Promoting a Combination Approach to Paediatric HIV Psychosocial Support

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Ninety percent of the 3.4 million HIV-infected children live in sub-Saharan Africa. Their psychosocial well being is fundamental to establishing and maintaining successful treatment outcomes and overall quality of life. With the increased roll-out of antiretroviral treatment, HIV infection is shifting from a life-threatening to a chronic disease. However, even for paediatric patients enrolled in care and treatment, HIV can still be devastating due to the interaction of complex factors, particularly in the context of other household illness and overextended healthcare systems in sub-Saharan Africa.

This article explores the negative effect of several interrelated HIV-specific factors on the psychosocial well being of HIV-infected children: disclosure, stigma and discrimination, and bereavement. However, drawing on clinical studies of resilience, it stresses the need to move beyond a focus on the individual as a full response to the needs of a sick child requires support for the individual child, caregiver-child dyads, extended families, communities, and institutions. This means providing early and progressive age appropriate interventions aimed at increasing the self-reliance and self-acceptance in children and their caregivers and promoting timely health-seeking behaviours. Critical barriers that cause poorer biomedical and psychosocial outcomes among children and caregiver must also be addressed as should the causes and consequences of stigma and associated gender and social norms.

This article reviews interventions at different levels of the ecological model: individual-centred programs, family-centred interventions, programs that support or train healthcare providers, community interventions for HIV-infected children, and initiatives that improve the capacity of schools to provide more supportive environments for HIV-infected children. Although experience is increasing in approaches that address the psychosocial needs of vulnerable and HIV-infected children, there is still limited evidence demonstrating which interventions have positive effects on the well being of HIV-infected children. Interventions that improve the psychosocial well being of children living with HIV must be replicable in resource-limited settings, avoiding dependence on specialized staff for implementation.

This paper advocates for combination approaches that strengthen the capacity of service providers, expand the availability of age appropriate and family-centred support

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Introduction

Nearly 3.4 million children, 90% of whom live in sub-Saharan Africa, are currently living with HIV, and more than 500,000 were infected perinatally in the past 2 years [1]. Recent advances in antiretroviral treatment (ART) and improved health coverage mean HIV-infected children are living longer healthier lives into adolescence and adulthood [2,3]. As a result, pediatric HIV care programs need to extend beyond focusing on survival, and work towards maximizing children’s physical and psychosocial well-being.

Living with HIV infection significantly impacts the psychosocial well-being of children and their families, and has been linked to higher rates of mental health problems [4]. HIV infection often requires that these children confront multiple challenges as they age, such as bereavement of lost caregivers and family members, internalized stigma and discrimination, issues involving disclosure, and difficulties understanding ART and adherence [5,6]. There is strong evidence regarding the negative effects of HIV on cognitive development and functioning among children living with HIV, suggesting a need for early childhood intervention [7,8]. HIV-infected children are also at risk for developing conduct problems and engaging in high-risk behaviours as they grow into adolescence [9], which in turn can affect adherence and treatment outcomes, transmission to others, and overall well being [10]. Conversely, psychosocial well being has been linked to improved health outcomes and quality of life among HIV-infected children [11].

