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Review Article

Disclosure Experiences and Challenges Among Children and Adolescents Living with HIV/AIDS in Nigeria-A Review of the Literature

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Abstract

Context: Disclosure of HIV positive infection status in children and Adolescents is multifaceted and should take into consideration their age, psychosocial maturity, cultural and clinical context. This study was conducted to examine disclosure experiences and challenges among children and ALWHA in Nigeria.
Evidence Acquisition: We conducted narrative review of relevant literatures by searching PubMed, Google scholar and Medscape using predetermined keywords.
Results: Findings are presented under themes of process of disclosure and age of disclosure, reasons and challenges of disclosure, reactions and responses to disclosure, consistent with various authors. This study shows that the mean age and reasons for HIV positive status disclosure are variable. Disclosure was mostly executed at home and mostly carried out by parents or caregivers of HIV-infected children. Reactions of children and ALWHA upon disclosure was mainly negative and ranged from feeling of anger to expression of shock to feeling of sadness and to crying. Barriers to HIV-positive status disclosure among caregivers were perceived sense immaturity and age of the child, fear of stigma, fear of child's inability to cope, fear of blaming the parents and refusal to take antiretroviral (ARV) drugs. While caregivers highlighted several factors that affect disclosure of HIV status to children and adolescents, this study reveals both positive and negative impact on their emotions.
Conclusions: It is of note that approach to disclosure is critical, therefore caregivers and healthcare workers should be properly trained and supported with resources required to effectively carry out disclosure. There is need for continuous research to understand and develop age and culture specific approaches to disclosure in children and adolescents in Nigeria.

Keywords: HIV, AIDS, Disclosure Experiences, Disclosure Challenges, Children and Adolescents, Nigeria

1. Context

Disclosure is a complex psychosocial challenge (1). While the introduction of antiretroviral therapy (ART) has offered hope to children living with HIV and AIDS (2), disclosure of HIV positive status to a child generates rise in emotions among health care professionals, parents and guardians. Significant number parents or caregivers are reluctant to inform their children about their HIV infection status because majority of HIV infected children became infected through vertical transmission. The ensuing parental guilt about transmission (3) distinguishes this disease from other life-threatening pediatric illnesses. HIV-infected children are often confronted with the pressure of having to deal with their seropositive status as they grow from adolescence into adulthood and this have a strong impact on their health and social behavior including peer relationship, sexual behavior and medication adherence. Although disclosure of HIV positive status increases chances of survival (4) through increased medication adherence (5) and improved self-esteem (6), there is risk of emotional consequences in one or both parents especially in mother-to child transmission (7). Hence, in relation to the parents, HIV status disclosure is often driven by risk of stigma and emotional consequence.

The number of children living with HIV and AIDS are on the rise. In 2019, an estimated 38 million people were

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living with HIV worldwide of which 2.8 million were children age 0 - 19 years (8). According to the United Nations Agency for International Developments (9), an estimated 37.9 million people (including 1.7 million children) were living with HIV worldwide in 2018 and around 21% of these populations are unaware of their HIV positive status. Nigeria has the second highest prevalence of HIV in the world (10). An estimated 1.9million people are living with HIV in Nigeria with a prevalence of 1.4% (11). Among countries in West and Central Africa, Nigeria has the highest number of HIV-infected adolescents with a prevalence of 3.5% (12). It is estimated that 230,000 adolescents aged 10 - 19 are living with HIV in Nigeria of which 5400 have yielded to AID-related deaths (13). HIV positive status disclosure is critical in children and adolescents for the long-term management of the disease. When to carryout disclosure, how to carry out disclosure is not well characterized especially in multicultural environment like Nigeria. There is lack of culture specific approaches to HIV status disclosure in children and adolescents. Although the World Health Organization and Medecins Sans Frontieres have specified recommendations for HIV status disclosure in children, they do not provide context specific approaches with consideration of different cultural perception of child's age, psychosocial development and maturity (14). The study aim is to conduct a review of the literature on experiences and challenges of HIV positive status disclosure among children and adolescents living with HIV and AIDS (ALWHA) in Nigeria and to identify factors relating to disclosure and non-disclosure and to recommend strategies for successful disclosure.

