

Family Policy and HIV/AIDS

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Since the identification of Human Immunodeficiency Virus (HIV) as the etiologic agent of Acquired Immunodeficiency Syndrome (AIDS), the world has witnessed an unprecedented aspiration to end the spread of HIV and find a cure. Tremendous gains have been made over the past three decades in the control and treatment of HIV. Indeed, antiretroviral treatment (ART) has transformed HIV infection from a death sentence to a chronic disease. Nonetheless, a cure for HIV infection is still an aspiration (Passaes & Sáez-Ciri3n, 2014).

Although around 78 million people have been infected with HIV and roughly 39 million have died since 1981, the fight against HIV has saved millions of people from HIV infection and AIDS-related death and illness. Across the globe, for example, 2 million people became newly infected with HIV in 2014, compared to 3.1 million in 2000. Since 2004, the number of deaths due to AIDS-related illness has fallen by 42%. That is, by the end of 2014, 1.2 million people died from AIDS-related illness compared to 2 million in 2005 (UNAIDS, 2015). Another positive achievement is that, as of June 2015, 15.8 million people were accessing antiretroviral therapy, a significantly higher number than the 13.6 million reported in June 2014. In fact, UNAIDS (2015) announced that the goal of having 15 million people on ART by 2015 has been met nine months ahead of schedule. Despite all of this, more work needs to be done, and the fight to end the epidemic of AIDS is not over.

The *2030 Agenda for Sustainable Development* identified the world community's new pledge to end the AIDS epidemic. Sustainable Development Goal 3 (SDG3) proposes to "ensure healthy lives and promote well-being for all at all ages," and Target 3.3 proposes to "By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases. I think the fight to end the epidemics of AIDS is possible, as articulated in many scientific publications, such as a Defeating AIDS—Advancing Global Health Report (2015).

Before we delve further into the discussion of AIDS and families, it must be acknowledged that ending the epidemic of AIDS hinges on and is connected to achieving other *Sustainable Development Agenda 2030* Goals (SDGs), such as "ending poverty in all its forms everywhere (Goal 1); ending hunger, achieving food security and improved nutrition and promote sustainable agriculture (Goal 2), and achieving gender equality and empower all women and girls (Goal 3)." The research literature on AIDS has demonstrated the associations between these factors and the AIDS epidemic (see for example, Dunkle & Decker, 2013; Mufune, 2015; Pellowski, Kalichman, Matthews, Adler, 2013;

Richardson et al., 2014; UNAIDS, 2008). In fact, in its 2015 Terminology Guidelines, UNAIDS’s definition of vulnerability correctly captured this association. It referred to vulnerability as “unequal opportunities, social exclusion, unemployment or precarious employment (and other social, cultural, political, legal and economic factors) that make a person more susceptible to HIV infection and developing AIDS” (p. 50). Further, the links between ending the AIDS epidemic and the success of other SDGs (e.g., SDGs 10, 16 and 17), was highlighted by UNIADS recent report “*On the Fast-Track to end the AIDS epidemic*” (2016).

With this brief introduction, the current paper examines the connection between HIV/AIDS and families and how family and couples-focused HIV prevention intervention programs can help reduce the spread of HIV in conjunction with other established methods. Also, this paper proposes some recommendations that should contribute to *ending the AIDS epidemic by 2030*.

In one of its publications, UNAIDS (2010) rightly stated that although several evidence-based prevention programs do exist, most of them suffer from common flaws. A chief flaw is that most of them focus on reducing individual risk. This individualistic orientation toward HIV prevention interventions, which was based on several theoretical models (e.g., the Information-Motivation-Behavior Model, the AIDS Risk Reduction Model, and the Health Belief Model) dominated the AIDS literature for many years (El-Bassel, Terlikbaeva & Pinkham, 2010; Kippax, 2012). Yet, recent work has shown that couples- and family-centered approaches to HIV prevention intervention are successful in the fight against the spread of HIV and minimize its impact on the infected and affected family members, as well as enhance the outcomes of HIV care and treatment (Myer et al., 2014).

Family plays critical role in promoting health, preventing diseases, and providing care and support for its ill members. In the case of HIV/AIDS, “The family is on the front line in preventing HIV transmission, providing education and reinforcing risk reducing HIV-related behaviors for those living with HIV. The family is also the de facto caretaker for those living with HIV” (American Psychological Association, 2010, p. 3). In other words, HIV/AIDS is a family disease (Belsey, 2005; Richter et al., 2009)

The focus on family and AIDS has been addressed in many health organizations, including UNAIDS. For example, in 2010 in Doha, Qatar, Mr. Michel Sidibé, the Excusive Director of UNAIDS in a speech delivered at the colloquium *on the Empowerment of the Family in the Modern World: Challenges and Promises Ahead*, said:

The epidemic still frays and unravels families. . . . Yes, families can be, and are, torn apart by AIDS. But let’s look at this another way: Families can also be highly protective, inoculating members against the worst outcomes of AIDS. They offer a dependable means of prevention education and the clout to keep children in school, on track and out of risk. Family support can improve adherence to treatment, provide sustaining care and offer the first line of defense against stigma and isolation. And in the largest sense, strong families contribute to community—and by extension national—stability. (pp. 1-2)

Now that we have established the centrality of family in the fight against the AIDS epidemic, next I provide a brief summary on HIV/AIDS couple-focused studies followed by a brief summary on family-centered studies.

