

Long-term psychosocial challenges for people living with HIV: let's not forget the individual in our global response to the pandemic

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Since the beginning of the HIV epidemic, people living with HIV have faced numerous psychological and behavioral challenges. With the advent of antiretroviral therapy (ART) there have been dramatic shifts in some of these key challenges and new ones have come to the forefront. This paper highlights several critical psychological and behavioral aspects of HIV disease, a few of which require focused attention, including mental health, stigma and disclosure, adherence, and sexual behavior. Although the focus is primarily on adults living with HIV, we also comment on some of the additional challenges for children and young people. Our critical examination in these areas draws upon the lessons learned in contexts in which ART has been available for a decade, and we explore what is currently happening in settings with more recent treatment access. In the end we offer our insights into what we may expect in the future, and provide recommendations for ongoing prevention and care initiatives with adults, children, and young people affected by this disease.

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Introduction

Most individuals with serious, progressive illness confront a range of psychological and behavioral challenges, including adherence to complex and sometimes toxic medication regimens, the prospect of real and anticipated losses (at the personal, familial, and community levels), changes in quality of life, the fear of significant physical decline and death, and coping with the uncertainty of the course of the illness. HIV/AIDS brings additional challenges. It is unusual in the extent of stigma associated with the disease and the modes of transmission, and the fact that it is both infectious and potentially fatal. As a result of the risk of HIV transmission and the potential for the development and transmission of treatment-resistant virus when adherence is poor, there are individual psychological and behavioral challenges, with significant public health consequences that must be addressed.

Although the patterns of HIV infection have varied with the social and economic conditions of affected countries

25 years into the epidemic, HIV and poverty are inextricably linked. Most HIV-positive individuals are living in impoverished communities, have lower levels of education than the general population, and face challenging life circumstances such as unemployment, homelessness, a lack of adequate health insurance, incarceration, and other social vulnerabilities [1,2]. Contextual forces involving race, class, and sex intersect in vulnerable communities to shape HIV/AIDS risks, which in turn influence individual-level physical and mental health outcomes [3,4]. Many individuals living in extreme poverty, particularly women, must weigh the risk of becoming HIV infected against other risks associated with poverty, including the loss of income, food, shelter, safety, and support for children [5]. They may have little choice but to engage in sexual risk behavior or put themselves in potentially violent situations in order to meet their own or their family's basic living needs [6]. In many countries, substance use is also a third factor in the mix. Many HIV-infected individuals are thus living in vulnerable communities and

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have already experienced stressful experiences and traumatic events before infection associated with these structural factors. Furthermore, the high rates of HIV infection in ethnic minority men and women, men who have sex with men, and other marginalized groups such as injection drug users and sex workers, means that many HIV-infected individuals, before infection, experienced years of discrimination because of sex, race, sexual orientation, and class that can result in hopelessness, poor coping, loss of personal agency, depression and other mental health problems [5]. Histories of stress, trauma, and discrimination may have contributed to the behavioral risk that led to HIV infection, whereas these same contextual factors can contribute to diminished coping capabilities leading to significant psychological distress and behavioral challenges when living with HIV.

Unfortunately, in contexts of extreme poverty in which basic living needs such as food, shelter, and clean water are not guaranteed, psychological needs can be seen as secondary to physical health and the other basic physical needs of living [7]. There is increasing awareness on the part of healthcare providers and governing and social service agencies that ignoring psychological factors can contribute to long-term harm to the individual and to the public health. Although a review of all psychosocial challenges associated with HIV is beyond the scope of a single paper, this article highlights several psychological and behavioral aspects of HIV infection that require focused attention as ART becomes increasingly available in developing countries where most HIV cases exist. Mental health, stigma, disclosure and social support are domains discussed extensively in the literature as being important in the lives of people living with HIV, and also as factors that are consistently associated with treatment adherence and sexual behavior, two behavioral outcomes that are important to the health and wellbeing of the individual as well as the public health. We will focus our comments in these particular domains where much has been written in countries where ART has been available for many years, and we also discuss the implications for areas of the globe where ART is now more widely available.