Until recently, attempts to understand the experiences of children who face traumatic situations, including life-threatening or chronic illnesses focused on the identification of risk factors for long-term mental health problems. However, there is now a greater recognition of the importance of resilience; why, when faced with adverse situations, some children are able to adjust better than others [12]. Scholars and practitioners involved in supporting HIV-infected orphans and vulnerable children (OVC) advocate for approaches that identify factors that promote resilience rather than a focus on ‘pathologies’ [13,14]. Studies indicate that individual characteristics, resources, and competencies – including age, cognitive capacity, sense of purpose, and belief in a positive future – contribute to resilience; supportive and accepting environmental conditions help shape resilience by mitigating the negative effects of adversity [15]. Resilience in HIV-affected children is also influenced by the complex interplay between individual-level factors, family-level factors such as caregiver well being or illness, institutional-level factors such as access to health services and education, and societal factors such as stigma [5]. Over the last decade, research into the psychosocial well-being of children who are orphaned or affected by HIV has explored factors that contribute to their unique vulnerabilities [16], and found that these vulnerabilities are often associated with coping with the illness or loss of a parent, and compounded by associated stigma. In resource-limited settings, support for HIV-affected children and their caregivers has been delivered largely through community-based mechanisms. Although these interventions make intuitive sense and build on local capacity, the evidence linking interventions with outcomes is, unfortunately, limited. A recent review by Betancourt et al. [17] found that mental health and resilience HIV studies are rarely based on quantitative data. According to Betancourt et al., the few studies that are quantitative disproportionately focused on individual factors and failed to consider the full range of features known to contribute to resilience [17].

Providing psychosocial support specifically to HIV-infected children and their families becomes more challenging as these children are coping with their own illness in addition to the familial impacts of HIV. Promotion of ‘positive living’ and use of support groups are approaches used by the oncology community; these approaches assist clients to live a fulfilling life in spite of a chronic illness or disability [18]. Any approach to providing psychosocial support specific to HIV-infected children must address factors related to living with a chronic disease, but also must consider the profound HIV-specific factors such as stigma and discrimination,
challenges surrounding disclosure, treatment access, and retention in care. To maximize positive outcomes, psychosocial support interventions should be coordinated with clinical care, and reach children and caregivers where they are – in their communities, clinics, and schools.

Moreover, most current efforts to improve the psychosocial well being of HIV-infected children are resource-intensive programmes developed primarily in the United States and Europe [5,19]. This review advocates that psychosocial support programmes and interventions for HIV-positive children be adapted to create feasible interventions in resource-limited settings. Investments should prepare health workers, lay counsellors, and support groups to better support children and caregivers, and interventions should better equip schools to be supportive environments for children on treatment. This paper will explore the negative effect of several interrelated HIV-specific challenges on the psychosocial well being of HIV-positive children: disclosure, stigma and discrimination, grief and bereavement. Applying an ecologic perspective and a framework of approaches that promote resilience, it will also review interventions for individual children and their caregivers, family-centred approaches, programs that support or train healthcare providers, community interventions for HIV-positive children, and initiatives that improve the capacity of schools to provide more supportive environments for HIV-infected children.

**HIV-specific challenges to psychosocial well being**

**Disclosure**

Disclosure of both a child's and a parent's HIV status to a child can be challenging for caregivers and healthcare providers. Barriers to appropriate and sensitive disclosure include factors such as child’s neurocognitive development, caregiver fears for the child’s well being, caregiver’s concerns about feelings of blame or anger, uncertainty about the correct timing of and approach to disclosure, and fear of isolation and stigmatization if the child discloses to others [20–23]. Barriers may be compounded by the occurrence of stigma-by-association, caregiver changes due to AIDS-related deaths, and an overstretched healthcare system [5,20].

Studies from the Democratic Republic of Congo, Ethiopia, Kenya, and Thailand show that rates of disclosure to children are low, with all studies showing disclosure rates of less than 20% [24–29]. Little age-specific data on disclosure rates to HIV-infected children are available for high-prevalence settings [20]; qualitative research suggests that many children discerned their HIV status, either independently during routine engagement with the healthcare system, or through compelling a caregiver to tell them [19]. Despite caregiver reluctance, a review concluded that disclosure to children may positively impact self-esteem and mental health [30]. Nondisclosure may leave a child feeling isolated, create family rifts, and bring about accidental disclosure in an unsupported environment [5]. Upon disclosure, some children or adolescents experience sadness or anger, but these feelings are gradually replaced with calm, relief, and comfort in understanding their condition, reasons for medication-taking, and satisfaction with the ability to openly ask questions and participate in their own care [31–33]. Children, and often caregivers, need guidance for making decisions about to whom it is beneficial to disclose and for what purpose. Incremental and developmentally appropriate disclosure with increasing age, in the context of ongoing support, has positive effects on the HIV-infected children’s physical and psychosocial well being [30].

