Preventing HIV infections in children and adolescents in sub-Saharan Africa through integrated care and support activities: a review of the literature

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Sub-Saharan Africa has been hit harder by the HIV/AIDS pandemic than any other region of the world, and children under age eighteen represent one-third of all new HIV infections occurring there annually. While HIV prevention efforts targeting youth are well established, few prevention programmes provide comprehensive care and support services. One reason for this is that prevention messages are often targeted only at older adolescents, and care and support activities typically emphasise the needs of younger children. By expanding prevention activities to younger children, and expanding care and support activities to older adolescents, more holistic, and truly integrated programmes can be developed which address the common factors which make children of any age particularly vulnerable to HIV infection, namely: inadequate access to health care and unstable familial and social environments. This paper reviews evidence of the potential impact of care and support activities on HIV prevention among youth, and presents a conceptual framework for the development of comprehensive, effective, integrated HIV/AIDS prevention and care programmes tailored to the specific needs of youth.

Key Words: AIDS, intervention, psycho-social support

Introduction

From the early years of the epidemic until recently, bi- and multi-lateral donors have dedicated the majority of available HIV funds to prevention activities. This approach reflected assumptions that care and support efforts were too costly, logistically cumbersome, or politically charged; and that epidemiologically, prevention efforts, at the earliest stages of an epidemic, are more important than care (Bloom, 1999; Collins & Rau, 2000; Farmer & Over, 2000; Gellman, 2000). Recently, however, the recognition of several factors, such as the continuing, overwhelming number of new HIV infections, the failure of many prevention-only programmes to yield significant reductions in HIV incidence, the growing numbers of children orphaned, and the increasing grassroots demands for improved access to treatment, has led donors, governments, international NGOs, and other resource and decision-making bodies to re-evaluate what constitutes effective AIDS programming (Kerckoven & Hammeijer, 1998; Manning, 2000).

Evidence from effective, successfully integrated programmes in developed countries, as well as Uganda and Thailand, has led to a growing consensus that the expansion of care and support services can result in better control of the pandemic (Zuniga, 1999; WHO/UNAIDS, 2000). However, the extension of these services to children under 18 and the potential impact of these services on preventing new infections among youth, has been insufficiently addressed, and few programmes have been implemented which provide comprehensive HIV prevention and care and support services to all youth, regardless of age.

Since the HIV virus was first identified in 1981, more than 3 million children have been born HIV positive and the mothers of over 80 million children have died from AIDS (UNAIDS, 2000). Although the concept of ‘childhood’ is defined differently in every culture, common to all definitions is the notion that childhood is a period of rapid growth and development. During the years of physical growth in which a child matures toward adulthood, the child is also developing psychologically and in ways that define intellectual, social, spiritual, and emotional characteristics. Although the UN Convention on the Rights of the Child declared that children are “entitled to special care and assistance” and that this care and assistance should enable “full and harmonious development” (UNCRC, 1989), the HIV/AIDS epidemic has impeded millions of children from fulfilling this right.

This paper explores the definition of ‘integrated’ HIV/AIDS prevention and care and support programmes for youth, and reviews the published and ‘grey’ literature for evidence of the potential impact of care and support activities on HIV prevention among youth. Finally, a conceptual framework for the development of comprehensive, effective, integrated HIV/AIDS prevention and care programmes is presented which addresses the specific needs and contextual environment facing youth in sub-Saharan Africa.

Methods

Descriptive and analytical studies addressing the effectiveness of HIV/AIDS prevention or care and support programmes focused upon youth were identified by searching
electronic databases of the peer-reviewed medical journals and the 'grey' literature (literature not formally published including programme reports, policy documents, dissertations, and conference abstracts). The search utilised both formal and ad hoc methods. A systematic electronic and manual search was conducted of peer-reviewed and non-reviewed articles to identify reports of care and support interventions in sub-Saharan African populations that included youth aged 0–18 years.

Medical databases searched included Medline, AIDSline, and Pline, as well as a selective review of EMBASE, BIOSIS, SCISEARCH, and SIGLE. In addition, several websites were accessed such as the XIII International AIDS Conference, UNAIDS, and a wide range of local and international non-governmental HIV/AIDS organisations.

