Psychiatric aspects of HIV/AIDS in adolescents

HIV infection will increasingly be seen in adolescents as more infected children receive treatment.

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HIV infection in adolescents presents particular challenges with respect to providing comprehensive care. Psychiatric and psychosocial issues need careful attention, as they have an impact on physical well-being and on the ability of infected adolescents to live their lives to the fullest extent possible with the infection. The aim of this article is to highlight some of these issues and how health care workers can include psychiatric aspects in the provision of comprehensive HIV care to adolescents.

Epidemiology of HIV infection in adolescents in South Africa

The 2002 Nelson Mandela HSRC seroprevalence survey[1] showed that the prevalence of HIV in youth aged 15 - 24 years was 9.3% (males 6.1%; females 12%). Modes of transmission include mother to child transmission *in utero* and transmission through early and unprotected sex and sexual abuse.[1] Factors that promote early sexual experiences include substance abuse, mental illness and family breakdown. Of children infected through vertical transmission, 5 - 25% survive into adolescence – some of these having survived without antiretroviral therapy (ART) (so-called 'slow progressors').[3]

Prevention of HIV infection in adolescents

There is a significant focus on reducing risk-taking behaviour and early sexual experiences in adolescents. Many prevention programmes have been developed, but not many have been systematically evaluated. Of those that have been evaluated, programmes that focus on an integrated approach to adolescent well-being (including attention to developmental issues, psychosocial issues, substance abuse reduction, safe sex) appear to be most successful.[4] There is evidence that mental disorders may predispose to an increased risk of exposure to HIV, and intervention in terms of actively treating mental disorders should be part of this integrated approach.[5]

Psychiatric disorders in HIV-positive adolescents

Neurocognitive disorders

HIV-positive adolescents may develop neurocognitive disorders as a result of direct infection of the brain. This may present with cognitive, motor and behavioural problems. Visuomotor skills are also frequently impaired. Common presenting symptoms include school failure, hyperactivity and poor concentration and mood changes, as well as specific motor difficulties. Direct effects on the brain need to be differentiated from effects due to other disorders such as mental retardation, prenatal exposure to drugs or alcohol, inadequate perinatal care, neglect and sometimes overprotection leading to lack of stimulation. Management of neuro-cognitive disorders includes appropriate use of ART, as well as supportive psychosocial interventions for both the adolescent and the caregiver.

Psychotic disorders

Psychosis can be the primary presenting clinical problem of late-stage HIV disease. The clinical picture is usually a mixed picture of cognitive, mood and psychotic features. There is usually (but not always) other clinical evidence of late-stage HIV disease. The presence of a major psychiatric disorder in an adolescent with HIV infection that is related to the infection is usually an indication for ART. Major psychiatric disorders such as schizophrenia and bipolar mood disorder often present for the first time in adolescence. This can create diagnostic problems in the HIV-positive adolescent, as it is not always clear whether the psychiatric disorder is primary (e.g. schizophrenia) or secondary (due to a general medical condition such as HIV or opportunistic infection or substances). There are implications in terms of management as both the HIV infection and the psychiatric symptoms must be managed. Patients with a major psychiatric disorder secondary to HIV infection need careful monitoring of prescribed psychotropic medication as they tend to be very sensitive to some of the side-effects of these medications.

Depression

Depression is common in adolescents with HIV infection (a prevalence of 44% with major depression in one study of adolescents attending an HIV clinic). Adolescents may present with somatic complaints, conduct problems, irritable mood, poor concentration and poor school performance. There is good evidence that depression in people with HIV infection responds well to medication and psychotherapy. As with antipsychotic medication, care needs to be taken with dosing and drug interactions when prescribing antidepressant medication.

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Other psychosocial issues

Adolescent development

The primary task of adolescence is to develop a sense of identity. Adolescents have increasing cognitive capacity to understand abstract concepts and to question circumstances in which they find themselves. Acceptance by their peer group becomes very important, and their focus is future-oriented, in terms of occupational and social spheres. Sexuality and relationships are also a primary focus for adolescents. It is important to understand the impact of a life-threatening and chronic illness (which often affects others in the family besides the adolescent individual) on individuals at this stage of development, as it has implications for adherence, disclosure, bereavement and the development of sexuality.

