Growing Up With HIV in Southern Africa: HIV-Infected Children and Adolescents

Abstract

In South Africa according to the 2013 mid-year population estimates the overall HIV prevalence is 10% with the total number of people living with HIV estimated at approximately 5.26 million. Thus Southern Africa has been declaring a long war against the HIV epidemic and South Africa is still bearing the brunt of this epidemic. In sub-Saharan Africa, where there is ongoing prevention-of-mother-to-child transmission (PMTCT) of HIV infection and disease, there remains an expanding number of young individuals who will spend the rest of their lifetime coping with the reality of HIV infection, being managed with a chronic disease and expected to remain on lifetime chronic antiretroviral medication. The effects on HIV infected children and adolescents are multi-faceted and complex, but emerging problems such as HIV drug resistance and transition programme difficulties with distant and perhaps unknown goals need to be tackled. In addition, as children are growing and maturing with HIV-infection and being treated with long-term antiretroviral medication and regimens, more clinical complications, other than death, and complications of their medications are observed, including cardiac diseases, malignancies, growth failure, a wide range of skin diseases, renal and bone complications, neurocognitive problems, co-infections, neuropsychiatric co-morbidities, dyslipidaemias and earlier lung conditions. Practical issues regarding disclosure to young HIV-infected individuals, transitioning care and HIV-infection in the adolescent years will be addressed and this article will highlight certain considerations, including caring and monitoring of children and adolescents living with HIV, exposing vulnerable populations, establishing research interests and identifying some challenges between resource-rich and resource-poor settings.

Keywords

HIV infection; Southern Africa; HIV-infected children; HIV-infected adolescents; Transition care

Introduction

South Africa has been declaring a long war against the HIV epidemic prevailing in sub-Saharan Africa and in particular South Africa at present bears the brunt of the HIV epidemic [1]. Although the response to the AIDS epidemic was initially slow in South Africa, intervention strategies have been applied intensely and extensively. 2 However, certain South African and international medical authorities have deemed these efforts as not as successful for vulnerable populations [2]. Vulnerable populations described on the background of the HIV epidemic include displaced individuals from conflict and economically-torn regions, individuals that seek refuge using alcohol or recreational drugs or traditional (herbal) medications, young black African women, black males, children born to HIV-infected mothers and children in transition care to adolescence and adulthood [3]. HIV surveys revealing incidence and prevalence data are essential to track epidemiological trends and virus molecular and genetic emergence, however human behaviour activities and social data are also critically required, especially within the younger populations [4].

In South Africa according to the 2013 mid-year population estimates, the overall HIV prevalence is approximately 10% with the total number of people living with HIV estimated at approximately 5.26 million. The 2013 statistics also state that an estimated 15.9% of the South African population is HIV-positive. In addition to these geographical statistics there is an estimated 3.4 million children living with HIV globally [4]. There is a development of differing epidemics within the HIV pandemic globally and emerging patterns in sub-Saharan Africa with growing numbers of perinatally infected patients growing into adulthood and then adults growing into senior citizenship. Health care providers should focus beyond the single goal of prolonging the survival of HIV-infected children and adolescents and rather concentrate on each individual’s broader health care programmes and goals. In sub-Saharan Africa, where there is ongoing prevention of mother-to-child-transmission (PMTCT) of HIV infection and disease, there remains an expanding number of young individuals who will spend the rest of their lifetime coping with the reality of HIV infection, being managed with a chronic disease and expected to remain on lifetime chronic medication, not without side-effects, adverse drug events and long-term physiological complications [5]. The purpose of this article is to highlight the following, namely:

a) To sustain care, management and monitoring of children and adolescents living with HIV
b) To continuously assess and be aware of social-psychological issues for infected young, older children and adolescents.

c) To recognise the medical phenomenon of transition HIV care from child hood to adulthood.

d) To recognise complications from anti-retroviral therapy in HIV-infected children and adolescents.

e) To create and sustain a greater awareness and understanding of HIV care, management and treatment in vulnerable populations.

f) To establish ongoing research and interest in resource-limited settings, where children and adolescents live with the realisation that many factors of this infection and disease are still unknown.

g) Staffing in developing regions of the world.

h) And realise that the optimal treatment and management of treatment-related events require current and future research goals towards identifying the challenges between resource-rich and resource-poor settings [6].

