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Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach

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Abstract

As antiretroviral therapy becomes more widely available in low-resource settings and children with HIV/AIDS live for longer periods, disclosure of HIV diagnosis to infected children is becoming increasingly important. This article reviews the current literature on HIV-related disclosure in light of theories of cognitive development, and argues for the adoption of a process-oriented approach to discussing HIV with infected children. Disclosure presents unique challenges to healthcare workers and caregivers of children with HIV/AIDS that include controlling the flow of information about the child's HIV status to him/her and deciding on what is in his/her best interest. Health care workers' and caregivers' views regarding disclosure to children may often be contradictory, with healthcare workers likely to support disclosing the diagnosis of HIV/AIDS to children and caregivers more reluctant to discuss the disease with them. There is a clear need for practical interventions to support paediatric HIV disclosure which provide children with age-appropriate information about the disease.

Introduction

Globally, 2.3 million children under the age of 15 years are living with HIV/AIDS (UNAIDS/WHO, 2005). In South Africa an estimated 3% of children between the ages of 2 and 14 years are HIV-infected (Shisana et al., 2005). As HIV treatment becomes available in low-resource settings and children with HIV/AIDS live longer, the question of disclosure of HIV status to infected children is becoming increasingly important. Knowledge of HIV status may affect compliance with antiretroviral therapies and influence children's participation in healthcare decision-making.

Despite the importance of this issue, there has been surprisingly little research into paediatric HIV/AIDS disclosure, particularly in sub-Saharan Africa with its great burden of HIV/AIDS among children. Internationally, rates of disclosure seem to be low. Research from the US, suggests that less than half of HIV-infected children have been disclosed to (Flanagan-Klygis et al., 2002; Lipson 1993). Studies on current disclosure practices are sparse, but in some studies, parents report that they are reluctant to disclose the HIV diagnosis because they believe that the child is too young to fully comprehend what being HIV-positive means (e.g. Ledlie, 1999; Weiner et al., 1996).

Unlike infected adults, HIV-infected children usually have little control over when and how they are informed of their status, as their caregivers (including biological, foster and adoptive parents, or extended family) control the flow of information about their HIV-status to them and others. Caregivers and healthcare workers are, therefore, presented with an array of challenges around disclosure, including deciding on what is in the child's best interest and when and how information about his/her HIV status will be shared with him/her (Brown et al., 2000).

In contrast to the view that young children do not understand illness, research drawing on Piagetian theory suggests that even young children are able to understand health and illness (Bibace & Walsh, 1980). Lipson (1993; 1994) suggests that disclosure should be viewed as a process, rather than an event, that is matched to the child's cognitive development and aims to provide him/her with age appropriate information. This review synthesizes the relevant literature on cognitive development in light of existing evidence regarding HIV disclosure to infected children, and proposes a process-oriented

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approach to understanding disclosure to HIV-infected children. We suggest that the appropriate question is not ‘At what age should children be told of their HIV-positive status?’ but rather ‘How should we best understand the processes of HIV disclosure to children through time?’

Caregivers’ and healthcare providers’ differing perceptions of disclosure

The literature indicates that stigma and discrimination (Lewis et al., 1994; Meyers & Weitzman, 1991), parental guilt regarding pregnant mother to child (PMTCT) transmission (Cohen, 1994; Lipson, 1993), the disproportionate impact of HIV/AIDS on vulnerable members of society (Lewis et al., 1994; Meyers & Weitzman, 1991) and the multi-generational impact of HIV/AIDS on families that creates a variety of family configurations (as opposed to the nuclear family) (Bor & Du Plessis, 1997; Pfaff, 2004) all present challenges to diagnosis disclosure.