Manual search techniques, including systematic visual searching of the bibliographies of articles identified during the online searches in health, medical, and social science journals, and books, were also conducted, as well as a review of final project reports and programme evaluations from various international donor agencies and implementing organisations. The articles that were identified in turn identified additional sources as well as MeSH and freetext terms which allowed for an additional round of online and manual search incorporating these new terms.

Articles and reports that reported evidence of effectiveness on HIV risk reduction in the defined population were included in the following review, and incorporated into the conceptualisation of the proposed framework linking HIV prevention to care and support activities. The proposed framework was also informed by field observation and evaluation assessments of HIV/AIDS prevention, and care and support programmes, implemented by diverse organisations in several sub-Saharan African countries.

Defining care and support and integrated programmes for youth

The extension of care and support to people living with, and affected by, HIV and AIDS, has been defined in many different ways. Most definitions include the provision of: 1) counselling and testing; 2) clinical care and treatment; and 3) home care and family counselling (World Bank, 1999).

Programmes which aspire to provide more comprehensive care and support often include three more activities: 4) ensuring human and legal rights of people living with HIV/AIDS (PLWHA); 5) working to combat stigma and discrimination; and 6) strengthening communities to care for PLWHA and orphans (Osborne, 1996). Together these six services can be understood to support two main objectives: improving health infrastructures and strengthening families and communities.

Tailoring care and support programmes to children includes the same basic components but also involves recognising the different needs of infants, children, and adolescents — whether infected or affected by HIV/AIDS. Each of these groups has specific concerns and specific physical and emotional needs. These different needs should not mask, however, the ties which unite these groups — both in terms of the causes of vulnerability (for example, the loss of a parent) or in terms of the obstacles to receiving care and support. Clearly, youth of all ages suffer because of weak health infrastructures, and suffer from poor access even when adequate health resources are available. Likewise, youth of all ages are vulnerable to the devastating consequences resulting from disrupted and fractured families and communities.

Few integrated HIV/AIDS prevention and care and support programmes have been developed which recognise the needs and opportunities of targeting all youth — from newborn to mature. To date, most HIV/AIDS prevention programmes have focused their efforts only on older adolescents, while care and support programmes for youth have emphasised newborns and younger children. Developing truly integrated programmes which reach youth of all ages — expanding prevention messages to younger aged children and expanding support to older aged children — also expands the effectiveness of programmes. By incorporating the twin goals of improving health infrastructures and strengthening families and communities, HIV prevention programmes targeting youth can build sustainable and credible programmes, while improving the quality of life for youth affected and infected with HIV, and simultaneously preventing future infections.

Preventing HIV infection through improving the health infrastructure

During 1999, more than 600 000 children were infected with HIV, primarily through mother-to-child transmission (UNAIDS, 2000). Nearly 85% of these children reside in sub-Saharan Africa. This toll of infection occurs despite well known protocols that can effectively eliminate nearly all transmission from an infected mother to her child.

In 1994, administration of zidovudine to mothers during pregnancy and labor, and to infants for 6 weeks after birth was shown to reduce perinatal transmission (Connor, Sperling, Gelber, Kiselev, Scott, O'Sullivan, Van Dyke, Bey, Shearer, Jacobson, Jimenez, O'Neill, Bazin, Delfraissy, Culnane, Coombs, Elkins, Moye, Stratton & Balsley, 1994). Use of this regimen in more developed countries, coupled with increased prenatal HIV-1 counselling and testing, has reduced perinatal transmission rates to as low as 4–6% (Wade, Birkhead, Warren, Charbonneau, French, Wang, Baum, Tesorio & Savicki, 1994). Simpler and less expensive short course antiretroviral regimens have since been developed and shown to decrease perinatal transmission in less-developed countries (Dabis, Msellati, Meda, Welfens-Ekra, You, Manigant, Leroy, Simonon, Cartoux, Combe, Ouangre, Ramon, Ky-Zerbo, Montejo, Salamon, Rouzioux, Van de Perre & Mandelbrot, 1999; Ditrame ANRS 049 Study Group, 1999; Guay, Musoke, Fleming, Bagenda, Allen, Nakakibiito, Sherman, Bakaki, Ducar, Deseyeve, Emel, Mirochnick, Fowler, Mofenson, Miotti, Dransfield, Bray, Mmiro & Jackson, 1999; Saba, 1999; Shaffer, Chuachowong, Mock, Bhdrakom, Siriwasin, Young, Chotpitayasunondh, Chearskul, Roongpisuthipong, Chinanoy, Karon, Mastro & Simonds, 1999; Wiktor, Ekpi, Karon, Nkengasong, Maurice, Severin, Roels, Kouassi, Lackritz,
Coulibaly & Greenberg, 1999). For example, the use of two doses of nevirapine (at the onset of labor and 48–72 hours postpartum) reduces perinatal HIV-1 transmission by 60–80% and has a cost of only US$4 (Guay et al., 1999).

