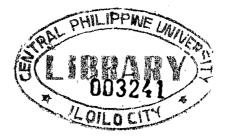
DISCLOSURE EXPERIENCES AND CONSEQUENCES OF PEOPLE LIVING WITH HIV/AIDS: A PHENOMENOLOGICAL STUDY

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by

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ABSTRACT

This is a qualitative research-case study approach, guided by phenomenology. The participants of the study were the six (6) men having sex with men (MSM) diagnosed to have a positive HIV serostatus. Data sources included key informants observations and use of audio-tape. Furthermore, data were collected through face-toface, conversational semi-structured interview with each of the participants using an interview guide.

To ensure trustworthiness in qualitative research, the study was guided by the procedures deemed suitable and explicit for qualitative research by Lincoln and Guba. The confidentiality, informed consent, and ethical considerations were greatly observed.

Data were analyzed using Colaizzi's Phenomenological Approach.

Major Findings

1. There were six (6) participants in this study who were self-confessed having sex with men. Four were homosexuals while the other two were bisexuals.

- 2. The youngest among the participants was 28 and the oldest was 46. All were single, and without partner at the time of the interview. Four were college graduates, one was a two-year vocational graduate, and the other one was a high school graduate. Due to their health condition, three were unemployed, while one was still applying for a job. Another was a casual government employee and one was self-employed.
- 3. While five of them have their HIV screening done when they were hospitalized, one of the participant had his reactive result discovered while having a medical examination for the purpose of working abroad. All of them received their confirmatory diagnosis while confined in the hospital.
- 4. Five were admitted in a hospital because of Pneumonia, while the other one because of Loose Bowel Movement (LBM). Among the six, the earliest confirmatory diagnosis was on March 2012, with the most recent was July 2015.
- 5. Each of the participants had different responses and sequence of reactions upon the discovery of their positive serostatus,. However, such stage was compared to grieving process including stages of shock, denial, anger, bargaining, guilt, depression and acceptance. Depression was identified as stage of deep sadness and sometimes having moments of suicidal thoughts. Responses varied in intensity, frequency and duratio
- 6. While four have their status known to parents, siblings, close relatives or loyal friend right after the discovery, the other two have their own share of struggles in making decision on how to tell their parents regarding their condition, both of them had suicidal ideation during those times that they have it kept to themselves.

- 7. There were many reasons why the participants disclosed their condition. Those included the importance that the family knows what they were going through, the expectation of support, both moral and financial, the existence of trust and loyalty, the hope for acceptance, and the affirmation of love. Some also anticipated the release of burden that finally, there were no more skeletons on their closet.
- 8. Recognition that there were close-minded people who could not accept nor understand, the presence of stigma and discrimination associated with the disease, the fear of isolation, and expectations of blame and negative reactions were considered by the participants as reasons of nondisclosure. Also the decision of containment of the information and filtering of the people to whom they would disclose, were for the reason of protecting the dignity of family and one's self, preservation of self-respect, and consideration of health condition of loved ones.
- 9. There were different initial reactions from the persons to whom the participants have disclosed their diagnosis to. Such may or may not be affected by their contemporary health condition while hospitalized. These reactions were silence, shock, blame and crying. Some have affirmed their love and support. However they reacted, it made a great impact on the participant's battle with survival.
- 10. As experienced by the participants, the results of their disclosure were mostly positive. These include release of burden, having peace of mind, being positive and happy. The acceptance, care, love and support they have received from their family helped them in fully accepting their condition and in moving forward. One reconciled with siblings, one also claimed that their family got more bonded.

- 11. The variation on family background of the participants also resulted to the different results of their disclosure. Undeniably, there were also negative effects in the disclosure of all participants. Luckily for four, it only happened to some point, like being isolated by the family or keeping distance because of the fear of getting infected right after being discharged from the hospital. Such treatment by the family was claimed to be no longer existing by the time of interview.
- 12. Disclosure also resulted to broken connections and isolation by friends. One participant also had much trust on a close neighbor who he didn't expect to have the information leaked to other people, causing its spread in their home town. Another participant was also known to have positive HIV serostatus in their neighborhood. Both participants were still experiencing discrimination by familiar faces, yet both were learning to ignore such people, appreciate the love and support of people who love them, and focus on their health and future.
- 13. Discrimination by the family was experienced and accepted by four participants because they understood that such was brought about by family's precautions, misinformation and/or the fear of being infected. All claimed that their family were currently as open-minded as they could.
- 14. Despite knowing that HIV/AIDS is associated with stigma and discrimination, the outlook and interpretation by the participants varied with regards to this. At some point they experienced discrimination because of their diagnosis and/or appearance. One participant shared being discriminated by a health care provider. All of them confessed that they got hurt when they were being discriminated.

