

# BRIEF COMMUNICATION

## DISCLOSURE OF HIV ILLNESS STATUS TO CHILDREN AND ADOLESCENTS: When, how and by who?

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### I- THE GLOBAL BURDEN OF HIV INFECTION IN CHILDREN

According to UNICEF [1], two million HIV positive women become pregnant every year. In 1999; an estimated 600.000 children aged 14 or younger became infected with HIV bringing the number of children living with the human immunodeficiency virus which causes AIDS to 1.2million. Of these, almost nine-tenths were in sub-Saharan Africa. Approximately 90 % of infants and children with HIV have become infected through mother-to-child transmission (MTCT) during late pregnancy, labour, childbirth or breastfeeding. In the absence of preventive measures, the risk of a baby acquiring the virus from an infected mother ranges from 15-25% in industrialised countries and 25-35% or higher in developing countries. According to the World Bank [2], in 2002, 800.000 children under the age of 15 contracted HIV and most live in sub-Saharan Africa. HIV infection amongst children is an increasingly serious problem, threatening previous gains in reducing child mortality.

The mean survival for children with prenatal HIV infection has been reported to be between 8.6 to 13 years, and between 36% to 61% of infants with perinatally acquired HIV are expected to survive to age 13 years; and the mean survival of children after a diagnosis of AIDS is made, is no longer than 5 years [3]. Consequently, the disclosure of a diagnosis of HIV infection/ AIDS to a child is becoming an increasingly common clinical issue and is a complex process that presents a challenge to both families and health care providers. Children often encourage status disclosure, yet there are few empirical data on which to base these recommendations [4].

It is also interesting and surprising to note that this issue of disclosure of HIV status to children is not clearly addressed in Africa which carries the greatest burden of the disease.

### II- WHY ARE HEALTH CARE PROFESSIONALS AND SOME PARENTS RELUCTANT TO INFORM THEIR CHILDREN ABOUT THEIR POSITIVE HIV INFECTION STATUS?

According to the American Academy of Pediatrics (AAP) [3], 25-90% of school-age children with HIV infection / AIDS have not been told they are infected. The reasons expressed include concerns about the impact that disclosure may have on a child's emotional health and fear by the parents that the knowledge will negatively affect a child's emotional will to live.

Additional reasons often given by parents of HIV- infected children include a sense of guilt about having transmitted infection to the child, anger from the child related to knowledge of perinatal transmission and fear of inadvertent disclosure of the child. Disclosure of status may also lead to stigmatization, discrimination or ostracism towards the child and other family members. Health care professionals and families are also concerned about the difficulty children have keeping a "Secret" and limiting the disclosure to selected persons.

According to the American Psychological Association (AAP) [5], secrecy becomes increasingly more difficult as children live longer, experience more medical procedures, interventions and hospitalizations and grow to adolescents exploring sexuality in the normal course of development. Because of the multigenerational nature of pediatric HIV, disclosure to the children often leads to difficult questions about transmission, parents' sexuality and / or drug use history, as well as questions about death, their own as well as their parents.

### III- WHAT ARE THE ADVANTAGES OF DISCLOSURE?

According to the American Academy of Pediatrics (AAP) [3], studies on the impact of HIV in

fection / AIDS disclosure to children are limited. Preliminary work suggests that, children who know their HIV status have higher self esteem than infected children, who are unaware of their status. Parents who have disclosed the status to their children, experience less depression than those who have not. Other benefits include the potential for improved treatment participation and psychological functioning.

#### IV- HOW TO DISCLOSE

Disclosure is a process rather than an acute event that begins and ends with telling the child or adolescent the diagnosis [6]. The complexity of issues surrounding disclosure mandate that families have time and opportunities for discussion of issues such as preparing the child, finding the right words to say, deciding whom to tell and when to tell, and defining and considering how to manage any risks. A multi-systems approach to disclosure can help families assess the various systems which impact their lives so that they can identify obstacles and locate sources of support. Multi-systems levels include: the individual child, the parent-child relationship, siblings, extended family and non-blood kin, relationships with health and mental health providers, schools, community, church, child welfare, legal services, and other social systems. Disclosure can assist families in identifying concerns, needs, and strengths of the child, risks related to stigma and discrimination within the family, at school, and within the community, health and mental health resources and legal resources [6]. Disclosure of HIV diagnosis to children and adolescents is a well-known psychological issue, yet a very individual process. As families and providers move through the process of disclosure, they will ask many questions and weigh various options. The exact time, content and circumstance of each disclosure will be a product of numerous and unique considerations.

Take some comfort in what you know about HIV/AIDS, how your child learns new information, what your child may already know about HIV and what feels most supportive to your family [7]. Think about what you want your child to know. Perhaps your child has been taking medications, or asking questions. Have some HIV-related information ready before you get started. Get ready materials that have an optimistic tone. Children may want to know if they are going to die, have they got infected, or if they will become sick. Know how you will answer these questions. Also consider your own feelings about these concerns. You may choose to wait to have the conversation until you get some emotional support.

Children will need different types and amount of information depending on their ages. Begin with some simple ideas that you think are most important.

Very small children may be too young to be told the name of the disease or many details, but try to be as honest as possible. Disclosure occur little by little in age-appropriate ways the children get older. Young children need information mostly about things that affect them right now. School-aged kids may need some basic information about what to do if they bleed. All children should be taught that it is not a good idea to touch any ones blood. Teenagers may require more information about prevention and transmission. All children should know they cannot infect friends through casual contact. It may take a long time to absorb the information. Let your child know that he or she can speak freely. You want your children to see you as a trustworthy adult so they will feel comfortable coming to you for more questions in future. The child may feel isolated, angry, scared or depressed by his or her HIV status. Arrange a supportive network consisting of health-care providers, trusted family and friends [7].

