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Illness Narratives of Children Living with HIV Who Do Not Know Their HIV Status in Ghana: “I’m sick, but I don’t know the sickness”; A Qualitative Study

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Abstract

Despite available guidelines for disclosure of HIV status to children, most children living with HIV are unaware of their diagnosis. We sought to characterize the concepts of illness and treatment among children living with HIV who do not know their status. As part of the Sankofa trial we interviewed 435 children aged 6–18 enrolled in clinical care at pediatric HIV clinics at two teaching hospitals in Ghana. Theoretic thematic analysis generated themes among responses.

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The children believe they come to the clinic to collect medication, to address specific symptoms, to prevent and treat ‘sickness’, or as part of their routine. Most children learned of their ‘illness’ from a family member. A majority (73.5%) of children had never talked about their ‘illness’ with anyone else; many feared consequences. Children living with HIV who do not know their status exhibit signs of anticipated and internalized stigma regarding their unknown ‘illness.’ An understanding of the way children conceptualize their illness has implications for health promotion and the provision of appropriate information to children living with HIV.

Resumen

A pesar de las pautas disponibles para la divulgación del estado del VIH a los niños, la mayoría de los niños que viven con el VIH desconocen su diagnóstico. Intentamos describir los conceptos de enfermedad y tratamiento entre los niños que viven con el VIH que no conocen su estado de infección. Como parte del ensayo Sankofa, entrevistamos a 435 niños de 6 a 18 años inscritos en atención clínica cuidados en clínicas pediátricas de VIH en dos hospitales docentes en Ghana. El análisis temático teórico generó temas entre las respuestas obtenidas. Los niños creen que vienen a la clínica a recoger medicamentos, a tratar síntomas específicos, a prevenir y tratar “condiciones” o como parte de su cuidado rutinario. A través de entrevistas, aprendimos que la mayoría de los niños aprendieron de su “enfermedad” de un miembro de la familia. Esta mayoría (73.5%) nunca habían hablado sobre su “enfermedad” con nadie más; debido a muchas consecuencias temidas. Los niños que viven con VIH que no conocen su estado, exhiben signos de estigma anticipado e internalizado con respecto a su “enfermedad” desconocida. El entender la forma en que los niños conceptualizan su enfermedad tiene implicaciones para la promoción de la salud y el suministro de información adecuada a los niños que viven con el VIH.

Keywords

Disclosure; Children Living with HIV/AIDS (CLHIV); Illness Narratives; sub-Saharan Africa

INTRODUCTION

Most children living with HIV reside in sub-Saharan Africa (SSA). Of these, an overwhelming majority (62–90%) are unaware of their HIV-positive diagnosis (1). With meticulous adherence to antiretroviral therapy (ART), children infected with HIV can survive into adulthood and assume responsibility for their own care (2–4). The issue of how and when to inform children of their status has received attention in recent years. Evidence to support disclosure is robust, and both the American Academy of Pediatrics and the World Health Organization support status disclosure in an age-appropriate fashion and recommend that disclosure be integrated into clinical care (5–9).

Natasi and colleagues describe a “culturally constructed clinical practice model,” in which illness narratives guide practice (10). ‘Illness narratives’ are stories which express understanding of the etiology and outcome of illness within a broader socio-structural environment (11, 12). In pediatric oncology, which has served as an exemplar for the benefit of disclosure, illness narratives of children with terminal cancer produce a framework on which the argument for disclosure was based (13, 14). Like pediatric cancer patients,

children infected with HIV have likely developed explanations for the lived experience of their illness (15–17). In the 1980's Bibace and Walsh suggested that illness perceptions in children progress analogously to Piaget's stages of cognitive development, maturing from illness as an external phenomenon to a psychologic and physiologic one (14, 18). Yet, it is unclear how a child living with HIV perceives the illness experience when the child has not been informed that he or she has HIV.

