

Mental health issues of children infected and affected by HIV and AIDS

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Children of today are the youth of tomorrow. Human immunodeficiency virus (HIV) affects this very precious generation and bear grave consequences to our future, our nation, the continent and the world at large. It will adversely impact the health statistics, economic growth and above all the morale of nations. Children with HIV disease have been called “the missing face of acquired immunodeficiency syndrome (AIDS)” because, more often than adults, they lack basic health care and they have been “missing from global and national policy discussions.”[United Nations Children’s Fund 2005]

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), in 2009, 33.4 million people were living with HIV around the world; 2.1 million of them were children aged <15 years.[United Nations Children’s Fund 2005] India has an estimated 202,000 children infected by HIV/AIDS.[Joint United Nations Programme on HIV/AIDS 2004] Using a conservative vertical transmission rate of 30%, a new cohort of approximately 56,700 HIV infected infants, is added every year.[National AIDS Control Organisation 2006] Over 90% of the children acquired the infection by mother-to-child transmission. Significant advances in the treatment of HIV have led to dramatic improvements in health outcomes for children born with HIV.[McConnell et al. 2005] Antiretroviral therapy (ART) has dramatically reduced rates of morbidity and mortality.

In India, National AIDS Control Organisation (NACO)’s action in 2006 to enhance the ART rollout for children has breathed new life and hope into the lives of children living with HIV. These

successes, however, are accompanied by several challenges such as difficulty in maintaining good adherence to a lifelong regimen, managing long term adverse effects, development of resistance and treatment failure, and rehabilitation of these children into society.[Shet and Kumarasamy 2008] Many children and adolescents continue to live either with their own or a parent’s HIV illness as a highly stigmatised, chronic or fatal transmissible illness with dramatic implications for their physical and mental health and overall general well-being.[McConnell et al. 2005]

Mental health issues of children infected with HIV/AIDS

Mental health issues of children involved with HIV/AIDS include social stigma, disclosure of HIV status, compliance and adherence to medical regimen and coping with bereavement and physical as well as mental health consequences due to direct effect of HIV/AIDS on developing CNS.

Stigma: Stigma has been associated with depression and makes it less likely that a person with HIV will enter treatment or, if treated, will keep appointments and take medicines as scheduled. HIV-positive children face stigma and discrimination at school, home and social situations leading to emotional crisis, hardship and social isolations. They may not even want to go to school or may believe they do not deserve to reach their goals in life. Disclosure of either a child’s HIV-positive status or the parent’s status can burden the child with coping with stigmatisation. HIV-related stigma may be internal stigma, received stigma or stigma by

association with parental HIV/AIDS.[Krauss et al. 2006]

Disclosure of HIV status: Disclosure of HIV diagnosis to infected children is a complex process that presents a challenge to both families and health care providers. 'For God's sake, please don't disclose the fact to my child,' is a common response from the parents.

Obstacles to disclosure of HIV diagnosis to children include fears regarding a decrease in the child's will to live, fears regarding retaliation or discrimination based on stigma, parental guilt about prenatal transmission of HIV infection, child's difficulty keeping a secret and parent's denial and/or difficulty confronting their own illness.[National AIDS Control Organisation 2006]

Disclosure may be partial or complete depending on the age and level of functioning of the child. Partial disclosure aims to describe what's happening to the body and what treatments will help to resolve this, rather than naming the virus or illness. Complete disclosure involves open discussion about the virus, infection, and all other issues relating the HIV infection.[National AIDS Control Organisation 2006] This must be done together with the child and parent/caregiver.

Compliance and adherence to medical regimen: HIV-infected children need to adhere to complicated medication regimens, attend numerous medical appointments and undergo frequent diagnostic procedures. There are 2,300 children, who are receiving ART in India.[National AIDS Control Organisation 2006] For HIV-infected children, the possibility of stigma and discrimination may complicate adherence to medications that must be taken throughout the day, often when the child is in school.[Armistead et al. 1998] Child may ask, "None of my friends are taking medications, why should I take so much medications daily!?"

