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## Redefining the perceived quality of life of PLHIV through Counseling Programs: A Case Study of Pinoy Plus Members

### INTRODUCTION

One of the most prevalent diseases that affects people nowadays, and remained one of the most serious problems facing the youths is the human immunodeficiency virus (HIV) (Hellmann, 2014; Rogan, et al., 2010; Moremen, 2010). During the course of years 2001 and 2009, the incidence of HIV in seven countries which includes the Philippines have escalated by more than 25%, even though 33 countries have been said to have the incidence of HIV fall by more than 25% (Philippine National AIDS Council, 2010, 2011; International Labour Organization, 2012). In the Philippines, as of May 2013, there had been 415 new reported HIV individuals, and this is significantly higher for about 52% compared to the same period last year (Department of Health, 2013).

When the HIV epidemic rose, there came the stigma and discrimination against the people living with HIV (PLHIV). Stigma against PLHIV has been an issue to be concerned about, because according to Piot (2001) stigmas that are HIV and AIDS related are "real or perceived negative response" to a person by other persons, group or communities, and are characterized by "rejection", "denial", "discrediting", "disregarding", "underrating", and "social distance". These stigmas lead to various "discrimination" and violation of human rights". Moreover, according to the address of Ndungane (2003), former Archbishop of Cape Town, stigma against PLHIV should be eradicated for it prevents PLHIV to be productive and to live with hope, and is therefore, negatively affects the PLHIV's quality of lives.

The increase of PLHIV and the stigma against PLHIV, gave the important role of non-governmental organizations (NGOs) to be involved in influencing the quality of life

of people living with HIV and educating people about HIV. In the Philippines, the alarming increase of PLHIV gave various NGOs the necessitation needed for the treatment, care and support for PLHIV; and one of these organizations is the *Pinoy Plus Association Inc. or Pinoy Plus*. According to the Philippine National AIDS Council or PNAC (nd), the *Pinoy Plus* is the "only association in the Philippines" that is an organization only for people living with HIV; its main objectives are to give services like treatment, care, support and referrals to PLHIV and other organizations related and affiliated with it.

This case study research seeks to examine the effect of NGO- Pinoy Plus, to the perceived quality of life of its members; prior to and after joining the respective NGO through the concepts of Veena Das' Stigma, Contagion and Defect; and framework derived from Robins' (2006) "Bare Survival" and "New Life". This research will be beneficial to the Pinoy Plus' policies and actions on their treatment, care and support, most especially on the counseling programs. To a larger extent, hopefully the output of this research will serve as one of the basis for future plans and actions of non-governmental and governmental organizations in understanding and addressing the quality of life of people living with HIV.

### **LITERATURE REVIEW**

The literature review for this study comprises of books, journal articles, and electronic sources that are related to the Quality of Life (QoL) of people with illnesses specifically the PLHIV. This portion of the study will give insights on the Quality of Life, roles of NGOs, and the micro and macro perspective on the HIV epidemic. QUALITY OF LIFE

The quality of life or QoL is a broad concept that has disparate philosophical, political and health-related definitions (Donald, 2009). By its broad concept, according to Donald (2009), QoL could be defined in many ways. Vyavaharkar et al. (2011) supported this by stating that QoL is defined through a number of different dimensions that includes status- in relation to illness, socioeconomic, personal goals, life satisfaction, and many others.

Due to the scholars and intellectuals' various definitions of QoL, measuring and incorporating QoL with scientific study is difficult according to Vyavaharkar et al. (2011). Despite the fact that there are different definitions of QoL, all of the definitions tackle the same dimensions concerning social life, health well-being, personal experiences,

politics and economics.

According to Vyavaharkar et al. (2011) assessing and understanding the QoL of people with illnesses is important for: (1) Documenting the burden of the disease; (2) evaluating treatments; (3) tracking health-related changes over time; (4) gauging returns from healthcare investments; and assessment of QoL can be a basis for health outcomes (Aragone -sLo pez, Pe rez-A vila, Fawzi, & Castro, 2012). It can also improve patient care through, as stated by Donald (2009): (1) improve patients' QoL ways in improving; (2) widening the parameters of benefits; (3) indicating a need of supportive interventions; (4) aiding decision-making; and (5) informing resource allocation and health care policy.