It has been stated in the medical literature that “the disease has been rightly likened to a whirlwind, sweeping everything before it as millions become infected, fall ill and die” [7].

**HIV and Children**

Historically, as infectious diseases spread to endemic or pandemic proportions, often women and children are mostly affected. The HIV pandemic continues its global spread as indicated by disease impact outcomes, and the number of children infected and dying increasing. This is especially observed in developing countries and regions of emerging and economical growth [8]. The overall transmission rates (without any form of medical intervention) are between 25% and 45% of all children born to HIV-positive mothers in Africa [9]. The main route of transmission of HIV from mother to child is via the placenta (in utero), especially during labour and delivery and post natally through breast feeding. The effects of HIV on children and adolescents are multi-faceted and complex and selected reasons will be stated, namely-

a) They are part of a physically growing population.

b) They encounter complex stages of development, emotionally and sexually.

c) And they remain the future of nations.

These complex effects need to be factored into the HIV care packages for children and adolescents and adapted accordingly to the geographic region and evolving HIV epidemic. Some considerations include the following, namely-

a) Care packages for HIV-exposed infants.

b) Care packages for HIV-infants and children not receiving antiretroviral (ARV) medication.

c) Care packages for HIV-infected children on ARVs.

d) Consent preparation for HIV diagnosis.

e) Psychosocial support structures that are prepared to assess adherence to therapy in children, adherence counselling and HIV-status disclosure.

f) Nutritional support.

g) Monitoring of growth development.

h) And management of the complications of ARV therapy in children [10].

In addition to these HIV care package strategies, there are four integral components of prevention of mother-to-child transmission (PMTCT) that need to be categorised and are dependent on accurate and accessible HIV diagnostic facilities. HIV diagnosis should be offered and available in resource-poor conditions with limited resources and staffing expertise for the following women- and child-related clinical scenarios, namely-

a) Primary prevention of HIV, especially amongst women of child-bearing age.

b) All pregnant women should be offered or have access to HIV counselling and testing services.

c) Adequate and reasonable management during labour and delivery irrespective of their HIV-serostatus and.

d) Timeous follow up of infants born to HIV-positive mothers or mothers at high risk [11].

However, as HIV-infected children are growing and maturing with the initiation of intervention, prophylactic and treatment programmes, more clinical complications, other than death, are observed such as these selected examples-

a) Cardiac diseases, including dilated cardiomyopathy, pericardial effusion, left-ventricular diastolic dysfunction, increased left ventricular wall thickness, associated with the prolonged use of certain anti-retroviral drug classes, such as the protease inhibitor agents.

b) Malignancies that include cervical cancer, Burkitt’s lymphoma and Kaposi sarcoma.

c) Growth failure.

d) A wide range of skin diseases.

e) Renal diseases.

f) Bone problems such as osteoporosis and osteopenia.

g) Neurocognitive diseases.

h) Chronic lung conditions and disease.

i) Lipodystrophy and dyslipidaemia.

j) And hyperlactataemia [6,12-14].

New developments in ARV therapies over the past few years have transformed HIV-infection from a palliative and
prophylactic infection to a sustainable and manageable chronic disease. It should be noted that in developed countries mother-to-child-transmission (MTCT) of HIV-infection rates are clinically significantly lower than over the past few years as perinatally HIV-infected children and adolescents have been initiated on ARV therapy and enrolled into HIV care package programmes [13]. In sub-Saharan Africa, as a consequence of sustainable MTCT initiatives and programmes, newly infected children are started on ARV treatment early in their lifetime and this expands to older children and adolescents requiring lifelong treatment and life-term HIV management including routine and regular laboratory and clinical monitoring [3,5,6]. Due to the increasing population of children initiated on long-term ARV therapy, the following consequences have and can be expected, namely-

a) More children initiated on ARV therapy globally
b) More children on long term ARVs
c) More HIV-related morbidity and mortality clinical events
d) HIV and tuberculosis co-infection will continue to arise and drug resistance for both diseases will increase and prevail
e) ARV drug resistance. that includes major and minor drug-related mutations, will become a realistic clinical phenomenon
f) And long-term toxicity of lifelong ARV therapy will realise into clinical complications and consequences for those individuals starting ARV treatment early in their life-span [5,6].

