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HIV/AIDS Affected People and Social Exclusion: A Review of Literature

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Abstract

HIV/AIDS affected People are in very vulnerable condition due to the nature of the virus or diseases they suffer. Like other vulnerable segments of society, the number of HIV/ AIDS affected people is increasing alarmingly. Although it is hard to know the exact number of HIV/AIDS affected people living in the world, but available data shows that in 2015, there were 36.7 million people living with HIV and 1.1 million people died from AIDS related causes worldwide so far. In Asia and the pacific countries an estimated 5.1 million people are living with HIV including 300,000 newly infected in 2015. Among them about 9,600 Bangladeshi people are suffering from this virus. Once when a person is affected with this virus or AIDS, he/she becomes isolated from the community, family, even from the health providers. Not only the affected people, the family of the victims also faces stigma and discrimination. The aim of the article is to critically examine the prevalence and situation of HIV/AIDS affected people and the implication of social exclusion theory in their day to day life.In order to understand the matter we will discuss different forms of deprivation, discrimination, stigmas and their impact on HIV/AIDS affected people. The article is based on secondary data. For collecting secondary data we extensively searched various published research reports, books, journal articles, video documentaries etc. The literature shows along with other types of social exclusion, ignorance and misunderstanding continue to undermine efforts to end HIV/AIDS, though the world has committed to ending the AIDS epidemic by 2030.

Key words: HIV/AIDS; Social exclusion; Stigma; Discrimination

Introduction

Today the world has conceded the historicity of HIV/AIDS epidemic and the situation faced by the affected people. The people who have been

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suffering from the virus or diseases caused by it, have also been facing vulnerable circumstances in the society indeed. HIV and AIDS affected people are the most severely disadvantaged, whether on grounds of color, casts, economic status, age, sexual orientation or gender. As in the case of most other stigmatized health conditions such as tuberculosis, cholera and plague, fundamental structural inequalities social prejudices and social exclusion explain why women, children, sexual minorities and people of color are disproportionately impacted by AIDS and the accompanying stigma and discrimination (Bharat,2002). Poverty, stigma, lack of access to care, low education, gender inequality, and lack of a facilitative legal environment are various dimensions of exclusion of HIV/AIDS positive people those lead them to be excluded again. The sufferers become in many cases completely isolated or excluded from usual social settings.Jonathan Mann, then director of the WHO Global Program on AIDS, identified three phases of the HIV/AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination, and denial. He noted that the third phase is "as central to the global AIDS challenge as the disease itself" (Mann, 1987). Despite international efforts to tackle HIV/AIDS since then, stigma and discrimination (S&D) remain among the most poorly understood aspects of the epidemic. In this regard HIV and AIDS transmission have some relations with the theoretical aspect of social exclusion.

Objectives

a. To explore the prevalence of HIV and AIDS all around the glove.
b. Tofind out the nexus between HIV/AIDS and Social Exclusion.
c. To gain an in-depth understanding to address the problem.

Methodology

This paper is based on secondary data extracted from published journals, conference abstracts, reputed books, video documentaries and some national and international official reports as the article is a summary of an evaluation research. To limit the literature through inclusion criteria of systematic review, the methodological filters were applied.

Findings

Prevalence of HIV/AIDS

HIV infection damages the immune system and can progress to AIDS. Globally, AIDS is well documented as both a disease and a development problem. It is showing itself to be a worldwide risk, not isolated in any specific geographic locations or high risk populations (BRAC-ICDDR, B 1998).

In 2015 there were 2.1 million new HIV infections worldwide, adding up to a total of 36.7 million people living with HIV. Available data shows that in 2015, there were 36.7 million people living with HIV and 1.1 million people died from AIDS related causes. In Asia and the pacific countries an

estimated 5.1 million people are living with HIV including 300,000 newly infected in 2015 (UNAIDS, 2016). The vast majority of people living with HIV are in low- and middle-income countries. According to WHO, sub-Saharan Africa is the most affected region, with 25.6 million people living with HIV in 2015. Sub-Saharan Africa accounts for two-thirds of the global total of new HIV infections. An estimated 35 million people have died from AIDS-related illnesses since the start of the epidemic, including 1.1 million in 2015 (WHO, 2016).In Asia and the pacific countries an estimated 5.1 million people are living with HIV including 300,000 newly affected. Among them about 9,600 Bangladeshi people are suffering from this virus (UNAIDS, 2016).