Living with the virus: mental health challenges

It is a near universal experience that when one hears or reads the words 'you have HIV' the individual's definition of his/her self changes, regardless of culture, race, age, geography, social or economic status, or relationship status. For some, it is a total surprise; for others it is a confirmation of what he/she has suspected. For most, it is typically an isolating and daunting moment with significant psychological ramifications.

Typically, the psychological issues associated with HIV illness evolve for individuals and families over the dynamic course of HIV illness and vary depending on the stage of the illness [8,9]. With ART, there has been a shift in emphasis from coping with severe illness, death and dying, and multiple losses to living with and managing HIV as a chronic health condition. This has not, however, eliminated the psychological impact of infection. Coping with the uncertainty of future health and HIV stigma remain the most difficult psychological challenges that permeate many facets of life, even in the context of optimal access to ART. People living with HIV may exhibit a variety of responses requiring different types of medical attention and psychological support.

First are relatively normative responses. Upon learning the diagnosis, the individual needs to integrate new information into his/her existing identity that translates into questioning assumptions about many aspects of one's life, rethinking priorities and goals, and acquiring new skills that may be necessary to accomplish reformulated goals. The individual is likely to experience alternating feelings of shock, disbelief, panic, fear, guilt, shame, anger, despair, hopelessness, and numbness. Supportive counselling and increased access to existing social supports may be sufficient to help individuals cope with these feelings [8,9].

Second are responses complicated by histories of stressful or traumatic experiences. For some HIV-infected individuals, psychological distress occurs in response to real or feared societal response such as the loss of home, employment, rejection by partners, family and community, and violence. In such cases, individual and family psychotherapy with a mental health professional is helpful in responding not just to HIV, but to the context of the infected person's life [8,9].

Finally, for some HIV-infected individuals, there may be exacerbations of pre-existing psychiatric disorders, including substance abuse/dependence or precipitations of new onset disorders, in which psychiatric syndrome-specific treatment, sometimes including psychopharmacology, must be among the interventions provided. Studies have shown that adults and children living with HIV and/or at risk of acquiring HIV are at an elevated risk of psychosocial distress and psychiatric conditions, particularly depression [10–15]. Although the specific role of HIV is not clear, a number of those studies have found clear and important associations between the prevalence of psychiatric disorders and psychological symptomatology and poor quality of life, elevated sexual risk behavior, poor adherence, and poor health outcomes. For example, chronic and intermittent depressive symptoms in HIV-positive women are associated with disease progression, lower CD4 cell counts, and higher baseline viral load levels; and, in general, women with chronic depression

have mortality rates twice as high as those with little or no depressive symptoms [16,17].

In addition to the direct effects of HIV on the infected individuals' mental health, it has become increasingly evident that HIV is a disease that has significant and complex psychological effects on children, partners, and other family members. Whether or not the infected individual is symptomatic, family members often have persistent fears about impending illness, changing roles, dependency and loss of functioning in the ill, and death. These effects can be most pronounced in spouses or partners and children of the individual with chronic illness [18–23]. Changing roles related to care-giving, income generation, or parent–child relationships can occur. Children may need to become caregivers to their parents, often causing significant feelings of distress, inadequacy, anger, and depression [24]. Studies of chronically ill patients and their families have shown that the debilitating effects and unpredictability of disease contribute to family member distress [25–29]. It is thus important to identify and understand the relationship between medical and psychosocial factors that affect depression and health outcomes in people living with HIV and their families. By identifying key psychosocial factors that are amenable to change, clinical interventions to promote health can be enhanced and must be considered as part of the public health response to the HIV pandemic.

Stigma and disclosure

HIV disclosure entails communication about a potentially life-threatening, stigmatized and transmissible illness. Given the stigma associated with HIV and the modes of transmission, there have been mild to severe negative consequences of HIV disclosure (e.g. discrimination, rejection, hostility, and violence). At the same time, there can be significant benefits of disclosure in terms of social, material, and emotional support [30]. Very importantly, disclosure may be necessary for accessing and maintaining adherence to available treatments, as well as accessing mental health and supportive services, and preventing HIV transmission. Disclosure of HIV status is, however, a personal matter and non-disclosure may occur as a result of fears of rejection or harm, feelings of shame, desires to maintain secrecy, feelings that safer sex obviates the need for disclosure, fatalism, perceived community norms against disclosure, and feelings that individuals are responsible for protecting themselves [31,32]. Decisions about disclosure in families are complicated by the fact that there are many people involved, including young children. There may be significant differences within a couple or among other family members regarding the desire to disclose, the reasons for wanting to disclose, to whom to disclose, when to disclose, and how to disclose.