Studies have shown that most HIV transmission occurs in committed relationships (Bloom, Agrawal, Singh, & Suchindran, 2015; Matovu, 2016), with women being particularly vulnerable to HIV infection through their HIV infected partners (Badahdah, 2016; Go“kengin et al., 2016). To illustrate, three-quarters of HIV-positive women from Morocco and Iran have acquired the infection from their husbands. Hence, couples-centered HIV prevention interventions, which focus on couples as a unit of behavioral change and analysis, are important in reducing HIV-infection and in improving the wellbeing of couples (Jiwatram-Negrón & El-Bassel, 2014; Wechsberget al., 2015; Witte et al., 2014). While not a main concern for this current paper, various definitions of “couple” have been employed. Some studies, for example, have used the length of relationship, while others defined couples as those who are married (Jiwatram-Negrón & El-Bassel, 2014).

With this in mind, two systematic reviews of couple-based HIV prevention interventions were found in the literature; one was published in 2010 and the second one in 2014. The first study (Burton, Darbes & Operario, 2010) reviewed several behavioral prevention and intervention studies. The authors concluded that notwithstanding the limitations of couples-focused approaches to HIV prevention, couples-focused programs, compared with control groups, reduced unprotected sexual intercourse and increased condom use (p. 8). The second study (Jiwatram-Negrón & El-Bassel, 2014) reviewed biobehavioral and biomedical on HIV prevention and intervention studies since the beginning of the HIV epidemic. The authors concluded that the reviewed study interventions were effective in reducing sexual and drug-risk behavior, HIV-incidence among HIV-negative sex partners and viral load among HIV-positive partners, increasing access to HIV-testing and care, and improving adherence to ART (p. 1864).

What are the benefits of couples-based HIV prevention interventions approaches? El-Bassel and Wechsberg (2012, pp. 1864-1865) identified the following advantages:

- help couples recognize their mutual responsibility to protect each other from HIV infection and urge them to stay healthy;
- highlight the relationship’s context (e.g., love, trust, closeness, commitment) and its connection to HIV acquisition;
- help create a safe environment where couples can talk about important and sensitive topics such as sexual coercion;
- allow couples to learn and practice essential skills, such as communication and problem-solving;
- promote accountability and increases commitment to change; and
- enhance adherence to antiretroviral therapy (ART).

Although the couples-based approach has several advantages, as stated above, we must keep in mind that to bring an *end to the AIDS epidemic by 2030*, we must combine this approach with other proven approaches to the fight against HIV (Pequegnat & Bray, 2012). That is, there is no one size fits all approach in the fight against AIDS.

Family, as Belsey (2005) stated, “will remain the dominant and natural grouping in society providing emotional and material support essential to the growth and well-being of its members” (p. 11). There are various definitions of family within and outside the AIDS literature (Anderson, 1988; WHO, 1994). According to Levine (1990), for example, “Family members are individuals who by birth, adoption, marriage or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need.” In the context of AIDS, Pequegnat (2011) argued that family can be “a single seropositive individual who lives with his/her children, ... a grandmother taking care of her grandchildren because their parents died of AIDS or abandon them, ... a family can be a couple of mixed serostatus, a family can be a couple who are both seropositive, who are deciding whether to have a child or not” (p. 5). From these definitions and others, the connection between family and AIDS is clearly inseparable.

The illness and death of a family member, due to HIV or any other illness, has substantial financial, social, emotional, economic implications for the entire family. Hence, family-centered programs are very effective for dealing with HIV and other health-related, such as providing care and support for its members (Sandler, Schoenfelder, Wolchik, & MacKinnon, 2011; Steinberg & Morris, 2001). Family is important for several reasons, as summarized by the California Healthcare Foundation (2009, p. 7): Family members have frequent and ongoing contact with the patients, family members often share similar value systems and cultural backgrounds with the patients, family members have intimate knowledge of how patients think about the illness and how they manage the disease, and often patient-family relationship and communication patterns existed before the onset of illness. In the case of HIV/AIDS, Richter and colleagues (2009) explained that AIDS, especially in high HIV prevalence countries, is a family disease, because transmission occurs mainly through family relationships, and hence family can play a key role in HIV prevention. In addition, families provide comfort and care to those who are infected by HIV.

