Kenya: HIV Comprehensive Care Clinic

TECHNICAL BRIEF

Positive Health, Dignity and Prevention: Engaging People Living with HIV in Prevention

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What is Positive Health, Dignity and Prevention?

Prevention efforts need to target specific population groups and be tailored to their particular needs. Historically, HIV prevention efforts have tended to focus on reducing HIV risk among HIV-negative people or those with unknown serostatus, while overlooking the specific role that HIV-positive people can play in prevention. Significant gains in the treatment and care of people living with HIV (PLHIV) and attention to and funding of ARV treatment have resulted in larger numbers of people living longer with HIV. There is thus a growing recognition of the urgent need to find effective ways to engage this population in HIV prevention efforts that are appropriate to their needs.[1,2] "Positive health, dignity and prevention" (PHDP) (alternatively known as "prevention with positives" or "positive prevention") engages people who know they are living with HIV in prevention. It involves supporting HIV-positive people to learn and practice how to live healthily and minimize the risks of their spreading the virus to others.[3,4]

Program planners are beginning to recognize that improving access to HIV prevention and treatment and raising awareness about risk reduction among PLHIV may be as effective as concentrating on HIV-negative people. While there is no firm consensus on what PHDP entails, it generally includes activities centered on:

- Enabling HIV-positive individuals to be physically and mentally healthy through a focus on antiretroviral therapy (ART) and healthy living[5]
- Preventing further transmission of HIV through: early disclosure; correct and consistent condom use by serodiscordant couples; ART; prevention of mother-to-child transmission (PMTCT); and sexually transmitted infection (STI) screening and treatment
- A growing movement that recognizes the value of involving people living with HIV in prevention activities, leadership, and advocacy[4]

Battling the Stigma of HIV/AIDS in Ethiopia

HIV Testing and Counseling: an Entry Point for Accessing HIV Prevention, Treatment, and Care

Until recently, HIV testing and counseling (HTC) has been mistakenly perceived as an HIV prevention intervention. However, there is no compelling reason to believe that simply knowing one's status (the testing component) is likely to have a positive prevention outcome. The successes attributed to HCT may be largely due to the prevention efficacy of the skills-based counseling, rather than HIV test itself.[6] In the absence of a meaningful counseling process, HTC could conceivably pose a risk for people who test HIV negative and assume that they are not vulnerable.[7,8]

Alternatively, HTC should be regarded as an entry point to HIV treatment and PHDP. Research indicates that the preventive benefits of HTC are greatest for people who test positive, given that they tend to adopt protective behaviors that will reduce the risk of HIV transmission to others, while seronegative people are more likely to continue engaging in unsafe sexual practices following an HIV-negative test result.[9] Another study similarly concluded that women who tested positive for HIV reported increased condom use, while individuals who tested negative reported more concurrent sexual partners in the last month after testing.[10] There is evidence that suggests that knowing one is HIV positive does not guarantee condom use; however, in one study, nearly half of the people who were on or about to start ART reported having recently had unprotected sex.[11,12]

Evidence suggests that approximately 60% of people living with HIV are unaware of their status and are therefore unknowingly passing the virus to others.[13] Given that HTC largely benefits HIV-positive people, with support, HTC can help enlist HIV-positive people into HIV prevention efforts. Some positive prevention programs focus on ensuring that HIV-positive individuals find out about their HIV status and disclose their status to their partners. Being aware of one's status enables preventive behavior, such as informed partner selection, safer sex practices, and increased access to care and treatment.

HIV counseling and testing for couples has had success in reducing risk behavior and HIV transmission among serodiscordant married or cohabitating couples.[14] Research in Uganda found that HIV disclosure supported risk reduction and improved care-seeking behavior, partner testing, reduced anxiety, increased sexual communication, and motivation to plan for the future.[15]

Serodiscordance: HIV often occurs in stable relationships

Historically, HIV prevention messages have tended to focus on perceived high-risk sexual behaviors, such as engaging with sex workers or having unprotected casual sex. However, a number of studies have shown that a large portion of HIV infections occur in stable relationships, due either to the prior infection of one of the partners or infidelity. Recent data indicate that most new HIV infections occur among HIV serodiscordant couples and that disclosure and condom use among such couples remain low.[4] Few HIV prevention programs target couples, overlooking an important HIV prevention opportunity. This need becomes more pressing since HIV-positive people live longer lives thanks to ART, thereby increasing the number of people in serodiscordant relationships.