Illness narratives among children living with HIV have been explored to a limited extent by others (15–17). In the United States, a grounded-theory analysis of drawings showed that children who do not know they are HIV-positive exhibit emotional distress and disturbed self-image (15). In another study in Brazil, children living in an AIDS institution who did not know their status exhibited confusion regarding the need to take medication (19). Semi-structured interviews with Congolese youth living with HIV revealed that, before knowing their diagnosis, youth reported non-adherence to medications (16, 17). One participant recalled: *“Before, I was refusing to take my medicine, but since they announced to me that I was infected with that disease, I started taking medicines without any problems”* (16, 17).

In this study, we explored the illness perceptions of children enrolled in a disclosure intervention study in Ghana (20). To our knowledge, this is the first qualitative study exploring illness perceptions of children infected with HIV in SSA prior to disclosure.

METHODS

Design

This study examined qualitatively the illness perceptions of children living with HIV who had not yet been informed of their HIV diagnosis. The data were collected in interviews at baseline as part of the Sankofa study, a randomized controlled trial that tested a pediatric HIV disclosure intervention (20). Study procedures were approved by the Institutional Review Boards of University of Ghana Medical School, Komfo Anokye Teaching Hospital, and Yale University Human Investigation Committee.

Study Setting and Recruitment

Full details of the Sankofa protocol have been described elsewhere (21). In brief, participants were enrolled in the Sankofa disclosure intervention study at Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana, and the Korle-Bu Teaching Hospital (KBTH) in Accra, Ghana, between January 2013, and June 2016. Together, these sites provide care to 3500 children living with HIV. The children routinely attend clinic every three to four months and more frequently as needed. The study was introduced to attendees by designated site project staff members during regular clinic visits (21). The study was explained, and written consent was obtained from caregivers while verbal assent was obtained from children. Non-disclosure was ascertained from screening questions administered to caregivers and medical records. Children aged 7–18 who were enrolled in clinical care who did not know their HIV status were eligible to participate. Exclusion criteria for the children included: HIV-infected children less than 7 years of age and children with congenital or developmental disorders, comorbidities such as sickle cell disease or diabetes that require

frequent clinic visits or hospitalizations, clinically identified AIDS-defining illness present in the GHS chart at entry, or end-stage AIDS clinically identified in the GHS chart at entry. This sub-study included 435 out of a total 446 Sankofa child participants. Qualitative interview data were missing for eleven of the child participants.

Interview Procedures

Interviews were conducted with the child participants through individual face-to-face interviews at baseline following enrollment to the study. Four study staff with backgrounds in clinical psychology conducted the interviews in a private setting in the clinic. They were actively employed by each hospital and responsible for HIV and sexually transmitted infection-related counselling. They have experience in qualitative research and the data was analyzed by team members (NNR and HF) who have experience in qualitative research. In order to avoid potential accidental disclosure and to foster trust, children were interviewed in the presence of their caregivers.

Interview guides with semi-structured, open-ended questions and prompts were used to explore the child's illness perceptions. Interviews lasted approximately 20 minutes. Interviews were conducted in either English or Twi/Ga (local languages) and responses were recorded. The child was asked "Can you tell me why you are at the clinic today?" The interviewer would use whatever cognition the child used in his or her response for the rest of the discussion. This included queries such as: "How long have you had [*this condition/illness*]?" How did you learn that you have [*this condition/illness*]?" Do you know anyone else who has [*the same condition/illness or have to take medicines*] like you? Does having [*this condition/illness or taking medicines*] affect your life very much compared to other kids? Have you ever talked about having [*your condition/illness or taking medicines*] with anyone? If yes, the interviewer asked who had been told and "What kind of things did you talk about?" Who knows about [*condition/illness or that you have to take medicines*]?" Do you ever have any questions about [*your condition/illness or medicines*] or things that you'd like to talk about with someone but haven't been able to?

Responses to open-ended questions were recorded in the first person (e.g.: "Because I am having rashes on my body") and with interviewer's observations (e.g.: "Came for laboratory test. Child has no idea about what is wrong with her"). Responses ranged from 1–2 words (e.g.: "don't know") to longer phrases (e.g.: ""No idea. (Child sat down quietly when asked the above question and was just looking around.")), with an average length of 7 words per record in answer to the first open-ended question and 5 words per record in answer to the second open-ended question.