Since the beginning of HIV epidemic, the impact of HIV/AIDS on the social lives of people living with HIV and their families has been at the center of the fight against AIDS. A main concern has been prejudice and discrimination against people living with HIV and their family members (Badahdah, 2010). Research has shown that because of AIDS-related stigma, the families affected by HIV experience verbal and physical harassment, violence, and exclusion.

AIDS-stigma undermines HIV prevention intervention programs. HIV-stigma deters, delays, or reduces the likelihood of family members getting tested for HIV, using safe sex practices, disclosing their health status, and adhering to HIV treatment (Badahdah & Pedersen, 2010). To illustrate, Katz and colleagues (2013) reviewed 75 studies (34 were qualitative and 41 were quantitative) on the connection between

HIV-stigma and treatment adherence. One of the themes identified in the review was the importance of support received from spouse and family to overcome the impact of HIV-related stigma and other obstacles to care and successfully adhere to treatment. That is being said, a central approach to ending the AIDS epidemic though, as suggested by UNIADS recent report (2016) eliminating “stigma and discrimination against people living with and affected by HIV through promotion of laws and policies that ensure the full realization of all human rights and fundamental freedoms” (p. 4).

Another line of research has focused on the impact of parental HIV status on their children. A recent review of 30 studies on the impact parental HIV/AIDS on children’s psychological well-being reported that AIDS orphans and vulnerable children had poorer psychological well-being than children from HIV-free families or children orphaned by other causes (Chi & Li, 2013). The impact of parental HIV status on children is also illustrated by the employment of the concept “parentification,” which refers to a setting “where the child assumes developmentally inappropriate levels of responsibility due to the parent’s physical incapacity or absenteeism” (Stein, Riedel, & Rotheram-Borus, 1999). In some situations, due to the low levels of physical and emotional wellbeing of parents living with HIV, children assume responsibility for taking care of their sick parents (Cederbaum, Hutchinson, Duan, & Jemmott, 2013). This role reversal might be caused and exacerbated by factors such as fear of stigma, which limits them from seeking and receiving all kinds of support.

Some of the family-centered intervention programs promote healthy positive relationship between parents and children by focusing on positive functional parenting practices, such as monitoring, expressing warmth, and using effective communication skills. Such parent-intervention programs have been used among adolescents with such issues as substance use (Kumpfer, Alvarado, & Whiteside, 2003), delinquency (Webster-Stratton & Taylor, 2001), suicidal tendencies (Rotheram-Borus, Piacentini, Miller, Graae, & Castro-Blanco, 1994), low school performance (Stormshak, Connell, & Dishion, 2009), and tobacco use (Thomas, Baker, & Thomas, 2016).

The risk of acquiring sexually transmitted infections (STIs) including HIV is quite high during adolescence and early adulthood (Caruthers, Van Ryzin, & Dishion, 2014). Adolescence is the period when many young people become interested in sex and start exploring their sexuality. Adolescents and young people, especially girls, are very vulnerable to HIV infection. Globally, by the end of 2012, young people aged 10–24 years represented approximately 15% of all people living with HIV and young people aged 15–24 accounted for 39% of new HIV infections in people aged 15 and older (UNAIDS, 2014). With these statistics in mind, family-centered intervention programs that target young people are important in the fight against AIDS. Hence, family-based approaches to HIV prevention during this time are important. In these programs, parents and caregivers serve as educators and role models, supervise and monitor adolescents’ behavior, and are sources of support and care. According to the Guttmacher Institute (2016) 70% of male adolescents and 78% of female adolescents talked to a parent about at least one of six sex education topics: how to say no to sex, methods of birth control, sexually transmitted infections (STIs), where to get birth control, how to prevent HIV infection, and how to use a condom, which refers to closeness of parents,

parental warmth, support, and child attachment to parents (Markham et al., 2010), is important in understanding the role of families in HIV-prevention.

Most of the research on family-based interventions has focused on delaying sexual debut among adolescents and reducing risk behavior among those who are sexually active. Qualitative and quantitative studies have found connectedness to be a protective factor for ever having had sex (McNeely et al., 2002; Sieving, McNeely, & Blum, 2000), as well as a protective factor for early sexual debut (Bingham & Crockett, 1996) and young people engaging in risky sexual behavior (Dittus & Jaccard, 2000; Downing et al., 2011; Hutchinson et al., 2003; Wamoyi et al., 2011).

Parents can be both positive and negative role models for their children. The negative role model that some parents play can predispose their children to HIV infection. For example, children of HIV-positive parents are at increased risk for sexually acquired HIV infection and tend to engage in risk behaviors (Cederbaum, Hutchinson, Duan, & Jemmott, 2013). In a review of medical charts of HIV-positive young people, Chabon, Futterman, and Hoffman (2001) found that a high percentage of young people who sexually acquired HIV reported at least one parent with HIV infection. These youths were more likely to initiate sexual intercourse at a younger age and were more likely to report risky sexual experiences (p. 659).