#### STIGMA, CONTAGION AND DEFECT

Veena Das' concepts: Stigma, Contagion and Defect, were also inquired in this research to understand better the Pinoy Plus PLHIV informants' perceived QoL. These concepts of Veena Das would more likely help explain how the Pinoy Plus' counseling programs affect how its PLHIV members redefine their QoL, since Das' concepts on Stigma, Contagion and Defect are evidently some of the factors that affect how people with illnesses live and perceive their QoL.

According to Veena Das (n.d.) Goffman's term for stigma refers to the "culturally acceptable" or inferior condition, trait or behavior; and Das also stated that stigma presents itself "most clearly in what is at stake in face-to-face relations", although the programs and policies of different institutions are involved in both the "production" and "amelioration" of stigma.

Veena Das' concept of contagion on the other hand is "the potential for a condition to be transmitted from one person to another". It has been said that contagion and stigma "tend to slide to each other", and with that notion Das argued that, "biological course of the illness comes to be related to its social course". Defect is another term brought up by Das in her work "Stigma, Contagion, Defect: Issues in the Anthropology of Public Health.". It refers to the people that are "appearance-impaired", or have physical disabilities or disfigurements.

## PHILIPPINE HIV EPIDEMIC

Based on the studies of Rogan, et al. (2010), Moremen (2010), and Hellmann (2014), human immunodeficiency virus (HIV) is one of the most prevalent diseases that affects people nowadays. According to the head of World Health Organization's HIV Department, Hirnschall (2014) cited in Hellmann (2014), that even though the HIV infection rates dropped by 0.33% between the years 2001 and 2009, as Hellmann (2014) perceived it, it is still as an "uneven" progress. Hellmann (2014) also stated that the rate of HIV infections is increasing among the homosexual men.

In the past, HIV had been labelled as "low and slow" in the Philippines (Salvana E. M., 2012; Montoya, 2013). The reason for this is because HIV cases have low development compared to other countries from the South East Asia. Cited possible reasons for this low prevalence are: Filipino circumcisions, geography, relative sexual conservatism and minimal intravenous or IV drug use (Salvana E. M., 2012). But in year 2007 up to now, HIV has been labeled as "hidden and growing" (Montoya, 2013). This label, on the other hand, is because of the fact that HIV incidence rates have been rising to an unprecedented level, and some factors for this are casual sex, poor condom use and misinformation (Salvana E. M., 2012; Salvana, 2010; Montoya, 2013).

In the Philippines, from year 1984 up to 2013, the cumulative total of reported cases of people living with HIV or PLHIV is 12, 421, which composes of 10, 758 men and 1, 652 women; and this also includes youths ranging from 15 to 24 years old, and children below 15 years old (Montoya, 2013). According to the Philippine National AIDS Council (2010, 2011), from years 2001 to 2009, the incidence of HIV in seven countries which includes the Philippines have escalated by more than 25%, even though 33 countries have been said to have the incidence of HIV fall by more than 25%. Based on the report of the Department of Health (2013), in the Philippines, as of May 2013, there had been 415 new reported HIV individuals, and this is significantly higher for about 52% compared to the same period last year.

## NGOs

The United Nations (UN) was the first to invent the term NGO (Park, 2002:60; Bidet, 2002:

271; Anheier et al., 2001:4 cited in Kim, 2004). As stated by Kabdiyeva (2013), the concept of NGO is a broad term that includes various sets of organizations; they are: (1) private, (2) non-profit organizations, (3) aim to serve particular social interests by through advocacy and operational efforts on social, political and economic goals (Teegen et al., 2004 cited in Kabdiyevam, 2013).

The non-governmental organizations (NGOs) play a decisive role in developing and improving the lives of people living with HIV (PLHIV), through organizing and establishing various activities and advocacies. More often than not, studies suggest that NGOs and their activities manifested positive outcomes in improving the lives of PLHIV (Elkington, Robbins, Bauermeister, Abrams, McKay, & Mellins, 2010; Christian Relief and Development Association, 2006). According to C.S. Veerematha, positive outcomes of NGOs are in part due to the strategies that they adopt, some of these strategies are: peer-group approach, capacity building, condom promotion activities, accessibility of IEC materials, STD treatment and counselling, outreach work strategies and community level intervention.