**Stigma and discrimination**

Social exclusion and stigma within communities promote vulnerability and poorer outcomes in HIV-infected children and adolescents [34,35]. Studies of children living with HIV have shown that experiences of stigma and discrimination can lead to poor mental health, social isolation, postponement of education, exclusion from religious organization, and reduced health-seeking behaviors [36,37]. For children with HIV-infected caregivers, and particularly those who have lost parents to AIDS, stigma-by-association can also result in poor mental health outcomes [37,38]. Experiences of stigma and discrimination take various forms including reduced social support, familial neglect, verbal assault, and physical abuse [38]. Stigma felt towards HIV-infected children is strongly associated with being bullied and victimized [39].

In order to promote mental health, well being and resilience among HIV-infected children, issues such as stigma and discrimination need to be understood and addressed through programs and interventions at the peer, family, and community levels [14]. At the peer level, stigma can be reduced by HIV awareness programming in schools and individual-level interventions that teach HIV-infected children how to seek support and openly talk to trusted peers [14,40]. Open communication, and in home discussion about HIV can help lessen the internalized stigma that may exist within families [13,40–43]. Community level interventions include campaigns and social support groups that will increase awareness about stigma within the larger communities [14,41–44].

**Grief and bereavement**

Although scale-up of ART has enabled many to live longer and healthier lives, far too many children still suffer the trauma of losing family members to HIV/AIDS. For those who are positive themselves, this raises additional
fears about their own mortality and life prospects. Qualitative research among children, healthcare providers, and caregivers documents the crucial need for support for grief and bereavement; this is particularly challenging in settings in which talking about death with children is not encouraged [45,46]. HIV-infected children face varying degrees of grief that accompany AIDS-related bereavement. The degree of grief varies by age, the child’s comprehension of their own HIV and health status, succession planning for caregiving arrangements following parental loss, and gender norms around grieving and emotions [46]. Grief and bereavement after the loss of a family member is expected to have a profound impact on the psychosocial well being of any child; however, when death is caused by HIV/AIDS, additional challenges are introduced, including effects from financial hardship, disruption in care, and stigmatization [47].

Though it is not known how many orphaned children are themselves infected [47], issues surrounding caregiver loss will likely have significant impact on an HIV-infected child’s disease. Children who are aware of their own status may have anxieties or misconceptions about their own illness, and along with coping with grief, may need support to feel hopeful about their own potential for survival and well being. The illness of a caregiver may mean that the health needs of a positive child in the household have been neglected [47]. In addition, children may be subjected to unstable home environments after the death of a primary caregiver. In sub-Saharan Africa, orphans are often cared for by extended family, which may include elderly or distant relatives who are themselves inadequately prepared to care for an HIV-infected child. Or, those who remain in child-headed households are at further risk for poor coping and interrupted care due to their fragile family situation.

Healthcare providers often feel they have limited capacity, training, or time to support HIV-infected children in their grief experience. To mitigate this grief, psychosocial interventions must foster an enabling environment for open communication, and build the skills of key adults in their lives – surviving caregivers, teachers, and healthcare providers [48].

