Review Article

Psychosocial Issues of Children Infected with HIV/AIDS

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ABSTRACT

The chronic medical conditions in the paediatric population pose a range of potential psychosocial challenges not only to the child, but also to the family members and health care providers. This paper comprehensively reviews the psychosocial issues of children infected with HIV and AIDS and offer some of the strategies to address the issues comprehensively by multidisciplinary team.

Key words: *Children, human immunodeficiency virus infection, psychosocial issues*

INTRODUCTION

Human immunodeficiency virus (HIV) acquired immuno deficiency syndrome (AIDS) continue to pose a catastrophic public health threat reaching crisis proportions among young people. HIV is a global threat of significance to child and adolescent emerging as a biological, psychological and social problem. The number of children living with HIV infection and AIDS are on the rise. It is estimated that India has the largest number of AIDS orphans with the Joint United Nations Programme on HIV/AIDS UNAIDS estimating the number to be 2 million. Nearly 4% of the 2.4 million HIV infections in the country believed to be among children due to vertical transmission. Despite significant reduction in vertical transmission following intense focus on preventing parent to child transmission, new HIV infections among children are still being diagnosed.[1]

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Globally, it was estimated that in the year 2008, there were 33.4 million people living with HIV, out of which children below 15 years constituted 2.1 million.[1] It was estimated that India has an overall prevalence of 0.31%.[2] The increased access to antiretroviral treatment resulted in increased survival rates among the children infected with HIV/AIDS and also led to the improved quality of life of seropositive children. This continues to have increased impact on child's and adolescents' mental health. The chronic medical conditions in the pediatric population pose a range of potential psychosocial challenges not only to the child, but also to the family members and health care providers. This paper comprehensively reviews the psychosocial issues of children infected with HIV and AIDS and offer some of the strategies to address the issues comprehensively.

NEUROLOGICAL AND NEURO DEVELOPMENT SEQUELAE OF HIV INFECTION

Neurological, neuropsychological, and developmental manifestations of HIV disease are the earliest and most

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devastating markers of infection in children. Earlier studies of Central Nerve System CNS manifestations of HIV disease suggested that 40-90% of infected children had some degree of neurologic involvement.[3] Prospective studies documented serious signs of 8-13% of neurodevelopment delays in HIV infected children and 19-31% in children who met the diagnostic criteria for AIDS.[4] Moreover, the severity of neurological and neuropsychological problems increased with the severity of HIV related illness; the children with the most significant developmental delays reported to have higher viral loads and the most severe non-neurological health-related symptoms.[5] Two relatively distinct neuro-developmental patters have been described are Progressive Encephalopathy (PE) and Static Encephalopathy. HIV related PE occurs in 50% of pediatric patients with AIDS.[6] Delayed developmental milestones, poor expressive and receptive language development and motor development skills are some of the direct impact of HIV on neuro-developmental of pediatric patient.[7]

EMOTIONAL AND BEHAVIOURAL PROBLEMS

Children with chronic illness, in general, are found to be at greater risk for psychiatric problems, including depression, anxiety, and feelings of isolation.[8,9] Children with HIV/AIDS have additional factors in complexity of their illness and treatment as well as in the adverse psychological circumstances and poverty in which many live.

Prevalence rates for psychiatric disorders in perinatally-infected children vary from 55% to 61%. The most common disorders found are anxiety disorders, followed by attention-deficit hyperactivity disorders, conduct disorders, oppositional defiant disorders, and mood disorders.[10]

A prospective cohort study designed to examine the long-term outcome among HIV infected children and HIV uninfected infants born to HIV infected parents reported an incidence of 6.17 psychiatric cases per 1000 person-years. This was significantly higher than the incidence of 1.70 cases per 1000 person-years in the general pediatric population. It was also seen that the knowledge of HIV seropositivity status and having experienced a significant life event were both significantly associated with an increased risk of psychiatric hospitalization.[11]

The studies addressing the impact on the mental health of children either affected or infected with HIV/AIDS are meager in India. Grover, *et al.*[12] studied behavioral disorder among 140 HIV positive and negative children. The results revealed 19.3% of HIV infected children scored within the normal range on CBC in contrast to 81.7% of controls. Das[13] studied emotional and behavioral problems among 50 HIV infected children. Higher behavioral problems, i.e., rule breaking behavior among those children whose parents disclosed their HIV status and those children who are discriminated by other children due to their HIV status.

STIGMA, SECRECY AND DISCLOSURE

A major factor that distinguishes HIV/AIDS from another chronic or terminal illness is the stigma. Too often many HIV infected children, and their families live in a "conspiracy of silence"[14] and shame associated with AIDS. Illness is often kept as a secret. One of the disturbing consequences of "conspiracy silence" is that the families may be withdrawn, become socially isolated and become emotionally cut off from traditional support systems. Parents delay disclosing the children as well as their own HIV/AIDS illness status due to stigma and possible social consequences. Disclosures forces parents to confront their personal responsibility and to acknowledge the negatively sanctioned behaviors related to sexual activity or substance abuse. Unable to tolerate their own guilt, remorse, and psychological pain parents withdrawn and deny an illness that is evident to their children and loved ones. Maternal concerns include fear, anger, blame and stigmatization from family and friends, as well as from their children further complicate the issue. In the presence of social disapprobation, many parents prefer to keep their as well as their children diagnosis secret from family, friends, and society as a whole. Self-imposed secrecy and reactions to social stigma may preclude families from procuring necessary treatment seeking assistance with permanency planning for infected as well as affected children, and obtaining needed forms of social support.