#### LITERATURE GAP

Studies related to the QoL usually implements quantitative method as their main inquiry (Robberstad & Olsen, 2010; Mayo, 1999; Eurostat News Release, 2014; European Commission, 2013; The Organisation for Economic Co-operation and Development, 2011; World Health Organization, 2004; Reis, et al., 2011; Jia, et al., 2004; MH, et al., 2011). Only a few studies inquire QoL through qualitative methods, some examples of these are studies of Poston, et al., (2003) and Basavaraj, Navya, & Rashmi, (2011); therefore it limits the review of related literatures for this study.

#### RESEARCH QUESTION

This case study research seeks to explore the effect of *Pinoy Plus*' programs to the perceived quality of life of its PLHIV members; and it attempts to answer the general question: How does *Pinoy Plus* affect the perceived quality of life of its PLHIV members? Moreover, it also seeks answers to the following questions:

(1) What are the programs offered by *Pinoy Plus* to its PLHIV members? This question will

explore not only the programs offered by Pinoy Plus, but also the (1.1) objectives and goals (1.2) processes of the programs in the PLHIV's recoveries and (1.3) social integrations.

What are the perceptions of the informants on their health after joining Pinoy Plus? This question explores the (2.1) self reported health and (2.2) emotional state of the PLHIV and (2.4) their medication adherence, in relation to the programs offered by Pinoy Plus.

What are the perceptions of the informants on their social well being after joining Pinoy Plus? This question explores (3.1) the changes in the relationship with their friends and families, (3.2) participation on activities and organizations, and (3.3) their sense of being safe and secure, in relation to the programs offered by Pinoy Plus.

What are the perceptions of PLHIV regarding their quality of life after joining Pinoy Plus? This question deals with how the informants perceive their overall health and social well being, in relation to the programs offered by Pinoy Plus.

## FRAMEWORK

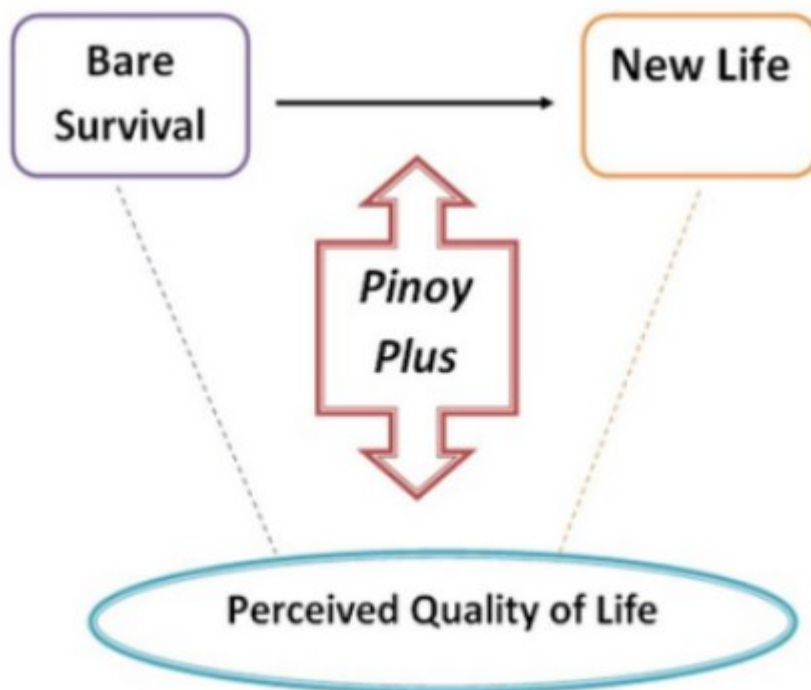
The conceptual framework of this case study research uses Steven Robins' (2006) concepts of "Bare Survival" and "New Life". The term "Bare Survival" and "New Life" were concepts used by Robins (2006) to investigate how PLHIV in South Africa redefine their social identity and commitment to activism.

The term "Bare Survival" is defined as perceived lives of PLHIV before joining various organizations, and having the rights to treatments care and support. It is usually associated with the inequalities, "near death" experiences by PLHIV; and their susceptibility to the "structural violence" (Farmer, 2004).

"New life" is another term that was incorporated in the framework of this study. This term is defined as the perceived lives of PLHIV after joining various organizations, and having the rights to treatments care and support. This term is associated with how the PLHIV redefine their social integrity and commitment to social movements related to HIV.

