

STIGMA AND DISCRIMINATION AMONG THE PERSONS LIVING WITH HIV/AIDS: PUBLIC SECTOR AND COMMUNITY PERSPECTIVE'S IN BITUNG MUNICIPALITY NORTH SULAWESI

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ABSTRACT

Background: Stigma and discrimination persist resulting many people living with HIV hide their status for fear of losing their jobs, social status, and the support of their families and communities. **Methods:** This case study presents collecting evidence and reviews factors relate to HIV/AIDS programme provided by public in Bitung Municipality, North Sulawesi Province, Indonesia. The objectives of this case study are to identify policy of HIV/AIDS program in local context and to learn the collaboration of local public services' activities relate to health particularly to lessen the stigma and discrimination of HIV/AIDS. **Results:** Stigma and discrimination may be reduced through structural intervention at local level, community intervention and individual intervention. The interventions should be understood by health providers relate to HIV/AIDS prevention and control program at all stages. To reduce stigma at the community level can be integrated into HIV/AIDS programs by facilitating the participation of people living with HIV/AIDS.

Key words: stigma, discrimination, HIV/AIDS

ABSTRAK

Adanya stigma dan diskriminasi terhadap penderita penyakit HIV/AIDS dimasyarakat menyebabkan penderita menyembunyikan keberadaan mereka. Hal tersebut dikarenakan mereka merasa akan kehilangan pekerjaan, status sosial yang direndahkan dan berkurangnya dukungan dari keluarga dan masyarakat. Studi kasus ini mempresentasikan hasil pengumpulan data yang berbasis bukti, dan mengkaji faktor-faktor yang berhubungan dengan program penanggulangan HIV/AIDS dari sektor publik, terutama pada konteks lokal serta mempelajari kolaborasi sektor-sektor publik yang terkait dengan kebijakan program penanggulangan HIV/AIDS, khususnya mempelajari stigma dan diskriminasi dari penyakit ini pada masyarakat. Stigma dan diskriminasi dapat ditanggulangi melalui beberapa struktur intervensi di tingkat nasional dan khususnya tingkat lokal. Demikian juga intervensi terhadap masyarakat dan individu melalui integrasi program penanggulangan HIV/AIDS dengan memfasilitasi partisipasi dari penderita HIV/AIDS.

Kata kunci: stigma, diskriminasi, HIV/AIDS

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INTRODUCTION

Stigma and discrimination persist resulting many people living with HIV hide their status for fear of losing their jobs, social status, and the support of their families and communities. The stigma and discrimination decreased the change for them not to receive proper treatment and in the other way increased the chances of HIV spreading undetected.

Indonesia's conservative climate means that men who have sex with men, sex workers and intravenous drug users (groups amongst whom HIV/AIDS is most prevalent) are sidelined and the disease often wrongly viewed as a punishment for such individuals' 'deviance' (Parker & Aggleton, 2003).

Stigma is defined as an attribute or quality which "significantly discredits" an individual in the eyes

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of others. Importantly, stigma is a process. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Fear and moral judgment are considered to be the root sources of HIV/AIDS stigma. HIV/AIDS is associated with many different fears. People may fear the casual transmission of the virus, fear the loss of productivity of People Living with HIV/AIDS (PLHAs), and fear that resources may be wasted on PLHAs, fear living with the disease or fear imminent death. Similarly, moral judgment may cause stigma. PLHAs are often seen as culpable and deserving because the transmission of the virus is linked to stigmatized behavior, which allows people to understand HIV/AIDS in terms of the concept of blame. It is important to note that HIV/AIDS stigma can be experienced not only by people living with HIV/AIDS but also by people who are suspected to be living with HIV/AIDS because of their association with HIV/AIDS. UNAids differentiated two kinds of stigma. External stigma refers to actual experiences of discrimination. Internal stigma is the shame associated with HIV/AIDS and a PLHAs' fear of being discriminated against (Brown, Trujillo and Macintyre, 2001).

Internal stigma is also called self stigma. Self-stigma can be defined as an individual's internalization of the societal attitudes s/he experiences, or anticipates, in society. Self-stigma incorporates feelings of shame, dejection, self-doubt, guilt, self-blame and inferiority. It leads to high levels of stress and anxiety, and contributes to denial. On discovering their HIV-positive serostatus some people withdraw from society and stop participating in social activities because of their lowered self-esteem and sense of self-worth. Some give up work and 'wait to die' (UNAIDS, 2002). Manifestation of stigma usually is occurred in the legal contest through institution such as education, employment, health care included aids program, religious institution, community and individual.

This case study presents collecting evidence and reviews factors relate to HIV/AIDS programme provided by public and private in Bitung Municipality, North Sulawesi Province, Indonesia. Bitung Municipality is more heterogeneous in socio-demographic with increased economic growth rate, and become an attraction for investors and migrants and potentially contribute in increasingly complex urban development. The tourism, which is supported by the trade, service, fishery, is a one leading sector of development of Bitung

City. On the other side, the increasing communicable diseases including HIV/AIDS are very potential in this city because of the contribute factors above. The prominent efforts of the local government under the leadership of mayor and vice mayor to initiate inter-sectors effort to prevent the spreading of HIV/AIDS are recognised in North Sulawesi Province through health city policy and HIV/AIDS control programme.

