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## Buttoned the Unbuttoned: Brief Insights from People Living with HIV/AIDS and Their Caregivers

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### Abstract

The number of people infected with HIV continues to increase globally, despite recent advances in treatment and prevention. Statistics show that an estimated 36.9 million people around the world were living with HIV in 2014, with 2 million people became infected with the illness (UNAIDS, 2014). To aggravate matters, people living with HIV/AIDS (PLWHAs) continue to face many forms of stigmatization throughout their lives, despite the various measures or initiatives taken by themselves and others to minimize them. However, little has been done on examining the creation of newly invented identities as an equally important measure/initiative taken by PLWHA and caregivers, to lessen stigmatization and to gain the support that they direly needed. Moreover, little is known about the awareness of human rights among PLWHA and their caregivers. Using ethnographic methods to collect data in the form of face-to-face interviews and participant observations, the proposed study explores the newly invented identities created by PLWHAs and their caregivers, how they develop and express them, and the ways in which they integrate human rights awareness into the creation of these identities. Approximately 13 (N13) PLWHAs and caregivers mainly from the Kuching area were purposively selected. Findings revealed that, participants developed certain initiatives to reduce stigma; and they also portrayed low level of knowledge related to their rights. The outcomes were then translated into stigma reduction initiatives in which these initiatives can be deployed to minimize stigmatization and gain social support that are direly needed. This indirectly, tightened their rights for better living. The study also suggests some modifications in existing policies and programs both at local and national level so that to improve their quality of life in general.

**Keywords:** HIV, AIDS, Caregivers, Stigma

### **Research Background**

Studies related to HIV/AIDS received myriad attention from academic scholars (Zamri, 2010; Wong et al., 2011; Judgeo & Moalusi, 2014). These studies ranged from stigma and discrimination to the experience of PLWHAS for social support. Although scientific studies on HIV/AIDS and related fields are considered vast and varies, studies on HIV/AIDS and related issues in Kuching, Sarawak are still in its infancy. Many studies on HIV/AIDS conducted in Malaysia have focused on medical areas and issues such as the impact of HIV/AIDS and factors contributing to the rising numbers of HIV/AIDS cases in Malaysia. More needs to be done on examining the social aspects of HIV/AIDS. This study attempts to explore and examine the experiences of PLWHAs and their caregivers and to come up with a new interpretation, although this may be based on known material or may bring new evidence to bear on an old issue.

This study also attempts to offer an academic account of the experiences of PLWHAs and their caregivers in gaining support, exploring how and on what basis PLWHAs and their caregivers invented their newly acceptable identities thus transferred their support through communication networks and close relationships. Therefore, the research questions among others are what are the newly invented identities that PLWHAs and their caregivers create in the effort of reducing stigmatization and gaining support? What are the strategies that they use to assert the newly invented identities as they move across different spaces to reduce stigma and gain support in the process? And how the awareness about human rights among PLWHA and their caregivers assist them to create the newly invented identities?

The objectives of this study are to examine newly invented identities created by PLWHAs and their caregivers and how they create these identities to reduce stigma and gain support, to investigate the strategies they use to assert these identities to minimize stigma and gain support, and to examine the ways in which awareness about human rights is integrated into the creation of these identities.

### **Literature Review on Related Issues**

Studies on HIV/AIDS and its related problems have focused primarily on sufferers/victims in specific areas, such as epidemiology, social support, social networking and social relationships; the attention given to caregivers tends to be discounted when a society assumes that their contributions and involvement are insignificant (e.g. Dorsey et al., 1999; Joslin, 2002; Feist-Price, 2003; Calin, 2005). To date, ignoring studies in other fields, studies in Malaysia taking PLWHAs and their caregivers as subjects are believed to be far from sufficient. Most studies of social support and social have concentrated predominantly on other illnesses, such as diabetes, cancer and Alzheimer's, leaving the area of HIV/AIDS and related areas only partially explored. A study on People Living with HIV/AIDS (PLWHAs) and their caregivers related to stigma, discrimination and disclosure was done in 2010 (Zamri, 2010). Findings based on this study show that PLWHAs and caregivers experienced harsh stigma and discrimination whilst searching for social support. Unlike some common chronic diseases, PLWHAs and caregivers for some reasons have been refused to be given assistance, especially when to do so will invite stigma. Consequently, personal networks and relationships which have steadily developed are demolished. At the time when they need support, fewer and fewer supportive

networks and relationships on which they can rely on (Zamri, 2010; 2011). The existence of stigma and discrimination occurred due to their unacceptable risky identities which were perceived by society as bad and wrong. Among the identities revealed were drug users, unemployed, transsexual sex workers, homosexuals including gay and lesbians, and HIV sufferers and/or bearers.