Data and Analytic Procedures

The transcribed interviews were coded and thematically analyzed using an inductive technique (22). Two researchers (HF and NRR) initially developed a framework of key issues and themes. Initial codes were generated using open coding (23). The first data were compared for similarities and differences and coded into categories that reflected the children's perceptions. Codes were compared, and similar codes were clustered and given an initial label, thus forming a category. The data were analyzed for relationships among

categories. For example, in response to the question, “can you tell me why you are at the clinic today,” the codes (1) for appointment, (2) for laboratory testing, (3) for injection were collated into the theme “Routine experiences of clinical care.” Many responses included multiple reasons for the visit, thus themes are not mutually exclusive. Themes which characterize more than 20 responses per question are summarized here; these are considered to have reached thematic saturation (24). Further analysis produced other categories. A comprehensive data chart was constructed by extracting segments of data from the transcripts and arranging these in a matrix according to emerging themes. After verification, the corpus of extracts was managed using a password-protected Microsoft Excel spreadsheet (25). Draft copies of the written report were shared with each member of the research team for review, verification, and comment. Children’s ages are reported in brackets following quotes. In response to dichotomous questions, frequency of response is reported.

RESULTS

Participant Characteristics

Sociodemographic characteristics of participant caregivers and children have been published (26, 27). In brief, 78% of caregivers reported self-employment and 63% reported a monthly household income of 300 Ghana Cedis (GHS) (equivalent to approximately 90 USD at the time of the study) (26). A majority of caregivers (72%) had completed elementary education or less (26).

Characteristics of participant children are reported in Table I. Children ranged from 6 to 18 years of age (mean = 9.78). There were approximately equal numbers of males (51%) and females (49%). Most children acquired HIV via maternal to child transmission (83%). Of the children with available CD4+ counts results (n=351), 23% had a CD4+ count of <500 cells/mL, meeting WHO classification for ‘mild to severe HIV-associated immunodeficiency’; 9.4% had a CD4+ count below 200 cells/mL, meeting criteria for AIDS (28, 29).

Reason for The Clinical Visit

Interviewers asked children “*Can you tell me why you are at the clinic today?*” This was followed by further prompts, as needed. Responses were available for 335 children. The following themes emerged:

The need to collect medication.—The most cited reason for clinic attendance was to collect medication. Some children who mentioned medication linked the need to take it to specific health concerns or symptoms: “*I have been having stomach and headaches occasionally, whenever that happens I come here for medication.*” [12 years of age] Others associated the need to take medicine to unspecified illness. “*I came to collect medicine because I have a disease in my body.*” [11 years of age]. Other children expressed that they took medication but did not know why: “*My aunty said my medicine is finished so I came to collect more. I don’t know why I take the medicine.*” [9 years of age]. Others indicated that though they took medication, they were specifically not sick: “*I came for a check-up and I will later be given medicine. There is nothing wrong with me.*” [10 years of age]

Specific ailment or physical malady.—Children expressed that they were attending clinic to address specific physical concerns. Common ailments included stomach pains, cough, headache, rashes, and ear problems. Other children said that they attended the clinic due to chronic conditions other than HIV/AIDS: *“I [am] coming for[a] check-up and medicine because I am sick. Mother told me something hit my heart when I was young. (Child suspects something is wrong but only the mother knows. His mother told him something hit his heart when he was young requiring regular check-up and medication).” [12 years of age]*

Ignorance.—Many children could not offer any explanation for why they were at the clinic. *“I just followed my dad here and I have no idea why I’m here.” [10 years of age]*

Routine lived experiences of clinical care.—For many children, clinic visits appeared to be routine (unlinked to either illness or treatment). This included visits for: review (the common terminology to describe appointments), blood work, or injections. *“I came for review. It means seeing the doctor and talking with him about your problems. I am not sick.” [11 years of age]*

Phenomenon of unnamed sickness.—Other children felt they were coming to the clinic because of sickness, often highlighting the unknown nature of that sickness. *“Because of persistent sickness” [11 years of age]. “(Child said she knows she is sick but does not know what specific sickness she is suffering from, she has tried several times to ask the doctor but anytime she makes an attempt other people may be around).” [15 years of age]*