**Gender**

Gender norms and inequities impact the psychosocial health and well being of children [49]. The socially and culturally constructed expectations of how women and men behave play an important role in HIV risk and vulnerability, and negatively impact health outcomes. These dynamics can impact women and girls’ access to essential resources and care, and affect men and boy’s perception of need and availability of care, particularly in which services are initiated through maternal child health (MCH) settings. Harmful norms related to masculinity influence risk perception and risk taking, and limit the communication needed for disclosure, and discourage their seeking care or asking for emotional or other support. Gender norms for girls limit their ability to refuse unwanted sex, access critical information and resources, and also hamper their ability to comfortably disclose HIV status. Furthermore, gender distinctions in the ways that boys and girls experience and cope with HIV requires tailored responses to these differences. Sex-disaggregated data are needed to better understand important differences between the ability of boys and girls to cope with infection, stigma, needs for disclosure, use of protective practices, and care-seeking. Community interventions such as Stepping Stones and Program H engage women and men, boys and girls, in dialogue and life skills building exercises aimed at transforming the underlying gender norms that facilitate HIV risk and hinder meaningful uptake of services [50,51], and can contribute to a more supportive environment for both boys and girls living with HIV.

### Interventions for improved psychosocial outcomes

Psychosocial well being is multifaceted and with impacts on mental health and social adaptation. Applied to HIV-infected children, it includes the ability to cope with the illness or death of caregivers; the resilience to live positively despite the challenges associated with HIV; and the social, emotional, motor, and cognitive capacity to participate as full members of society at present and in the future [52]. Psychosocial support is helpful to meet the ‘age-appropriate and relevant emotional, spiritual, cognitive, social and physical needs (of HIV-infected children) through interactions with their surroundings and the people who care for them’ (Fig. 1) [48].

Given its complex and multidimensional nature, psychosocial well being requires support for individuals and families, as well as a supportive community environment – the three key points of intervention which are implicit in the ecological model (Fig. 2). Psychosocial programs can take the form of one-to-one counselling sessions, caregiver support and training, support groups for children-caregiver dyads, peer/mentorship from youth living with HIV, and recreational therapy developed to tackle AIDS-related grief and bereavement [45], and can be implemented by healthcare providers, peer counsellors, mentors, OVC programs, and community support groups. However, improving the social integration of HIV-infected children may require interventions within schools and other societal foundations, such as faith-based institutions, that have the potential to mainstream children, by showing them that they are welcomed and accepted in these sites, and by helping them see that they are contributing members of their
communities. In light of the limited evidence on interventions, existing initiatives should be assessed in terms of appropriate programmatic content, effective mode of delivery, and feasibility in resource-limited settings.

**Individual and family-level interventions**

Interventions designed to minimize stigma, support disclosure, and improve adherence and retention in care include one-to-one counselling, mentoring, and the active engagement of people living with HIV in community programmes [22,45]. The Regional Psychosocial Support Initiative (REPSSI), which began as an interagency movement that pioneered community and family psychosocial support interventions to address needs of children affected by AIDS and their households, uses tools such as CARE International’s *Hero Book* in Zambia, that empowers HIV-infected children to face, address, and respond to stigma and discrimination [53].

Appropriate psychosocial support is also needed to improve disclosure to children and to help them make decisions about disclosure to others. Whereas child-focused interventions that support disclosure and build self-efficacy can address internalized stigma, family-centred resilience approaches are necessary to ensure a

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**Fig. 1. Psychosocial support for HIV-infected children adapted from Regional Psychosocial Support Initiative 2003.** PSS, psychosocial support. Permission obtained from Regional Psychosocial Support Initiative.

**Fig. 2. Building resilience: examples of combination interventions using the ecological model.**
more supportive environment for the child. Family members, particularly those a child trusts, play an important role in helping children to interpret the difficulties they face [54–56]. A child’s ability to cope with HIV-specific stressors is affected by the quality of caregiving, both child and caregiver knowledge of the child’s status, and the relationship and age of the caregiver. Caregiving may be influenced by social stigma, financial limitations, and emotional strain [57,58]. As many cultural factors affect disclosure, the process is expected to vary with context, and disclosure support programmes must be adapted for cultural fit and feasibility in resource-limited settings [20]. In addition to the WHO guidelines, multiple handbooks and provider training materials have been developed to support parents and providers with disclosure [59].