Arun *et al*.[15] studied the perception of caregivers about the disclosure of diagnosis of HIV infection to children in the Indian context. The study revealed that only 7 out of the 50 children (14%) were aware of their HIV status while 43/50 (86%) were unaware; as reported by their guardians/parents. Majority of caregivers felt mid-teenage as the appropriate age for disclosing the HIV infection and the parents were the appropriate persons to reveal the infection status.

ADOLESCENCE ISSUES

For HIV infected children who live to adolescence, the normal developmental challenges of this stage, including puberty, sexuality and the desire to "fit" or be "normal" are seriously complicated by HIV disease. The detrimental effects of HIV on growth and

pubertal development pose significant challenges for the infected young people living into their `teenage years. Nevertheless, as HIV infected children move through adolescence and become sexually active, they require significant support in managing the complex issues of integrating healthy sexual development with their HIV infection. American Academy of Pediatrics Committee on Pediatrics AIDS[16] states that adolescents should know their diagnosis in all cases. Teens should be fully informed of their health status so that they can make informed decisions regarding their actions and life choices. The youth will often need repetitive education around daily living with the virus and how it will mold decisions that they make in their social lives. These decisions involve managing their own health, disclosing to friends and significant others, and making healthy sexual choices. While the youth progresses through different life stages, they will experience new and different realizations in relation to their diagnosis. Youth needs to address a number of adaptations, ranging from greater demands for self-management of their health care, the impact of their illness on their emerging sexuality and independence.

DEATH AND BEREAVEMENT

As the disease progress, children confront the physical and mental decline associated with AIDS. Family members are overwhelmed at this stage and have difficulty in communicating with the child about the issues related to prognosis and death. More than coping with their own mortality; the children and adolescents have to cope with mortality of their loved ones with HIV/AIDS. Facing and understanding their own possible death are major challenges faced by children and youth with HIV/AIDS. The cognitive and emotional maturity of the child often determines their level of awareness about their own mortality, as well as their coping skills and defences to deal with this realization. Children's reactions can range from unawareness of the finality of death in very young children, to increasing awareness and anxiety in the elementary age period, to major existential conflicts in teenagers. Sensitive psychological interventions with a child helps in expressing his or her anxieties associated with separation from parents and dying. Special attention must be paid to the issue of pain management at this stage, particularly for young children with limited ability to communicate information to care providers effectively.

PSYCHOSOCIAL INTERVENTIONS

The family having children with HIV/AIDS is generally a family dealing with crisis, illness, lack of resources, and social isolation, and in need of medical, psychological and social services. It is important to assist these children, and their families through inter-disciplinary interventions oriented to improving the quality of life. Family-centered approaches have been advocated to address family stressors, adaptation, and cultural factors impacting on the whole family. They also provide appropriate support for the infected child and his/her siblings, and connect families to services and community resources such as medical, mental health, social welfare services, and respite care through case management. The therapeutic intervention with families coping with HIV/AIDS must begin with the concept of empowerment. The diagnosis of HIV cause family to separate from normal healing rituals, loss of family gathering and friendship groups. The families may be helped in reconstructing the former family supports that are no longer available. Often families must be helped to develop new rituals to draw together those who need support, particularly in the terminal phase of the illness.

As reported earlier, the children with HIV infection present with a wide range of psychiatric conditions which warrant intensive intervention. Therapeutic support has the greatest role in the care of the children with HIV infection. Supportive and cognitive therapy for these children and their parents and families is essential because they are most vulnerable to mental health problems, separation and loss.

CONCLUSION AND RECOMMENDATION FOR FUTURE RESEARCH

Despite of significant advances in HIV treatment and care, children continue to be born with HIV infection due to the low coverage of Antenatal Care ANC and Prevention of Parent to Child Transmission PPTCT services in India. Moreover, with advances in medical treatments, HIV/AIDS has been transformed from an acute illness with a vastly foreshortened life span to a condition with many characteristics of a serious chronic illness. Hence, caring of children infected with HIV pose significant challenges to clinicians and mental health professionals. Given the myriad psychosocial stressors and issues encountered by HIV infected children and youth, comprehensive mental health care services remain crucial.

When it comes to the disclosure of HIV/AIDS infection status to the children, there is no clear consensus among the practitioners and parents on when to disclose the HIV positive status to the child. Moreover, most of the disclosure guidelines address on illness aspect and treatment adherence. After the HIV diagnosis has been disclosed to the infected child, there is a need to monitor in every follow-up visit, the child's level of functioning, behavioral changes, emotional

and psychological adjustment by the health care provider. There is also a need to develop culturally and developmentally appropriate clear cut framework to handle the post-HIV disclosure psychological impact on HIV/AIDS infected children as there is no literature available to address this issue.

As the children move into adolescent stage, the emergence of sexuality issues needs to be addressed by care providers as the parents feel uncomfortable to do so. Care providers should talk about sexual development, reproductive health issues, sexual behaviors, safe sex practices and relationship issues with adolescents. This will prevent the indulgence in high-risk behaviors among the adolescents and encourage safe healthy sexual behaviors and practices. This can be achieved through integrating life skills training to the adolescents for their optimal growth and development.

Studies that track a cohort of such children and families over time, and have several data collection points are desperately needed to ascertain the changes that occur in the psychosocial and behavioral aspects of HIV/AIDS. More studies need to be conducted to understand the effect of HIV/AIDS on family structure, and family life developmental cycle stages.

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