Reviews of high-prevalence Sub-Saharan countries found that up to half to two-thirds of HIV-positive people in stable relationships had an HIV-negative partner.[16,17,18] In almost half of the cases in one review, the woman was found to be the infected partner, challenging the commonly held perception that it is only men who are putting their female partners at risk.[16] Research in rural South Africa on HIV concordance and discordance among migrant and non-migrant couples in 2003 found that the direction of the spread of HIV was not only from returning migrant men to their partners, but also from women who stayed at home to their migrant partners.[19]

Factors influencing transmission in serodiscordant relationships include low risk perception and social norms that contribute to low rates of HIV counseling and testing, resulting in large numbers of individuals being unaware of their HIV status.[20,21] For those who do know their HIV-positive status, fear of stigma and discrimination may prevent or delay disclosure. This lack of disclosure coupled with other structural issues, such as the cost of and poor access to HIV treatment and other health services, may delay HIV-positive individuals from beginning ART leading to higher viral loads.[19] Cohabiting couples often have low rates of condom use and may continue to have unprotected intercourse, despite knowledge of their serostatus.[18]

Thus, it is extremely important to consider the circumstances that place HIV discordant couples at increased risk for transmission of HIV and other STIs.

Avoidance of unprotected sexual intercourse and enrolling HIV infected partners in serodiscordant relationships on ART are regarded as important complementary measures to prevent HIV transmission. This is because heterosexual infectivity in individuals on effective combination antiretroviral treatment is low, a probability of less than 1 in 2,000 risk exposures[22]. Putting HIV-positive people in relationships on ART irrespective of their CD4 count is a prevention measure that works for couples. (See the section below on treatment for prevention.)

The potential conflict between newly diagnosed discordant partners has to be addressed and must include ongoing support in addressing the underlying aspects of discordancy. "Couples require support, whether the relationship is sustained or not, and couples who choose to stay together require access to a repertoire of strategies to manage their approach to sexual intimacy, while minimizing HIV transmission risk."[23]

Sexuality and Prevention: Increasing Protective Behaviors

A recent study in Uganda found that most PLHIV had made changes to their sexual behavior to reduce HIV transmission risk. This primarily related to condom use (with HIV-positive people being three times more likely to use condoms than people who were HIV negative or did not know their status), although a fairly high proportion of PLHIV, particularly women aged 30-49, had not had sex in the past year. Abstinence appears to be a fairly widespread phenomenon among PLHIV, whether intended as a prevention strategy or not.[23] PHDP communication should thus address sexuality in relation to abstinence, in addition to other aspects of sexuality.

The Ugandan study found some uncertainty about the risks of reinfection of a positive partner, or the risks of transmission in the context of ART. In some parts of the world, PLHIV have used the strategy of "serosorting" — preferring to have a partner who is also HIV positive. This does not appear to be the case among South African heterosexual couples[24] and is likely not true for other SADC populations. Although unprotected sex between two HIV-positive people does not carry a risk of HIV transmission, there are health implications, notably recombinant viruses, drug-resistant viruses, and superinfection.[25]

Despite the low risk of transmission among people with an undetectable viral load, condoms and lubricant should still be promoted given their effectiveness. This is especially important in contexts where access to treatment is poor. A World Health Organization (WHO) systematic review found that consistent condom use by men who have sex with men cuts the HIV transmission risk by 64% and the risk of acquiring an STI by 42%.[26] Discussing the STI-prevention benefits of condom use was recommended as a strategy for promoting condom use with HIV-positive people.[27]