- 15. Disclosure and stigma experienced by the participants were two of the major highlights in the life of a PLWHA. Realizations of being an HIV positive was also a major period in finding the purpose of disease, the changes it brought to their lifestyle and spirituality, and future goals.
- 16. The analysis of data resulted the identification of four themes. These are Facing the Discovery of the Positive HIV Serostatus, Disclosure Experience, Effects and Consequences of Disclosure, and Realizations of Being an HIV Positive.

Conclusions

- 1. The discovery and diagnosis of positive HIV serostatus was a major life-changing event that affected the participants physically, emotionally, and psychologically.
- 2. The association of HIV/AIDS with stigma and discrimination made it harder for the participants to accept their diagnosis.
- 3. The participants' decision to disclose have considered various thoughts of what it could result to: negative reactions such as blame, isolation, rejection and discrimination were expected, however the hope of receiving support, understanding and acceptance, the conviction of the importance of family's awareness of their condition, the purpose of releasing their burden, and the existence of trust and respect were reasons of disclosure.
- 4. Reactions to disclosure was affected by the state of health of the participants, and the person's understanding of the disease and relation to the participant.
- 5. Disclosure of positive HIV serostatus had positive effect if it was to immediate family member, close relative or loyal friend. Other than them, negative results

could happen. Thus it is on the PLWHA's prerogative to whom his disclosure could provide a constructive result.

- 6. Disclosure to family had expectations of blame and rejection, yet their unconditional love was expressed through acceptance, understanding and support.
- Stigma and discrimination could be experienced by PLWHA because of misunderstanding the disease and leakage of information and yet could be disregarded through own choice and mind set.
- Living with HIV provided the participants with opportunity to reflect back on their lives to make changes on their personal habits and lifestyle, as well as finding reasons and purpose on their second lives.
- 9. The themes from this research were considerably important in understanding the disclosure and stigma experience of people living with HIV, however, this may only be applicable to those who have been into critical health condition and have struggled for their survival.

Recommendations

Based on the findings of the study, the researcher presents the following recommendations:

People living with HIV/AIDS. Information regarding HIV/AIDS should be intensified. Such facts would not only increase awareness regarding the disease but also give better understanding of how it could affect health, and provide the drive to accept the diagnosis. Awareness, understanding and acceptance were the main core of how to effectively manage the disease. Disclosure to family such as parents and siblings was deemed important and of great help in fully accepting the diagnosis and in moving

forward. Definitely, negative reactions could not be avoided but their unconditional love would rise above it all, thus acceptance, care and support would be the effect.

Parents, siblings, relatives and friends. Being informed about HIV/AIDS could be of great aid in understanding the diagnosis. It could facilitate in the acceptance, support and care to the PLWHA, as well as providing comfort and motivation in their battle against HIV. Absence of discrimination have a great impact on PLWHA's acceptance and management of the disease.

Department of Health, healthcare provider, counsellor, support groups. Raising public awareness and information dissemination regarding HIV/AIDS must be given emphasis. Such actions could help, if not totally eradicate, in minimizing the stigma and discrimination by the public towards PLWHA. Also, there should be updates and trainings on health care providers, counsellors and support groups to have awareness and understand their roles in assisting the PLWHA, and that discrimination must not be experienced by them. Presence of effective counselling would be a greater help not only in PLWHA's understanding of the diagnosis but also in their acceptance, decision to disclose to significant other and management of health.

Hospitals, HIV Treatment Hub, Testing Centers. Health institutions must provide training to the medical staff as well as constant updates and seminars regarding the care for PLWHA, not only to provide better service to them, but also for the protection of themselves by having precautionary measures in handling PLWHA. Together with the treatment hubs and testing centers, protection of the PLWHA's anonymity and confidentiality but be reinforced. Provision of programs wherein concerned people as

well as PLWHA could be updated regarding HIV/AIDS and that constant counselling could be done to them and their family.

Other researchers. This research only focused on MSM with HIV/AIDS and all of the participants have experienced being into critical health condition that their main fight was their battle of survival against the disease. Such is a major factor that affected their decision to disclose as well as in their way of dealing with stigma and discrimination experienced. The researcher find it significant to investigate those PLWHA that were diagnosed during Voluntary Counselling and Testing (VCT) or Medical Examination, wherein their disease were managed even before their health deteriorated. Such information on their decision to disclose to family even in good state of health is important in identifying the factors and reasons that motivated them to do so, thus HIV advocates, health care provider and most especially the counsellors, would be more equipped in handling and encouraging PLWHA to disclose their diagnosis. Their experiences of stigma and discrimination must also be taken into consideration so that effective plans and programs could be formulated to address such problem.

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