Families living with HIV

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Abstract
Given the historical emergence of the AIDS epidemic first among gay men in the developed world, HIV interventions have primarily focused on individuals rather than families. Typically not part of traditional family structures, HIV-positive gay men in Europe and the US lived primarily in societies providing essential infrastructure for survival needs that highly value individual justice and freedom. Interventions were thus designed to focus on at-risk individuals with programmes that were age and gender segregated. As the epidemic has unfolded, the early focus on individuals has become inadequate: families live with HIV, not just individuals. Families’ structure, economy, migration patterns, and developmental life cycles are affected by HIV, and these changes radiate throughout the community creating parallel stresses. Family-based, intergenerational models of detection, prevention and treatment services offer enhanced opportunities for effective interventions and suggest very different intervention settings and strategies. However, these models also require addressing the family’s basic needs for survival and security in order to be successfully implemented and sustained over time. As HIV was an opportunity for marginalized persons in the developed world to ‘turn their life around’, the strengths of families in the developing world may be mobilized to contribute to the community’s long-term health, survival and security needs.

Introduction
When documenting the scope of the HIV pandemic, the number of HIV-infected persons is the typical yardstick: there are 38 to 42 million persons living with HIV and nearly 13 million AIDS orphans (WHO, 2003). However, these individuals are linked and nested within their families, society’s basic social unit (Repetti et al., 2002).

Families are affected by HIV, not individuals (Boyd-Franklin et al., 2000; Pequegnat et al., 2001; Pequegnat & Szaponick, 2000; Schuster et al., 2000). The impact of HIV radiates intergenerationally, from grandparents who must assume responsibility for their children, to AIDS orphans who become young parents, having had no role models during their own childhood (Rotheram-Borus et al., 1997). Yet, intervention models consistently focus on medical and psychosocial interventions for individuals. When a family model is adopted, the framework for existing interventions shifts. Simultaneously, the economic safety nets serving as a backdrop to evidence-based interventions in the developed world (e.g. health insurance, disability payments, child welfare, subsidized housing) are not typically available to the areas most impacted by HIV (e.g. Africa and Asia). Without consideration of the family’s economic context, combating HIV will not be a high priority activity.
Given these concerns, we aim to examine the historical roots of current HIV intervention models and how existing medical and psychosocial intervention models shift when a family perspective is adopted.

**Historical roots**

HIV was identified in the US (Gottlieb et al., 1981), perhaps the culture globally with the strongest tradition of *individual* welfare, *individual* justice, and *individual* freedom (Spiegel, 1982). Gay men were the first persons identified with HIV and the disease became so identified with the gay community that it was first named GRID: gay-related infectious disease (CDC, 1982). In the US at the time, many gay men were perceived as living alone, in less stable partnerships than a long-term marriage (Bell & Weinberg, 1978), and were highly stigmatized (Herek & Glunt, 1988). In addition to the stigma associated with being gay, HIV was associated with sexuality, often culturally unsanctioned sexuality, and death, further increasing its stigma.

HIV was also found primarily in large urban centers (Shapiro et al., 1999) in which access to those at risk for HIV was primarily through organizational settings that were age segregated (e.g. schools, workplaces, drug treatment centres) and often gender segregated as well (jails, gay or lesbian service organizations, women’s health clinics).

In contrast to these transmission patterns, more than 90% of the world acquires HIV heterosexually. Among HIV-positive women in Africa, 60% to 80% have only had one lifetime sexual partner; in Asia, more than 90% have only had one lifetime sexual partner (Collin, 2000). Those acquiring HIV are typically living within extended family networks. While HIV is found in large cities, many countries have more HIV-infected persons living in family clusters in small rural villages with few formal organizational entry points for interventions (e.g. Uganda and China) (Kaleeba et al., 2000; Zimmer & Kwong, 2003). The historical context of the epidemic’s emergence is at odds with the current context of transmission and affected populations.