Antiretroviral Treatment: a New Breakthrough in Prevention

An emerging area that needs more attention in positive prevention programs is antiretroviral therapy for prevention. Observational studies suggest that antiretroviral therapy reduces the sexual transmission of HIV in generalized epidemics.[28] ART reduces the concentration of HIV, making it a major prevention intervention. ART lowers HIV-1 plasma ribonucleic acid (RNA), thereby reducing the infectiousness of PLHIV on treatment as well as lowering the risk of tuberculosis transmission by 80-92%.[29,30,39] Studies of serodiscordant couples found that if the virus has been undetectable for six months, there is no risk of transmitting HIV as long as the infected partner strictly adheres to his/her ART regimen and is free of STIs.[31] Given the overwhelming success of the HIV Prevention Trials Network (HPTN) 052 study, which found that immediate highly active antiretroviral therapy (HAART) reduced transmission to seronegative partners by 96%[32], as well as other studies, there is conclusive evidence that treatment prevents morbidity, mortality, and transmission of HIV and tuberculosis.[30]

There is also evidence that being on treatment increases HIV prevention behavior.[24] Despite initial fears that ART would lead to increased risk behavior (behavioral disinhibition), research from several African countries has shown that PLHIV have tended to become more careful after commencing treatment. This could be because ART service provision also presents an opportunity for behavioral risk reduction (when accompanied by targeted prevention counseling and condom distribution). Emphasizing the transmission-preventive benefits of treatment has been found to be a useful point of discussion for clinicians in encouraging patients to commence ART.[33]

Encouraging HIV-positive people to consider initiating ART as a way to achieve an undetectable viral load is an important new breakthrough in PHDP. However, there is little evidence that the HIV-prevention effects of ART have been broadly promoted or communicated in Sub-Saharan Africa, perhaps due to fears of a potential drop in HIV-risk reduction behaviors. In the United States, programs that aim to enroll all PLHIV on ART, regardless of their CD4 count, have been criticized for misleading PLHIV by not fully explaining the prevention rationale.[58]

Prevention of Mother-to-child Transmission: a Crucial Intervention for Women and Infants

The desire of people living with HIV to conceive is an important area to address. A recent study in Kenya argued that the intention to conceive may be contributing to the epidemic among HIV discordant couples.[34] Another study found that one-third of women who were surveyed became pregnant after finding out they were HIV positive and that half of young HIV-positive women were not using any form of contraception.[23] A focus on reproductive decision making in couples where one or both partners are HIV positive, and that can guide them in taking viral load into account, is important in any program aimed at HIV prevention in couples.

The prevention of unintended pregnancy and mother-to-child transmission (PMTCT) are key in positive prevention as infants born to mothers with HIV are at a high risk of acquiring HIV in Africa.[35] PMTCT is a crucial intervention for HIV-positive mothers and mothers-to-be. Studies have found that there is an unmet need for family planning among HIV-positive women. Integrating family planning and HIV services at the policy, systems, and service delivery levels is a critical priority for SADC Member States as it would help PLHIV increase contraceptive use, reduce unwanted pregnancies, and plan for safer pregnancies.

Despite having the technology to reduce MTCT to less than 2%, there continue to be many issues that prevent the success of PMTCT efforts. For example, between 2005 and 2009, only 56% of pregnant women in South Africa received antenatal care at least four times during pregnancy.[36] Pregnant mothers' regular access and adherence to ART continues to be a concern. Disclosure of one's HIV status remains an issue among couples, so a woman may not be fully compliant with ART if she is trying to hide the medicines from her partner.

Despite these challenges, significant progress has been made in preventing mother-to-child transmission in the past decade. In the Southern African region, Botswana, Namibia, South Africa, and Swaziland have all achieved more than 80% coverage of antiretroviral prophylaxis to prevent mother-to-child transmission (UNAIDS 2010). Malawi and Uganda have set a strong example by adopting WHO's newest PMTCT strategy, "Option B+", which ensures that all pregnant HIV-positive women receive ART for the duration of their life.[37] Seven other countries in Sub-Saharan Africa have coverage levels of 50% to 80%. Sub-Saharan Africa as a whole achieved 54% coverage.[36]