Due to their differing perceptions of what disclosure means and different relationships with the child, caregivers and healthcare providers seem to have differing approaches to disclosure to the HIV-infected child. Caregivers may be reluctant to disclose to their HIV-infected child because they view it as a distressing moment when the disease is ‘named’ (Lipson, 1993; 1994). When disclosure of the child’s serostatus is likely to result in the exposure of the HIV-positive status of other family members, caregivers’ reluctance to disclose the diagnosis may also be motivated by their fear that s/he may indiscriminately disclose to others (Waugh, 2003) and their need to protect the family unit from being stigmatized.

Healthcare providers, by contrast, often support disclosure (Flanagan-Klygis et al., 2002), viewing it as a process in which age-appropriate information is shared with the child to enable him/her to make sense of his/her illness-related experiences (Lipson, 1993; 1994; Waugh, 2003). Healthcare providers, therefore, tend to view the child as an autonomous individual who has the right to know about his/her disease status (Pfaff, 2004) and are often more likely than parents to support disclosure to the HIV-infected child as they view non-disclosure as unethical and as a potential impediment to his/her coping ability. For example, Flanagan-Klygis et al. (2002) found that of the 75 physicians in their study, 76% believed that non-disclosure contributes to feelings of isolation, depression and increased anxiety. This is not surprising as, in contrast to caregivers, healthcare providers function in an environment in which HIV/AIDS is readily discussed. Their knowledge of a range of disclosure experiences and its impact on the child’s coping ability, curiosities, fears and anxieties may lead to their feeling torn between what they believe to be best for the child, on the one hand, and respecting caregivers’ wishes on the other (Flanagan-Klygis et al., 2002; Lipson, 1993).

Factors associated with disclosure

Table I summarizes the factors associated with diagnosis disclosure to HIV-infected children.

HIV-infected children are generally less likely to be told of their illness than those with other illnesses, e.g. cancer (Hardy et al., 1994). Under certain limited circumstances, however, caregivers may indeed favour disclosure to their HIV-infected child. Among a sample of 99 caregivers in the US, Weiner et al. (1996) found that opposition to family secrets, a belief that the child has the right to know, concern that the child will find out about his/her diagnosis from someone else, concerns about transmissibility and the wish to achieve greater intimacy with the child were associated with diagnosis disclosure. In other studies (also conducted in the US) precipitating factors for disclosure included fears of accidental disclosure (Instone, 2000; Nehring et al., 2000), illness progression and the appearance of visible signs of illness (Instone, 2000; Mellins et al., 2002), the child’s persistent illness-related questions (Lester

Table I. Factors associated with diagnosis disclosure to HIV-infected children.

Factor	Reference
Demographic factors, e.g. gender of caregiver	Thorne et al., 2000; Weiner et al., 1996
Fear of accidental disclosure	Instone, 2000; Nehring et al., 2000; Weiner et al., 1996
Illness-related fears, e.g. transmissibility, illness progression, assistance with treatment adherence	Instone, 2000; Mellins et al., 2002; Weiner et al., 1996
Child’s illness-related questions and belief in the child’s right to know	Lester et al., 2002, Nehring et al., 2000); Weiner et al., 1996
Caregiver HIV status and disclosure experiences	Flanagan-Klygis et al., 2002; Ledlie, 1999; Lee & Johann-Liang, 1999; Lipson, 1993; Waugh, 2003; Weiner et al., 1996
Age and cognitive ability of the child	Flanagan-Klygis et al., 2002; Funck-Bretano et al., 1997; Ledlie, 1999; Lester et al., 2002; Lipson, 1993; Mellins et al., 2002; Weiner et al., 1996

et al., 2002; Nehring et al., 2000), needing the child's co-operation with treatment adherence (Mellins et al., 2002) and parental illness or death (Lester et al., 2002).

Influence of demographic factors on disclosure

The evidence regarding the influence of demographic factors on disclosure is inconclusive. It has been suggested that disclosure is associated with primary caregivers who are female, families of higher socio-economic status (Weiner et al. 1996) and caregivers who are not biological parents (Thorne, et al. 2000). These findings vary across studies, however.