Adherence

Compared with younger children, adolescents have the capacity for a much clearer understanding of their illness, including that it is incurable and that it may be fatal. However, denial may be used as a way of coping with fear based on their improved understanding. Their strong orientation to the present often means that risks, particularly of dying, are seen as distant. A number of factors characteristic of adolescence may result in inconsistent adherence. These include the need to express independence, peer pressure, not wanting to be different and feelings of being invincible resulting in increased risk-taking behaviour, distrust or rejection of authority figures and attraction to alternative or non-conventional sources of information (resulting at times in misinformation about HIV and ART). When asymptomatic, adolescents are more likely to be less conscientious about adherence. Hormonal changes in adolescence may result in emotional ups and downs, complicated by side-effects of ART.

The extent of disclosure also affects how much responsibility an adolescent can take. As mentioned above, the onset of serious mental disorders peaks in adolescence and this may also have an impact on the capacity to adhere to treatment. The disrupted environments in which some adolescents live may also make it extremely difficult for them to adhere.

Adolescents want to take more responsibility for themselves and the transition from total supervision to independence needs to be carefully negotiated.

Management of adherence in the adolescent

One has to aim for a situation where the health care team, the child and the caregiver work together in managing the treatment. Issues around disclosure need to be discussed on an ongoing basis with the caregiver, to ensure that the adolescent is appropriately informed. Concerns around confidentiality from both the caregiver and the adolescent must be addressed. The health care team may often need to be an advocate for adolescent patients in terms of understanding their developmental needs. Cultural traditions and norms may sometimes need to be explored and challenged in addressing these needs.

Both the caregiver and adolescent must be fully informed about the medication, side-effects and important drug interactions. It is helpful to expand the support system wherever possible.

Disclosure

It is important to understand that disclosure is not a one-off event, but is a process that happens over time, particularly in children and adolescents as they develop. Most caregivers find this process difficult, and need information and support in order to disclose developmentally appropriate information to their child or adolescent. Caregivers need to feel that they have some control over this process, and that they are not being coerced into divulging information without a thorough consideration of the consequences of such disclosure and a sense that they are ready to deal with these. They may need to be reminded that children may at first be sad or even angry following disclosure, but with support usually come to terms with their diagnosis.

The caregiver is the person who is most suitable to disclose, but in exceptional circumstances a health care worker may need to undertake disclosure. There may be special circumstances with adolescents with developmental delay, cognitive difficulties or serious psychiatric illnesses and information should be given according to the individual's level of understanding, which should be reassessed periodically.

Adolescents begin to be able to think beyond what is immediately present and can be felt and touched, and to think about ideas and possibilities. Friends and peers are important. Adolescents develop their own identity, have strong feelings (often judgemental), and can be impulsive. Accurate and detailed information can be given in response to questions or to expand information given earlier. Realistic information about health status should be given. Ways to live meaningfully with HIV are often a more important concern than mode of transmission. Anxiety about being different and fear of rejection is strong. Being assured that their status and what they say is confidential is important. Normal teenage striving for independence may complicate the response to disclosure (e.g. decrease in adherence). Issues of possible disclosure to others should be discussed, but the adolescent should make his/her own decisions on this matter. Assurance of support and willingness to help should be given, but adults need to avoid seeming intrusive.

Bereavement

HIV-positive adolescents and their caregivers may experience multiple losses and children often live in households where other members are infected and may become involved in the care of terminally ill members of the household. There are many cultural taboos around death, and talking about death and people who have died. Loss of a parent or other family members can affect all aspects of an adolescent's life, including adherence. It is important to be aware that children of different ages have different understandings of death. Only gradually do they develop an understanding that death is permanent and final. Adolescents understand that death is permanent and final. They realise that all people eventually die, but tend to see their own death as happening at some distant time in the future.