Finally, disclosure issues emerge as infected individuals consider sex, reproduction, and intimacy needs.

Sex and sexuality

Typically, when someone is first diagnosed with HIV or AIDS there is a significant decline in sexual interest and activity, especially when individuals are symptomatic with HIV-related illness. Especially in the context of access to effective ART, however, most individuals will want to resume sexual activity with time [33,34]. The process of re-engaging in sexual activity and romantic relationships can be difficult, as many feel inhibited by anxiety over disclosing serostatus, with a fear of rejection from potential partners, fear of infecting others, and negotiating safer sex. These fears are anxiety producing and contribute to feelings of loneliness and despair, but they can be overcome and sexuality can remain a vital part of their life [35]. Sex, for most people is an integral part of life and quality of life, whereas for some it is integral to their survival [36]. A fairly large body of evidence consistently demonstrates that the practice of unprotected intercourse varies by partner type, with unprotected sex more likely to take place within the context of established relationships [37,38]. For many women (and men) the desire and intent for pregnancy are motivating factors for engaging in unprotected sex, in spite of the presence of HIV [39]. Furthermore, many women are not always in control of their sexual lives. Rape, forced sex, and cultural expectations may interfere with prevention efforts [4,6]. All of these realities must be considered by the prevention agenda because people living with HIV often hear the message (whether real or imagined) that they have no legitimate right to a full sexual life or procreation after an HIV diagnosis.

Research has shown that most people living with HIV do not engage in sexual risk behaviors with HIV-seronegative or unknown status partners [40–44], but a sizeable minority continue to present a public health risk [40,42]. The availability of ART has introduced a new dynamic because a false sense of security may arise as a result of a belief in reduced infectivity associated with a reduced or 'undetectable' viral load [45–48]. In addition, there is the concern that medical treatment advances may lead to a diminished sense of the negative consequences of HIV infection and an increased complacency towards safer sex practices [49,50]. We have also witnessed an increase of viral resistance in people living long-term with HIV [51] and an increased frequency of a drug-resistant virus in newly infected individuals [52,53]. There is thus a growing public health concern about transmission risk behaviors among individuals with antiretroviral-resistant HIV infection [54–58].

Mental health factors can play a significant role in the ongoing transmission of HIV because numerous

studies have reported an association between negative affective states, including specific psychiatric disorders, and increased sexual risk behavior in both adolescents and adults. This association has been seen across a wide range of populations, including adult men and women [59], men who have sex with men [60–63], HIV-positive adults [59], minority women [64,65], substance users [66], gay and bisexual men [61,67] and adolescents and young adults [68,69]. Until recently, most HIV prevention programmes have targeted the uninfected. Stimulated partly by advocacy processes such as those linked to the Greater Involvement of People with AIDS, researchers and clinicians have recently come to recognize the importance of including HIV-positive individuals in safer sex interventions.

Health management and adherence

Advances in HIV medication treatment have been dramatic over the past decade, resulting in sharp reductions in HIV-related morbidity and mortality in high resource countries with long standing access to ART. Even in such settings, however, not all individuals living with HIV/AIDS are able to take advantage of these medical treatment improvements because of access disparities, arduous regimens that can interfere with everyday life, and competing subsistence needs such as housing, transportation, and financial constraints that make treatment adherence difficult [70–72]. Given that missed doses of ART are associated with the development of resistant virus that may lead to treatment failure, clinical progression, and the possible transmission of ART-resistant strains of HIV, the problem of non-adherence poses a significant public health challenge [73].

Factors that have often been linked to poor adherence to ART include depression, substance use, low literacy, and unstable housing [74,75] as well as pill burden and significant side effects that interfere with normal daily functioning [76]. Factors associated with better adherence include positive social support, strong beliefs about the necessity of medication, self-efficacy for adherence, and a good understanding of the purpose of treatment [77–79]. Some experts have grouped the range of factors associated with adherence into four main groups that include structural and individual level factors: (i) patient factors, such as alcohol and other substance use, age, attitudes towards treatment, and personality characteristics; (ii) medication characteristics, such as dosing complexity, number of pills, or food requirements; (iii) interpersonal characteristics, such as the doctor–patient relationship, and other social supports; and (iv) system factors, such as healthcare infrastructure and ART distribution mechanisms [77,80].