Yet, many evidence-based interventions were developed with high-risk populations in which the epidemic was first identified in the developed world. Advantages such as broad access to condoms, screening and treatment for sexually transmitted diseases, and national awareness of the means of HIV transmission were present in the communities in which HIV interventions were designed, but were often unacknowledged in the description of interventions (Kelly et al., 1991; Rotheram-Borus et al., 1991). A broad range of effective programmes was developed to reduce the likelihood of HIV infection, and the programmes were typically designed for a specific age-segregated risk group (adolescents, elderly, middle childhood children, injecting drug users) or gender (gay men, pregnant women). In the developed world, these programmes tended to focus solely on HIV-related problems; health care could be accessed by the poorest when need was great, especially for a terminal disease such as HIV (US Department of Health & Human Services, 2004a). Housing, food, police protection and clean water were typically available, even if the access was more limited among those living with HIV compared to other segments of the population in the developed world. Most commonly, HIV services focused primarily on social and prevention services that emerged because of an individual’s HIV infection (e.g. HIV testing services, HIV-related legal services). The existence of other persons dependent on the infected person was largely ignored in early, individually focused interventions.

Reflecting the individual focus of early HIV interventions, the language used to describe HIV was consistently framed as a problem of individuals: for example, ‘persons with AIDS’,...
‘persons living with HIV’, and ‘AIDS orphans’ are standard terms in the research literature. Language powerfully shapes our thinking, emotions and behavioural responses to a problem (Foucault, 1978), implying who is responsible for the problem and limiting the means and strategies for problem solving. In particular, the label of ‘orphans and vulnerable children’ suggests that children are victims of the disease (as distinct from their parents who are responsible for disease acquisition), deserve our charity (rather than framing the issue as one of human rights), and orphanages may be perceived as a solution (easy to hold a donor’s name).

Given the concurrent stigma associated with HIV, anonymity and confidentiality have become key concerns in the design of HIV-related services for gay men and persons of ethnic minority status, those most affected by HIV. However, when persons are highly enmeshed in small social networks, excessive concerns regarding anonymity and confidentiality are likely to reinforce stigma.

The early definitions of HIV also led to organizational settings that deliver testing, prevention, and treatment for individuals. For example, perinatal HIV testing is for women, not couples expecting a child (Pediatric AIDS Foundation, 1999). Prevention programmes for stopping maternal to child transmission are typically placed in women’s health clinics or obstetrics clinics. Orphanages have been an ineffective, age-old strategy to support parentally bereaved children, yet are being established in many places in Africa (Barnett & Whiteside, 2003). Internationally, current practices for HIV detection, prevention, and treatment are designed for seropositive individuals. For example, as noted above, guidelines for HIV testing (WHO, 1995) emphasize individual rights at the expense of family and group rights and responsibilities. In the developing world, the need for family based testing has begun to be acknowledged (e.g. in Vietnam, where initial work on need and feasibility has been conducted) (Bain et al., 2004). Relative to most of the developed world, other cultural heritages, particularly those in sub-Saharan Africa, have stronger traditions of extended families and tribes that have interlocking rights and responsibilities. The time for these individual frameworks is over, especially as the pandemic is centred in the developing world.

The Impact of HIV on Families

While the immediate, direct toll taken by HIV is great, the indirect toll on children, spouses, extended family and the next generation extends far beyond individual illness and even death. When the public health focus remains on epidemiological profiles of infected persons, the implications for their families and social networks goes unacknowledged. For example, in Thailand, where only 1.8% of adults are HIV-positive (approximately 650,000 persons), about one in four grandparents will have custody of an AIDS orphan (Watcher et al., 2002). With a relatively low rate of infection, a pervasive societal impact occurs. HIV impacts families ‘first and worst’ (Barnett & Whiteside, 2003): it influences the family’s structure, economic resources, migration patterns and developmental life cycles.

