RESEARCH PAPER

Impact of Psychosocial Factors on Access to Antiretroviral Therapy in Hiv-Positive Children

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ABSTRACT

AIDS / HIV is a debilitating and deadly disease affecting people around the world and it comes without notice, like all diseases. Specifically, during their gestation period, childbearing women with AIDS / HIV face constant psychological problems, although the pregnancy itself may be normal and healthy. In the pediatric population, chronic medical problems present a range of potential psychosocial difficulties not only to the infant but also to family members and health care providers. Children's psychosocial problems contaminated with HIV and AIDS and propose some of the approaches by multidisciplinary team to address these issues comprehensively. To many health workers in HIV-endemic nations, the delivery of HIV therapy and testing services for children remains an uphill task. It is well recognized that a healthy mental state is a major determinant of a normal pregnancy, and is the starting point for a successful quality of life. Communities appear unprepared and uneducated to incorporate these individuals seamlessly into their communities, causing these patients to be marginalized and alienated. It is imperative, for all the above reasons, that community and medical professionals respond and provide all the necessary support and advice to HIV-positive child bearers in an attempt to alleviate their concerns and relieve their distress. The aim of this paper is to summarize the challenges faced by HIV patients in order to survive and integrate into society, identify the main reasons for low public awareness, address the current situation and provide potential solutions to reduce stigma among HIV patients.

Keywords: AIDS, stigma, HIV, infection, society, Children, psychosocial issues.

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Introduction

Human immunodeficiency virus (HIV) acquired immunodeficiency syndrome (AIDS) continues to pose a devastating threat to young people's public health, approaching crisis proportions. HIV is a globally significant threat to the development of children and adolescents as a medical, psychological and social issue. There are growing numbers of children living with HIV infection and AIDS. India is estimated to have the largest number of AIDS orphans, with the United Nations Joint Program on HIV / AIDS UNAIDS estimating the number at 2 million. About 4 per cent of the country's 2,4 million HIV infections were believed to be among children as a result of vertical transmission. Studies of affected children's have increased considerably in recent years, and a great deal of attention has been given to the topic of women and health. A lot of research programs were undertaken by physicists, psychologists, sociologists and historians. HIV-AIDS is one of the subjects which has been studied extensively during gestation. Given a significant reduction in vertical transmission following an intensive focus on preventing the transmission of parents to children, new HIV infections among children are still diagnosed (Geneva, 2009).

Care and support for children who are diagnosed and/or affected by HIV / AIDS, including the provision of pediatric HIV care, is growing globally and nationally. UNICEF / UNAIDS ' campaign "Unite for Children, Unite Against AIDS" seeks to provide either antiretroviral or cotrimoxazole care, or both, to 80 per cent of needy children (UNAIDS, 2008). The number of

HIV-positive children under the age of 15 who undergo antiretroviral therapy (ART) remains low (Qazi and Muhe, 2006; Arrive et al., 2008; *Lancet,* 2006; Kline, 2006). HIV-AIDS is known to be one of the most damaging diseases during gestation, with both medical and ethical implications, resulting in women being stuck in social barriers (Lapointe et al., 1985; Semprini et al., 1987; Marte and Anastos, 1989). Globally, it has been estimated that there were 33.4 million people living with HIV in 2014, of which 2.1 million were children under the age of 15. Indian prevalence was estimated to be 0.31 per cent overall (World Health Organization, 2014). The increased access to antiretroviral therapy resulted in increased survival rates among HIV / AIDS-infected children and also contributed to improved quality of life for seropositive children. This continues to have a growing effect on the mental health of children and adolescents. The chronic medical conditions in the pediatric population present a number of possible psychosocial problems not just for the child but also for family members and health care providers (Belman, 1992).

HIV disease severity

The lowest neurocognitive effects are seen in HIV-infected children with a history of higher severity of disease, suggesting a significant contribution to neurodevelopmental disability at a later age from residual HIV-induced cerebral injury. In reality, a Class C disease control and prevention center event has been associated with lower scores in general cognition, processing speed and verbal output (Cohen et al., 2015; Brackis-Cott et al., 2009; Smith et al., 2012). This is consistent with finding poorer outcomes in children with lower nadir CD4 + T-cell measurements and higher zenith viral load in HIV-infected children, although this correlation may not be consistently found due to small study groups (Cohen et al., 2015; Smith et al., 2012; Nachman et al., 2012). Younger age of HIV diagnosis is also associated with higher levels of neurodevelopmental delay (Kandawasvika et al., 2011; Smith et al., 2000), and it has been found that encephalopathy occurs more often in children diagnosed with PHIV than in adults after a short period of HIV infection (Chan and Brew, 2014). Overall, these results strongly indicate that children who are perinatally infected are more vulnerable to CNS damage from HIV infection than older children or adults.