Figure 1 shows the conceptual framework of Quality of Life of PLHIV. It shows how the Pinoy Plus programs affect the perceived QoL of the informants through their life to be able to explore the "Bare Survival" and "New Life" of the informants, this research specifically

focuses on their perceived QoL. Understanding the QoL of the informants consists of two variables, these are health and social well being. The indicators for the informants' perceived health that were inquired were their: (1) medication adherence, (2) self-reported physical health, and (3) self-reported emotional/psychological health. The indicators that dealt on the perceived social well being of the informants, were (1) relationships with family, (2) activities and organizations, and (3) sense of being safe and secure.



**Fig. 1 Conceptual Framework**

#### METHODS

The case study research study will execute Creswell's (2002, 2006) qualitative research method approach. All data needed were collected from the PLHIV members of Pinoy Plus. Focused ethnography (Ku hn, 2013; Higginbottom, Pillay, & Boadu, 2013; Knoblauch, 2005) will be used in this study, and part in parcel with this that will be performed are series of participant observations, semi-structured interviews and surveys. The main agenda for the participant observations and semi-structured interviews is to determine and elaborate the perceived QoL of PLHIV members of Pinoy Plus prior to and after joining the Pinoy Plus. The survey, on the other hand, was used to determine the graphic

profiles of the informants for this research.

This research paper will also follow the ethical guidelines of the University of Santo Tomas Sociological Society and World Health Organization. Prior to conducting the research, consent forms based on the World Health Organization were formulated in order to ensure and protect the informants' privacy and confidentiality.

This case study research performed semi structured in depth interviews and survey, which composed of open and closed end questions (Reja, Manfreda, Hlebec, & Vehovar, 2003; University of Illinois Extension Service-Office of Program Planning and Assessment; Schuman & Presser, 1979; Horst & Martens, 20130). Incentives or tokens were given to the informants as appreciation and gratitude for participating in this research.

For the socio-demographic profile of the informants, Statistical Package for Social Sciences (SPSS) was used. The qualitative data were coded through Atlas.ti software, and this software was used in determining the emerging themes that this research focused on.

## **LIMITATIONS**

Even though this case study research was able to produce data and results, which are applicable to the design of the study, the research was faced several limitations. One of the limitations faced by this research is the sample size. This research has a small sample size, and is therefore limits the generalizability for this study. Another limitation faced by this research was that the data that were collected and analyzed are self-reported data. As stated by Labaree (2013) they have several potential biases that may serve as limitations for this research, some of these potential biases are selective memory, telescoping, attribution and exaggeration.

## **FINDINGS**

The focus of this research is on the NGO- Pinoy Plus Inc. and its PLHIV members who are currently taking up counselling programs offered by the NGO. The primary data for this case study research were collected mainly through semi-structured in depth interviews and surveys. There were five male informants for this study, each of them were given



the opportunity to pick their own pseudonyms for confidentiality and anonymity. The names that they have chosen were: Jay, Gelo, Nigel, Bench and Kane.

The first table that the research will present is the socio-demographic information of the informants based on their self-reported details. The second sets of tables will discuss the qualitative data gathered from the five informants of this research.

**SOCIO-DEMOGRAPHIC PROFILE OF THE INFORMANTS BASED ON THEIR SELF-REPORTED DETAILS**

Table 1 shows the name, age, employment status and civil status of the informants for this research. The research consisted of five (N=5) informants. For confidentiality purposes, the real names of the informants were not presented rather, their chosen pseudonyms, and these were Jay, Gelo, Nigel, Bench and Kane. The ages of the informants range from 27 years old to 40 years old. Two informants (Nigel and Gelo) are in the minimum age bracket, which is 27 years old; and only one of the informants, Kane, is on the maximum age bracket, which is 40 years old. As shown in the table above, three of the informants are single and the other two are cohabiting/live in. The table employment status of the informants, as presented on the table, four of the informants are self-employed and only one is unemployed.

**Table 1: Socio demographic profiles of the informants based on their self-reported details**

Name of Informants	Age	Employment Status	Civil Status
Jay	28	Self Employed	Cohabiting/Live in
Gelo	27	Unemployed	Cohabiting/Live in
Nigel	27	Self Employed	Single
Bench	30	Self Employed	Single
Kane	40	Self Employed	Single

The next few sets of tables to be discussed are in relation to how the informants perceive their quality of lives. There are four general variables- health well being, economic satisfaction, social well being and Pinoy Plus counselling programs interventions. Two of the general variables consisted of various subcategories that serve as the variables' indicators. Health well being, on one hand, consisted of self-reported physical health, self-reported emotional/psychological health and medications. On the other hand, the social

well-being's subcategories consisted of relationship with friends and family, activities and organizations, and sense of being safe and secure. Each of the informants answers have been categorized in these four general variables.

