIH. The World Health Organization (WHO) published guidelines for HIV disclosure in 2011 (see box), though largely based on findings from the United States, with unknown applicability to high HIV prevalence settings. In response, NIH funded several studies on disclosure in China, Haiti, Dominican Republic, Zimbabwe and other countries in sub-Saharan Africa. The emphasis currently in the NIH portfolio is on testing the effectiveness of interventions.
**Landmark guidelines on HIV disclosure**


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**BOX 2 – Key recommendations from the WHO Guidelines on HIV disclosure counseling for children up to 12 years of age**

Noting low quality and absence of evidence:

1. Children of school age should be told their HIV-positive status; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure.
2. Children of school age should be told the HIV status of their parents or caregivers; younger children should be told this incrementally to accommodate their cognitive skills and emotional maturity.
3. The decision on who will disclose to the child will be guided by the intention to improve/promote the child’s welfare and minimize the risk to his/her wellbeing and to the quality of the relationship between child and parent/caregiver.
4. Initiatives should be put in place to enforce privacy protection and institute policy, laws and norms that prevent discrimination and promote tolerance and acceptance of people living with HIV.
Published Abstract

**Objectives:** To facilitate replication and adaptation of pediatric HIV disclosure interventions, we identified key components of a child-friendly cartoon book used to guide Namibian caregivers and healthcare workers (HCWs) through a gradual, structured disclosure process.

**Design:** Qualitative interviews were conducted with caregivers and HCWs from four high-volume pediatric HIV clinics in Namibia.

**Methods:** Semi-structured in-depth interviews with 35 HCWs and 64 caregivers of HIV+ children aged 7-15 were analyzed using constant comparative and modified grounded theory analysis. Major barriers to disclosure were compared to accounts of intervention success, and themes related to key components were identified.

**Results:** The disclosure book overcomes barriers to disclosure by reducing caregiver resistance, increasing HIV and disclosure knowledge, and providing a gradual, structured framework for disclosure. The delayed mention of HIV-specific terminology overcomes caregiver fears associated with HIV stigma, thus encouraging earlier uptake of disclosure initiation. Caregivers value the book’s focus on staying healthy, keeping the body strong, and having a future ‘like other kids’, thus capitalizing on evidence of the positive benefits of resilience and hopefulness rather than the negative consequences of HIV. The book’s concepts and images resonate with children who readily adopt the language of ‘body soldiers’ and ‘bad guys’ in describing how important it is for them to take their medicine. Discussion cues ease communication between HCWs, caregivers, and pediatric patients.

**Conclusion:** Given the urgent need for available pediatric HIV disclosure interventions, easily implementable tools like the Namibian disclosure book should be evaluated for utility in similar settings.

**Availability:** Subscription or pay for access.

**Comment and implications for Policy and Practice**

To address the gap in disclosure protocols, practical guidelines and intervention trials, the Namibian Ministry of Health and Social Services worked with health care workers (HCWs) and
others to develop a support package to assist caregivers and HCWs with disclosure to children. The centerpiece of the package is a colourful child-friendly cartoon booklet organized into five chapters: Chapter 1 describes how medicines keep ‘body soldiers’ strong and protect the child from getting sick, so he can grow up to be a successful adult. Chapter 2 describes the ‘bad guy’ who can make them sick by attacking their body soldiers. Chapter 3 describes the importance of taking medicine regularly to keep the ‘bad guys’ asleep and thus allow the body soldiers to be strong and numerous. Chapter 4 describes how the ‘bad guy’ can wake up if medicines are not taken correctly. Chapter 5 leads to full disclosure by explaining that the ‘bad guy’ is names HIV and that ‘body soldiers’ are CD4 cells, and the medicines are called antiretrovirals” (p. S82).

According to the authors, the intervention has been integrated into routine HIV outpatient care country-wide and is targeted to begin at age 6 with the goal of achieving full disclosure by 10 years of age. The paper describes the evaluation of how the cartoon book helps to overcome specific barriers through a cross-sectional study of the disclosure intervention at four of the highest volume pediatric HIV clinics in Namibia. Overall, the authors conclude that the main messages of the cartoon book allay “fears of stigma and psychological harm by focusing on medication use to keep body strong rather than HIV disease” (p. S83), using a gradual structured process, age-appropriate accurate information in simple terminology with future-focused messaging.