2. Evidence Acquisition

A literature search on the disclosure experiences and challenges among children and adolescents living with HIV and AIDS in Nigeria was carried out in October 2020 by means of a multiple electronic database search. We conducted the search in PubMed, Google Scholar and Medscape using keywords like "disclosure experiences", "HIV", "AIDS", "Challenges", "Children and Adolescents", "Nigeria". The search was limited to studies conducted in Nigeria and in academic literature referring to disclosure of HIV positive status in children and adolescents including reports written by organizations. The review included full-text articles, abstracts and reports. A total of 52 articles referring to the experiences and challenges of HIV positive status disclosure in children was reviewed. The search terms included combinations intended to capture report of disclosure experiences and challenges under the theme basic characteristics of adolescents, reaction upon disclosure including disclosure impact on emotion, challenges of HIV status disclosure. Studies that do not include children or Adolescents were not included in the review. It is of note that references cited in the articles used were included if eligible.

3. Results

Disclosure of HIV positive status to children and adolescents extends beyond revealing seropositive status to include divulging information about health and associated issues. Disclosure challenges triggered by the fear of transmission and the need to promote compliance with constant and often toxic regimen begins to emerge as children advance in age (5). While programmatic lessons have revealed the need to understand relationship between disclosure experience and compliance to antiretroviral (ARV) regimen among children and adolescents, studies on correlation between personnel who carried out disclosure, environment where disclosure is being carried out and the outcome of disclosure are limited. Some significant findings that emerged in this review are presented under three themes which have been found to be consistent with various authors. Central themes that emerged were process of disclosure and age of disclosure, reasons and challenges of disclosure, reactions and responses to disclosure. These themes are further unpacked below.

3.1. Process of Disclosure and Age of Disclosure

This review shows that majority of parents/caregivers are of the opinion that parents should be the ones to disclose HIV positive status to the child. Disclosure mostly took place at home (15, 16) and situations where disclosure was executed by healthcare workers, there were no notifications of serostatus disclosure (15). This is because parents/caregivers feel that it is their responsibility to carryout disclosure and because home is the place where a child is perceived to feel safe and less nervous. Available literatures have revealed that when and how to disclose to children their HIV positive status is one of the biggest psychosocial challenges faced by caregivers (17-19). Negese et al. (20) suggested that disclosure of HIV positive status should be executed in an ideal environment that supports collaboration between caregivers and healthcare providers. The reasons for varied age of disclosure appears to be similar across the studies. Caregivers feel comfortable enough to carry out disclosure in late adolescent years because it is perceived that this is the time when the child is psychologically mature enough to comprehend the situation. A systematic review of HIV status disclosure in resource limited settings revealed different opinion about the optimal age of disclosure in children (21). However,

the African network for children affected by HIV/AIDS (ANNECA) recommended that pediatric HIV disclosure should begin as early as 5 - 7 years old (22). Corresponding to this, the Nigeria National Guidelines for Pediatric HIV/AIDS Treatment and Care recommended that disclosure process should be initiated in the same age range on account of the child's cognitive ability and consent of parent/caregiver (23). The concept of disclosure was described as a one-time event in two studies during which the child was told the name of their diagnosis or the reason for taking medicines (15, 16). This is contrary to several studies conducted in which children experienced partial disclosure before being told their HIV positive status (14, 24-26). Nevertheless, WHO strongly recommends that disclosure of HIV infection status to school aged children and younger children should be executed progressively to accommodate their cognitive skills and emotional maturity (27). HIV positive status disclosure in an incremental and supported fashion promotes healthy psychosocial adaptation and development (28).