First Realization of ‘Illness’

Children were asked: *‘How did you learn that you have this ‘illness’?’*; 169 answered. A majority of children said that a family member had informed them. *“(Grandmother and doctor asked her to be taking the medicine.)” [15 years of age]* Others said they had learned from clinical visits. *“The doctors write it in my folder.” [10 years of age]* Many reported awareness due to symptoms or bodily signs. *“I know myself. I have stomach aches and I have been having the pain.” [12 years of age]*

Disclosure to Others

Children were asked: *“Have you ever talked about having your ‘condition’ or ‘illness’ [child’s terminology used] or taking medicines with anyone?”* Of 320 respondents, a minority (26%) indicated ‘Yes,’ while a majority (73.8%) of respondents indicated ‘No.’ Those children who had never told anyone (n=236) were asked to extrapolate why they had not; 187 responses were recorded. Answers to the question *“What brings you to the clinic today”* are included in double brackets.

Cannot express why.—Most often, children were unable or unwilling to express why they had never told anyone else about their illness or condition. *“I don’t have any particular reason.” [[My time is due to meet with the Doctor. But there is nothing wrong with me.]] [7 years of age].*

Told not to by someone else.—Many children said they were told not to share information about their ‘illness’ by someone else. *“Because my mother told me not to tell anybody.”* *[[I came because I am sick.]]* *[11 years of age]* This was also cited by children who attributed clinic visits to specific, non-stigmatized health concerns: *“If I say it, I will be disobedient.”* *[[Headache.]]* *[8 years of age]*

Internal or External Stigma.—Other children indicated that they had not discussed their illness/condition with others due to secrecy, stigma, or both. *“I don’t want anybody to see that am taking medicine.”* *[[To collect medicine]]* *[11 years of age]* Some extrapolated the social consequence of discussion: *“(Because if they get to know they would not play with her.)”* *[[Came for medication for chest and back pains.]]* *[13 years of age]* Fear of maleficence was also described: *“They may make the condition worse through witchcraft.”* *[[Came for review; (Child is aware she has “germs” in her blood)]]* *[8 years of age]*

Other Reasons.—Less common explanations included that nobody had asked (reflected by 2 responses), others wouldn’t believe them (reflected by 1 response), or that they were feeling well (reflected by 1 response): *“Am feeling better because of the medicine. That is why I don’t discuss with others.”* *[[I came because of sickness.]]* *[14 years of age].*

DISCUSSION

In this study, we explored the illness perceptions of children living with HIV who had not been informed of their diagnosis. None of the children indicated awareness of having an HIV diagnosis when asked why they were attending the outpatient [HIV] clinic. Many children mentioned physical manifestations of illness as the reason for clinic attendance. This included both symptoms possibly linked to HIV-infection (e.g., rash) and those not necessarily linked to their HIV-infection (e.g., eye problems). Symptoms related to opportunistic infections or sequela of HIV were not mentioned by the child participants. However, about a fifth of children in our cohort had baseline CD4+ counts below 500 cells/mL, meeting WHO criteria for ‘mild to severe HIV-associated immunodeficiency’ (28, 29).

We previously reported that the overall disclosure rate among school-aged children in Ghana is low as 21% (30). Reasons for non-disclosure include caregiver fears that it will cause undue psychologic injury to children and that informed children living with HIV will subsequently disclose to others (31, 32). In contrast to the common caregiver concern that children who had been disclosed to would be unable to keep their status secret, a majority (73.8%) of children interviewed reported that they did not talk to others about their illness/unwellness. Many children reasoned that they maintained secrecy because their caregiver had asked them to. Other children attributed their secrecy to fears of adverse repercussions despite presumably *not knowing* their HIV status. Interestingly, these findings are similar to those from a qualitative study conducted by Abubakar and colleagues, which showed that among children living with HIV who *knew* their status in Kenya, secrecy was maintained because of fears of rejection, isolation, or stigmatization (33).