The study also suggests that, in the process of looking for support, PLWHAs and their caregivers have invented new identities thus manipulating such identities for a good deed in allowing them to approach social support. Some of the identities invented received approval from society, thereby making social support easily transmitted. However, how they invent thus 'manipulate' these new identities requires further investigation.

On the other hand, in terms of identity, the need to study how these new identities are manipulated is largely attributed to the fact that people create multiple identities and express them in different ways for various reasons throughout their lives. Some of these identities include risky identities, which are created by specific groups of people to navigate their way *legally and safely* (often putting their life at risk in the process) through this world that continues to practice many forms of discrimination based on individuals' behaviours and practices deemed risky by the society (Kearney & Donovan, 2013). Identities are complex constructs created through the interaction and intersection of diverse factors pertaining to subjectivity such as age, race, ethnicity, religion, class, gender and sexuality. Adding to this complexity is the fact that people employ various strategies to take on multiple identities as they move through time and across space. Such strategies include a situational selection of ethnic identity among ethnic subjects (Nagata, 1974) and strategic negotiation of identities among gay men where they assert a public heterosexual identity whilst keeping a private homosexual identity to avoid prejudice and discrimination (Seidman, 2002; Jerome, 2013; del Aguila, 2014). The same can be said for PLWHAs who may have adopted various strategies in expressing newly invented identities (including risky identities) as they move across various spaces – be they public, private, physical, virtual, urban and rural. Therefore, in addition to the abovementioned objective, this study will examine the strategies PLWHAs use to assert newly invented identities as they move across different spaces to gain such support and reduce stigma and discrimination in the process.

From the perspective of human rights issues, PLWHAs are not fully aware of their rights in terms of social support. According to Universal Declaration of Human Rights and was proclaimed by United Nation in 1948 stated in Article 1; all human beings are born free and equal in dignity and rights (<http://www.un.org/en/universal-declaration-human-rights/>). This declaration gave evidence about no discrimination should happen in any part of our life regarding ethnic and gender. Findings from research show the level of discrimination towards PLWHAs and their caregivers can be reduced though knowledge about strategies to cope with HIV/AIDS (Farotimi et al., 2015). United Nation also provides platform to support International Guidelines on HIV/AIDS and Human Rights. After several consultations with expert in human rights and HIV, the guidelines was published in 1998 by Office of the United Nations High Commissioner for Human Rights (OHCHR) and Joint United Nations Programme on HIV/AIDS (UNAIDS). There are also other documents and publications on HIV and AIDS produced by OHCHR ([www.ohchr.org](http://www.ohchr.org)).

## **Methodology**

This section explains the research design and some limitations related to the methodology chosen for this study. This study is mostly carried out Kuching. It is where most PLWHAs can be found compared to other cities in the state. Most of the activities contributing to problems related to HIV/AIDS occur daily, such as drug use, homosexuality and prostitution and on the assumption that most of the information and services provided to PLWHAs were readily available.

Overall, the population for this designated study is People Living with HIV/AIDS and their caregivers who settled in Kuching areas. The population of interest (Frankfurt-Nachmias & Nachmias, 1992; Black, 1999) consisted of individuals who identified themselves as sufferers and/or caregivers who took care of persons (spouses, children, brothers, friends and partners) who had been diagnosed as HIV seropositive, carriers or AIDS sufferers; and lived within the Kuching vicinity. The sample (Bouma & Atkinson, 1995; Black, 1999) consisted of PLWHAs and caregivers of PLWHAs who were aged at least 18, provided at least one type of assistance to PLWHAs and lived within the community in the town area. A purposive technique was used to select participants who obeyed the criteria; this excluded caregiver who lived in institutional settings and young caregivers under the age of 18. The key informant who works at the Ministry of health has been identified to assist in finding the participants.

The main techniques employed for gathering information were personal in-depth interviews, online (email) interviews, and (participant) observation. Data were analyzed with the assistance of qualitative software and several themes have emerged for the analysis process. To prevent losing important cues and to increase the level of validity and reliability, back translation technique is used for the interviews which were done in Bahasa Malaysia. This study applied certain ethics and regulations, including ethical approval, informed consent, privacy, confidentiality of the data, correct representation and cultural sensitivity.