Unlike historical indicators of seriousness of HIV disease, the HIV load and CD4 + T-cell count show less strong associations with neurocognitive output (Hoare et al., 2012), and this association has not been observed in some recent studies in children stable on cART (Cohen et al., 2015; Brackis-Cott et al., 2009). Although HIV load and CD4 + T-cell count are widely used as measures of systemic severity of HIV disease, to which the CNS may be exposed, they may not be a reliable HIV effect indicator for the CNS. Systemic HIV load does not always reflect HIV load of cerebrospinal fluid (CSF), which could be a better predictor for cerebral HIV disease. Studies have, however, failed to demonstrate a correlation between CSF viral load and neurocognitive activity in establishing adequate viral suppression with cART (McCoig et al., 2002; Nightingale et al., 2014). This may be due to the insensitivity of widely used detection tests or CSF viral load being an incomplete surrogate for brain-tissue HIV replication, but may also suggest more prominent roles in chronic HIV-induced cerebral injury for other pathogenic mechanisms (Nightingale et al., 2014).

Neurological, Neuropsychological and Developmental Manifestations of HIV in Children's

The earliest and most damaging markers of infection in children are neurological, neuropsychological, and developmental symptoms of HIV disease. Earlier studies of symptoms of HIV disease in the Central Nervous System CNS revealed that 40-90% of infected children had some degree of neurological involvement (Cohen et al., 2015). Prospective studies have reported severe signs of 8-13% delays in neurodevelopment in children infected with HIV and 19-31% in children who meet the diagnostic criteria for AIDS (Pulsifer and Aylward, 2000). In addition, with the severity of HIV-related disease, the incidence of neurological and neuropsychological problems increased; the children with the most serious developmental delays reported higher viral loads and the most extreme non-neurological health-related symptoms (Epstein et al., 1988). For Progressive Encephalopathy (PE) and Static Encephalopathy, two fairly distinct neurodevelopmental patters have been identified. In 50 percent of pediatric AIDS patients, HIV linked PE occurs (Brackis-Cott et al., 2009). Delayed developmental milestones, low expressive and responsive language production and motor skills are some of the key impacts

of HIV on pediatric patient neuro-development (Hein et al., 2000).

Psychiatric disorders

In general, children with chronic illness are found to be at greater risk for psychiatric problems, including depression, anxiety, and loneliness feelings (Mellins et al., 2003; Leserman, 2000). Children with HIV / AIDS have additional factors in the difficulty of their diagnosis and treatment, as well as in the adverse psychological conditions and the deprivation many live in. Prevalence rates for psychiatric disorders in children with perinatal infection range from 55% to 61%. The most common disorders are anxiety disorders, followed by attention deficit hyperactivity disorders, disorders of behavior, disorders of opposition, and mood disorders (Mellins et al., 2003).

A prospective cohort study designed to examine the long-term outcome among HIV-infected children and HIV-uninfected babies born to parents diagnosed with HIV recorded an incidence of 6.17 psychiatric cases per 1000 person-years. That was significantly higher in the general pediatric population than the incidence of 1.70 cases per 1000 person-years. It was also found that awareness of the HIV seropositivity status and a significant life event were both significantly associated with an increased risk of psychiatric hospitalization (Denise et al., 2004). Throughout India, the research discussing the mental health effects of children either diagnosed or infected with HIV / AIDS are negligible. Grover, et al. 2007 Behavior disorder among 140 HIV-positive and negative children was studied. Contrary to 81.7 percent of tests, the results revealed 19.3 percent of HIV-infected children scored on CBC within the normal range. Das, 2009, examined emotional and behavioral problems among 50 children infected with HIV. Higher behavioral issues, i.e., rule breaking conduct among children whose parents disclosed their HIV status and children discriminated against by other children because of their HIV status.

Psychosocial Interventions

The family with children with HIV / AIDS is typically a family in need of medical, psychological and social care that cope with disaster, disability, lack of resources and social isolation. Helping these kids and their families through interdisciplinary approaches aimed at improving the quality of life is critical. Family-centered approaches to tackle family stressors, adaptation and cultural factors affecting the whole family were advocated. We also provide adequate support for the infected child and his / her parents, and link families by case management to services and community resources such as medical, mental health, social welfare and respite care. The idea of empowerment has to continue with therapeutic intervention for families dealing with HIV / AIDS. HIV diagnosis leads families to break from regular rituals of recovery, loss of family meeting and group friendships. The families may be supported to rebuild the support of the former family that is no longer available. Families also need to be encouraged to establish new rituals to unite those in need of support, particularly in the terminal phase of the disease.

As mentioned earlier, the HIV-infected children have a wide variety of psychological disorders that require intensive intervention. Therapeutic assistance plays the greatest role in caring for the HIV infected children. Supporting and cognitive therapy is essential for these children, their parents and their families because they are most vulnerable to mental health problems, separation and loss.