A systematic review highlighted several approaches associated with increased adherence in HIV-infected children [60] including an intensive, family-centred, community-based psychotherapy intervention [61] and home-based nursing programme [62]. Additional approaches include involving caregivers in a family-centred approach [63] and follow-up counselling [64]. In light of linkages between adherence, treatment outcomes, and psychosocial well-being, interventions must also address the evolving needs of children with their caregivers to ensure children develop the responsibility and autonomy necessary for self-care. Evidence shows that family-based interventions are effective in some cases at reducing internalized stigma from community levels [65]. A 2011 review of psychosocial support for children living with HIV noted that supporting caregivers through training and skill-building is key to expanding access to psychosocial care among HIV-infected children [19]. The Joint Learning Initiative on Children and HIV/AIDS, which established an interdisciplinary learning network and championed family-centred care and households as the basis of support, published its final work in 2009, identifying best practices and evidence around interventions targeting a broader group of children impacted by HIV and AIDS. These include social protection approaches, income transfers, and other family-focused services. Several examples of promising family-centred programmes are highlighted in Table 1 [66–68].

Replicating and rolling out these interventions and services in sub-Saharan Africa can be demanding [19,69]. However, most evidence supports the focus on longitudinal approaches to the family, specifically the child-caregiver dyad as the root of how children learn coping mechanisms and develop resilience [70,71]. Negative family dynamics influenced by partner violence, parental alcohol abuse, aggressive parenting (which can be triggered by stressful events such as loss of income or job, death, HIV acquisition), and internalization of community-level stigma must be identified and prevented [14,72]. Additionally, support for HIV-infected children who will experience the loss of caregivers must start before bereavement, with succession planning, and anticipation of the child’s needs for continued care—medical, emotional, and basic child care.

### Healthcare services interventions
Positive interactions with healthcare providers can contribute to building coping mechanisms and resilience in HIV-infected children, whereas high satisfaction and trust in healthcare providers can reduce the negative

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<th>Table 1. Examples of family-centred interventions.</th>
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<td>1. Family-centred adherence in Burkina Faso</td>
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<td>2. The VUKA Family Intervention in South Africa</td>
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<td>3. The Memory Book and the Journey of Life Regional Psychosocial Support Initiative (REPSSI) in Botswana, Ethiopia, Kenya, Malawi, Mozambique, Namibia, and Zimbabwe</td>
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Initiative Privée et Communautaire de lutte contre le VIH/SIDA (IPC) provides support for families affected by HIV. Children are identified through interventions such as voluntary counselling and testing, antenatal care, and PPTCT services, and referred for care and support. With the aim of improved treatment adherence, the programme has trained 30 community carers to support in paediatric adherence, disclosure within families, and build understanding around treatment and adherence. Children and families are supported through home visits and family meetings [66].

This 10-session, cartoon-based curriculum, focuses on loss and bereavement, HIV knowledge, disclosure, and stigma for HIV-infected 10–14-year-old paediatric patients and their caregivers [67]. The Memory Book tool was developed to support caregivers and children in dealing with grief and bereavement through improved communication on loss, pain, sadness, and emotions in general. It has been used by multiple projects, including the Million Memory Project in Zimbabwe and other countries [68]. The Journey of Life is a tool to facilitate mobilization of communities to support both caregivers and children in need, by encouraging reflection and discussion, and providing the information and skills to be able to plan a course of action. It is composed of Awareness Workshops, Action Workshops, and Picture Codes. Its application in multiple countries has resulted in better caregiver skills to address death, grief, and inheritance issues, improved child participation, greater collective sense of responsibility for children, improved referral systems to government structures for further specialized support [68].