Despite this reduction, many countries in sub-Saharan Africa are nonetheless having trouble implementing short course antiretroviral treatment. Barriers include inadequate maternal-child health care infrastructure, lack of prenatal HIV counselling and testing programmes, and limited resources. Improving access to health care is the key to addressing each of these barriers. Currently, only 42% of women in sub-Saharan Africa have access to a health professional at the time of delivery (Graham & Newell, 1999), and prenatal HIV counselling and testing is non-existent, or severely limited, in most of the continent. With recent improvements in HIV-1 antibody assays, a counselling and testing programme can provide same-day test results. Rapid testing programmes had high overall acceptability in studies in Uganda and South Africa (Downing, Otten, Marum, Birahawho, Alwano-Edyegu, Sempala, Fridlund, Dondero, Campbell & Rayfield, 1998; Webber, Swandumdever, Grabow & Foure, 2000). Widespread availability of voluntary prenatal counselling and testing to identify HIV seropositive individuals coupled with the use of short course nevirapine therapy could prevent 250 000 to 400 000 infants from becoming infected with HIV in sub-Saharan Africa annually. While elective caesarean delivery also reduces HIV transmission, the feasibility of this alternative in sub-Saharan Africa is minimised by cost, staffing and the possibility of postoperative complications.

Postnatal HIV transmission is more difficult to prevent (for a range of both medical, cultural and practical reasons), and can account for one-third to one-half of all transmission (Saloojee & Violiari, 2001). While exclusive breastfeeding appears to have less risk than mixed feeding (Coutsoudis, Pillay, Kuhn, Spooner, Tsai & Coovadia, 2001), a comparison of breast and formula fed infants in Kenya clearly found that (at 24 months) more breast fed children than formula fed children acquired HIV (36.7% vs. 20.5%) (Nduti, John, Mbori-Ngacha, Richardson, Overbough, Ndinya-Achola, Bwayo, Onyango, Hughes & Kreiss, 2000). A meta-analysis of the timing of breast milk HIV transmission found that early cessation of breast feeding (at six months) would avert some, but not most, infant HIV infections due to breast feeding (John, Richardson, Nduti, Mbiri-Ngachad & Kreiss, 2001). Another concern is a recent report (Nduti, Richardson, John, Mbiri-Ngacha, Mwatha, Ndinya-Achola, Bwayo, Onganyo & Kreiss, 2001), though controversial (Newell, 2001; Thompson, 2001), of an association between breast feeding and increased maternal mortality.

Voluntary HIV counselling and testing programmes are also important in the primary prevention of HIV infection in children. VCT can protect future generations of children in highly endemic countries by protecting their mothers from becoming infected if they are not already HIV positive. A recent study in Kenya, Tanzania and Trinidad found a 50% decrease in unprotected intercourse with non-primary partners among HIV-1 negative individuals receiving VCT (VCTESG, 2000). A previous meta-analysis of VCT concluded that testing resulted in a reduction in unprotected intercourse for HIV serodiscordant couples as well (Weinhardt, Carey, Johnson & Bickham, 1999).