Stigma and Disclosure

The stigma is one major factor which distinguishes HIV / AIDS from another chronic or terminal disease. Too often many children diagnosed with HIV and their families live in a "conspiracy of silence" (Faithfull, 1997) and AIDS-related shame. Illness is often held as a secret. One of the troubling consequences of "conspiracy silence" is that families can be removed, socially isolated, and emotionally cut off from traditional support systems. Due to stigma and possible social implications, parents postpone disclosure of the children as well as their own HIV / AIDS status. Disclosures requires parents to confront their personal responsibility and identify the activities that are negatively prohibited in relation to sexual activity or substance abuse. Unable to accept parents disconnected from their own shame, sorrow and psychological pain and deny a condition that is evident to their children and loved ones. Maternal issues include fear, anger, blame and judgment from family and friends, as well as from their children complicating the issue further. In the face of social disapproval, many parents prefer to keep their diagnosis as well as their children secret from relatives,

friends and the whole society. Self-imposed secrecy and social stigma reactions can prevent families from seeking assistance with permanent planning for infected and affected children and obtaining the required forms of social support.

The caregivers ' understanding of the diagnosis of HIV infection being revealed to children in the Indian sense. The study revealed that only 7 out of 50 children (14%) were aware of their HIV status while 43/50 (86%) were unaware; as their guardians/parents reported. Most caregivers believed that mid-teen years were the right age to divulge the HIV infection and the parents were the right people to announce the status of the infection (Arun *et al*., 2009).

Accessibility to therapy

Although a doctor has no legal requirement to treat any patient, fear of infection is not an ethically correct reason for a doctor to refuse HIV-positive patients' therapy. Actions such as failing to provide medical assistance and treatment for women in childbearing are a huge insult to human dignity (Corbin and Strauss, 2008; Demmer, 2011). But it is not just the clinicians who are responsible for the lack of health care in pregnant women; it is common knowledge that a high-risk pregnant woman, even for HIV infection, is not forced to be tested or treated against her will, even though such a decision may adversely affect the fetus. Therefore, recognizing the need to seek help is extremely important for patients, as there is a strong correlation between physical and psychological disorder. Statistics show that the morbidity and mortality rates in patients seeking medical treatment are much higher (Green and Thorogood, 2014; Kajubi et al., 2014; Kiwanuka et al., 2014).

In medical and social circumstances relating to AIDS, considerable attention has been paid to the right to liberate oneself from prejudice. Stigma is a multifaceted social system with its own path; beginning with labeling, separation, loss of status and ending in discrimination. The effect of vulnerability and susceptibility to stigma is well known to vary from person to person. The key aim of modern medicine is to eradicate stigma and discrimination, and to guarantee confidentiality in research and therapy (Kohrt et al., 2012; Lee and Oberdorfer, 2009; Lester et al., 2002).

Death and Bereavement

As the disease progresses, children are faced with AIDS-related physical and mental deterioration. At this point, family members are overwhelmed and have difficulty communicating with the child about the issues associated with prognosis and death. More than facing their own mortality; children and adolescents have to deal with HIV / AIDS mortality from their loved ones. Children and young people with HIV/AIDS face and recognize their own potential deaths as major challenges. The child's cognitive and emotional maturity also influences its level of awareness of its own mortality, as well as its coping skills and defenses for dealing with this knowledge. The reactions of children can range from unawareness of the meaning of death in very young children, to increased knowledge and anxiety in the elementary age era, to significant existential conflicts in adolescents. Responsive psychological interventions with a child help to communicate his or her anxieties related to parental separation and death. At this point, particular attention needs to be paid to the issue of pain management, especially for young children with limited capacity to effectively communicate information to caregivers.

Conclusion

Due to the low coverage of Antenatal Care ANC and Prevention of Parent to Child Transmission PPTCT services in India, children continue to be born with HIV infection despite significant advances in the treatment and care. In addition, with advancements in medical treatment, HIV / AIDS has been transformed from an acute disease with a greatly foreshortened life span to a condition with many features of a serious chronic disease. Hence, caring for HIV-infected children raises major challenges for physicians and mental health professionals. Despite the various psychosocial stressors and problems faced by children and young people infected with HIV, robust mental health services remain vital.

When it comes to disclosing the children's status for HIV / AIDS infection, there is no clear consensus among practitioners and parents on when to disclose the child's HIV positive status. Moreover, several of the recommendations on disclosure tackle the dimension of disability and commitment to treatment. After the HIV diagnosis has been revealed to the infected child, the child's level of development, behavioral changes, emotional and psychological improvement by

the health care provider must be monitored in each follow-up visit. Cultural and developmentally relevant clear-cut structure for coping with the psychological effect of post-HIV disclosure on infected children with HIV/AIDS is also needed, as there is no literature available to address this issue. As the children pass into puberty, care providers need to discuss the appearance of sexuality issues as the parents feel insecure in doing so.

Care providers will discuss issues relating to sexual wellbeing, reproductive health concerns, sexual behaviour, safe sex practices, and teenage relationship issues. This will prevent the indulgence of adolescents in high-risk behaviors and promote responsible, healthy sexual behaviors and practices. This can be accomplished by incorporating life skills instruction for teens to improve their growth and development. Studies that monitor a population of such children and families over time and have multiple data collection points are critically needed to determine the changes occurring in HIV / AIDS psychosocial and behavioral aspects. Further studies are needed to understand the effect of HIV / AIDS on the family structure and the developmental process of family life stages.

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