3.2. Reasons and Challenges of Disclosure

The reasons for HIV positive status disclosure are summarized in Table 1. Common reasons for serostatus disclosure were child's refusal to take medicines, caregiver's perception that child was mature to understand implication of the disease, so child can take responsibility for his or her health, so child can be discreet with medicine, insistent of the involved healthcare professional that disclosure should be carried out, fulfillment of child's right to know (15). Other reasons were child's frequent questions regarding the use of drugs, caregiver's need to facilitate adherence to antiretroviral therapy (16). Disclosure was also related to the sex of the child, positive infection status of the mother and mother's level of education (29). Alternatively, caregivers' reasons for HIV positive status non-disclosure included perception that child was too young and immature to understand the implication of the disease, fear of inadvertent disclosure to other children including friends and family members (15, 29, 30). Other reasons included fear of child's cognitive inability to cope with pressures that comes with awareness of seropositive status, fear of blaming parents (15, 29), fear that child will stop taking medicines (15). Some caregivers reported feeling that they do not have the skills required to disclose to the child (16). Important factor that influence lack of disclosure is caregiver's HIV infection status; HIV negative parents are more likely to disclose to their children compare to parents who are HIV positive. This may be due to fear of potential expression of blame and hatred between the child and HIV positive parents. This resonates with a study conducted in Addis Ababa, Ethiopia which revealed that uncertainty about the child's ability to cope with the information, fear of upsetting the child, fear of social rejection and isolation are the reasons why caregivers would be reluctant to disclose HIV diagnosis to their children (26).

HIV positive status disclosure by parent/caregiver has the disadvantage of incomplete disclosure due to the fear of perceived stigmatized behavior and negative emotional reaction following disclosure to the child especially in vertical transmission cases. One of the studies reported that the caregiver lied to the child in certain instance when child asked questions relating to diagnosis (16). A study conducted in Brazil highlighted the importance of giving complete and precise information about HIV (31). Our finding also shows that parents/caregivers are more likely to disclose to male children compared to their female counterparts. This can be associated to caregiver's concern about discrimination related to future intimate partner of HIV infected female child. More studies are required to explore the association between gender and HIV positive status disclosure in children. While there are concerns about psychological and social impacts of HIV seropositive status disclosure in children, study has revealed that HIV infected children who are aware of their serostatus have positive attitude towards life compared to children who are not aware of their HIV infection (25). Additionally, positive health behaviors (increased medication adherence, improved clinic visits) and psychological benefits have been identified as benefits of disclosure in children (32).

3.3. Reactions and Responses to Disclosure

The emerging themes related to impressions upon disclosure of HIV positive status in children and adolescents are shown in Table 2. Informing children about their HIV positive infection status is obviously an emotional and critical point in continuum of HIV care. Most children were not aware of their HIV status prior to disclosure across the studies. One of the children expressed feeling of awareness upon disclosure in one study (15), another study revealed that the child became aware during caregiver's conversation with the doctor (16). Emotional reaction among disclosed children and adolescents ranged from being shocked to feeling of sadness to crying. Majority of children across the studies expressed negative reactions. A study conducted in North Gondar, Northwest Ethiopia revealed that children reacts differently to news about HIV positive status (20). None of the studies evaluated child pre- and post-disclosure and relationship to adherence to ART. There are limited evidence to reveal impact of disclosure on retention in care including emotional, physical and social outcome in children.