METHODS

This case study was intended to answer the following questions: what is the policy from the public sectors in Bitung Municipality related to health in stigma and discrimination of HIV/AIDS; how the public sector identified and responded of this issue, and what are the community activities to accept and support person with AIDS.

The objectives of this case study are as follows: to identify the policy of HIV/AIDS program related to stigma and discrimination in local context, and to learn the collaboration of local public services' activities relate to health particularly to lessen the stigma of HIV/AIDS.

A qualitative approach to data collection was implemented for this case study. In this case study, the construct validity, was conducted in three key stages. First, conducting a literature and document review to give background and context. Second, preparation of data collection tools such as constructing a protocol for in-depth interviews that sought to determine issues relevant to the participants' situation. Third, determine the field areas. Fourth, data collection using in-depth interview to the public sector in order to obtain a grounded understanding of activities toward stigma and discrimination to PLHA.

RESULTS

Indonesia National AIDS Program, Strategy Toward Stigma and Discrimination

Indonesia established its National AIDS Commission (NAC) in 1994 to focus on preventing the spread of HIV; addressing the needs of people living with HIV/AIDS; and coordinating government, nongovernmental organizations (NGOs), private sector, and community activities. The National AIDS Strategy for 2003–2007 stressed the role of prevention as the core of Indonesia's HIV/AIDS program while

recognizing the urgent need to scale up treatment, care, and support services. The Strategy emphasized the importance of conducting proper HIV/AIDS and sexually transmitted infection (STI) surveillance; carrying out operational research; creating an enabling environment through legislation, advocacy, capacity building, and antidiscrimination efforts; and promoting sustainability. Building upon this framework, the National AIDS Strategy for 2007–2010 added the priority targets of reaching 80 percent of MARPs (Most at Risk Populations) with comprehensive prevention programs; influencing 60 percent of MARPs to change their behaviors; and providing antiretroviral therapy (ART) to 80 percent of those in need.

Strategy toward stigma and discrimination in Indonesia is not been emphasized in national action strategy. However, a new National AIDS Strategy for 2010–2014 has been launched to continue to guide the response to the epidemic.

One of the problems related to universal access was stigma and discrimination as conceptualized by several researchers. First, because HIV/AIDS is associated with marginalized behaviors and groups, people living with HIV/AIDS are perceived from marginalized groups. Second, HIV/AIDS exacerbates the stigmatization of individuals and groups who are already marginalized, which increases their vulnerability to HIV/AIDS, and which in turn causes them to be further stigmatized and marginalized. Surveys, interviews, and researches indicate those serious problems of stigma and discrimination remains for people living with AIDS, their immediate family and friends. This discourages people from wanting to know their HIV status.

Prevalence of HIV/AIDS in North Sulawesi and Bitung Municipality

North Sulawesi is the 10th rank of HIV/AIDS cases in Indonesia (Ditjen PP&LL MOH RI, 2011). There were 787 cases of AIDS in the whole province. The port city of Bitung, some 60 km from Manado, had the second highest prevalence of patients (196 cases consisting of 100 HIV and 96 AIDS patients after Manado. There were HIV/AIDS patients in each of the 15 districts, towns and cities in North Sulawesi by narcotics-related cases 95, and homosexual cases 14 patients and bisexual cases two patients (Priyambodo, 2011; Lomban, 2011).

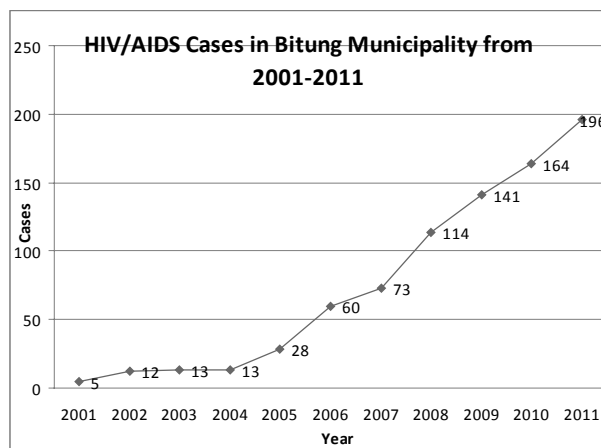


Figure1. HIV/AIDS Cases in Bitung Municipality from 2001–2011.⁴

According to sex, majority is women (54% women vs. 46% men), majority is in adults age group and many of them have been infected through engaging in risky behaviors; heterosexual (93,4%), IDU (1,53%), homosexual (1,02%), and also perinatal infection (3,06%), transfusion (0,5%) (Dinkes Kota Bitung, 2010).

