



Understanding the Effects of Stigma and Coping Mechanisms of People Living with HIV

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ABSTRACT

Human Immunodeficiency Virus (HIV) is one of the most epidemic, incurable and stigmatized virus at present. Since the start of the virus, there had been millions of people infected and died because of it. Aside from the risk of possible death, stigma and discrimination are two of the most dreadful experiences that people living with HIV (PLHIV) face in their communities. This led to the purpose of this study, which is to understand the stigmas and their effects alongside with the coping mechanisms of PLHIV. The researchers utilized a qualitative questionnaire distributed to the informants. Research protocols and ethical considerations were done in the study's implementation. The data gathered shows that informants experienced social and physical discrimination, self-stigma and fear of disclosure which made them pity their situations, inflict abuse to themselves and let abuse be inflicted to them by others. They cope up through their spiritual faith, support from their family and their HIV support group. It was emphasized by the informants that the HIV support group, especially their counselors are of great help and encouragement for them to continue with life. Thus, these results call for a strengthened set of policies in educating and involving the PLHIV's families in dealing with their condition, empowering the HIV support groups institutionally and financially and even having broader information dissemination about HIV in order for these fighters to keep normalcy in their lives around their communities.

Keywords – HIV, People Living with HIV, Stigma, Effects of Stigma, Coping Mechanism

Introduction

Human Immunodeficiency Virus (HIV) is a virus that attacks the immune system and may lead to Acquired Immunodeficiency Syndrome (AIDS) and if not treated early, leads to death. Man's immune system contains white blood cells that help fight the infections in the human body, thus it is a vital aspect of our physical being (Kapila et al., 2016). HIV is transmitted in different ways and sexual transmission is the most common one, especially with males engaging in homosexual intercourse (Mor & Dan, 2012).

More than 75.7 million people have been infected with HIV since it started, and there are over 32.7 million PLHIV who died worldwide (UNAIDS, 2019). In terms of HIV prevalence among various global regions, Eastern and Southern Africa has the highest number of PLHIV at 20.7 million which is equivalent to 54% of the global total. Next to it is Asia and the Pacific with 5.8 million PLHIV which is 15%

of the global total. Then it is followed by 4.9 million (13%) PLHIV in Western and Central Africa, 2.2 million (6%) of PLHIV in Western and Central Europe and North America, 2.1 million PLHIV (6%) in Latin America, 1.7 million (4%) in Eastern Europe and Central Asia, 330,000 PLHIV in the Caribbean and lastly, 240,000 PLHIV in the Middle East and North Africa. As we can see here, significant number of PLHIV are located in the top two regions: Eastern and Southern Africa and the Asia and the Pacific. They are also in the top two positions in terms of number of newly infected with HIV (730,000 and 300,000) and number of related deaths (300,000 and 160,000) (UNAIDS, 2020).

In one of the countries in Asia and the Pacific, the Philippines alone, there are over 97,000 adults and children living with HIV (UNAIDS, 2019). According to the Department of Health (DOH), the agency

in-charge with health in the said country, there are over 26 newly diagnosed HIV cases per day and continuously increasing by year. From all of these numbers, there is really a need for both international and national organizations/institutions to address the issue and also to cater well to the needs of PLHIV to defer striking mortality rate.

Moreover, HIV kills more young individuals and dying with HIV is still considered to be a shame in the Philippines (Santos, 2016). Up until now, with alive or dying PLHIV, there is still a strong discrimination against them. According to Tran et al (2019), stigma and discrimination are two of the greatest challenges that PLHIV face which negatively affect their quality of life even their treatment outcomes. This claim is also supported by the Senate Economic Planning Office (2020) which stated that discrimination among PLHIV normally leads avoidance of HIV services. This is how serious discrimination is. Due to these reasons, the researchers sought to document the experiences of the PLHIV in Cagayan Valley, Philippines since there is a limited or near to none qualitative researches done about them in this area. This administrative region is comprised of five provinces: Batanes, Cagayan, Isabela, Nueva Vizcaya and Quirino. Most of the researches about PLHIV in the Philippines were done in the National Capital Region (NCR), thus the researchers wanted to emphasize and properly document the condition of PLHIV in the non-urban areas, like here in Cagayan Valley. By doing this, there will be a possibility of institutional review on the programs implemented that fights discrimination among PLHIVs and the results of this research will certainly give voice to the PLHIV especially on their fight against the stigmas of having the virus.