Caregiver's HIV-status and disclosure experiences

Research suggests that open communication with children about their HIV status is the exception, rather than the rule (Flanagan-Klygis et al., 2002; Instone, 2000; Mellins et al., 2002). Caregivers may be reluctant to disclose to their children partly because of their anxieties about having to answer questions about their own infection and how the disease entered the family (Ledlie, 1999; Lee & Johann-Liang, 1999). Caregivers may also be reluctant to disclose to their children due to their fears of exposing the family to stigmatization through accidental disclosure (Flanagan-Klygis et al., 2002; Waugh, 2003), their own painful or disappointing disclosure experiences (Lipson, 1993) and their feeling uncomfortable about openly discussing HIV/AIDS and its implications with their child (Schonfeld, 1997). In addition, caregivers' fears that disclosure will negatively affect their child's health by, e.g., hastening disease progression (Lipson, 1993) and fears that the child may suffer psychological harm (Weiner et al., 1996) may also be related to non-disclosure.

Age and cognitive ability

Age remains the strongest predictor of whether or not the child has been disclosed to (Mellins et al., 2002; Flanagan-Klygis et al., 2002). Caregivers' belief that their child is too young, both emotionally and cognitively, to understand the disease and comprehend its implications is one of the most commonly cited reasons for non-disclosure (Flanagan-Klygis et al., 2002; Ledlie, 1999; Lester et al., 2002; Lipson, 1993; Weiner et al., 1996). Parents generally view children below the age of five years as too young for disclosure of HIV status, and children over the age of twelve as old enough (Funck-Bretano et al., 1997). The choice of adolescence as an optimal time for disclosure may relate both to perceptions that children are able to cope with the information cognitively, and to concerns that as children become sexually active they may transmit the virus (Funck-Bretano et al., 1997). In two studies comparing groups of children who had been disclosed to and those who had not, the disclosed groups were significantly older than the non-disclosed groups (Mellins et al., 2002; Weiner et al., 1996).

Varying degrees of disclosure

Diagnosis disclosure between the ages of six and eleven may not necessarily take the form of full, open disclosure as caregivers may offer information about serostatus incrementally. Children in this age group may not be completely unaware, but they may also not have been fully informed of their diagnosis (Funck-Bretano et al., 1997; Lester et al., 2002). Disclosure patterns by caregivers range from full disclosure to partial disclosure to no disclosure (Funck-Bretano et al., 1997; Nehring et al., 2000). Partial disclosure refers to the strategy whereby parents provide children with information about their illness without naming the disease specifically. It is part of a process in which gradual steps are taken towards full disclosure (Waugh, 2003), often involving the use of metaphors to describe the disease. HIV may, therefore, be described without attaching a name to it, e.g. telling the child that s/he has 'germs in the blood' (p. 320) (Weiner et al., 1996).

Due to the stigma associated with HIV-infection, caregivers may display a strong tendency towards partial disclosure (Weiner et al., 1996) as they may find it easier than full disclosure (Instone, 2000; Waugh, 2003). Thus partial disclosure, secrecy and deceptive information (providing explanations that may be intentionally confused with other, unrelated medical conditions that are viewed as more acceptable, e.g. asthma) (Weiner et al., 1996) are viewed as useful steps in the disclosure process that represent a compromise between caregivers' need for secrecy and their child's need for information.

Disclosure in Sub-Saharan Africa

In-depth examinations of paediatric HIV/AIDS disclosure issues in sub-Saharan Africa are sparse. However, two related studies conducted in a paediatric HIV/AIDS facility in South Africa have yielded findings that mirror the international data. In these studies, caregivers interviewed reported low disclosure rates (9%) (Moodley et al., 2006) and healthcare providers reported low levels of direct involvement in disclosure to HIV-infected children (18%) (Myer et al., 2006). In addition, healthcare providers tended to view disclosure as a process involving general discussions with the child about his/her health at the age of six and specific discussions about HIV/AIDS at the age of 10 years (Myer et al., 2006), while caregivers provided the ages of 11 and 12 years as optimal for discussions about their illness and specific discussions about HIV status, respectively (Moodley et al., 2006).