The Role Public Sectors Related to Health, Local AIDS Commission, and Religious Leaders toward stigma on HIV/AIDS in Bitung

One of the champion of HIV/AIDS activities at Bitung is Mayor of Bitung through his leadership on 2006 Bitung include in the rare municipality in Indonesia which have local regulation on AIDS program. Through this decree at this city all government agencies and community should concentrated to prevention and control of HIV/AIDS which support by all sectors with annual local budget, at the year of it is allocated for HIV/AIDS Rp 275.945.600/ \$32.087 (63,03% of total budget of Bitung: Rp 437.807.000/\$50.908) (Dinkes Kota Bitung, 2011).

In Bitung prevention and control of HIV/AIDS is regulated by local decree of mayor Bitung on December 29 in the year 2006. In this decree regulate how to manage, lead and coordinate AIDS prevention and control program at Bitung through Local Aids Commission (LAC). The budget for those purposes is come from annual local budget. This local decree among others stated that health providers should serve PLHIV and their families without discrimination (Local AIDS Commission Bitung, 2011).

The activities of the LAC such regular meeting several agencies and civil society to coordinate HIV/AIDS activities, promotion to institution such a churches, schools, mosques, hamlets and sub-districts; promotion to motor bikers (ojek), seamen, port labor, truck drivers, company labor and hookers; condom distribution to information to cafes and hotels, conducting meeting with pimps, those activities is implemented in coordination with municipal agencies.

To manage HIV AIDS program LAC develop Standard Operating Procedure (SOP) for working groups called POKJA, building communication mechanism and coordination among stakeholders of the LAC members related institutions to create understanding that HIV/AIDS problems were mutual responsibilities. Meetings with PLWHA through special moment such as World AIDS Day, advocating to the public sectors such as social, tourism, policy, narcotic bureau, military.

Regular training to the ministries and priests concerning the prevention of HIV/AIDS and how to handle the patients including promotion program of HIV/AIDS in prison are part of the LAC tasks.

DISCUSSIONS

A review of community-based interventions in Southeast Asia shows that while reducing stigma is rarely the only focus of an intervention, it is nonetheless an important part of many programs. Interviews with staff from community-based organizations reveal that negative attitudes decline as a “side effect” of other project activities. Efforts to reduce stigma at the community level can be integrated into HIV/AIDS programs by facilitating the participation of PLHA, addressing the prevention- to-care continuum, and involving many segments of society in program activities (Blankenship *et al*, 2006). It seems in participating of PLHIV organization as main strategy for reducing stigma and discrimination.

The case study identify several important factors relate to activities on stigma and discrimination on AIDS, these are: leadership of the mayor and collaboration among local aids commission with NGOs and religious leaders; structural intervention at national and local level; and popular movement and population group as subject of activities toward stigma and discrimination.

Leadership of the Mayor, and collaboration among local aids commission with NGOs and local religious leader

In Bitung the leadership of the Mayor Bitung on AIDS activities is quite prominent, the process of legislative agreement, information and lobby to church community and conservative groups, alliance with NGOs and Health Activities pin point his leadership. This leadership is shown in the form of legal law on AIDS activities, and have an impact to the activities of local aids commission. However in the local decree activities to reduce stigma and AIDS discrimination only mentioned for health providers.

Structural Intervention at Local Level

At the national level, in Indonesia the strategy there is certain policy related to stigma and discrimination, these are law related to women empowerment and violence against women, law related to vulnerable groups, law on harm reduction, national police regulation on human right approach in carrying out national police task, regulation on gender mainstreaming, decree for workers from ministry of labor, policy of ministry of social affairs.

In the local level there is policy that health providers should give health services to PLHA through local aids regulation while at national level there is policy that health providers should not discriminate their clients and population their served, however as reported in the year 2005 Indonesia 14% PLHA indicated that health providers refuse to treat them because they have positive status, so there should specific afford to health providers, while in this case study it seems training and materials on stigma is integrated not specifically mentioned it is part of services for HIV/AIDS patients. There should be a specific materials for stigma and discrimination provided by MOH and health agencies, which give comprehensive overviews about the root cause, social related factors, activities and impact on it to health providers.

Popular movement and population group as subject of activities toward stigma and discrimination

In the local level there is policy that health providers should give health services to PLHA through local aids regulation while at national level there is policy that health providers should not discriminate their clients and population their served. This case study attention

of PLHA to external stigma, while internal stigma is focused by local NGOs through peer educator and other activities at local level, HIV/AIDS-related stigma and discrimination.

CONCLUSION

As it is shown in this case study, stigma and discrimination may be reduce through structural intervention at national and local level, community intervention and individual intervention. The interventions should be understood by health providers relate to HIV/AIDS prevention and control program at all stages, including communities who are involved in reducing stigma and discrimination of HIV/AIDS. The leadership and the role of the major and vice major were shown have an impact to the activities of Local AIDS Commission in order to control the HIV/AIDS programme including stigma and discrimination of HIV/AIDS.

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