South Africa follows the public health approach to ARV drug choices and regimens using standardised protocols and includes routine HIV-1 RNA viral load monitoring for the detection of treatment failure [15]. The scale up of ARV therapy in South Africa has been accompanied by the emergence of ARV drug resistance, as has been observed in other countries. Therefore prevention, surveillance and monitoring of HIV ARV drug resistance mutations are critical and essential for clinical and public health HIV programmes in South Africa and in turn, global HIV prevention programmes must be co-ordinated nationally, regionally and globally [16-18].

Objectives of disclosure for young HIV-infected individuals

It is said in South Africa that disclosure is a journey and not a destination. However there are two main objectives of disclosure, namely-

a) To equip and empower parents or care-givers with essential information on the current management and treatment of HIV
b) To convey the potential for a relatively normal healthy life with a good chance for an extended life expectancy, if treatment adherence is maintained and sustained

The child’s knowledge of their illness needs to be assessed and an age-appropriate process for disclosure should be started. Several studies show that increased knowledge and understanding about HIV infection and disease can assist in the following ways, namely-

a) To facilitate the child’s adjustment within the family, to the illness itself, within society and their culture and to HIV care management and treatment regimens
b) To boost the child’s self-esteem
c) To increase and sustain adherence to treatment and monitoring
d) To decrease risk behaviour, such as sex with multiple partners, alcohol and drug abuse
e) And to build strong family ties that may enable all to tackle future challenges [19-21].

Symptomatic children should be informed of their HIV serostatus as they could access information from other sources that may be confusing, misleading, inaccurate or unsafe. However, adolescents must know their HIV serostatus. They need to appreciate how their future actions may impact on their health and should also be informed of any or potential clinical HIV drug trials and what implications could arise should they participate.

Actual disclosure to young HIV-infected individuals

Questions need to be asked and contemplated, such as the timing of disclosure, how should it be done and very critically by whom? The timing of disclosure depends on the maturity of the child and possible co-existing neurodisabilities [19]. However, it should be noted that the difficulty of the eventual revelation will only get worse if the process of disclosure is delayed or behaviour denial is exercised. There are additional contextual challenges including trying to prevent disclosure of the mother’s HIV serostatus, avoidance to addressing their own feelings which are strongly guilt-ridden and the ever present feeling and fears of discrimination and stigma. Particularly in rural settings and undeveloped areas, care givers and health care workers typically and routinely think disclosure is a discreet event [22]. Adolescent often report that they are not given enough opportunities to ask questions. The understanding of HIV infection and its modes of transmission need to be understood with an emphasis that the knowledge of the diagnosis should be dealt with as private and strictly confidential. In older adolescences the main task of the multidisciplinary medical and care team is to empower the individual with understanding, life support structures and behaviour confident thoughts.

There are disclosure areas that can be targeted, namely-

a) Encouraging the young person to take responsibility for managing their medication and sexual relationships
b) Providing post-sexual exposure prophylaxis and emergency contraception and access for assistance by competent staff
c) Providing information about planning to have their own children
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Be prepared for and accept silence
Try to share the diagnosis as quickly and as timeously as possible, do not delay
Involve the whole (multidisciplinary) team
Question time must be repeatedly encouraged
Use clear and appropriate explanations of the diagnosis and HIV disease
Use educational materials appropriate to the age and stage of development
Promote the sharing of feelings

Table 1: General principles for disclosing HIV status [24,25].

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<td>1</td>
<td>Date of disclosure should not coincide with other dates such as birthdays, anniversaries etc.</td>
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Transcending care

The advances in ARV development and the release of newer drugs have translated into more HIV-infected children surviving into adulthood [28]. The transition phase between paediatric to adult care requires clinical staff for HIV support, management and treatment preparation so that they do not get lost to follow up at this important juncture. According to the authors Reiss and Gibson [29], the definition of transition is quoted as the following “Transition is a multi-faceted, active process that attends to the medical, psychosocial, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system. Health care transition facilitates transition in other areas of life as well (such as work, community and school).” However data is limited regarding the outcomes of HIV-infected youth after transition to adult health care [30]. Qualitative studies emphasize the importance of an individualised approach to the transition process, including addressing health insurance, alcohol and drug treatment and awareness, housing, transportation, training and education, employment circumstances and the effective management of psychiatric comorbidities [31]. Further studies looking at outcomes of transition and identifying determinants of a successful transfer or even unsuccessful transfers are needed in resource-rich and resource-poor settings.