**BOX – Piaget’s stages of cognitive development**

The authors quote several references on gradual pediatric disclosure which are based on Piaget’s theory of development. Piaget’s is one of two main developmental theories, the other being Vygotsky’s theory. The main difference between these theories is that Piaget saw the individual acting on his/her environment as the main driver of cognitive development, whereas Vygotsky argued that children learn through mediated social interactions with other people who give meaning to objects and events. Given this important difference, Piaget theorized that development from infancy to adulthood occurred through four consecutive stages: 1) sensorimotor, from birth to about 2 years, during which time the child interacts with the world through his/her senses; 2) preoperational, from about 2 to 7 years, during which time the child is transitioning towards, but has not yet mastered, mental operations; 3) concrete operations, from about 7 to 11 years, during which time children learn best through hands-on discovery learning relating to real world events and objects; 4) formal operations, which develop progressively from about 11 years of age onwards, during which time the individual begins to be able to think abstractly, released from the constraints of the immediate material reality. Gradual disclosure is intended to help the child comprehend what they can at each particular cognitive developmental stage.
Maternal and child psychological outcomes of HIV disclosure to young children in rural South Africa: the Amagugu intervention


Published Abstract

Objectives: Increasingly, HIV-infected parents are surviving to nurture their children. Parental HIV disclosure is beneficial, but disclosure rates to younger children remain low. Previously, we demonstrated that the ‘Amagugu’ intervention increased disclosure to young children; however, effects on psychological outcomes have not been examined in detail. This study investigates the impact of the intervention on the maternal and child psychological outcomes.

Method: This pre-post evaluation design enrolled 281 HIV-infected women and their HIV-uninfected children (6-10 years) at the Africa Centre for Health and Population Studies, in rural South Africa. The intervention included six home-based counselling sessions delivered by lay-counsellors. Psychological outcomes included maternal psychological functioning (General Health Questionnaire, GHQ12 using 0,1,2,3 scoring); parenting stress (Parenting Stress Index, PSI36); and child emotional and behavioural functioning (Child Behaviour Checklist, CBCL).

Results: The proportions of mothers with psychological distress reduced after intervention: GHQ threshold at least 12 (from 41.3 to 24.9%, P<0.001) and GHQ threshold at least 20 (from 17.8 to 11.7%, P=0.040). Parenting stress scores also reduced (Pre M=79.8; Post M=76.2, P<0.001): two subscales, parental distress and parent-child relationship, showed significant improvement, while mothers' perception of 'child as difficult' was not significantly improved. Reductions in scores were not moderated by disclosure level (full/partial). There was a significant reduction in child emotional and behavioural problems (CBCL Pre M=56.1; Post M=48.9, P<0.001).

Conclusion: Amagugu led to improvements in mothers' and children's mental health and parenting stress, irrespective of disclosure level, suggesting general nonspecific positive effects on family relationships. Findings require validation in a randomized control trial.

Comment and implications for Policy and Practice

As indicated by the authors, the “conceptual framework of this intervention is based on well-established evidence that the quality of the parent-child relationship is important for children’s psychological wellbeing” (p. S68). Even if not informed, children “pick up” on parental moods and behaviour and may blame themselves for imagined wrongs which compound their sense of anxiety about their parent’s health and wellbeing. This paper reports on a pre- and post-intervention evaluation of Amagugu in which HIV-infected women with an uninfected child were enrolled in a follow-up of an earlier study of breastfeeding and vertical transmission (Mamaengane). The outcomes assessed were maternal psychological functioning and parenting stress as well as child emotional and behavioural disorders. Just over half (291 of the 525 available mothers from the original study) entered the trial and completed the follow-up. An earlier publication by this group showed that the number of mothers who disclosed to their children increased following the intervention (Rochat et al, 2014). In this study, the proportion of mothers showing psychological stress above the cut-off point and parenting stress, as well as child emotional and behavioural problems, decreased from pre- to post-intervention, though there was no effect of disclosure type (full, partial or none) on the outcome measures. On the basis of these findings, the authors conclude that the intervention has positive non-specific effects on family relationships and communication.