Several additional, non-antiretroviral interventions have been studied to reduce MTCT, for example, virucidal cleansing of the infant and the mother’s vaginal canal (Biggar, Miotti, Taha, Mitmavalye, Broadhead, Justesen, Yellin, Liomba, Miley, Waters, Chiphangwi & Goedert, 1996; Msellati, Meda, Leroy, Likikouet, Van de Perre, Cartoux, Bonard, Ouangre, Combe, Gautier-Charpentier, Sylla-Koko, Lassalle, Dosso, Wellens-Ekra, Dabis & Mandelbrot, 1999; Gaillard, Mwanynumba, Verhofstdete, Claeys, Chohan, Goetghebeur, M Validate, Ndinya-Achola & Temmerman, 2001), antibiotic treatment for bacterial chorioamnionitis (Goldenberg, Vermund, Gopfert & Andrews, 1998), and nutritional supplementation (Burns, FitzGerald, Semba, Hershov, Zorrilla, Pitt, Hammill, Cooper, Fowler, & Landesman, 1999; Coutsoudis, Pillay, Spooner, Kuhn & Coovadia, 1999; Fawzi, Masaamata, Hunter, Urassa, Renjifo, Mwakagile, Hertzmark, Coley, Garland, Kapiga, Antelman, Essex & Spiegelman, 2000). Results from these approaches so far have been disappointing — none have showed efficacy at reducing perinatal transmission. However, some of these approaches did contribute to positive overall outcomes, significantly reducing maternal and neonatal mortality and morbidity. While these approaches have yet to demonstrate substantial impact in preventing HIV transmission, they illustrate the importance of developing the health care infrastructure for rapid implementation of innovative low-cost therapies, as they become available.

Improving the health infrastructure should not be limited to improving access to appropriate counselling and medical care for mothers, but also must include improving access to condoms, STI treatment and HIV counselling and testing for children and adolescents. In most countries in sub-Saharan Africa, adolescents have little or no access to health care providers for information on contraception and HIV protection, or for STI treatment (Miller & Rosenfield, 1996). Overburdened HIV counselling and testing programmes turn away adolescents because of real or imagined concerns of parental permission or assumption of low risk. Expanding the infrastructure and improving access to these services, particularly when tailored to children and adolescent audiences, is an essential part of improving overall care and support services.

Preventing HIV infection through strengthening affected families and communities

Numerous studies have shown that a child’s vulnerability to HIV infection increases as the stability and socio-economic status of his/her family declines (Muller & Abbas, 1990; Bailey, 1992; Baang, Mbuene, Nsau & Mandala, 1994; Topouzis, 1994; Konde-Lule, Sewankambo, Wawer & Sengonzi, 1996; Nakuti, Mukasa, Sewankambo, Willme & Lwanga, 1996; Ellford, 1997; Levine, Michaels & Back, 1998; Njoroge, Ngugi, & Waweru, 1998; Vitthyasai, 1998; Yawo, Namshubuga, Buyita & Kosingi, 1998). For example, a survey of eight sub-Saharan African countries found that the proportion of orphans attending school was 15–70% lower than children with two parents (UNAIDS, 2000). Although initial
research of HIV in sub-Saharan Africa found greater prevalence among wealthier, better-educated individuals, as the epidemic has spread and matured, more recent studies have consistently found an association between low levels of education and increased risk of HIV (UNAIDS, 2000).

Children whose parents are infected with HIV, and who may or may not be infected themselves, face both emotional and physical risks. A Ugandan study that traced 460 5–15 year old children orphaned by AIDS found that nearly two-thirds of the children had left school as a result of lack of fees, one in 30 had been sexually abused, and two in five showed signs of psychological disorder (Lwanga, 1991). This result is not universal, and in other studies (Ryder, Kamenga, Nkkusu, Batter & Heyward, 1994; Foster, Shakespeare, Chinemana, Jackson, Gregson, Marange & Mashumba, 1995), even within Uganda (Kamali, Seeley, Nunn, Kengeya-Kayondo, Ruberantwari & Mulder, 1996), much less impact is reported. The difference between these extremes may be the level of involvement of extended families and communities in providing care and support.