Even when economic security and health care are available (e.g. in Europe, the US or Australia), families affected experience a negative intergenerational impact of HIV (Campo, 2004). Poverty is universally linked to HIV; HIV has primarily affected those families in the developed world living with only a marginal safety net and facing the multiple adversities of inner-city life: community violence, substance abuse subcultures, recent immigration and fragile support networks. During the parent’s HIV illness, the child may assume the responsibility of monitoring and maintaining the parent’s health (Stein et al., 1999). As the
parent faces stigma and social isolation (Herek & Glunt, 1988), at times away from their
country of origin, the children may become the parent’s emotional ballast. As the parent
with HIV anticipates a foreshortened future, the child may precipitously begin having their
own children in an attempt to provide the opportunity for a dying parent to become a
grandparent (Rotheram-Borus & Lightfoot, 2000). When a parent dies, children of parents
with HIV may lose even more than their primary caretaker (Rotheram-Borus et al., in
press). In the developed world, children are often forced to leave their homes and schools
when parental death results in discontinued rent subsidies (NYC Human Resources
Division of AIDS Services, 1993). Basic social services are typically designed only for the
person living with HIV, not with the family or larger community in mind. For parentally
bereaved children, the negative impact of parental death is not only accompanied by
disruptive changes in housing and education, but the loss of friends and neighbours – a long
list of unnecessary stressors that would not have occurred if a family model had been
adopted in the provision of HIV services (Forehand et al., 1991).

Internationally, the impact of HIV on the number and composition of a family’s
household has been quite uneven across countries. When the HIV prevalence rate is near
10%, about 2 to 3 adults die annually in a community of 100 households (Barnett &
Whiteside, 2003). The World Bank reports that when at least one member dies from AIDS,
the size of the household is similar in some places (e.g. Kagera), but drops substantially in
other countries (e.g. by about 25% in Rakai, Uganda, and Thailand) (World Bank, 1997).
While 2 to 3 HIV-related adult deaths appears a relatively small number among 200 to 300
adults, the cumulative impact is great. In sub-Saharan Africa, these deaths have resulted in
an estimated 12.3 million children orphaned by the disease (UNAIDS et al., 2004). The
lifespan is declining rapidly throughout much of the developing world (World Bank, 2000).
Even more important than changes in the number of family members, the form of the
family is significantly modified: child head of households, the elderly caring for grand-
children from multiple children, homeless youth forming a new family and clusters of
families joining for mutual survival (Guest, 2003).

The structural changes are accompanied by significant losses in income; HIV is the
fastest way for a family to move from relative wealth to relative poverty (Barnett &
Whiteside, 2003). In developing nations, nearly 50% of the infected population is
comprised of young people aged between 15 and 45 who are the family’s primary
breadwinner (Fleming et al., 1988; UNAIDS, 2004). When the workforce is decreased by
AIDS, much-needed human capital is also lost (Over, 1992). Research in South Africa has
shown that households affected by HIV/AIDS rely more heavily on social welfare
programmes than non-affected households (Booysen & Bachmann, 2002); however, most
countries in the developing world do not have social safety nets. Because of the additional
costs associated with having a family member with HIV/AIDS, affected households spend
less money on food, which may contribute to malnutrition. Moreover, AIDS-affected
families tend to use more of their savings and take out new loans to defray disease costs,
burdening household resources with debt repayment and medical costs that may push
families into poverty (Booysen & Bachmann, 2002). These losses affect the next generation
of children and their grandparents who traditionally depend upon the economic stability of
the middle generation (Collard, 2002).

Services to meet survival and security needs are not available in Asia and Africa, the
regions most impacted by HIV (Barnett & Whiteside, 2003; UNAIDS/WHO, 2003). The
unmet needs for essential services often overshadow HIV for most families. For example,
why would infected people prioritize coping with their HIV infection (which may kill them
in 10 years) when they do not know how to feed themselves and their children today or fear their family may be killed in an ongoing civil war? Even in the US, young mothers who live in neighbourhoods with high drug abuse and become infected by their partner do not prioritize caring for their infection (Campo, 2004). Therefore, in poverty-stricken inner cities, sequential generations of young, ethnic minority women are becoming infected (Campo, 2004).

To cope with children bereaved by AIDS, many families are sending children from cities to traditional tribal villages (Barnett & Whiteside, 2003), leading to significant demographic shifts. When mothers become HIV infected, the number of future births declines and child mortality increases (UNAIDS/WHO, 2003); it is far less likely for family traditions to be transmitted with fewer children and role models. The developmental life cycle of families (Combrink-Graham, 1988) is broken. Typically, families become focused on the nuclear family when children are babies; there is a broader exploration of the world as children and adolescents age into young adulthood (around the age of 15 in the developing world), which is interrupted by parental HIV illness. The ill parent’s loss of income may prevent their children from attending school (about 16% less are able to attend school) (World Bank, 1997). In both the developed (Stein et al., 1999) and developing world (Barnett & Whiteside, 2003), children must assume adult roles and responsibilities, including family support and physical care for other family members. These ‘parentified’ children experience a range of lost developmental opportunities that forever alter their life course.