**BOX 4 – The Amagugu intervention**

The intervention has three stages that occur over six sessions:

Stage 1: Disclosure preparation: The mother is encouraged and supported through one-on-one counseling to adopt an active coping style to her HIV infection and she is trained in HIV disclosure, including the use of child-friendly HIV education tools and materials.

- Session 1: Positive parenting (one-on-one counselling)
- Session 2: Positive families (counselor facilitated meeting)
- Session 3: Positive practices (one-on-one training session)
- Session 4: Positive life stories (one-on-one counseling)

Stage 2: Shift to health promotion and health-seeking: The child is taught about the mother’s HIV and accompanies her to her HIV clinic. Children’s questions are answered and HIV demystified. Children participate in discussions about care and custody.

- Session 5: Positive planning (one-on-one training)

Stage 3: Play for communication: Mothers are trained to use play for communication with a handmade doll to facilitate communication with children about their feelings and concerns. Children are rewarded for their participation and pride, a sense of belonging and safety are encouraged in a positive HIV family context.

- Session 6: Positive futures (one-on-one training)

Published Abstract

This Comment focuses on the HIV concerns of children and adolescents aged 10–17 years who are exploited in the sex industry through selling sex, and does not consider other forms of sexual exploitation. The term "sexually exploited children and adolescents aged 10–17 years who sell sex" describes the behavior that renders this group at-risk of HIV and does not describe identity. Children younger than 18 years who sell sex, irrespective of the reason, are considered under international law to be sexually exploited children. It is of course essential that evidence and rights-based efforts should be improved to protect children from all forms of sexual exploitation, including preventing them from ever getting involved in selling sex. It is crucial, however, that programs and policies for sexually exploited children and adolescents aged 10–17 years who sell sex are not merely based on assumptions. Instead, policy makers, programmers, researchers, and youth organizations should work together to ensure that adolescents are involved at all levels of program and policy design, implementation, and evaluation, so that the response is shaped by their realities, needs, and aspirations.

Availability:

Comment and implications for Policy and Practice

The authors begin their commentary by saying that “One of the crucial gaps in the current HIV response is that we are not reaching children and adolescents aged 10-17 years who sell sex, with life-saving prevention, treatment, protection, care or support” (p. 97). Although there are no global estimates of this group of children, many studies show that substantial numbers of sex workers began selling sex when they were younger than 18. Youth are more susceptible to a range of threats, including sexual risks and violence, than older individuals, as well as having less control over their sexual encounters, and they face more barriers to legal, clinical and welfare services and more harassment than adults. Current interventions for sex workers are not tailored towards young people and generally children are forcibly removed from the situation and placed in statutory care, an approach which forces youth who sell sex and their activities further underground. The authors argue for an age-differentiated harm reduction approach, which provides access for these young people to all sexual and reproductive health services as well as more and better research to determine which approaches work best for various youth sub-groups, such as those who are homosexual, bisexual or transgender.
Mothers who sell sex: a potential paradigm for integrated HIV, sexual, and reproductive health interventions among women at high risk of HIV in Burkina Faso.


Published Abstract

Background: Antenatal care is a point of entry into the health system for women across Africa and may facilitate the uptake of HIV services among female sex workers (FSWs). This study aimed to evaluate the determinants of motherhood among FSWs, their sexual risks, and their engagement in health care.

Methods: A cross-sectional study was conducted from January to July 2013 among FSWs in Ouagadougou and Bobo-Dioulasso, Burkina Faso. The study used respondent-driven sampling for HIV testing and behavioral data collection. Predictors of motherhood and the association of motherhood and sex work dynamics were assessed separately using logistic regression.