Even under the most ideal circumstances with strong social support and reduced stigma, poor adherence can occur [81–83]. Initial studies of ART use in resource-poor settings reported high rates of adherence [84,85]. Given limited resources before 2004, however, ART use was initially confined to the very sick and highly motivated. Those studies were thus based on highly selected populations. It is predicted that adherence problems will become more evident as more patients are started on therapy earlier and require maintenance on therapy longer [86,87]. Recent studies from Africa [86,88–92] have reported adherence rates more comparable to those in the developed world and in countries such as Brazil [93,94], Thailand [95], and Caribbean countries [96,97]. Ten years of experience with ART in the United States and European countries has shown that adherence worsens over time as HIV illness improves, symptoms weaken, and side effects increase; adherence is not static, but rather changes with time [76], and long-term programmatic efforts may be necessary for long-term effects.

The special case of children and young people living with HIV

Although many of the issues presented above are also relevant for HIV-infected children and adolescents, there are several additional factors to consider for children. These issues have been presented in a number of previous publications, including review articles [98–100] and empirical studies [14,101]. Perinatally HIV-infected children who have survived past early childhood have been exposed to years of active HIV disease resulting from lack of treatment [66,67]. HIV impairs growth and development and has a destructive effect on the central nervous system. Consequently, significant neurodevelopmental and cognitive deficits have been found in studies of children in resource-rich settings where children have survived living with HIV [98]. Unfortunately, there is a paucity of studies of children's neurocognitive development when living with HIV in resource-poor settings where the majority of perinatally infected children die before school age. The neurocognitive problems observed in children who survive can affect their ability to perform in school, develop friendships, and function independently. Several recent articles have also found high rates of mental health problems, although the role of HIV in this process is not clear [101]. Infected children must also confront the social ramifications of having a chronic and stigmatizing disease, including disclosure of illness and ostracism. Children may not know their diagnosis, not because the diagnosis has not been made, but because caregivers have not told them because of a fear of child reactions including distress, anger at parents, and disclosure to others. Non-disclosure in this context

has a potent impact on adherence, because these children do not know why they take medications [30]. For children and young people who do know their diagnosis, there are complicated decisions related to disclosure to others that may affect friendships and sexual relationships. As children age into adolescence, a normative stage of 'desire to fit in', sexual and drug experimentation, as well as a time when non-adherence becomes more prevalent, issues related to the transmission of HIV, including ART-resistant strains of the virus become a public health concern [79].

Finally, perinatally infected youth of all ages must cope with the impact of parental illness and loss that may occur at all stages of development. It is predicted that by the year 2010 there will be 25 million orphans in the world as a result of AIDS. Loss of a parent is a stressor linked to poor behavioral outcomes [98]. Many perinatally infected children and young people have already experienced trauma and stress related to poverty and losses related to early separations from biological parents, deaths of many family members from AIDS and other causes, as well as changes in caregivers [98]. Studies from African countries have found that compared with non-orphans, children and young people who have lost at least one parent to AIDS have more unmet basic living needs, less access to school, and more psychological problems including negative mood and pessimism [102–104]. Given the devastating effects of family and community destruction resulting from years of poverty, racism, family relocation and migration, violence, and famine, many African children orphaned by AIDS are at great risk of poor mental health and health outcomes, being given limited resources, stigma, exploitation by new caregivers, and a dearth of appropriate caregivers.

General recommendations for prevention and care

There are striking commonalities in the vulnerabilities of HIV-infected adults and children across the globe, with poverty, minority status, family disruption and exposure to violence and substance abuse complicating adjustment to HIV/AIDS. Increasingly, there is a call for attention to social factors, i.e. structural inequalities such as sex, poverty, and interpersonal violence, as primary determinants of health outcomes, shifting the focus of intervention from the individual to larger societal structures. It is essential that we address these social inequalities and work to implement change in local, national, and global policies, structures, and norms in order to improve the health and well-being of adults and children living with or vulnerable to becoming infected with HIV. This should not be pursued, however, in the absence of also providing for the wide range of

psychosocial needs that people living with HIV may have before or as a result of their illness. Therefore, although it may be difficult to justify the provision of mental health or other psychosocial services when individuals do not have food, or shelter, or other basic living needs, to ignore the former may severely limit the ability of individuals and families to sustain the latter, when they are provided [105].