The structural, economic and developmental shifts in a family’s lifecycle are concurrently reflected in the community’s response to HIV. When 290 million Africans survive on less than $1 daily (Cameron, 2000), family survival is interdependent with their neighbours’ welfare. In Kyalitsha, South Africa, if families fail to share food when available, the family starves during the next economic downturn; survival in a society with a very high rate of lifetime unemployment depends on strong community support networks (Van Derberg & Smit, 1990). However, when many families are accommodating AIDS illness and death, a family’s ability to survive is further jeopardized (Rugalema, 1999). Under such stress, a family’s attitude towards children shifts; in 1992, 62% of South Africans in Soweto believed that the government was responsible for children orphaned by AIDS (Steingberg et al., 2000). Given these community shifts, it is critical that family-based interventions become routine.

**Family-based Interventions**

Significant social problems are being created by mounting individual-oriented services and interventions. For example, large-scale perinatal HIV testing and treatment programmes have led women to be identified as seropositive prior to male family members learning of their serostatus; the first family member identified as HIV seropositive often becomes labelled as the person responsible for transmission of HIV infection to the family. The woman is at risk of being abused, ejected from the family, or even killed depending on the country, religion and local norms. Where resources are scarce and the monthly cost of antiretroviral treatment approaches monthly household income, families may be faced with deciding which, if any, members of a household who suffer from HIV receive treatment (Booysen & Bachman, 2002). Rather than pitting generations and genders in a power struggle for resources, arguments of blame and stigma, HIV interventions could build on the strengths of the family social network to arrive at solutions for the next generation affected by HIV.
For example, HIV testing is currently delivered to individuals at health care clinics or even in community marketplaces. HIV testing could be redesigned from individual delivery in a clinic to being family based and delivered at home. Pre-test counselling would be family education, providing parents with the opportunity to participate in educating their children, as well as providing a setting for confidential and extended, post-test counselling. For example, in Uganda, home-based testing dramatically increases the uptake of HIV testing in rural areas (Were et al., 2003), even when antiretroviral therapies are not available. Potentially, family-based screening may be cost-effective, as multiple persons are informed and tested simultaneously. If the family were the testing unit, dialogue around three central issues would shift: 1) if, when, how, and to whom to disclose one’s serostatus; 2) replacing individual decision making on future plans to become a family’s joint problem to solve; and 3) creating an immediate social safety net to the HIV infected family members. Shifting the discourse may lead to a broad number of new options for increasing HIV testing from its current rate of 5% internationally (WHO, 2003).

Similarly, family-based HIV testing can initiate a pathway for family-based prevention and treatment programmes. Currently, when one family member becomes identified as HIV seropositive, not all members at risk have testing available to them. Treatment is even less likely to be available. In contrast, HIV could be integrated into existing public health programmes that have been in place for 30 years addressing problems such as maternal and child health programmes mounted by the United Nations for child malnutrition (e.g. Philani in South Africa) or homeless youth programmes (e.g. YUDEL, Kampala, Uganda) (Van Derberg & Smit, 1990).

Families are the primary source of all health-related behavior patterns (Doherty, 1992), including HIV (Tinsley et al., 2004). Most current evidence-based prevention programmes fail to utilize intergenerational social networks to combat HIV (Pequegnat & Szaponick, 2000). For example, in a recent review of HIV programmes for adolescents and children in Africa (Valerio & Bundy, 2004), parents were included as a target intervention population in only 1 of the 21 exemplary HIV prevention programmes (Soul City in South Africa).