4. Conclusions

Although disclosure of HIV positive status constitutes an important part of HIV and AIDS health care package in children and adolescents, the approach to disclosure is important to attaining sustainable health outcome and psychological benefits. While there are limited context specific evidences on when and how to carryout disclosure in HIV infected children and adolescents, the findings in this review and other available literatures enabled us to make context specific preliminary recommendations and pinpoint areas of further studies. First, Nigeria is a multicultural environment and disclosure needs to be addressed while considering cultural perception about child's maturity, age and emotional health. There is need to tackle fear of HIV related stigma and discrimination through improved psychosocial support services that promotes positive social adaptation and resilience in PLWH. Secondly, there is need to develop context specific protocols and guidelines for pediatric HIV status disclosure. HIV positive status disclosure is a critical and composite issue that should involve multidisciplinary approach to address the constantly changing needs throughout child's development. Caregivers and children should be supported with appropriate resources that will help mitigate potential negative consequences of HIV positive status disclosure. Healthcare workers should be supported with appropriate training and knowledge required to effectively carry out disclosure. Finally, more researches are needed to develop effective approaches to disclosure. This will promotes implementation of age and culture specific approaches to disclosure. Quantitative and qualitative studies are needed to analyze post-disclosure outcomes including physical, emotional, social outcome and adherence to ART. Longitudinal studies are needed to provide insight into correlation between personnel who carried out disclosure, environment where disclosure is being carried out and the outcome of disclosure in children. This will provide clinicians with effective support services for children and caregivers.

Footnotes

Authors' Contribution: Study concept and design: OAA and OPN. Analysis and interpretation of data: OAA, OPN, UVO, IAD, OGO, and UBO. Drafting of the manuscript: OPN, OAA, UVO, IAD, OGO, and UBO. Critical review of the manuscript for important intellectual content: YAA, OAA. and UVO. Statistical analysis: YAA, OAA, and UVO.

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Table 1. Children and Caregivers' Characteristics and Reasons for Disclosure

Authors	Sample Size/Study Site	Disclosed Children, No. (%)	Non-Disclosed Children, No. (%)	Mean Age at Disclosure, y	Caregivers' Preferred Person to Carry out Disclosure	Disclosure Environment	Reasons/Factors Affecting Disclosure
Odiachi (15), 2017	34 parents/caregivers of HIV infected children/Pediatric clinic of the University of Abuja Teaching Hospital (UATH), Nigeria	15 (100)	NA	11	Father = 36%; mother = 43%; HCW = 14%; accidental disclosure = 7%	Home = 79%; Hospital = 21%	Child refuse to take medicine; so child can take responsibility for his/her health; child stop taking her medicine; doctor asked that disclosure be done; child was now mature; child was asking questions; So child can know why he is taking medicines; so child will know how to live their lives; so child can be discreet with his medicines.
Brown et al. (16), 2011	96 Caregivers/Pediatric infectious Disease Clinic of the University College Hospital, Ibadan, Nigeria	13 (13.5)	83 (86.56)	9	Parents = 63.5%; health worker and parent = 14.6%; health worker with parental consent = 11.5%; other family members = 2.1%; Others = 8.3%	Home = 85%; hospital = 15%	Child was asking question regarding the use of drugs; child was asking question regarding illness; the need to facilitate adherence to ART. caregiver's believe that child was mature; Others
Ubesie et al. (30), 2016	Caregivers of 107 HIV-infected children/Pediatric HIV Clinic of the University of Nigeria Teaching Hospital, Enugu, Southeast Nigeria	31 (29)	76 (71)	12	NA	NA	NA
Eneh Augusta et al. (29), 2011	223 mothers of HIV positive children/Infectious disease clinic of the University of Port Harcourt Teaching Hospital (UPTH), Nigeria	NA	NA	NA	Mum and dad = 38.1%; mum = 22.4%; doctor and parents = 20.6%; dad = 13.3%; doctor = 11.2%	NA	Age of the child; sex of the child; mother's HIV status; mother's level of education

Table 2. Disclosure Reaction Among Children

Authors	Readiness/Awareness	Emotional Expression
Odiachi (15), 2017	Positive reaction: Already looked as though he was aware already; negative reaction: Child's refusal to accept HIV positive status	Positive reaction: No reaction, child was calm and did not show any feeling; negative reaction, child cried: shocked, child became cold, child was very sad, angry, he was somehow
Brown et al. (16), 2011	Positive reaction: Became aware during caregiver's conversation with doctor; negative reaction: NA	Positive reaction: NA; negative reaction: Became very sad

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