HIV infection in the older child or adolescent

“Age is the most unexpected of all things that happen to man” -Leon Trotsky 1879-1940 (proceedings from his diary in exile, found and read in 1959) Ageing is the term used to describe the decline of physical ability, appearance and mental agility such as retaining and processing information, mostly new information. It can also be defined as the deterioration of bodily functions over time. However the ageing process in patients who are HIV-infected whether ARV treatment naive or on long term HAART (highly active anti-retroviral therapy) is still not completely understood. Both HIV infections per se and ARV therapy contributes to the expressive phenotype of immune senescence (immune aging). This may be attributed to a combination of HIV infection and...
HAART that could likely have long-term dysfunctional effects on the mitochondrial DNA. These dysfunctional effects may include mitochondrial oxidative disruption [32,33]. Adolescence is defined as the transitional phase of growth and development between childhood and adulthood (Encyclopedia Britannica, contributor Mihalyi Csikszentmihalyi). The World Health Organisation defines an adolescent between ages 10 and 19 years. Little is known about the survival of HIV-infected children in Africa older than 5 years of age [34,35]. Decreased survival in Africa is explained by the lack of access to ARV therapy, a delay in laboratory and clinical diagnosis and inadequate and unreasonable management due to lack of expertise, resources and facilities [36]. Older children and adolescents are diagnosed late in Africa and most care-givers actually suspect the children may be HIV-infected before the eventual laboratory confirmation of the diagnosis [10,20]. A realistic factor should also be considered for adolescents living with a chronic illness in that transitioning into adulthood includes an important and valuable shift towards medical independence.

There is still a significant burden of HIV infection in Southern Africa who has acquired the disease perinatally [20]. However, there remains an urgent need for services and staff that will provide reasonable and appropriate HIV testing and monitoring, counselling pre-treatment initiation and during ARV therapy with HIV care and support packages and programmes.

Research avenues-new or unexplored

Research into ageing and the effects from HIV-infection has been neglected when compared to other areas of HIV research and this may be attributed to the success and effectiveness of ARV therapy and patient support. This does however set a tone for further research into HIV-infection, HIV-disease and ageing. The two questions that can now be considered seriously for HIV transmission in older individuals are-

a) The use of medication for sexual maturity and

b) The physiological effects of hormonal changes in adolescents

It has also been observed that older children and adolescents are usually or often excluded from clinical trials.

There remains limited data or published studies on the successes or failures of HIV-infected individuals in transit from childhood-facilitated care to adulthood-based care and the following research question have been identified, namely-

a) Which mental factors of the HIV infected individual affect the success or non-success during the treatment and age-related transition stage?

b) Is there any comparison between perinatally infected children and behaviourally infected children during the transition period?

c) Are there any differences in life style skills or behaviour trends between perinatally infected youth and behaviourally infected youth?

d) Do sexual behaviour and the types of sexual exposures enhance or deter the response to ARV therapy and HIV care packages and programmes?

Conclusion

In Africa, dedicated health services are limited for young people. Thus, there is an urgent need to develop and implement more effective policies and programmes aimed at early diagnosis and improvement of care. Finally, there are still enormous research gaps with regards to the effects of HIV-infection and disease on the paediatric population and these aspects need to be addressed before a critical point is reached, as the numbers of HIV-positive adolescents increase to adulthood. The transition phase is a neglected or underrated area for research and more qualitative study data is required from the African continent. Adolescents evidently contribute substantially to hospital admission in sub-Saharan Africa and this can be avoided by early diagnosis and timeous initiation of ARV therapy. The plight of children and adolescents still requires urgent attention and policy and programme revision in Africa

Acknowledgement

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