Pequegnat and Bray (2012) reviewed several programs that are considered couples- or family-focused, such as the Chicago HIV Prevention and Adolescent Mental Health Project (CHAMP), which been implemented in the United States, Trinidad and Tobago, and South Africa; the Parents Matter! Program (PMP); Parent/Preadolescent Training for HIV (PATH) Prevention; the Mother/Daughter HIV-Risk Reduction (MDRR) intervention, and Responsible, Empowered, Aware, Living (REAL) Men.

Another study reviewed what the authors referred to as “efficacious” family-based programs (Lightfoot & Milburn, 2012). The authors defined “efficacious” programs as those that were found to be effective in improving protective factors and reducing HIV-related risk and behavior in parents and their adolescent children (p. 121). These programs are:

- FACTS & feelings
- ImPACT (Informed Parents and Children Together)
- Project TALC (Teens and Adults Learning to Communicate)
- Familias Unidas
- Strong African-American Families
- Caribbean Family HIV Workshops
- STRIVE (Support to Reunite, Involve, and Value Each Other)

Lightfoot and Milburn (2012) identified four common elements in the above reviewed evidence-based interventions that should be followed in future work on family-based HIV prevention interventions programs. These are (p. 125-127):

- Parental Knowledge, Attitudes, and Values: Parents are the primary and preferred providers of information on sex and sexual behavior. Parents role in providing accurate information on these matters to their children is crucial (p.125);
- Foster Positive Relationships: A positive warm supportive relationship between parent and adolescent is associated with delayed sexual initiation, increased condom and contraceptive use, and lower pregnancy rates (p. 126);
- Increase Parent-Adolescent Communication: Focused on frequency of communication, specifically about sexual behaviors, reproductive health and condom use; communication skills, nonjudgmental responses; helping parents feel confident, competent, and comfortable talking about sexual behaviors and HIV-related topics (p.126); and
- Foster Parental Monitoring: Interventions that provide parents with experiences and skills that increase parental monitoring (p.127)

Other interesting programs are the ones that have focused on the prevention of mother to child transmission (PMTCT). As Betancourt, Abrams, McBain, and Fawzi (2010) argued, having multiple family members get tested for HIV and offering treatment encourages pregnant women to accept HIV testing and obtain their results, adhere to PMTCT regimens, and disclose their seropositive status to their partners (p. 2).

To conclude this review, designing future family-focused HIV prevention intervention programs should be evidence-based and easily adapted for different age groups and families from different socioeconomic backgrounds that face different types of risks. Also, the programs should fit the needs of families from different cultures, ethnicities, and religious backgrounds (Kumpfer, 2014). As Bell and McBride (2011) put it, “For an intervention to be culturally sensitive, it must have content that is welcoming to the target culture, contain issues of relevance to the culture, not be offensive, and be familiar to and endorsed by the target culture.” (p. 60). Similarly, the Declaration of Commitment on HIV/AIDS "Global Crisis - Global Action (2001, p.13) stated that “Affirming the key role played by the family in prevention, care, support, and treatment of persons affected and infected by HIV/AIDS, bearing in mind that in different cultural, social and political systems various forms of the family exist.” Again, as stated previously, in addition to family and couple focused programs, multiple approaches to HIV-prevention interventions should be employed. In some cultures, for example, parents do not feel comfortable talking about sex to their children (Seloilwe, Magowe, Dithole, & Lawrence, 2015) or the parents themselves are not educated or do not know much about sexuality (Bastien, Kajula, & Muhwez, 2011)

Policy Recommendations

To propose family policy related to HIV/AIDS, I believe policies that aim at HIV prevention interventions should also aim to protect, promote, and strengthen families (Strach, 2007). With this in mind, HIV prevention interventions should focus on the family as a unit rather than as a collection of individuals. Hence, the following recommendations are offered;

- Develop HIV prevention intervention programs that focus on comprehensive behavioral changes among family members;
- Design HIV prevention intervention programs that create environments that are conducive to encouraging family members to talk freely about factors that predispose its members to HIV infection;
- Provide accurate information, testing, counselling, support, and training for families to help them protect their children from HIV infection;
- Promote family-focused HIV prevention intervention programs that are suitable and appropriate for families from different cultural, ethnic, religious, and socioeconomic backgrounds;
- Promote family-focused ART adherence programs that train family members to be caring and supportive for HIV-infected members; and
- Review available HIV programs at all levels to ensure they contribute to empowering, promoting, protecting, and strengthening families infected and affected by HIV

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