Both epidemiological and intervention data support the focus on families (Pequegnat & Szaponick, 2000; Tinsley et al., 2004; Williamson, 2002). Within the developed world, a variety of familial influences on adolescent risk behaviours and young children’s attitudes and behaviours have been identified: sibling influences; the timing and content of parents’ conversations with young people; parental monitoring of activities; parents’ HIV-related knowledge and attitudes; the quality of the parent–child relationship; and family communication styles and rituals (Blum, 2002; Crosby et al., 2000; Kotchick, 2001; Miller et al., 1999; Schuster et al., 2000; Sigelman et al., 1993; Sigelman et al., 1995; Stein et al., 1999; Tinsley et al., 2004; Whitaker & Miller, 2000). When a parent serves as a teacher to their children, their own behaviour is influenced as much as their children’s; serving as a positive model elicits responsibility and safe behaviours by parents mentoring their children (Rotheram-Borus et al., 2001).

Internationally, there is a growing understanding for the need for family-based interventions. For example, the MTCT-Plus Initiative has focused on providing lifelong treatment for families affected by HIV/AIDS in resource-poor settings. By February 2003, 10,000 participants in 12 demonstration sites throughout Africa and Asia were enrolled (Rabkin & El-Sadr, 2003). Other family-based initiatives focused on case management and social service provision for families affected by HIV have been initiated in New York City (United Way of New York City, 2002) and Chicago (McKay et al., 2004). Moreover, evidence suggests that for HIV-positive, urban, low-income African American women,
interventions that stress a ‘family ecological’ approach rather than standard ‘person-centred’ approach are more efficacious in reducing psychological distress and family-related hassles (Szapocznik et al., 2004). In Uganda, a home-based, family centred programme has been established whose focus is to expand HIV testing and counselling, and to provide standardized basic care and antiretroviral treatments to families affected by HIV (US Department of Health and Human Services, 2004b).

Psychosocial interventions can help infected parents with HIV-related challenges with their children: making decisions about disclosure of serostatus, planning for a child’s long-term adjustment, maintaining parental roles while ill, helping children develop relationships with new caregivers, and helping children prepare life goals in the event of parental death (Rotheram-Borus et al., 1997; Rotheram-Borus et al., 2001). However, interventions assisting parents and families with these psychosocial challenges have only been evaluated in places where basic safety nets for survival and security are in place, such as the US (Pequegnat & Szapocznik, 2000). Interventions that fail to include the broader context of families’ survival and security needs (access to health care, food, water, shelter, employment) are not likely to be successful. In countries without social safety nets, family based HIV treatments and interventions are beginning to be combined with social enterprise models. Unless there are potential pathways out of poverty (e.g. education), there is no motivation for a family to aggressively avoid and proactively cope with HIV infection. As the number of families experiencing extreme physical illness and death rises, the importance of economic and social safety nets as a core component of any intervention programme also rises. The next generation of interventions for families living with HIV must address the comprehensive continuum of care: detection, medical, psychosocial, survival and security needs.

In order to accomplish such a goal, the intervention teams and the goals of HIV-related interventions must be substantially restructured. Social entrepreneurs and economists must be key partners with the existing teams of interdisciplinary HIV researchers and community activists: all partners must share a family perspective on the long-term welfare of children and families.

**Discussion**

Perhaps more than any other epidemic, HIV is a family illness. For all types of families and across both developed and developing nations, the impact of an individual’s HIV infection radiates across the entire family system. Caretakers, parents, grandparents, children, siblings, aunts and uncles shoulder the direct and indirect impact of transmission risk, caretaking burden, social stigma, physical illness and emotional distress. Research from the developed world has shown lasting repercussions for those left behind following a family member’s HIV illness and death (Rotheram-Borus et al., in press). In countries with the greatest rates of HIV infection (i.e. those in Africa and Asia), families and clusters of families are even more interdependent for survival, underscoring the need to adopt a family based paradigm for HIV prevention and intervention.

While the emergence of an individually focused approach to HIV prevention and intervention grew out of the historical origins of HIV disease, these paradigms no longer fit. While the face of HIV/AIDS has changed over time, moving into the developing world and the heterosexual population, theorizing and policy planning surrounding the disease have remained focused on the individual. While the importance of the family has been recognized by all major donors – UNAIDS, World Health Organization, The World
Bank – the implementation of policies to support families has only been initiated in 2 of 40 African countries (The World Bank Group, 2004). Clearly, recognition alone is not enough. Theorizing and policy making surrounding HIV prevention and treatment must shift structure and focus to address explicitly families with models for basic survival and security, including medical care and psychosocial support.

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References