## HEALTH WELL BEING

### Self-reported Emotional/Psychological Health

Table 2 shows Pinoy Plus informants responses on the question "How often are you preoccupied about your problems in life in general?" formed six emerging themes, these are acceptance and endurance, faith, future self, avoidance, defect and stigma. The majority of the informants' responses illustrate that they view their problems in life in general positively through accepting, enduring and having faith when it comes to their problems. The responses also showed that despite the positive responses there are also negative perceptions that can be thematized as defect and stigma.

**Table 2: Preoccupied on problems in life in general**

Emerging Themes	Sample Statements	Meanings
Acceptance and Endurance	"... kasi problema nandiyan lang. Kung iisipin mo lalo lang magpapababa sa amin, pero syempre hindi naman mawawala yan, dapat harapin pa rin." <i>[... because problems are always there. If you think about it, it will only bring you down. But of course, problems do not just disappear, you have to face it.]</i> "Hindi ko dinidibdib yung mga problema." <i>[I do not take my problems seriously]</i>	The informant associate problems they face in life as normal events, which happen in their daily lives and should be accepted and endured.
Faith	"Pagdating sa mga ganyan, usually ka-pag may problem ako ang number one na ano ko was to read the Bible." <i>[Usually, when I have a problem, the first thing that I do is to read to Bible.]</i>	Faith in God is a way in which the informant can be comforted in times of problems.
Future Self	"Mahirap kasi parang iniisip ko may pag-gasa pa ba ako na makapgtrabaho, may pag asa pa ba ako na mabuhay ng mata-gal, may pag asa pa ba akong matupad mga pangarap ko. Mahirap kasi, ako wala akong work ngayon, nagrerenta ng bahay, ang daming problema"	

Emerging Themes	Sample Statements	Meanings
Avoidance	"Kadalasan, pag nagiisa ako sa bahay. Pero iniwasan kong nag iisip, kasi sa sitwasyon ko"  <i>[Often, especially when I'm alone in the house. But I try to avoid pondering about it because of my situation]</i>	Pondering on problems tend to be avoided since it is something that can affect the health of the PLHIV.
Defect	"..... pero hindi ko namang sinasabing lahat ng pangarap mo mawawala kasi pwede ka naman magtrabaho pero limit na lang siya. Yun lang mas kinadepress ko ng almost kulang kulang na isang buwan."  <i>[..... I am not saying that all your dreams will be gone, because you can always find a job but it is limited. That made me depressed for almost one</i>	Because of the job limitations of the individuals with illnesses, some individuals perceive them-selves as not productive.
Stigma	"Tapos nung nalaman nila napakahirap sa akin kasi parang dinidiscourage ka nila"  <i>[It has been really hard for me when they (family) found out about my illness, because I feel like they are discouraging</i>	Illnesses could lead to discouragement and other negative actions that could hamper one's positive perception of life, and trigger problems.

Table 3 presents the responses of the informants when inquiring their perceived emotion/psychological health after joining Pinoy Plus, it shows that there is a positive perception on the informants' emotion/psychological health. However, there are also negative themes that emerged these themes are contagion and stigma.

**Table 3 Emotional/psychological health after joining the Pinoy Plus**

Emerging Themes	Sample Statements	Meanings
Support	"Kasi until now nandiyan pa rin sila (referring to the <i>Pinoy Plus</i> members). Kasi, lalo na nung nalaman na nagtritrial na ako. Text dito text don, musta pagtritrial mo, mga bawal na pagkain wag mokainin, bawal mag iisip, bawal magpuyat...yung mga bisyong bawal wag mong gawin."  <i>[Because up until now, they are still there to support me (referring to the <i>Pinoy Plus</i> members). They send me text messages, asking me how were my trials (ARV medication), telling me what food to avoid, avoiding staying up late at night and vices.]</i>	<i>Pinoy Plus</i> gives its PLHIV members moral support, which helps them, improve and develop their wellbeing.