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effects of stigma on adherence (Table 2) [64,73–75]. Healthcare providers must work closely with caregivers during the progressive disclosure process [30], particularly during the crucial period following diagnosis or disclosure [45]. However, limited resources and the lack of targeted training for healthcare providers on the paediatric disclosure process have been significant obstacles in sub-Saharan Africa for this important need [5]. Interventions requiring trained psychologists and counsellors are likely to have a positive impact on the psychosocial well being of children and their caregivers, but are often not feasible in resource-limited settings. Sub-Saharan Africa, home to one tenth of the world’s population, carries 25% of the global disease burden, but has only 3% of the world’s health workforce, and spends less than 1% of the world’s financial resources on health [76]. Although the reach of healthcare systems in sub-Saharan Africa is improving, delivering highly specialized interventions remains a challenge. Task-shifting approaches that allow for service provision through supervised community lay counsellors may permit wider dissemination of intervention and supportive services for children [77].

**School-based interventions**

Resilience is not only dependent on interactions with family, but with peers and teachers who also help children develop skills and values [78]. HIV can also affect child development, resulting in motor and neurocognitive difficulties that impact the ability to learn [75]. Although existing deficits may improve when children initiate appropriate treatment early, those initiated after infancy remain at significant risk for persistent developmental challenges [79,80]. In addition to contending with potential developmental delays, HIV-infected learners have to deal with intermittent or ongoing stressors: stigma, illness-related absenteeism, household mortality, or multiple caregivers, which can result in poor educational and developmental outcomes [81–83]. These factors can hamper educational progress at multiple levels: enrollment, attendance, academic performance, grade completion, and future educational expectations [82].

Regardless of these challenges, schools are one of the key environments in which children may develop resilience, and are considered an important locus of delivering interventions for all learners regardless of HIV status. The education system may contribute to psychosocial well being of HIV-infected children by addressing some of the structural barriers to school access, namely, poverty and food insecurity [84,85]. Disclosure in the school setting may also have positive outcomes. A study in Botswana found that two thirds of caregivers had disclosed to school staff, primarily to teachers [86]. In reaction to disclosure, caregivers experienced acceptance, reassurance, and support from school staff, suggesting that schools may act as environments in which HIV-infected children and their caregivers can receive additional psychosocial support. However, the education system can also become an arena in which stigma and discrimination are exhibited. If perceptions of HIV in any of these populations are not well informed, children may face social isolation by peers and teachers [87]. Prevention messaging and education campaigns on HIV prevention in schools have the potential to increase stigma and discrimination [88].

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Table 2. Health worker training and interventions to improve psychosocial well being.

| Paediatric AIDS Treatment for Africa (PATA) | Since 2005, PATA has held five Continental Summits, three Regional Forums, and 18 Local Forums in Botswana, Kenya, Lesotho, Malawi, Rwanda, South Africa, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe for PATA members from 228 facilities across 23 countries [75]. PATA forums bring together multidisciplinary teams to improve their knowledge and skills through participatory action learning [73]. EGPAAF has been supporting the Zambia Ministry of Health since 2008 with an evolving package of psychosocial support interventions which now include a 2-week paediatric HIV counselling training, a play therapy programme, and an adolescent-specific programme. Through these activities, 440 people have been trained in HIV counselling; 16 counsellors from nine organizations run weekly support groups and receive case review mentorship; 14 counsellors have been trained in play therapy; and 13 youth and nine adult mentors actively work with HIV-positive teens to address adherence, disclosure, and sexual/ reproductive health. In 2013, two developmental delay units were established, 40 clinicians were trained to identify and address HIV-related developmental delays, and 60 community volunteers have been recruited and trained [74].

| Training of Healthcare Providers for Improved Disclosure and Psychosocial Well being – Elizabeth Glaser Paediatric AIDS Foundation | A series of three developmentally appropriate handbooks and cue cards developed to assist healthcare providers and caregivers in disclosure to children of their HIV status. The first book is tailored for children aged 3–6, the second for children aged 6–10, and the third for children over the age of 9. Teen Talk is a comprehensive, 60-page question and answer guide covering a wide variety of topics about HIV for adolescents and youth. The disclosure booklets were piloted in South Africa and adjusted based on feedback provided [64].