It has recently becomes evident just how susceptible Asia is to the AIDS epidemic. Although relatively late to feel the global epidemic Asia is now experiencing the worst spread of the disease of any continent. (UNICEF1993;Chin, 1995).In fact, it has been estimated that without effective prevention efforts now more than 55 million Asians could be infected by 2020(Henry,1994).The epidemic of HIV/AIDS in Asia is not uniform (Hossain andFerdous, 2006). There are five broad epidemic pathways in Asia: sharply rising HIV prevalence among the selected risk groups in some countries (China, Indonesia, Vietnam) ; mature epidemic (parts of India , and Myanmar) ; the countries where massive intervention program has reduced the risk behavior (Thailand, Cambodia) ; low prevalence countries (Bangladesh, Pakistan, Sri Lanka, Laos, the Philippines, and East Timor) ; and parts of the Pacific region, where risk behaviors threaten a potentially more sever epidemic than elsewhere in Asia (MAP Report, 2004).

There is no reason to assume that Bangladesh will be immune to the Asian AIDS threat. The location of Bangladesh between Thailand and India, with their recent AIDS explosions, points to its susceptibility. Such AIDS risk indicators as a high STD prevalence (Sabin, et al.1997),widespread sexual networking and a large market in commercial sex (Naved,1996),untested blood supplies (Bhuiya, et al.1995),homo sexual activities (Khan,et al, 1997),and low condom use (folamar, et al,1996)also point to a high risk of AIDS in Bangladesh.

The HIV/AIDS epidemic has developed during a period of rapid globalization and growing polarization between rich and poor (Castells 1996, 1997, 1998). New forms of social exclusion associated with these global changes have reinforced pre-existing social inequalities and stigmatization of the poor, homeless, landless, and jobless. As a result, poverty increases vulnerability to HIV/AIDS, and HIV/AIDS exacerbates poverty (Parker, Easton, and Klein, 2000) along with stigmatization and discriminations.

Conceptual framework of Social Exclusion

Social exclusion is a multidimensional process of progressive social rupture, detaching groups and individuals from social relations and institutions and

preventing them from full participation in the normal, normatively prescribed activities of the society in which they live(Silver,2007). It is a theoretical concept, a lens through which people look at reality and not reality itself' (de Haan, 2001). The outcome of social exclusion is that affected individuals or communities are prevented from participating fully in the economic, social, and political life of the society in which they live(Young,2000). It is the focus of one of nine Global Knowledge Networks established to support the work of the World Health Organization's (WHO's) Commission on Social Determinants of Health (CSDH,2008).

Estivill has defined social exclusion as, "… an accumulation of confluent processes with successive ruptures arising from the heart of the economy, politics and society, which gradually distance and place persons, groups, communities and territories in a position of inferiority in relation to centers of power, resources and prevailing values" (Estivill, 2003). This definition highlights that, first, social exclusion comprises dynamic processes (as opposed to social exclusion being a 'state') and is, therefore, by implication, actionable through directed policy interventions. Second, social exclusion has multiple dimensions, such as political, social and/or economic, and groups may be excluded along one or all of these dimensions (Khosha, 2009). Kabeer reflects upon social exclusion as "… the multiple and overlapping nature of the disadvantages experienced by certain groups and categories of the population" (Kabeer, 2006)).

Alienation or disenfranchisement resulting from social exclusion is often connected to a person's social class, educational status, childhood relationships, living standards, or personal choices in fashion. It is the process in which individuals or entire communities of people are systematically blocked from (or denied full access to) various rights, opportunities and resources that are normally available to members of a different group, and which are fundamental to social integration within that particular group(The Slavation Army,2008).This term was used to denote various categories of people, identified as mentally and physically ill or handicapped, suicidal people, aged invalids, abused children, substance abusers, delinquents, single parents, marginal asocial persons and other social misfits (Silver, 1994).