The illness or death of parents or guardians because of HIV/AIDS can rob a child of the emotional and physical support that defines and sustains childhood. In communities with high rates of HIV infection, adults may be unable to assume the additional responsibilities of caring for children affected by HIV/AIDS. Fear of discrimination may lead to families keeping secret the knowledge of HIV infection rather than seeking help. Orphans are therefore likely to remain vulnerable to increased mortality and a range of social problems, including the possibility of increased sexual exploitation and abuse. Young people from families affected by HIV may seek emotional support and security through precocious sexual relations, thereby increasing their risk of HIV infection.

In the absence of adult caretakers, children take on additional responsibilities for survival of the family and home. One hundred and twenty million children between the ages of 5 and 14 work in conditions that are hazardous to healthy growth and development (ILO, 1997). Estimates suggest that as many as 100 million children worldwide are homeless or spend most of their time on the streets (UNICEF, 2000). As many as one million children are involved in commercial sexual exploitation every day (EPCAT, 1996). Studies from varied countries in sub-Saharan Africa have found between a quarter and a half of all girls are physically, sexually, and psychologically abused (CNUCED, 1999; Madu & Pelizer, 2000; UNAIDS, 2000). In 1999 in Botswana, a single NGO provided care to an average of 100 sexually abused children per month, over half of whom were under 12, and a quarter of whom were under five (UNAIDS, 2000). In one study in Zimbabwe, between 40–60% of rape cases brought to the attention of hospitals, police and courts were children; many more were believed to remain unreported (Meurings, Vor, Coutinho, Moyo, Mpofu, Oneko, Mundy, Dube, Mahlangu & Sibindi, 1995). These cases rarely result in prosecution, more rarely in conviction, and often there is not even the provision of counselling available to the victim (Chaudhry, Sangani, Ojwang & Kahn, 1995; EBWA, 2000).

To avoid infection, children need a supportive, enabling environment that provides them not only with the knowledge about how to protect themselves, but also with the motivation and the power to do so. To date, little research has been conducted about contextual constraints to behaviour change among children at risk for HIV infection. Current HIV prevention interventions, which are commonly tailored to older adolescents, and which largely rely on IEC messages about ‘safe sex’, are often poorly evaluated (Oakley, Fullerton & Holland, 1995; Stanton, Kim, Galbraith & Parrot, 1996) and rarely demonstrate sustained changes in risk behaviours (Agha, 2000). Although the need for a broader, contextual approach involving care and support in HIV/AIDS prevention programmes has been endorsed by UNAIDS (UNAIDS, 2000) and has been incorporated into new communications frameworks (Airhihenbuwa, Makinwa & Obregon, 2000), most programmes treat adolescents as individuals and ignore the conditions and constraints that govern their lives and define their ability to protect themselves from the risk of HIV infection. Contextual factors have been cited as an explanation for adolescent risk behaviours in a comparative analysis in seven less-developed countries (Dowsett & Aggleton, 1999) and have been recognised as important additions to cognitive behavioural theory models (Schietinger, 1998).

**Developing holistic programmes**

The characterisation of interventions as either ‘adolescent prevention’ or ‘orphan and vulnerable children’ has prevented the development of a holistic model for youth programmes which takes advantage of the proven synergies which make prevention more effective by including provisions of care and support, and make care and support more effective by including provisions of prevention programmes. For adults, voluntary counselling and testing (VCT) has traditionally been recognised as the key entry point for developing integrated prevention and care programmes. The role of VCT in children and adolescent programmes, however, has been more controversial.

Despite the desire for adolescents to know their HIV status, many programmes and published guidelines discourage testing for this group or institute policies which are arbitrary and discriminatory. For example, the ‘Model Guidelines for VCT of the Southern African Development Community’ recommends that: ‘Youth between 15 and 18 years old may receive services [only] if they are a “minor male”, already engaged in risk-associated behavior(s)’ (Futures Group International, 2002). Determining who is a ‘minor male’ allows for the introduction of gender bias and discrimination on the part of health practitioners, and discourages adolescents from seeking testing by creating two categories of adolescents: those permitted to receive tests versus those who are not. This standard also creates uncertainty and confusion among adolescents about the availability of counselling and testing services.