## **Result and Discussion**

Finding research participants is among the major problems due to stigma and discrimination faced by PLWHAs and their caregivers. Most potential respondents are not linked with each other as they are not actively involved in any association associated to their needs (e.g. Sarawak Aids Concern Society). Finding the respondents is mainly at the effort of the researcher. Although help is needed in identifying the potential respondents, but no assistance is gain from any organization and individual.

## **Demography of the Respondents**

Demographically, 13 research participants comprised of 10 caregivers and 3 sufferers @ bearers of HIV/AIDS. They are 9 males (including 1 transsexual) and 4 females (including 1 pengkid / tomboy); aged between 18 years to 65 years old of age. Based on their ethnicity, it is discovered that 9 respondents are Malays, 2 of them are Bidayuh and another 2 are Iban.

Intiatives Created by the respondents to Reduce the Practice of Stigma and Discrimination: Voices of PLWHAs and Their Caregivers

From the preliminary findings, we can briefly conclude that research participants did make some efforts to reduce the stigma and discrimination. Caregivers tend to maintain their current identities; creating a good identity is unnecessary as they are not in the position to seek for support. Social supports are not readily and widely available in Kuching. Therefore, research participants perceived there is no urgency to seek support.

Closely related to stigmatization and discrimination is the current identity embraced by most research participants. Preliminary finding reveals that almost half of the research participants categorized as caregivers were carrying 'considerably good identity' perceived by Malaysian society although some had been identified as drug users, transvestites, gay men and lesbian. These were not among the group who were strongly stigmatized and discriminated by the society at large which consequently shaping their networks and support relationships. Therefore, the needs to disclose their identity is not a priority. This is not the case for the sufferers who are embedded identities considered as 'unacceptable' and vulnerable to stigmatization such as gay man and drug abusers.

Conversely, sufferers of HIV/AIDS *maintain disclosure as they find no attempt to seek support*. As stigma related to HIV/AIDS is remain stronger, disclosure is simply unnecessary. Research participants argued that Kuching is such a small city; the community in which they live has a strong knit and intense relationship. Disclosing their health status will only creating other problems with the community especially to sufferers.

Due to the stigma attached to the disease, where it was perceived as "disease of the sinners" for those with old fashioned opinion, many AIDS patients shifted away and moved to the new places and avoid from seeking treatment from government hospitals. Many would rather seek treatment from private doctors or overseas to protect their own identity. In their new places, they have made some efforts to rectify their damaged identities as stated by participant as 'buttoned the unbuttoned'. As confessed by participant:

"All this while, we have been degraded by the society. And it's a fact that some of us indeed living against the nature. Its suit us (being discriminated and stigmatized). So we need to get it right now. Buttoned the unbuttoned (*betulkan seluar yang terlondeh*). Start a new life. God had giving us enough time to breath. We need to return back to the nature with the remaining life we have. At least we correct our wrongdoings. So when we leave the world, society can remember us in a good way. That's only my hope".

In order to fix their damaged identities, some put efforts to get job that deemed 'proper' by the society. A participant confessed:

"In fact, I am confused. Do not know which one is correct from the eyes of the society. I was a cleaner, and people belittling me. Once, I was a salesgirl, yet society remained degrading me. What else when I worked at a snooker center. It's a tough life. Seems that society does not want to give me a second chance. Never mind, I will try to find a job as a doctor or an engineer (laugh)"

Society generally understands that HIV/AIDS cases are very much related to wrong behaviour or wrong doings, and that people who suffer from HIV/AIDS were deemed to practice a wrongdoing behaviours such as homosexuality and random sex. These behaviours are considered unacceptable in Malaysian society. Statistics in general released that most of HIV/AIDS cases contributed by drug users / abusers and homosexual persons. This undoubtedly created misunderstanding among the general community. However, reports on HIV/AIDS in Sarawak showed that the main cause of HIV infections in Sarawak was due to unprotected sex, which is different from states in Semenanjung Malaysia. Heterosexuals have been identified as the main cause of AIDS transmission in Sarawak. This, from the perspective of the respondents, need to be corrected. Educating the roots of HIV/AIDS from their point of view will give impacts on how general society perceived HIV/AIDS as well as reducing stigma attached to it.