In an alternative conceptualization, social exclusion theoretically emerges at the individual or group level on four correlated dimensions: insufficient access to social rights, material deprivation, limited social participation and a lack of normative integration. It is then regarded as the combined result of personal risk factors (age, gender, race); macro-societal changes (demographic, economic and labor market developments, technological innovation, the evolution of social norms); government legislation and social policy; and the actual behavior of businesses, administrative organizations and fellow citizens (Gijsbers and Vrooma,2007).It refers to way in which individuals may become cut off from full involvement in the wider society. Social exclusion is not only the result of people being

excluded-it can also result from people excluding themselves from aspects of mainstream society(Gidden,2011-12).

Social exclusion may be happened at individual, group, community or professional level. At the individual level results in an individual's exclusion from meaningful participation in society(Lessa,2006). Certainly, there are instances in which individuals are excluded through decisions which lie outside their own control ((Gidden,2011-12). The groups at risk of being excluded: for example, the mentally and the physically handicapped, suicidal people, aged invalids, abused children, drug addicts, delinquents, single parents, multi-problem households, marginal, asocial persons, and other social misfits',(Lenoir, 1974).People are excluded from: for example, a livelihood; secure, permanent employment; earnings; property, credit or land; housing; the minimal or prevailing consumption level; education, skills and cultural capital; the benefits provided by the welfare state; citizenship and equality before the law; participation in the democratic process; public goods; the nation or the dominant race; the family and sociability; humane treatment, respect, personal fulfillment, understanding'(Silver ,1994).At a community level, many communities experience social exclusion, such as racial (e.g., black) (e.g., Untouchables or Low Castes or Dalits in Indian Caste System) and economic (e.g., Romani) communities(Baskin,2003).Today various Aboriginal communities continue to be marginalized from society due to the development of practices, policies and programs that "met the needs of white people and not the needs of the marginalized groups themselves" (Yee,2005).

Some intellectuals and thinkers are also professionally marginalized because of their dissenting, radical or controversial views on a range of topics. Landlessness is similarly an instrumental deprivation. A family without land in a peasant society may be deeply handicapped(Sen,2000).Exclusion is both a-process and product and involves some components.

Nexus between HIV/AIDS affected people and social exclusion

a. Stigmas

The word 'stigma' has multiple metaphors. In ancient Greek the concept was used to refer to body signs that distinguished the bearer as a person who was morally defective(Hossain,2011).Peter Piot, executive director of UNAIDS, identified stigma as a "continuing challenge" that prevents concerted action at community, national, and global levels (Piot, 2000).

AIDS related stigma and discrimination are complex social processes. They are neither unique and nor randomly patterned (UNAIDS/WHO, 2001). They usually build upon and reinforce pre-existing fears, prejudices and social inequalities pertaining to poverty, gender, race, sex and sexuality, and so on. Just like other forms of stigma, AIDS related stigma also results in social exclusion, scapegoating, violence, blaming, labeling and denial of resources and services meant for the consumption of all(Bharat,2002).

Throughout the world HIV/AIDS related stigma is known to have triggered a range of negative and unsupportive reactions. Various contexts - family, community, work place, health care setting – have been identified where stigma and discrimination is known to occur (UNAIDS, 2001; Malcolm et al. 1998).The various metaphors associated with AIDS have also contributed to the perception of HIV/AIDS as a disease that affects "others," especially those who are already stigmatized because of their sexual behavior, gender, race, or socioeconomic status, and have enabled some people to deny that they personally could be at risk or affected (UNAIDS 2000; Malcolm et al, 1998; Daniel and Parker, 1993). For an instance: the stigmatization of the African American identity in relation to diseases in the early twentieth century shows a remarkable continuity today in the context of HIV/AIDS at the turn of the century. An illustration of this is the stigmatization and harassment of the Haitian people in the early 1980s, who were accused of having brought AIDS into the USA (Farmer & Kim, 1991). It was also noted that religious doctrines, moral and ethical positions regarding sexual behavior, sexism and homophobia, and denial of the realities of HIV/AIDS have helped create the perception that those infected have sinned and deserve their "punishment," increasing the stigma associated with HIV/AIDS(Singh 2001).