Methods

The researchers used qualitative questionnaire as a tool which is under qualitative research methods. In order to have a brief background about it, the use of qualitative questionnaires was lifted from the areas of information studies research and archival studies which basically covers memories, opinions and experiences of the informants (Eckerdal, 2017). Since the focus of this study are the experiences of the PLHIV (from the stigmas, effects of stigma to coping mechanisms), qualitative questionnaire fit as a method of this research. The questionnaire was created using appropriate questions based on the study's objectives. This was validated by a panel of members from the university and also examined by the Department of Health Region 2 (Cagayan Valley) Office before floating it. Moreover, the questionnaire

has three parts. The first part includes questions about the stigmas being experienced by PLHIV, the second part comprises the questions about the effects of the stigmas they experienced and the last part are questions about their coping mechanisms. The researchers used purposive sampling method in gathering data to further understand the effects of stigma and coping mechanisms of PLHIV.

In aiming the objectives of this research, at first an in-depth interview was planned to be conducted, but because of circumstances it was not pushed through. Rather, the program head of the Department of Health on HIV requested the researchers to hand over the questionnaires to an HIV counselor and he will be the one who will give it to the informants. Due to this institutional restraint or limitation, the researchers went through the process but ensured that they discussed the protocols in distributing the questionnaires to the HIV counselor in charge. Informants of this research are seven PLHIV from Region 2 (Cagayan Valley) who willingly answered the questionnaire. Informed consent was obtained for participation in the study. The researchers also used document studies in examining the existing literature to validate the results of these study.

The analysis of the data was done through thematic analysis. Retrieved data from the informants were organized according to themes based on the objectives of the study which are as follow: PLHIV's experienced stigmas, effects of stigmas and their coping mechanisms. Coding was also utilized.

Results

For clearer understanding, a brief background of the informants is provided. All of the informants were male and their age is ranging from 19 to 28. All of them are single, two of them disclosed that they are currently working. Informant 1 is currently a service crew in a fast-food chain, Informant 7 is a make-up artist. On the other hand, Informants 3 and 5 are both students and Informants 2, 4, and 6 preferred not to give their occupation to protect their anonymity as PLHIV.

Stigmas Experienced by PLHIV

When we say stigma, it talks about the negative stereotypes toward individuals. As defined by the Joint United Nations Programme on HIV/AIDS (UNAIDS) (2011), it is a "dynamic process of devaluation that significantly discredits an individual in the eyes of others... When stigma is acted upon, the result is discrimination that may take the form of actions or omissions." In addition, George (2019) stated that "HIV-related stigma refers to the negative beliefs, feelings and attitudes toward people living

with HIV/acquired immunodeficiency syndrome.” Stigma is basically the public notion/mark of disgrace about a specific group of people, in this context, the PLHIV. The Philippines as a country is a conservative one, thus people have this stigma about the PLHIV, that they are entirely immoral and “dirty.” The result of this stigma to PLHIV are various kinds of discrimination and it can be from different contexts like family, community, health-care system and media. From this, we can say that stigma and discrimination are intertwined with each other.

The seven informants stated that they are still in the closet, meaning they were not yet disclosing their medical status to the public. When asked what they feared about their illness, their answers come in one theme: discrimination. As Informant 1 stated, *“Discrimination is my biggest fear especially when people avoid you and deny you opportunities like having a job because of your status.”* In addition, Informant 2 stated *“I feel hurt hearing negative comments about HIV.”* And lastly, Informant 3 added, *“They are saying that PLHIV are flirts and gross.”* These thoughts were shaped by their everyday dealings with their community and portrayals from media. Moreover, because of these perceptions, they all fear disclosing their status to people, even their loved ones.