Impact of disclosure on the child

There is no evidence to suggest that disclosure negatively affects HIV-positive children. Mellins et al. (2002) reported a non-significant trend toward less depression among children who knew their HIV status compared with those who did not. Slowing disease progression has also been observed for children who disclosed their HIV status to friends, compared with those who had not (Sherman et al., 2000). There is some evidence to suggest that non-disclosure may negatively affect HIV-positive children. Analysing children's drawings and stories, Instone (2000) uncovered feelings of loneliness, sadness and fear among HIV-positive children who reported that, despite not being told their diagnosis, they were aware of it but sensed that they could not openly discuss it with their parents. Though it is difficult to generalise these results, this study suggests that non-disclosure may be psychologically detrimental to HIV-infected children.

Children's understanding of illness

Children may experience confusion, fear and anxiety (Kister & Patterson, 1980) when faced with illness. However, contrary to their caregivers' perceptions, there is evidence to suggest that children's understanding of illness displays a developmental progression that encompasses Piaget's preoperational, concrete operational and formal operational stages (Bibace & Walsh, 1980). Children, therefore, understand and explain illness, its causes and cures in accordance with their stage of cognitive and emotional development. Within the context of disclosure, a shift is required from deciding whether or not to disclose to the HIV-infected child, to deciding how to provide him/her with age-appropriate information about the disease matched to his/her stage of cognitive development (Schonfeld, 1996).

Using Piaget's preoperational, concrete operational and formal operational stages of development, Table II below outlines the developmental progression of children's understanding of illness.

There is considerable support for the notion that children's understanding of illness in general (e.g. Kister & Patterson, 1980; Perrin & Gerrity, 1981) and HIV/AIDS in particular (e.g. Osborne et al., 1993; Schonfeld et al., 1993; Walsh & Bibace, 1990; 1991), increases with age. It has been shown that while children of all ages may be able to identify sex or drugs as the cause of HIV/AIDS, their accounts of how these agents act to cause HIV/AIDS, reflects their level of cognitive development. Children in the concrete operational stage, for example, may be able to provide a factually accurate understanding that HIV/AIDS is transmitted through sex, but may hold misconceptions about what sex is by, e.g. defining it as kissing (Walsh & Bibace, 1990). Such misconceptions reflect their limited understanding of internal body functioning that is characteristic of this stage (Schonfeld, 1996; Walsh & Bibace, 1990; 1991). As their understanding of HIV/AIDS deepens, children display an increasing sense of autonomy and personal control, consistent with their general develop-

Table II. Developmental progression of children's understanding of illness.

Stage	Age	Illness Explanation
Preoperational	2–6 years	• Symbolic thought develops and ability to use language increases (Smith, Cowie & Blades, 1998). • Child provides illness explanations based on *association*, i.e., any object, event, person or cause that s/he perceives to be related to it. • Child may still be unable to explain the link between the cause and the illness (Bibace & Walsh, 1998; Walsh & Bibace, 1990; 1991).
Concrete operational	7–10 years	• Child provides illness explanations based on *sequence*. • Child's illness descriptions progress from the belief that disease is transferred through contact, to an understanding that disease carriers can be internalized through swallowing or inhaling (Bibace & Walsh, 1998; Walsh & Bibace, 1990; 1991).
Formal operational	11 years and older	• Abstract thinking and reasoning develops (Smith et al., 1998). • Child begins to view body as a system and provides illness explanations based on *interaction* of number of factors. • Child's illness understanding develops from the belief that it is caused by internal organ malfunctioning to his/her ability to explain its cause as a complex interaction between host and agent (Bibace & Walsh, 1998; Walsh & Bibace, 1990; 1991).

mental progression. So, for example, children in the formal operational stage may understand that sex causes HIV/AIDS but, in contrast to younger children, they understand the complexities of biological functions and hence are able to accurately explain the mechanism of transmission (Walsh & Bibace, 1990; 1991).