b. Deprivation

More specifically in relation to HIV/AIDS, there is some evidence to show why racial minorities may be particularly vulnerable to HIV/STIs risk. In most countries men and women from indigenous groups and racial minorities generally have fewer opportunities for schooling and employment than the majority population. Because of the lack of racially disaggregated HIV/AIDS data and because prevention services first started among White, gay men, culturally appropriate preventive services for racial minorities are fewer(PAHO/WHO & UNAIDS, 2001). Children with HIV/AIDS or associated with HIV through infected family members have been stigmatized and discriminated against in educational settings in many countries. Stigma has led to teasing by classmates of HIV-positive school children or children associated with HIV (Gilborn et al. 2001). However, less concern has been shown for young people who are perceived to be responsible for their HIV infection and who are already stigmatized and discriminated against because they are sexually active, homosexual, or drug users. In the USA, for example, HIV-positive young gay men have been expelled from school and, in some cases, subjected to violence (Kirp et al. 1989). In the job fields affected people are also being deprived. There have been reports of workers refusing to work next to those with HIV or AIDS or those perceived to be PLHA. Schemes providing medical assistance and pensions to employees have come under increasing pressure in countries seriously affected by HIV/AIDS, and some companies have used this as a reason to deny employment to PLHA (Williams and Ray 1993; Whiteside, 1993).

c. Negligence

In societies with cultural systems that place greater emphasis on individualism, HIV/AIDS may be perceived as the result of personal irresponsibility, and thus individuals are blamed for contracting the infection (Kegeles et al. 1989). In contrast, in societies where cultural systems place greater emphasis on collectivism, HIV/AIDS may be perceived as bringing shame on the family and community (Panos, 1990; Warwick et al. 1998).In countries that are particularly hard hit, instances of violence and assault against HIV infected persons have been recorded. This often follows the public disclosure of one's HIV status as happened in the case of a young community volunteer GuguDlamini in South Africa who was stoned and beaten to death(Bharat,2002). Families and individuals are known to have gone to great extent to hide the presence of HIV infection from others in the community (Bharat, 1999). In contexts where HIV/AIDS is highly stigmatized, fear of HIV/AIDS-related S&D may cause individuals to isolate themselves to the extent that they no longer feel part of civil society and are unable to gain access the services and support they need (Daniel and Parker, 1993). From the legislative point of view, when supportive legislation exists, it is not always enforced. The failure of governments to protect the rights of PLHA through legislation or to enforce existing legislation has been described as a form of discrimination by neglect (Daniel and Parker 1993; Watney, 2000), as has the failure to provide effective prevention, treatment and care for those most vulnerable to HIV/AIDS and for PLHA. Revealing confidentiality also shows how the affected people are being neglected.Failure to respect confidentiality by clearly identifying patients with HIV/AIDS, revealing serostatus to relatives without prior consent, or releasing information to the media or police appear to be problems in some health services (Panos, 1990; Bharat et al. 2001; Singh, 1991).

d. Discrimination

Discrimination is the unfair treatment of an individual which limits or denies opportunities (Habib, E. S, 2009). It may act as an effective barrier to have services from any institute because of having HIV/AIDS.In the beginning of the epidemic, travel restrictions were placed on `foreigners' most of whom belonged to racial / ethnic, minorities (Sabatier, 1988). In the Gulf countries mandatory testing is followed for all foreign nationals and the HIV infected foreigners continue to be denied permission to enter the US (Solon &Berrazo, 1993). Despite widespread agreement that laws to prevent freedom of movement of people living with HIV/AIDS (PLHA) are ineffective public health measures, many countries have adopted policies restricting travel and migration. Discriminatory practices include mandatory HIV testing for individuals seeking work permits (AIDS BhedbhavVirodhiAndolan, 1993; Solon and Barrazo, 1993), the requirement that individuals seeking tourist visas declare their HIV

serostatus, and denial of entry to PLHA carrying medical drugs for HIV/AIDS treatment (Duckett and Orkin, 1989). A job is generally associated with better quality of life, and active and productive engagement in society. The availability of effective Anti-Retroviral Therapy (ART) has had a profound impact on the ability of people with HIV to remain in employment. A study by the Delhi State Aids Control Society, in collaboration with the ILO, at two ART centers in Delhi, however, revealed that almost half of all people living with HIV are unemployed. With no job and no source of income, people living with HIV are treated as a burden by the family (India Exclusion Report, 2013-14).