While the above statements are the perceptions of PLHIV regarding possible discrimination that they may experience when their status be disclosed, we will also discuss their actual experiences regarding discrimination. The researchers divided the type of discrimination into two: physical and social. In terms of physical, one of the informants stated: *“Yes I experienced discrimination in our school because of sudden weight loss, my friends teased me and said things like ‘I’m infected with HIV’ even though they do not know my real status. My classmates avoided me even though they do not even know my real status.”* From this data, we can say that the Filipino society still need to have a deeper knowledge and awareness in regards to HIV. We can also conclude here that the Filipinos still have a strong stigma for those PLHIV or those who were not even proven to be one. Secondly, in terms of social discrimination, Informant 3 stated that when he discovered that he has HIV, he segregated his personal belongings like plate, spoon, fork and cups because of his own fear that he may transmit it to his family through his saliva, which is one of the misconceptions about HIV. Informant 2 added that when he disclosed his status to his family, his mother segregated his personal belongings because of lack of knowledge about the virus. In addition, one of the informants even transferred to a different school

because of the fear of being discovered with HIV. These actual experiences of the informants made an impact on their lives, especially in molding their own perceptions about themselves. This will be discussed in the next section of this study.

Effects of the Stigma to PLHIV

The stigma and discrimination they experienced led to feeling of self-pity and even abuse of self and inflicted abuse by others. Informant 2 stated *“I perceived myself and my capacities as nothing now, it basically affected how I value myself.”* It is supported by (Adimora et al., 2019) who claimed that HIV-related stigma and discrimination have a significant influence on the PLHIV’s self-esteem, that leads to self-pity. It is also true in the results of the study of France et al (2015), wherein their results showed that “hopelessness and self-pity frequently emerged among participants’ core beliefs.”

Secondly, in terms of abuse of self, one of the informants slit his own wrist for being depressed due to his condition. This is basically a symptom of mental health issue. It was claimed by Thai et al., (2017) that there is really a “high prevalence of symptoms of mental health disorders among PLHIV.” Moreover, this data is supported by Turan et al., (2017)’s study wherein they stated that the PLHIV’s anticipated stigma from community creates internalized stigma in them that basically affect their mental health—which can lead to more serious mental issues or even death.

One of informants also experienced abuses from his partner who is also an HIV positive entirely because of their condition. Informant 3 stated *“My former partner abused me physically a lot of times because of our status- both of us being PLHIV. He chokes me. Sometimes, I just want to hang myself to death or overdose myself with my anti-retroviral (ARV) medicines.”* This is a proof that PLHIV face not just discrimination but also violence from others, especially their partners because of their condition. In addition, it is important to note that most of the finished studies about partner violence experienced by PLHIVs are just focused on women, there is limited number done on men especially in the context of a male-to-male relationship (Harris et al., 2017). This is somewhat a new terrain in the area of HIV studies.

Furthermore, the stated effects of stigma to the informants are somewhat similar to other studies’ results but still possess some differences. In the study of Turan et al. (2017), the effects of the stigma to their informants are lowered self-esteem, depressive symptoms and non-adherence to medical needs. Also, in another study done by Fatoki (2016), stigma’s

effects among PLHIVs are broken relationships and non-disclosure of their HIV status to their partners, families and most importantly to the public. These data are related in the first two effects of stigma specified in this study, specifically self-pity and self-abuse. Lowered self-esteem leads to self-pity and self-abuse is typically a symptom of depression. Moreover, the third effect of stigma from our results is abuse by loved ones (partners). This is something new in this HIV terrain of studies because written literature about abuse/violence experienced by PLHIV are in the context of male-female relationships and there is limited data on abuses done within male-to-male relationships which our data contain (Harris et al, 2017).

Coping Mechanisms of PLHIV

The effects of stigma and discrimination among PLHIV are really overwhelming for them since they are not just experiencing these from their communities, but also from their family members and loved ones. Pushing forward for their treatment journey, what keeps them going?

The informants all argued that their spiritual faith is where they are taking their strength and hope right now, especially in their situation. Some of them even read the bible and claim that praying and reading it basically give optimism in their lives. These data corroborate with Pinho et al.'s (2020) study which stated that PLHIVs highly consider religiosity/spirituality as significant in coping with their condition. As claimed in Rohman et al.'s (2020) study, PLHIV who interprets their HIV experiences in a spiritual way behaves in a manner of regaining their health status for they perceived that their illness is an expression of God's love and affection for them. Another proof to this is Brito and Seidi's (2019) study wherein their results led to concluding that religious coping has an impact on PLHIV's resilience and that it is one of the major factors that affect the latter's ability to overcome the complication of their illness.

