Published in final edited form as:
AIDS Care. 2013 June ; 25(6): 763–766. doi:10.1080/09540121.2012.748878.

"ARVs" as Sickness and Medicine: Examining children's knowledge and experience in the HIV era in urban Zambia

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Abstract

Since the roll out of no cost antiretroviral drugs (ARVs) in health centers in Zambia in 2004, the number of Zambians receiving treatment has substantially increased. While research has addressed adult responses to ARVs in Zambia and elsewhere, there is little known about how children experience and respond to the presence of treatment in their communities and households. The increasing acknowledgement that children provide care and treatment support to people with HIV in their households demands a better understanding of children's knowledge of HIV and ARVs. To examine children's ARV knowledge, this article focuses on three children's workshops carried out with 38 children ages 8 to 12, who participated in a yearlong ethnographic study in 2007 and 2008. All children lived in a low-income and heavily HIV-affected residential area in Lusaka, and many children lived with parents or guardians who had HIV. Findings suggest that when the children discussed ARVs, they made two intersecting points: 1) local conditions make living with HIV, even while on ART, difficult; and 2) children face particular challenges, concerns, and insecurities when caring for and living with the ill. Children's discussions about ARVs offer a deeper understanding of experiences of HIV and childhood in a disproportionately HIV-affected and low resource area. Such insights might productively inform future programming and research aimed at assisting children and adults.

Keywords

HIV/AIDS; antiretroviral therapy; children; Zambia

Children's care for family members who have HIV has received substantial attention in recent years (Ansell & van Blerk, 2004; Skovdal & Ogutu, 2009; Skovdal et al., 2009; Young & Ansell, 2003), and recent observations suggest that children play roles in helping adults adhere to antiretroviral therapy (ART or ARVs) (Foster et al., 2010; Hardon et al., 2007). While such observations raise questions about children's knowledge of ART, few studies have examined children's understandings of ART, except when children are taking ARVs (Li et al., 2009). The aim of this report is to begin the conversation about how ART has entered into children's lives, not as medicine takers, but as community members and social actors who live with and give care to the sick.

Setting

The research took place in Zambia's capital city Lusaka, in a low-income residential area (population approximately 130,000). The area has one health center, where an ART Clinic provides no cost treatment to a catchment area that extends beyond the residential area. The challenges of ART provision are similar to those discussed by other researchers in Zambia: distance to the clinic; long queues; shortage of staff and resources; high HIV stigma; disclosure difficulties; unofficial medical costs such as food and transportation; gender relations and inequalities; and the side effects of treatment (Chileshe & Bond, 2010; Murray et al., 2009; Schumaker & Bond, 2008).

Methods

Households and children

Thirty-eight children (ages of 8 to 12) participated in 12 months of ethnographic research during 2007 and 2008. The children were members of 25 households recruited for a household study concerned with children's roles in households with sick adults. Study protocol required that all children were healthy enough to carry out basic chores, but did not ask about HIV status. Using a case-comparison design, 17 households were recruited as case households when an adult was diagnosed with TB, a primary HIV-related infection in Zambia. Eight households served as comparison households, without any illnesses at recruitment. It is notable that after recruitment each comparison household dealt with serious illnesses such as TB, epilepsy, and malaria.

Ethnography

This project used team ethnography, in which two local research assistants and I systematically visited each household weekly. Ethnography is a methodology that draws on a range of methods, such as observation and interviews, to illuminate lived experience (Savage, 2000). Team ethnography "allowed comparison of observations and strengthened assessment of validity…it allowed for the interaction of multiple perspectives of 'insider/outsider'" (Mullings et al., 2001: 88). During household visits, we employed instant records and extended observations. Instant records consisted of drop-in visits at various days and times to record snapshots of household activities (Reynolds, 1991). Extended household observations led to findings about therapy management and children's roles, which were followed up through open-ended interviews, child-oriented research techniques, and six children's workshops held in a community building. [Author] 2011 offers a detailed description and analysis of my research method with children.

Children's workshops

Because children were uncomfortable discussing issues of illness and HIV in their households, I designed three workshops to elicit children's knowledge of and experience with HIV and caregiving (Author, 2011; Author, forthcoming). Each child attended one of three workshops that consisted of two activities. First, children were asked to list sicknesses that concerned them and answered a series of semi-structured questions about each sickness. Second, children were broken into small groups and asked to develop role-plays on the general theme "living with a sick person."

The workshops were conducted in Nyanja, the predominant language spoken in George. All workshops were recorded and transcribed by a local research assistant. The study was approved by [U.S.] University's Internal Review Board and the University of Zambia's Research Ethics Committee.

Results

Disclosure and medicine

At least one adult member in 16 of the 25 households was HIV positive. Because testing rates are low and there is substantial stigma surrounding HIV (Bond & Nyblade, 2006), these numbers may be low, particularly given the illness burden in the study households. No adult diagnosed with HIV had directly disclosed their diagnosis to the children in their households, instead referring to illnesses that were less stigmatizing (e.g. malaria). Children were rarely allowed to accompany adults to clinical visits that might reveal their guardian's HIV diagnosis.