Improving Diagnosis and Treatment of Sexually Transmitted Infections

Non-adherence to ART has been linked to continued unsafe sexual practices among PLHIV, with up to one-third of PLHIV having contracted new STIs post-HIV diagnosis, according to one study.[38] The effective diagnosis and treatment of STIs for people living with HIV and their partners is also an important part of PHDP, given that having an STI increases the risk of HIV transmission and acquisition, and is associated with increased viral load in genital secretions. The presence of an STI, such as genital herpes or syphilis, increases the risk that a person will transmit the virus if they are HIV positive or become infected with HIV if they are HIV negative.[39,40] Since most STIs remain asymptomatic, regular and appropriate STI screening is an essential strategy to limit PLHIV's transmission risk.

Addressing Alcohol Abuse

A number of studies have shown that men and unemployed people living with HIV have elevated levels of alcohol use (and other substance abuse) compared to the general population.[41] This may be due to stigma and the psychosocial consequences of being infected. Given that alcohol use increases the risk of HIV transmission, it is important to address as it is likely to be a significant problem encountered in men and unemployed people in promoting positive prevention. HIV prevention messages that are tailored to HIV-positive men should challenge beliefs and expectations that drinking alcohol enhances sexual pleasure and performance.[42]

Considering the Psychosocial Needs of PLHIV

The mental health consequences of being infected with HIV are often not recognized. Unsupportive environments characterized by enacted stigma, discrimination, irrational fear, and judgmental attitudes lead to the marginalization of PLHIV.[43] The impact of mental health on health-seeking behaviors and non-disclosure should be taken into account when designing effective PHDP programs that help people adapt to living with HIV.[44]

Depression, anxiety, post-traumatic stress disorder, a lack of trust in the health care system and government, and experiences of stigma have all been found to be more common among HIV-positive people as compared to the general population.[45] Addressing the mental health and psychosocial needs of PLHIV is another way to strengthen prevention interventions and treatment adherence.[46]

Focus on the Particular Needs of Young People Living with HIV

Approximately two million adolescents are living with HIV, with most unaware of their HIV status.[12] Recent survey data shows that only 15% of young women aged 15–24 years and 10% of young men in Sub-Saharan Africa have been tested and know their HIV status[47], highlighting that most HIV-positive young people are not being reached by PHDP efforts.

Young people living with HIV have similar challenges around HIV prevention and managing potential discordancy between partners as young people who are HIV negative. Disclosure may be a particularly sensitive issue for youth. HIV-positive young people in Botswana were said to keep silent about their status.[48] PHDP strategies are challenged to influence younger people, given the perception that HIV among youth has worsened, with more new infections attributed to a sense of irresponsibility towards others, risky behavior, and normalization of living with HIV due to improved treatment and care options.[23] It is also necessary to involve HIV-positive adults in HIV prevention programming that addresses youth vulnerability, for example, older PLHIV in age-disparate relationships.

A significant proportion of young people living with HIV may have acquired HIV perinatally. This presents a unique prevention opportunity, given the particular challenges that arise as a generation of children who acquired HIV at birth reach adolescence. Some children lack an understanding about their HIV status as a result of their caregivers' unwillingness to inform them about their status.[49] Another concern was highlighted in research from Uganda that found such children did not view themselves as HIV positive but as "innocent", and that most had not disclosed to their partner.[50] Young PLHIV may be marginalized and less able to engage in prevention of HIV transmission in relationships.

The greater likelihood of mental health problems, as discussed above, would also affect young PLHIV's relationships, adherence, and prevention needs. Access to ART is also a factor, given the capacity of ART to function as a prevention method. Currently, 54% of HIV-positive children in South Africa who require ART are receiving it.[51] This is further exacerbated by malnutrition, with 50% of children in African ART programs being malnourished.[52]

Advocacy for Positive Health, Dignity and Prevention

Whereas HIV and AIDS support programs likely contribute to HIV prevention, countries need policies that specifically support positive prevention interventions and to make a concerted effort to involve HIV support organizations in developing a movement around PHDP. This will require that PLHIV be knowledgeable about the concept of positive prevention and demonstrate attitudes that are conducive to the associated desired behavior change practices.[23]