We have witnessed the negative consequences of the lack of attention to the mental health needs of families and individuals coping with HIV among the poor and disenfranchised as well as those with sufficient economic and political capital, both before and subsequent to the availability of ART in high-resource countries. If, and when, we are able to improve equitable access to ART in a wider range of settings throughout the world, we are at risk of creating significant barriers to the future well-being of children, adolescents, and adults if we do not pay close attention to their psychological functioning and needs. It is thus essential that we apply the lessons learned from contexts in which ART has been widely available to settings where 'scale-up' of their distribution is more recent or is yet to come, while simultaneously considering the unique challenges of the local context.

We need to focus programmes and actions at many levels to implement and sustain effective HIV prevention and care initiatives. Broadly speaking, poor mental health serves both as a determinant, and an outcome, of HIV disease. Psychiatric co-morbidity in the context of HIV can contribute to diminished health outcomes, increased substance use, poor treatment adherence, increased sexual risk behavior, interpersonal violence, and other maladaptive behaviors. The provision of ART without accompanying mental health and other psychosocial services will leave us falling short of our potential to make a true and lasting beneficial impact on the most vulnerable among us. It is thus important for us to find ways to provide and sustain these necessary services for individuals and families in resource-poor countries with limited mental health infrastructure, as well as in settings that already have the capacity and means.

Although many hospital and community-based clinics already provide mental health services, formal mental health treatment is often not available [105,106]. We need to be creative in ways of providing mental health services in settings where such things may be 'foreign' to the culture and the local capacity. For example, psychological support, particularly around issues such as disclosure, adherence, and sex can be provided by peer counsellors, trained nursing staff, and lay counsellors from the community. At other times, we may need to build more formal mental health infrastructure.

In developed countries there are numerous efficacy-based interventions that target HIV-infected individuals and

their family members to promote psychological functioning, reduce sexual risk behavior, and improve adherence and overall health and well-being [107–109]. Very few such programmes have, however, been developed and tested in low-resource countries where the epidemic is having devastating effects.

To enhance efforts to curb the devastation caused by the HIV/AIDS epidemic, the Institute of Medicine [110] and the Centers for Disease Control and Prevention [111] in the United States, and the Joint United Nations Programme on HIV/AIDS and the World Health Organization internationally, have strongly recommended that prevention and treatment efforts be integrated, establishing prevention efforts with HIV-infected individuals as a primary objective, and calling for the expanded use of targeted, sustained, and evidence-based prevention interventions in HIV treatment settings. The rollout of ART offers a unique window of opportunity to integrate prevention interventions into both testing and treatment settings. This includes primary prevention messages for individuals testing negative and appropriate referrals for those testing positive; and the integration of prevention messages with adherence and psychosocial counselling, and family planning in ART treatment settings in order to strengthen both treatment and prevention outcomes.

Finally, we need to examine further the social and political factors that are associated with psychological functioning for all groups at risk. Future research needs to examine the interaction of structural and policy-level initiatives that address economic and social disparities with family and community-level psychosocial services (such as those provided by non-governmental organizations) in order to increase overall functioning for those already living with the disease and to prevent further transmission to uninfected individuals. As poverty and other social disparities not only lead to the risk of HIV but negatively impact psychological and behavioral outcomes given limited choices, social and economic policies and programmes need to facilitate increased access to education, work, and financial rewards for vulnerable populations. In the context of HIV prevention and care, there is a call for the merging of economic interventions with gender equity and HIV/AIDS prevention interventions, fully taking into account sexual relationships, other relationships of social inequality, economic contexts, and migration movements [112]. We also see a need to promote and support community-level support and grass-root mental health enhancing initiatives in order to strengthen the functioning and well-being of individuals and families living with and vulnerable to HIV, while also reinforcing the strength and resilience of the communities within which they live.

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