Therefore, public education and campaigns are important to break this barrier constructed by the society based on perception and ignorance. People need to have clearer and better understanding on what are HIV and AIDS, preventions and interventions. We need to relook at how to approach this problem with the community so that society does not respond with fear just by hearing the word HIV or AIDS and that it will not create a negative image of the country that could drive people away.

To ease their feeling related to stigma and HIV/AIDS, respondents themselves make efforts not to attach to the stigma but to broaden the concepts. That stigma is defined not to disgrace people but also to motivate affected people to correct their 'damaged identities'. One participant confessed:

"Indeed, stigma is painful. But without stigma, we also do not know that what we have done is wrong. Because we feel okay with our lives. But when society started to stigmatize us, then we know what we are doing is actually wrong and against the norms. I try to look at the positive sides of the stigma".

### **HIV/AIDS and Human Rights**

United Nations Human Rights of the High Commissioner states that human rights are universal and inalienable. In the words of preamble of the UDHR, human rights are 'a common standard of achievement for all people and all nations'. Everyone is equally entitled to human rights without discrimination of gender, religion, ethnicity, nationality or any other status.

Several aspects are examined in relation to right such as civil rights and social rights. Civil rights include individual freedom in expression, right of property and right to justice. Social rights are the rights that can ensure people live in dignity or civilized appropriate to the standard of living includes social welfare, education, health care and so on. The participants stated that the society still uniformed and unaware about the human rights in general, and PLWHAs and their families remain being an object of stigmatization. PLWHAs are hindered by the social and environmental barriers in realizing their rights.

Due to their low social economic background, most participants are not aware of their (human) rights. They also argued that materials related to human rights are not sufficient to enhance their understanding on this matter. Older generation and those with lower education are not well

informed about human rights. Part of the public society does not know about the basic human rights which made it even difficult to realize their needs. A participant confessed:

“Many people failed to understand human rights, because it simply nothing to do with their daily life. How to get better services from government, particularly on medical expenses as well as treatment services. Parents also do not know much about the rights for their children (especially for parental caregivers). Partly because their lower level of education. I think even *ketua kampung* have no idea about human rights”.

Another participant added that:

“Even general society perceptions towards human rights is low. If we ourselves cannot realize our rights, how can we expect others will concern about our rights. We must recognize our own right before we ask society to realize our human rights”.

Further explanation given by another participant,

“Sometimes, we need to understand that, this group, infected by HIV/AIDS at their later age, upon medical check-up if they come forwards, it is always fine for them, they still able to work, they still able to get proper education. And because they can get what other people get, most probably they don't concern with their rights, they just follow what others do, until, say, they become manipulated or mistreated by others, then they look for their rights. Looks like normal society don't know about their right, and our right as well. So they don't have right to tell them right? That's is my rights and that's yours, don't step on me”.

None of the respondents especially caregivers are looking for social support, implying that their rights for social support are absent. This applies to most caregivers partly because they are not the one who are in needs. HIV/AIDS sufferers after careful consultation with their doctors, had been well informed about their rights for social support including proper treatments. However, the sufferers do not practice the rights as doing so will accidently strengthening the stigma.

### **Significance and the Policy Implication : The Conclusion**

This study attempts to offer an academic account of the experiences of caregivers and their PLWHAs in gaining support by developing the initiatives to reduce stigma and discrimination, exploring how and on what basis caregivers build their support networks based / related to their identities and whether caregivers and PLWHAs do concern about their rights. Our interest leads us to strongly agree with the claim made by Sonn et al. (1999) that research and practice in the community are often addressed to those who are excluded from a sense of community and to those who feel morally excluded: the oppressed, alienated and stigmatized. We believe that the feasibility of the present study can best be demonstrated by studying a marginalized and discriminated community, in this case, that of caregivers of PLWHAs and the PLWHAs themselves.



In Malaysia, HIV/AIDS prevention and treatment programmes mostly focus on sufferers/patients. The findings of this study can be used to enhanced these programmes that should consider PHWLA caregivers. The findings also offer useful insights for the respective authorities to review their current social policy and intervention programmes. This include offering services targeted to (infected) families and explicit sex education program (in school) to reduce the rate of HIV/AIDS cases, enhancing collaborative efforts between society, school system and the public health experts (and department) and providing resources for educational programs.

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