Leadership by individuals living with HIV is critical in PHDP efforts, as is the response to HIV and AIDS in general.[53] One review from Botswana found that such engagements should be considered an "essential condition" for any HIV response, but that communities were not being effectively supported and the socio-cultural contexts related to prevention behaviors and underlying determinants of vulnerability were being overlooked.[2] The "Positive Health, Dignity and Prevention Framework developed by the Global Network of People Living with HIV (GNP+) and UNAIDS" offers greater promise of engagement of people living with HIV.[1] The movement is trying to advocate for a move "away from treating people living with HIV as passive targets of prevention messages towards recognizing them as active participants in the global HIV response".[54]

National networks of and for HIV-positive people are active throughout Southern Africa and have been successful in promoting PHDP on the ground. Their advocacy activities have firmly secured a place for positive prevention and the protection of human rights on high-level prevention agendas.

For example, the Treatment Action Campaign is a considerable success story in advocating for the rights and needs of HIV-positive people, particularly in relation to ART.[14 55]

Evidence of positive prevention at a programmatic level has yet to accrue. A study in Uganda found that while awareness of positive prevention (including safer sex, partner reduction, reinfection, and adherence) is high, it was not clear how consistently PHDP messages were delivered and whether knowledge was sustained. Although stigma still persists, they also found that PLHIV were better able to cope with it due to the PHDP activities, including support groups, being carried out by different service providers.[23]

Recommendations

- The inclusion of PLHIV in prevention programs has emerged as a critical aspect of the HIV strategy. Strategies aimed at engaging PLHIV in prevention need continued strengthening. PHDP needs to be scaled up, with a focus on supporting the role of HIV-positive women in HIV prevention, and the formation of more networks (and more visible networks) of HIV-positive people within the SADC region.

- There is a need for ongoing guidance to PLHIV on how to manage risks of transmitting HIV, including reinfection. Policy makers should promote the concept of PHDP in mobilizing positive prevention, including PMTCT, ART adherence, and sexual risk reduction. Currently HTC promotion tends not to go beyond promoting testing. The foundation for PHDP must be laid and the public should be educated about how to cope with HIV infection even before people are tested.

- Interventions should combine messages about disclosure, partner communication, family planning, treatment and the benefits of adherence, STI screening, and mental health services. The concept of PHDP should be used to promote holistic health and wellness, and equitable access to health care services, including psychosocial support. Messages that characterize HIV as a chronic illness remain important in challenging stigma and promoting attitudes that are conducive to good health. Policies should encourage the uptake of ART for all PLHIV with CD4 counts of 350 cells/mm3 or below at a minimum. Fixed-dose combinations should also be sought in order to improve adherence. PHDP strategies with a specific focus on young people living with HIV are also needed.

- Program managers, policy makers, and people living with HIV should advocate for a national programmatic focus and strategy on "positive prevention", which includes emphasis on reproductive health decision making for people with HIV. National AIDS Council sectors of PLHIV should be formed where they are currently lacking.

The Positive Health, Dignity and Prevention Framework developed by the Global Network of People Living with HIV (GNP+) and UNAIDS recommended the following components be included in PHDP Programs:

Preventing new infections

Access and availability of tools and technologies that help prevent sexual HIV transmission:

- Male and female condoms and water-based lubricants
- Male circumcision
- Antiretroviral therapy
- Post-exposure prophylaxis
- New prevention technologies, such as pre-exposure prophylaxis and microbicides, as and when they become available

Access and availability of services that help prevent vertical transmission:

- Primary prevention of HIV infection among women of childbearing age
- Preventing unintended pregnancies among women living with HIV
- Preventing HIV transmission from a woman living with HIV to her infant, including breastfeeding information and support
- Providing appropriate treatment, care, and support to mothers living with HIV and their children and families

Access to evidence-informed harm reduction for people who use drugs, including opiate substitution therapy.

Couseling for serodiscordant couples (including partner and couples testing).

Prevention, screening, and treatment of sexually transmitted infections, including viral hepatitis, and vaccinations for the human papillomavirus and hepatitis A and hepatitis B.

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