Despite nondisclosure, children emphasized their involvement with medication during the workshops, suggesting that they may learn about diagnoses through giving and observing medicine. When asked how they "gave care" to the sick, children's main response was that they gave and reminded adults to take medicine. Further, all role-plays on "living with a sick person" revolved around helping a sick person take medication at home. In some role-plays, children even labelled the medicine ARVs.

ARVs as sickness

Children in each workshop listed the sicknesses that concerned them most in George (Table 1). In two of the three groups, children placed ARVs on their lists. When asked to define ARVs, some children stated: "ARVs is a virus that causes disease" and "If the ARV enters you, you get sick of HIV." To understand why ARVs might come to stand for sickness, I turn to 11-year-old Rose, who insisted that ARVs was a sickness in both the workshop and during the home-based research. Rose had watched her uncle, grandfather, and grandmother fall ill with HIV-related illnesses. No one in the household disclosed their HIV diagnoses to Rose, even though Rose questioned them about the medications and was heavily involved in reminding them to take their medication. While it is impossible to draw direct connections between adult references to ARVs as signifiers of HIV and Rose's understandings that ARVs were a form of sickness, it is likely that Rose's understandings extended from careful attention to medical regimens. The pressing and continuous health problems faced by adults in her household confirmed her convictions.

ARVs and uncertainty

While a couple children said that ARVs were "medicine for AIDS," most children who identified ARVs as medicine said that it was used to treat people who were so ill that they could not walk. Children's ARV talk was laced with moral evaluation and uncertainty, most evident in their comments about bodily change and ARVs. For example, as some children suggested: "When they give you ARVs, if you are thin, you suddenly get fat and people will start to be wondering at you." In the ARV era, rapid weight gain can provoke gossip and confirm undisclosed HIV diagnoses (Schumaker & Bond, 2008).

Rapid weight gain might also indicate quick bodily deterioration, rather than a return to health. According to an 11-year-old girl whose mother had died from AIDS, a person taking ARVs "gets fat and dies." Her comment is a reminder of the deep impact of personal experience and history on children's understandings. Children's uncertainty about medicine was further reinforced in children's role-plays on "living with a sick person." Despite continual appeals to medication, the fictive households in the role-plays became stuck in cycles of deteriorating health, new diagnoses, and increasingly complicated medical regimens, rather than a linear trajectory to returned health.

Discussion

The children's discussions of ARVs were revealing of the social and economic factors that have shaped their experiences with HIV. They show that children face particular challenges and concerns in the HIV epidemic. For example, when children referenced ARVs as sickness or medication for severe, unending illness, they underscored the continuing silence around HIV, which has been interpreted as harmful to a child's wellbeing and a barrier to HIV programming in southern Africa (Daniel et al., 2007, Wood, Chase, & Aggleton, 2006). However, through a study of children ARV talk, it becomes clear that children also learn about HIV through attention to medication and side effects. ARVs as both term and medication has entered into settings where stigma shapes the conversations people have about HIV (Bond & Nyblade, 2006). Adults frequently referred to HIV status not by saying that someone was "on ARVs." Such language reassigns meaning to words so that the name of a treatment might easily come to stand in for the name of a disease.

Continuing death, morbidity, and stigma fueled children's skepticism of ARVs. Increased educational initiatives that focus on ART are necessary, but they will not change the underlying commentaries in children's statements. Children's ARV talk demonstrates that local conditions make living with HIV, even while on ART, difficult. This is not to argue against education. Children wanted to know more about illnesses in their households. Their watchfulness of medical regimens demonstrates this, and children advocated for information in this study and others in Zambia (Author, 2009A, 2011; co-authored 2010). However, their interest in building particular disease knowledge is not just about having information but about helping in strategic ways that promote their own and their family's wellbeing. Interventions and educational initiatives must respect children's lived experiences and histories. Further, recent interest in involving children in roles as treatment supporters requires a deeper understanding of children's household experiences and also how they learn about and address HIV in settings where direct talk is not the norm.

Acknowledgments

I would like to acknowledge Emily Banda and Olivious Moono who offered research assistance for this project. This work was made possible by my affiliation with the Zambia AIDS Related TB Project (ZAMBART). The study was conducted with a Dissertation Fieldwork Grant from the Wenner-Gren Foundation for Anthropological Research and a Fulbright IIE fellowship. Writing was supported by a grant from National Institutes of Health National Cancer Institute Community Networks Program Centers (U54 CA153460; Colditz).

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Table 1

Children's lists of sicknesses in George (in the order and language mentioned)

Workshop 1	Cholera, TB, AIDS, **ARVs,** Diarrhea, *Kudwala matenda* (different diseases), Skin cancer, *Chifuba* (cough), *Chimfine* (sneezing/cold), HIV, Chicken pox, Skin Rash, *Mendo Kuvimba* (swollen legs), *Kudwala meso* (sick eyes), *Mutu* (headache), Bleeding, Joint pain disease
Workshop 2	Malaria, Cholera, HIV, TB, *Mumala* (diarrhea), *Mutu,* AIDS, Dysentery, *BP* (high blood pressure), Stroke
Workshop 3	Malaria, TB, Cholera, *Chifuba*, AIDS, **ARVs,** *Chimfine*, *Mutu,* Stomachache, *Vilonda* (sores)