Even when adolescents do have access to VCT, the quality of the services provided is often unsatisfactory. One study of adolescents seeking testing in Nairobi, found that one out of four youth did not talk with a service provider either before or after the HIV test. These youth got their test results either as a written report or from a third person such
as a parent (Horizons, 2001). A related study in Uganda found that few care and support services were available for referral of adolescents (Horizons, 2001).

The disproportionate emphasis of care and support programmes on children, to the exclusion of adolescents and prevention messages, has been noted by a number of critics, including the World Bank (Levine, 2001). However, as children orphaned or abandoned because of HIV/AIDS develop an increased awareness of the causes of the familial and community upheaval surrounding them, there will be an increased need to directly address their fear of being infected, their need for prevention information, and their desire to be tested, regardless of their sexual risk behaviour. Rather than dismiss these fears as unwarranted, care and support programmes should consider VCT as an opportunity to reinforce prevention messages and reassure and empower uninfected children. While VCT can not serve as the central link between prevention and care and support programmes for youth, youth-friendly VCT services are an important component to expanding prevention programmes to encompass care and support, and expanding care and support to include prevention.

An example of the role of holistic programmes, and the outstanding need for them, can be illustrated through an examination of the Siyawela project of Hope worldwide, in Soweto, South Africa. It is estimated that by 2 015 orphans will comprise 9–12% of the total South African population (Hope Worldwide, 2002). This represents more than four million children under the age of 15. The Siyawela project has been working since 1999 to strengthen care and support for orphans and vulnerable children (OVC) and integrate programmes into existing community-based prevention and care activities (Hope Worldwide, 2002). By encouraging community mobilisation and strengthened referral systems, the project has developed a continuum of care through a network of support groups with linkages to the perinatal HIV research unit at Chris Hani Baragwanath Hospital and surrounding midwifery clinics. The project has integrated participatory research and community resource mapping of the areas surrounding clinics, trained childcare co-ordinators and home-based care providers, developed a referral-tracking network between all stakeholders and service providers, and supported voluntary counselling and testing services. Working with PLWHA, project staff have been able to help with disclosure of HIV status to immediate family and friends, conduct future planning for clients and their children, improve access and referrals to health care, provide basic needs (such as food, clothing and medicines), extend care to caregivers to prevent burn-out, and facilitate HIV testing of family members.

Conclusions

There is an enormous need for integrated prevention and care and support programmes for youth of all ages in sub-Saharan Africa. This article presents a model of integrated HIV/AIDS prevention and care programmes which combines traditional prevention programmes with the improvement of health infrastructures and the strengthening of families and communities. In addition to arguing for such programmes from a human rights perspective, this article reviews the published and ‘grey’ literature for evidence of the potential impact of implementing such programmes on preventing future HIV cases, and finds that substantial data exist which support such an approach.

Despite this accumulating evidence, and despite growing consensus, few programmes which deliver truly integrated programmes to youth exist. One major reason for this disconnect, is that prevention programmes and health care-based initiatives have yet to establish sufficient networks for effective referral and integration. Because the initial response to the HIV/AIDS epidemic emphasised health education and individualised behaviour change communication, few initiatives established ties with the health sector or community structures. While a few community-based organisations and home-based care volunteers are beginning to knit together prevention and care and support efforts (Gilborn & Nyonyinyonto, 2000; UNICEF, 2001), few large NGOs are taking children and adolescent’s specific needs into account through integrated programming. International donors and NGOs, even when acknowledging the importance of contextual issues and the need for integrated programmes, are often committed to evaluation indicators which measure only individual risk behaviour or seroprevalence rates, and ignore the importance of strengthened communities and comprehensive programmes to reducing the vulnerability of children and adolescents to infection. Lastly, in many countries, despite an escalating epidemic disproportionately affecting youth, official policies routinely fail to protect youth from exploitation or assure them access to basic education and health care. Integrated HIV/AIDS prevention, care, and support programmes targeting and tailored to the needs of youth can help insure that the ‘full and harmonious development’ promised by the UNCRC declaration is not merely a dream, but a reality.

Notes

1 Decreasing the risk of HIV infection at birth from 21–43% to 8% (Guay et al., 1999).

References


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