| Paediatric Disclosure Handbook series and Teen Talk – AIDSTAR-1 |
isolation of those already affected, particularly when HIV is portrayed as a death sentence, or the result of wrong behaviour. A concerted effort must be made to ensure that prevention messages do not stigmatize HIV-infected children and their families by emphasizing the successes of current ART regimens. Children living with HIV can also be at increased risk of getting bullied at their schools, and some research suggests that increased support from siblings and friends are protective factors from this form of discrimination [37,88]. School management and staff need to foster a nonstigmatizing environment in which HIV-infected children may be nurtured and supported by both their peers and teachers. Teachers may also be able to identify and nurture children’s strength and resilience, particularly if trust-based relationships develop between school staff and caregivers. Providing the necessary training for school staff and management is crucial to increasing access to psychosocial support in the school setting. An example of an initiative integrating psychosocial support for OVC and AIDS-affected children in the education system was implemented by the Associacao Reconstruindo a Esperanca (ARE), a local Maputo-based NGO and Ministry of Education (MINED) in 75 schools in Southern Mozambique. The final evaluation of the project estimated that the training received by 150 teachers increased access to psychosocial support to more than 25 000 AIDS-affected children in the schools [53]. In these and many other ways, schools can be leaders within the society in protecting HIV-infected children, adding greatly to the psychosocial support network these young people need and deserve.

**Conclusion**

A constellation of individual and environmental factors influence how HIV-infected children cope with the disease and survive into adulthood. This article calls for an expanded approach to paediatric HIV care that includes a strong component of coordinated psychosocial support to address the complex needs of HIV-infected children. Factors that influence the psychosocial well being of HIV-infected children should be considered from an ecological perspective to ensure combination approaches are well targeted and coordinated across individual, family, and community structural factors as these spheres interact with and influence each other. Programs must support long-term resilience of children, caregivers, and families, and enhance support networks in communities, schools, and healthcare centres. Only through concerted efforts at all levels can the complex challenges be addressed.

Given the complexities and the numerous biomedical, psychological, and social factors that interact to affect well being of HIV-infected children, and the evidence that treatment, survival, and later prevention outcomes all depend on effective support, it is imperative that greater investment in developing and evaluating developmentally appropriate combination psychosocial interventions for children occur as part of care and treatment programming. More rigorous studies are needed across disciplines to identify specific interventions, tools, programs, and policies that effectively address and overcome associated challenges related to disclosure, stigma, discrimination, and gender differences that still exist and negatively impact the psychosocial well being of children living with HIV. Interventions must engage both men and women to reduce the negative impact of gender norms on health-seeking behaviours, provide support to men as involved caregivers, and eliminate the violence and discrimination towards children and women in the household and in the community.

With increasing availability to paediatric ART, HIV is changing from a life-threatening to a chronic disease. Stigma, discrimination, disclosure, and cultural norms about grief and gender roles can result in negative psychosocial effects and hinder the success of care and treatment efforts for HIV-infected children. Improving resilience requires turning disclosure into an age-appropriate progressive process, addressing internalized and externalized stigma and discrimination, providing support for improved communication on issues of grief to help children respond to bereavement, and aiding them with fears for their own well being. This can only be done if we improve communication about HIV in families, health centres, and the community, and empower young people, women, people living with HIV, their families, healthcare workers, educators, and communities to reduce discrimination. These efforts must be active on all fronts: the individual, home, and community as well as in healthcare and educational systems. Only in this way will we be able to develop psychosocial support services, interventions, tools, and guidelines that address existing challenges. The examples covered in this article are only modest illustrations of the many promising approaches now under development to respond to the psychosocial needs of children and families; our challenge now is to ensure that evidence building keeps pace with evolving needs and program learning.

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**Conflicts of interest**

There are no conflicts of interest.

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