Racism and gender discrimination: Ways of exploitation

a.Racism

Race is one such group identity that is a source of stigma, prejudice and discrimination for thosepossessing that racial identity. In some settings, allocating resources on the basis of acceptability rather than of need may be a deliberate policy, because of racism, homophobia, or negative attitudes toward marginalized groups (Panos 1996; Parker, 2000). When the racial identity combines with a health condition such as, HIV/AIDS, it contributes to "double stigma" -tribal stigma and stigma due to HIV/AIDS status (Wailoo, 2002). Depending on racial misconception many foreigners suffer from discrimination. Foreign nationals engaged in sex work may be deported because of the risk they are said to pose to local clients. Early on in the epidemic, there were many reports of African students in Europe and Asia being detained or deported in this way (Sabatier 1988). Some governments, recognizing that such measures are ineffective, have introduced legislation to protect the rights of PLHA to education, employment, confidentiality, information, and treatment (Kirp and Bayer, 1992; Mann and Tarantola, 1992; Mann, Tarantola, and Netter, 1996). Racism and racial discrimination linked to HIV status,may be categorized as `Symbolic' stigma as the already stigmatized and marginalized racial groups are stigmatized further on account of their association with HIV. Conversely, HIV is assumed to be high among certain racial/ethnic groups on the basis of their past association with diseases such as cholera, plague, hookworm etc.(Wailoo, 2001).Worldwide the AIDS epidemic is most severe in the poorest countries and among people of colour(UNAIDS/ WHO, 1999). The reason is that conditions of poverty, hunger, powerlessness, and ignorance provide fertile ground for the spread of HIV and most black people and other ethnic minorities live in these very conditions(Bharat,2002).

b. Gender discrimination

HIV/AIDS-related stigmas & discriminations are linked to gender-related stigma. The impact of HIV/AIDS-related stigmas & discriminations on women reinforces pre-existing economic, educational, cultural, and social

disadvantages and unequal access to information and services (Aggleton and Warwick ,1999). Women are often more likely to be badly treated than men or children (Bharat and Aggleton 1999). Negative community and family responses to women with HIV/AIDS include blame, rejection, and loss of children and home (Parker and Galvao, 1996; Bharat and Aggleton 1999; Henry 1990). The strong linkages established early on of HIV/AIDS with gay men and other so called `risk groups', seem to have blinded social researchers and others to the factors of racial, class and gender relations that frame AIDS as a social and not a bio-medical problem alone (Racism, Racial Discrimination and HIV/AIDS(Bharat,2002). Gender differences in patterns of HIV infection vary widely around the world (UNAIDS,2000). The gendered dimension of the HIV epidemic is closely related to patriarchal values and norms and to the fact that women bear the major consequences of the epidemic on account of loss of livelihood, economic pressures, care of sick family members and stigma of AIDS (Bharat and Aggleton, 1999; Bharat, 1999; UNAIDS, 2001).

Limitations

This paper is basically based on secondary data. As its analysis is dependent on existing data related to the topic from various literatures, it does not present up to date primary data. Findings narrated here support that HIV/AIDS affected people are excluded from various dimensions of exclusion; but these findings are not supported byevidence based clinical and social research. This is why further documentation is recommended.

Conclusion

The vulnerability and stigmatization of HIV/AIDS affected people has been discussed in this paper. Asocial exclusion approachhas also been used to understandthe current level of social, educational, cultural,legaland service oriented disadvantages those theHIV/AIDS affected people have been facing for years. The findings of the study show the utility of applying a social exclusion framework to HIV/AIDS affected people. The use of a social exclusion lens on existing informationgenerates important knowledge and policyimplications regarding targeted prevention efforts.On thepart of researchers and academics, a strengtheningof frameworks to guide the investigation of socialfactors such as exclusion and to produce more appropriateresearch is needed (Khosha, 2009). On the other hand, some actionsto confining the prevalence of HIV/AIDS, commandments along with social awareness activities must be taken. Concerning government should take inclusive policy and need to create a worldwide database to prevent stigmas, discrimination regarding HIV/AIDS and social exclusion.

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