Adolescents are at a time in their lives where they need to become independent and to cope on their own. It may be particularly difficult for them to acknowledge their loss or to express it in ways they feel appropriate. They may also have difficulty seeking support, especially from adults, but sometimes even from peers, for fear of seeming weak. If the person's death coincides with disclosure about the cause of death or of their own status, this is particularly problematic. The death of a caregiver can set off a chain of losses for the child, including loss of a home, education

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and financial security. Unresolved grief can also affect the capacity of remaining caregivers to provide adequate care.

It is important for caregivers to understand that preparing for the death of a parent or other family member can help an adolescent to cope with the loss. Using memory boxes can be helpful, but the most important thing is to help the adolescent to express feelings. Contact with a trusted friend or with a sympathetic person outside the family can provide an opportunity for the adolescent to express feelings in private, without risk to feelings of independence. For someone who is isolated, encouragement to join a recreational or cultural activity may be an alternative. Practical steps to limit the extent of disruption of an adolescent's life are critical and it is particularly important to involve the adolescent as a valued participant in arrangements surrounding the death.

It is possible that the adolescent will regress to an earlier developmental stage after a bereavement. Encourage caregivers to talk about and share memories of the person who has died.

Sexuality

Children are sexual beings, but their experience of sexuality is not the same as that of adults, and sexuality changes with development. The most important factor influencing how children behave as sexual beings is the values and opinions of their caregivers. Caregivers need to talk to their children about sex, but few feel comfortable doing so. Lack of information, cultural taboos and discomfort affect caregivers' abilities to talk with their children. Health care workers can help caregivers develop skills and confidence in this area. If they start doing this when the child is young, then it is easier in adolescence. It is important to give information, but also to communicate values and understanding about sex and relationships. The kinds of things children want and need to know change with age. Developing sexuality should not be ignored in HIV-positive children and adolescents. Adolescents need help to understand the implications of whether or not they choose to be sexually active. Caregivers should talk about sexual development, reproduction, safe sex, relationships and values with their adolescent charges.

Acknowledgements

Much of the material for this article is derived from two excellent sources:

- Citron K, Brouillette M, Beckett A, eds. *HIV and Psychiatry; a Training and Resource Manual*, 2nd ed. Cambridge: Cambridge University Press, 2005: 181-195.
- Adherence Networking Group. Children's ART Adherence Resource Pack. Johannesburg: Perinatal HIV Research Unit, 2006.

They are well worth obtaining for further information and details.

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In a nutshell

- Psychiatric disorders are common in adolescents. HIV infection and its psychiatric consequences are also common in adolescents. It is important to identify psychiatric disorders both in terms of HIV prevention and treatment.
- The primary developmental task of adolescence is to establish one's identity. This results in an increasing need for independence and may result in denial of serious illness, rebellion against authority figures and questioning of facts about HIV infection and treatment.
- Psychiatric disorders associated with HIV infection in adolescents include neurocognitive disorders, psychosis and depression. All these disorders may require treatment with ART as well as psychotropic medication. It is important to be aware of drug interactions and side-effects of both ART and psychotropic medications.
- Common psychosocial issues in adolescents with HIV infection include adherence, disclosure, bereavement and sexuality.
- Effective management of these psychosocial issues requires a collaborative approach with both the adolescent patient and his or her caregiver.
- Adherence in adolescents is influenced by the extent of disclosure and acceptance of the illness, the health status of caregivers, the family environment in which the adolescent lives, and the adolescent's need for independence.
- Disclosure is a process in adolescents that is dependent on the individual's developmental phase as well as family and caregiver concerns and needs in this regard.
- HIV-positive adolescents may experience multiple bereavements, and these bereavements may result in significant disruption and other losses at the same time (such as loss of home, financial security and schooling).
- Sexuality develops during childhood and adolescence. Caregivers are the most appropriate people to discuss sexuality with their children and adolescents but seldom feel comfortable doing so. Health care workers need to assist them in undertaking this task.
- Sex education and discussions around sexuality should occur over time in the context of a trusted relationship and in the context of other developmental issues.