Psychiatric illness: In general, high rates of emotional and behavioural disorders have been reported in HIV-infected children and adolescents. Although determining whether HIV infection has a causal effect on children's emotional and

behavioural functioning is difficult. Regardless of causality, HIV-infected children are at risk for neuro-developmental and mental health problems which need to be considered by mental health providers.[Mellins et al. 2009]

Bereavement: Complicated grief reactions among relatives are common sequelae of death due to HIV infection. Up to 40% of HIV infected children have been reported to be orphaned. HIV deaths may often be stigmatised leading to a lack of funeral rituals, which are an important part of societal mourning in this region. Psychological intervention is appropriate if grief is unresolved in the context of dissipating and often hostile social support system.[Jayarajan and Chandra 2010]

Adolescent Issues: World Health Organization (WHO) considers adolescence as the period between 10 and 19 years. There are distinct groups of HIV, adolescents who have been infected around birth and those who become infected during adolescence. Adherence to long-term therapy is particularly difficult among adolescents. In addition to providing routine adherence assessment and support, health care provider should consider issues that are particularly relevant to adolescents like their desire for independence, denial and avoidance, promiscuous behaviours and relationships, the adolescents' perception of being immortal, lack of disclosure of HIV status and stigma. Some of infected children may have grown up to adolescents and may have started dating which has the risk of sexual adventures. Without knowledge, sexual transmissions occur when HIV status is not disclosed and proper preventive measures are not discussed with them. It is important to establish a mutual trusting relationship between the adolescent and the counsellor/physician.[National AIDS Control Organisation 2006]

Mental health issues of children affected with HIV/AIDS

The mental health issues associated with HIV illness in families evolve over the dynamic course of HIV illness and vary depending on the stage of their parents' illness. Children exhibit a variety of

responses to parental HIV diagnosis, illness or loss at any stage in this process. Developmental histories of poor or disrupted attachment and/or trauma (particularly common in children also affected by parental drug addiction) should also be considered. Children with parental HIV/AIDS may show exacerbations of pre-existing psychiatric disorder or precipitations of new-onset disorder.

Loss of a parent can lead to adverse consequences. Furthermore, the effect of parental death in this population is exacerbated by the stigma associated with losing a parent to AIDS, which can lead to secrecy and social isolation, limiting the extent to which children and their families are able to access support.[Drainin and Reich 2005]

The ill, as well as the affected, family members emotionally, physically and spiritually can feel plagued by what's called the Lazarus syndrome. This occurs when death is so close that funeral arrangements are prepared only to be cancelled because a medication or procedure has helped the sick family member reclaim life in the last moments. When children are repeatedly exposed to loved ones near death, often they can become emotionally numb to avoid grieving all the time.[Handel 2002]

AIDS and orphans: legal and ethical issues

HIV/AIDS adds to the controversy concerning the following rights for adoptive and foster parents and children: 1) the right of prospective parents to know the health status of the child, and the child to know the prospective parent's status; 2) the rights, responsibilities, and obligations of the foster child's biological family after the placement; 3) the rights of adoptive or foster parents to public welfare assistance, health care, educational grants, particularly if the child has HIV; 4) property rights of adopted or foster children within their new families; and 5) the legal and civil rights of abandoned children.[Siamwiza 1998]

The ethical issues surrounding adoption and fostering require extensive research and public debate, taking into account the impact of broad

socioeconomic changes affecting the extended family, as well as the impact of AIDS.

Conclusion

There is a growing body of literature on the psychosocial adjustment in children with HIV/AIDS; more work would be needed especially in the area of treatment interventions both non-pharmacological and psychopharmacological. The roll-out and increasing availability of ART for adults and children brings into focus the need to address disclosure, which supports the uptake of, and adherence to, treatment.

Additionally, the collaboration between the child psychiatrists, primary care physicians and paediatric specialists will require ongoing attention and research in order to optimise the multidisciplinary approach to the chronically ill paediatric patients with HIV/AIDS. Even if a vaccine or cure is found, psychiatrists will be called on to respond to the psychiatric sequelae of the AIDS epidemic for the next generation.

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