Moreover, the informants also stated that family support also contribute to their mental well-being. The more supportive and accepting the family is, the more hopeful they get. And this somewhat connected to their decision in thriving for treatment. One of the informants even stated that his mother is very hands-on in taking him to the treatment hub and earnestly taking care of him. It was stated in the study of Chinweokwu et al. (2018) that family support and involvement of the family members in the journey of PLHIV have a positive effect on the latter's adherence to counselling and treatment. Moreover, the results also corroborated with Kumar et al.'s (2015)' study wherein they focused on various coping strategies of

PLHIV and one of these is family support. The results of their study show that having a supportive family environment for PLHIV contributes to the latter's coping experience especially emotionally for their need of love and acceptance and instrumentally for their need of care in attending their health needs.

More importantly, the HIV support group attached to DOH Region 2 (Cagayan Valley) was perceived by all informants as a great help in their status. According to them, the support group and their HIV counselors provided them optimism on their condition and continuously motivating them to be braver in facing it. They also felt accepted and loved through the support group. It is consistent with the findings of Tumwikirize and Zwane (2016) that "PLHIV who participate in support group activities are more likely to have less HIV-related internal stigma, disclose their positive HIV status, reduce sexual risk behavior and adhere to treatment than PLHIV who do not participate." Moreover, in the study of Bateganya et al. (2015), the results showed that "support groups were associated with reduced frequency of HIV-related symptoms like anxiety, insomnia and depression. It is also positively related to improved access to medical and treatment needs." This is in turn saying that the government HIV/AIDS programs should look and invest more on strengthening PLHIV support groups and counselors and enhance it to be included as a vital part of their strategies in improving HIV/AIDS prevention and treatment.

Conclusion and Future Works

Stigma is really connected with discrimination. Living with HIV nowadays means PLHIV need to bear discrimination from people around them because discrimination itself is attached to the stigma and the virus. Most people especially in conservative Philippines think that the virus is also connected with shameful behaviors like men having sex with men and some also believe that being infected with the said virus is a punishment for their immoral behaviors. Due to these views, PLHIV have anticipated stigma and perceived stigmatizing experiences prior to disclosing their condition that normally leads to the fear of total disclosure on their part.

Moreover, the actual physical and social discrimination they experienced like mocking due to physical appearance and segregating their personal belongings caused them to feel self-pity and the need to abuse themselves and receive abuse from others. As stated above, in one of the cases of the informants, the stigma of having the virus led to his partner abusing him. This is true not just in heterosexual relationships,

but also in a homosexual one like informant's case. Since there are limited number of studies about partner violence in the context of male-to-male relationships among PLHIV, there is a new terrain to be explored.

From these stigmas, discrimination and its dreadful effects on them, the informants acknowledged that they are coping from their condition through strengthening their spiritual faith, receiving support from their family and from their HIV support group and counselors. These are basically their life-support right now.

Out of the data collected, it is important to note that NGOs and government-recognized support groups must be strengthened with needed financial and institutional support. There is a high possibility that support groups can help prolong the life of PLHIV because of their proper counselling that makes the latter think positively and continue living life beyond being a HIV-positive. Moreover, it is also important to note that programs in HIV/AIDS should strengthen their knowledge and awareness campaign for people to gradually accept the PLHIV in the community, for them to experience living a life without stigma and discrimination.

Ethical Considerations

The researchers strictly followed the protocols and the requests of the DOH Region 2 office in obtaining information from the informants. As stated above, the questionnaire used in this study was validated by the panel members of the university and the DOH Region 2 before giving it to the informants. Moreover, the researchers provided a brief orientation about research protocols on the HIV counselor who helped in distributing the questionnaires. Informed consent was also done. Anonymity of the informants was maintained all throughout the process. After the study's completion, a copy was given to DOH Region 2 which can be accessed by the informants.

Acknowledgement

The researchers wanted to extend their gratitude to the people behind the completion of this study, specifically to the officials and employees of DOH Region 2, to the HIV counselor who earnestly helped in distributing the questionnaires and most importantly to the seven brave informants who participated and patiently answered this study's questionnaires.

Authors Bio note



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