Disclosure as a 'process' rather than an 'event'

The preceding discussion has highlighted the complexities inherent in disclosing a diagnosis of HIV/AIDS to a child. Caregivers usually hold the power to decide what is in the best interests of the child and may be reluctant to disclose due to their need to protect the child/self/family unit and their belief that the child is too young to understand the diagnosis. When disclosing a diagnosis of HIV/AIDS to children naming the disease may be less effective in helping them cope with their HIV-status than providing them with age-appropriate information and explanations that are likely to help them to make sense of illness-related experiences and answer questions they may have (Gerson et al., 2001; Schonfeld, 1996; Waugh, 2003).

This review suggests the need to move away from viewing disclosure as a traumatic point in time in which the information that the child is HIV-positive is shared, to an ongoing, dynamic process-oriented approach that may resolve the tension between caregivers' and healthcare workers' views by narrowing the gap between their divergent understanding of disclosure and views of the child. Disclosure may, therefore, involve multiple conversations that are tied to the child's cognitive development and facilitate a gradual deepening of understanding of the impact of HIV infection (Gerson et al., 2001; Lipson, 1993; 1994).

A process-oriented approach views the child and his/her family as the unit of treatment and is based on an appreciation of their unique cultural and family environment (Meyers & Weitzman, 1991). Such an approach starts with a comprehensive individualized assessment of caregivers' and children's needs and the factors (e.g. family, psychosocial, cultural, religious) that may impact on disclosure (Flanagan-Klygis et al., 2002; Lipson, 1993; Osei-Hwedie, 1994). Disclosure to the child should, therefore, be carefully discussed with the caregiver to identify their disclosure needs in terms of issues such as, inter alia, who needs to be told (e.g. other caregivers) before the child can be told (Lester et al., 2002; Lipson, 1994; Pfaff, 2004); cultural beliefs and practices regarding appropriate ways of discussing sexually related issues with children and caregiver readiness to deal with the disease and disclose to their child (Ledlie, 1999; Pfaff, 2004). Multiple conversations between the caregiver and healthcare providers on such issues are crucial to disclosure discussions. Healthcare providers should create a supportive environment in which open, shared dialogue is utilized as a tool to access each individual caregiver's disclosure needs, concerns and fears (Gerson et al., 2001; Lipson, 1993; 1994; Waugh, 2003). Once these issues have been identified, healthcare providers can work with caregivers to generate ways to overcome their concerns and develop a developmentally appropriate plan for the disclosure to their child. Through this process, caregivers are prepared and equipped with the skills to, firstly deal with their own and their child's HIV-status and secondly, undertake disclosure to their HIV-positive child (American Academy of Pediatrics, 1999).

Conclusion

Diagnosis disclosure in the context of paediatric HIV/AIDS is fraught with complexities that relate to the social, familial and cultural environment of the child in which caregivers are reluctant to discuss the diagnosis with their HIV-infected child. This review has proposed that Piaget's cognitive developmental theory, which suggests that children possess the conceptual capability to understand illness, including HIV/AIDS, has much to offer in this regard (Bibace & Walsh, 1980; Walsh & Bibace, 1990; 1991). The focus of such disclosure should be on providing him/her with age-appropriate information about his/her illness that is matched to his/her cognitive level of development. Examining the applicability of this approach is an urgent research priority. Further, while much has been learnt about disclosing a diagnosis of HIV-infection to a child, there are still many questions that remain unanswered including: the impact of disclosure and non-disclosure and disease-related factors on HIV-infected children, and the cultural and family context within which decisions regarding disclosure are made. Finally, the voice of the child has remained silent in the disclosure debate. Accessing the perceptions of children and allowing them to provide insight into their lived experiences and articulate their needs and preferences is an area that has remained unexplored and should be addressed as a priority.

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