HIV-related stigma has been well-extrapolated and incorporates negative attitudes towards persons living with HIV/AIDS, fear of disclosure (anticipated stigma), and internalized stigma (34, 35). Children in our cohort exhibited signs of both internalized and anticipated stigma. Although nondisclosure may act as a protective factor with respect to avoidance of enacted stigma, internalized stigma has been shown to diminish quality of life among persons living with chronic illnesses and is associated with anxiety and depression (36, 37). This suggests that as these children age into adulthood, interventions to encourage adherence to medications, disclosure to sexual partners, and psychosocial well-being should build upon an understanding of lifelong experiences with stigma as well.

Caregivers also express concerns that disclosing to children will cause them distress. In pediatric oncology, social scientists find that even among children who “do not know” their condition, partial awareness along with a state of unknowing is present (38). The state of unknowing was mentioned often by children in our cohort: taking medication (but not knowing why), coming for check-ups (but not knowing the reason). Many children explained clinical care in a distinctly pre-operational manner, positioning caregivers as external phenomenon, driving decision-making. Other children went so far as to reiterate wellness (“but I am not sick”), drawing attention to the dissonance between attending a medical visit (where ART is routinely distributed) and internalized notions of wellness. Some children expressed a knowledge that there was an explanatory framework that had not yet been (but would be) revealed to them.

As disclosure protocols are designed, in-depth interviews before and after disclosure might expound upon some of the themes identified here. Before disclosing to children living with HIV, specialists should seek to determine the child’s current beliefs about illness and the source of those beliefs. Specifically, future work might extrapolate on how children’s understanding of illness (particularly illness defined by symptoms) relates to their understanding of the importance of medication and their overall adherence behaviors. A majority of children reported that they learned about their illness from a family member. Clinic-based disclosure interventions must be careful not to alter the trust between caregiver and child while also providing reliable, accurate information.

Our unique study population, very large sample size, and topic of interest make our findings unique. However, our study was in part limited by the cross-sectional design. Data regarding the illness perceptions of the children living with HIV were only captured at baseline. It would be valuable to capture the children’s illness perceptions over time and post-disclosure in future studies. In the Sankofa study, over the course of nearly three years, specialists met with children-caregiver dyads and built the skills necessary to facilitate disclosure. However, illness perceptions were not captured systematically over time. Future studies might also report objective measures of cognitive development using an adapted Piagetian assessment such as the Southern California Ordinal Scales of Development (39). This type of analysis would likely yield more information about beliefs, stigma, fears and developmental changes of children.

CONCLUSION

Children living with HIV who do not yet know their status have nevertheless formed explanations for their lived experiences with HIV. Held beliefs among children engaged in HIV-related care in SSA is of particular interest as national and regional disclosure protocols are standardized and disseminated.

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Table I.

Demographic and Clinical Characteristics of Study Participants (Children)

Variable	Number of Participants (%)
Clinic Location	
Accra, Ghana	206 (47.4%)
Kumasi, Ghana	229 (52.6%)
Gender	
Male (n, %)	222 (51%)
Female (n, %)	213 (49%)
Age (Mean, SD)	9.78 (2.27)
(Minimum, Maximum)	6–18
Years since HIV-Diagnosis (Mean, SD)	4.17(2.78)
Mode of HIV-Acquisition	
Maternal To Child Transmission	360 (82.8%)
Other	22 (5.1%)
CD4+ Count (cells/mL)	
0–100	19 (4.4%)
100–200	14 (3.2%)
200–500	47 (10.8%)
500–1000	142 (32.6%)
1000+	129 (29.7%)
Viral Load (copies/mL)	
Undetectable (< 20)	99 (22.8%)
21–100	31 (7.1%)
101–1000	33 (7.6%)
1001–10,000	28 (6.4%)
10,001–100,000	44 (10.1%)
100,001–1,000,000	38 (8.7%)
Over 1,000,000	6 (1.4%)
Schooling	
Currently in School (n, %)	427 (98.2%)
Not Currently in School (n, %)	6 (1.4%)