Results: Of the 696 women enrolled, the majority of participants (76.6%, n = 533) had at least one biological child. Mothers were more likely to have a nonpaying partner [adjusted odds ratio (aOR), 1.73; 95% confidence interval (CI): 1.20 to 2.49], and significantly less likely to currently desire to conceive (aOR, 0.21; 95% CI: 0.13 to 0.33). Motherhood was predictive of having reduced condomless vaginal or anal sex with a new client [age-adjusted odds ratio (aaOR), 0.80; 95% CI: 0.65 to 0.97] in the past 30 days, and increased condomless vaginal or anal sex with a nonpaying partner (aaOR, 1.49; 95% CI: 1.13 to 1.96). Motherhood was prognostic of a higher likelihood of ever being tested for HIV (aaOR, 1.89; 95% CI: 1.55 to 2.31). Motherhood was predictive of reporting limited difficulty when accessing health services (aaOR, 0.15; 95% CI: 0.67 to 0.34).

Conclusions: Motherhood is common among FSWs. The results indicate that FSWs who are mothers may have more exposure to health care because of seeking antenatal/perinatal services, presenting important opportunities for inclusion in the HIV continuum of care and to prevent vertical transmission.

Availability:
Comment and implications for Policy and Practice

The parenthood of marginalized groups such as sex workers, drug users and men who have sex with men, is a topic not much written about, although the Coalition for Children Affected by AIDS (www.ccaba.org) drew attention to it in its 2009-2010 series of meetings on family-centred services for children affected by AIDS. These resulted in a special issue of the Journal of the International AIDS Society (http://www.jiasociety.org/index.php/jias/issue/view/1446) and set in motion the development of an ethical decision-making tool for care workers supporting parents whose behaviours are stigmatized and whose family life is frequently hidden from view (http://www.ccaba.org/ethical-decision-making-tool-launched). In this paper, the authors take a somewhat different perspective, examining how motherhood might increase risk and/or protection among sex workers in Burkina Faso. Through interviews with a large sample of women, the majority mothers, the authors unravel the complex story of parenthood and partnerships among a group of women (sex workers) who are reported to have, on average, a 12 times higher risk of HIV infection than other women. Forced sex, being tested for HIV and using contraceptives to prevent pregnancy were common to both mothers and non-mothers, but mothers tended to have less education and were more likely to be married or co-habiting with a partner. In fact, mothers were 73% more likely to have a non-paying partner compared to non-mothers. Mothers were much more likely to use condoms with a paying client - presumably to keep themselves safe, amongst other reasons because of a sense of responsibility towards one or more children – but much more likely to have condomless sex with a non-paying partner. In addition, motherhood was a significant predictor of women’s entry into sex work to provide for a family. Mothers were also less likely to have sources of income other than sex work. On the protective side, mothers were much more likely to use health services than non-mothers. As has been concluded from previous studies, the need to care for children is a primary reason for going into sex work and staying in it. While sex workers frequently do not disclose motherhood for fear that their children will be forcibly removed from them, acknowledgement by health workers of motherhood and supportive services to protect both the mother and her children through sexual, reproductive and child health services, would go a long way to alleviate the difficulties these families face and their high risks for HIV infection and for remaining un-reached by HIV treatment and care.
Respondent-driven sampling (RDS) is a technique used to recruit hard-to-reach or hidden populations into studies in a way that takes account of the fact that their participation is not random. Random sampling, from which the claim can be made of representativeness, can only be achieved if the reference population is known; for example, all women in the villages in a particular ward. However, sex workers, drug users and other groups of people who are not readily visible and countable cannot be randomly sampled because the size and whereabouts of the population are not known. RDS is more methodologically rigorous than “snowball sampling”. Snowball sampling is network sampling, based on the identification of one member of the group that is being sought for recruitment, who then introduces the investigator to one or more members, who in turn introduce the investigator onwards until the desired sample size is achieved. In RDS, snowball sampling is used, but it is combined with a mathematical model based on the network size of each of the people who identify others. This is done so that the investigator samples proportions of people from sufficiently different networks in an effort to avoid bias. For example, in the study reviewed, the authors limited each onward identification to three people to avoid sampling sex workers from one particular area or who worked out of a limited number of bars etc.