The diagnosis disclosure is best undertaken as an on-going pattern of conversation between the child and the parent. Parents should communicate openness to inquiry about illness and treatments. Families and medical providers should be cautious about defining the child's life by his or her illness. Maintain an awareness of the impact of medical treatments, from daily medications to hospitalisations on the childrens' psychological status and self esteem [8].

On the whole, there are lot of factors that determine whether and how families disclose a child's positive status at an early age. How the child deals with the information is also related to how well the family deals with the parent's sero-status, how tolerant the community is, and the child's developmental status.

#### V- WHEN TO DISCLOSE

In January 1999, the American Academy of Pediatrics (AAP) [3] came out with the following recommendations on this issue. It states that:

A statement of reaffirmation for this policy was published in September 1, 2005.

1. Parents and other guardians of HIV-infected children should be counselled by a knowledgeable health care professional about disclosure to the child of their infection status. This counselling need to be reported throughout the course of the child's illness.
2. Disclosure of the diagnosis to an infected child should be individualised to include the child's cognitive ability, developmental state, clinical status, and social circumstances.
3. In general, younger children, if symptomatic with illness, are most interested in learning what will hap-

pen to them in the more immediate future. They do not need to be informed of their diagnosis, but the illness should be discussed with them. If children are informed of their diagnosis, considerable effort should be directed toward eliciting and addressing their fears and misperceptions.

4. The AAP strongly encourages disclosure of HIV infection status to school-age children. The process for disclosure should be discussed and planned with the parents and may require a number of visits to assess the knowledge and the coping capacity. Older children have a better capacity to understand the nature of their illness. Considerable efforts will need to be directed to facilitate coping with the illness. Symptomatic children, particularly those requiring hospitalization, should be informed of their HIV status. The likelihood of children inadvertently learning about their status in a hospital is high. Disclosure should optimally be conducted in a controlled situation with parent(s) and knowledgeable professionals.

5. Adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health, including sexual behaviour.

6. Adolescents also should be informed of their HIV status to make appropriate decisions about treatment and participation in clinical treatment trials. Physicians should also encourage adolescents to involve their parents in their care. The AAP also concludes by saying that this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variation, taking into account individual circumstances, may be appropriate.

Whatever the case, the cognitive level prior to disclosure, including the presence of any developmental and/or language disorders should be assessed. Evaluate the family's support system, including their church, friends, family, school and neighbours. This assessment should include a history of the parent's prior experiences, if any, with HIV disclosure in the communities. The disclosure plan should be discussed with the child's medical providers prior to disclosure, and determine what role the medical provider will take in the disclosure process [6]. Given changes in development and cognitive understanding, families need help finding the right words to say to their 4 year old or 8 year old or 13 year old child. They need support in timing disclosure and making other crucial decisions throughout the process of disclosure[5]. The exact time, content, and circumstances of each disclosure will be product of numerous and unique considerations [6].

## VI- WHO SHOULD DISCLOSE

According to the AAP[3], pediatricians may serve as advocates for children in their care to their parents. Health care professionals have an ethical obligation to provide counselling to respond to the need of adolescent patients and to ensure that adolescents have an opportunity for examinations and counselling apart from their parents. Consequently, physicians should provide full disclosure of HIV status to their adolescent patients. Physicians are also obliged to encourage adolescents to involve their parents in their care. Adolescents need to be informed about their illness to assist in their own care and to reduce the risk of transmitting the infection to others through unprotected sex or behaviours associated with illicit drug use. According to the American Psychological Association (APA) [5], psychologists can be among the team of professionals who support the process of HIV status disclosure. Most children and youths receive HIV care within a setting whether they have a health care team that often include a physician, nurse or nurse practitioners, and social worker. Some clinics have psychologists on staff while others do not. Psychologists can function as integral members of the health care team offering their skills and expertise to address the complex emotional, development, and socio-environmental issues associated with HIV disclosure of diagnosis. Along with other medical professionals, psychologists can be an important source of support and guidance to families. The parents and family remain the cornerstone of any disclosure process. Another hurdle is confronting an HIV-positive teenager on whom to tell and when. Although involving a supportive parent is ideal, many adolescents do not have such support, or fear hurting or losing the love of their parents. They need to rely on adults because the illness is also in sharp contrast to the developmental need to establish independence and identify with a peer group. Disclosure usually cannot be avoided, because it is difficult to conceal a complex anti-retroviral regimen from the people with whom one lives [9].

## VII- OTHER ISSUES

Another very important issue is education of children with HIV infection. Children and youths with HIV infection should receive the same education as those with other choice illnesses. Confidentiality about HIV infection status is mandatory and parental consent is required for disclosure. Youths also assent or consent as is appropriate for disclosure of their diagnosis [10]. Asymptomatic children with HIV infection cannot be distinguished from children without infection, and their educational opportunities should be the same as other children. Children

and youths with HIV infection should not be excluded from school or isolated within the school setting. Participation in school provides a sense of normalcy for children and offers opportunities for socialization that are important to their development. Those with HIV infection should participate in all school activities to the extent that their health permits which includes a spectrum of illness ranging from no symptoms to AIDS disease [10].

### VIII- CONCLUSION

HIV disclosure to a child or adolescent is a process rather than an acute event that begins and ends with telling him or her diagnosis. The exact time, content, and circumstances of each disclosure is a product of numerous and unique considerations.

Data, recommendations and national policies on this issue are scanty and come largely from developed countries.

We recommend that a deep reflection on this issue be carried out and national policies elaborated and adopted as part of national strategies for the fight against HIV/AIDS, especially in Africa which carries the heaviest burden of HIV infection ■

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