Emerging Themes	Sample Statements	Meanings
	"Kasi nakakatulong na sila sa mga kagya naming mga patient." <i>[Because they (Pinoy Plus) help HIV patients like me.]</i>	
Empowerment	"... meron kasi silang (referring to the <i>Pinoy Plus</i> ) tinatawag na Capacity Building.... Iimpower nila yung mga positive, people living with HIVs na maging productive and maging empowered yon. Nag iba pananaw ko sa buhay." <i>[They (referring to the Pinoy Plus) have this program called Capacity Building wherein they empower and help PLHIV to become productive, and because of that, my perspective in life changed.]</i> " Minsan nagkwekwentuhan (referring to PLHIV who are taking up counseling programs) nagshashare kung ano yung mga nararamdaman tapos nakakakuha kang lakas, inspiration, sa mga taong may ganon" <i>[Sometimes we (referring to PLHIV who are taking up counseling programs) share our experiences, and through those sharing, I gain strength and courage.]</i>	Sharing life stories with fellow-PLHIV and empowering them through the programs offered by <i>Pinoy Plus</i> like Capacity Building and counseling programs.
Belongingness	"Siguro dapat ibigay mo muna sarili mo sa community (referring to the <i>Pinoy Plus</i> community)." <i>[Maybe you have to give yourself first to the community (referring to the Pinoy Plus community).]</i>	The sense of belongingness depends on how the individual gives and opens his or herself to the community.
Contagion	"...kasi may nalaman ako na ganito pala... pagka may kapartner ka mahahawa yung kapartner mo." <i>[... because I found out that when you have a partner you can transmit (HIV) to your partner.]</i>	The individual perceive himself as a person who is very contagious due to his illness.
Stigma	"Parang nadodown ka na sa sarili mo, parang nadidiscriminate ka na kunwari may koting hindi pag kakakintindihan sa magkakapatid o pamilya, minsan nauangkat sa yung sakit." <i>[I feel so down. I feel like I am being discriminated. For example, when there is an argument with my brothers and sisters or with my family, sometimes my illness was brought up.]</i>	The individual's illness is sometimes an issue during arguments in the family.

*Self-reported Physical Health*

Table 4 shows the responses of the informants regarding their physical health after joining *Pinoy Plus*, it shows that most responses showed positive change on the informants' physical health and only one informant responded that there is no change in his physical health before and after joining *Pinoy Plus*. The reason for this is that he did not feel any symptoms of his illness. Four emerging themes (involvement, knowledge, asymptomatic) were formed after asking the informants about their physical health.

**Table 4: Perceived physical health after joining the Pinoy Plus**

Emerging Themes	Sample Statements	Meanings
Involvement	"Kasi na involve na ako sa sa mga capacity building na ginagawa nila and then eventually naging peer educator na din ako."  <i>[Because I got involved in the capacity-building program, and eventually I became a peer educator.]</i>	Being part in the programs and activities offered by <i>Pinoy Plus</i> helped them improve their perceived physical health.
Knowledge	"Nung nalaman ko na lahat yung mga tamang prosesos para mapatagal pa yung buhay ko. Na mas lalo ko pang alagaan sarili ko, wag ko baliwalain yung sarili ko."  <i>[When I learned about the right processes to make my life longer, I took care of myself even better.]</i>  "Dati kasi parang kabado ka lagi (referring to his physical health), knowledge e habang tumatagal lumalawak yan."  <i>[I used to worry all the time (referring to his physical health), but as time passes by I become more knowledgeable.]</i>	Being knowledgeable on the right treatment processes and lifestyles gave the PLHIV a better chance on improving their physical health.
Asymptomatic	"Kasi wala naman akong naramdaman."  <i>[Because I did not feel any symptoms.]</i>	How the individual defines his physical health depends on whether or not the symptoms of his illness is felt or observed.
Defect	"Ayon napapagod kasi hindi siya 100% na normal ganon"  <i>[I get tired. It's not 100% normal.]</i>	Due to his illness, individual perceives himself as not 100% normal compared to other individuals.

### Medications

Table 5 shows the informants' responses on the question "What are the possible reasons for your medication compliance?" Because during the interview all of them answered that, they comply with their medications. Based on the responses two themes emerged when they were asked the question "What are the possible reasons for your medication compliance?" these two themes are obedience and life. Most of the informants responded that they comply with their medications because that is what their doctors tell them.

**Table 5: Medication compliance**

Emerging Themes	Sample Statements	Meanings
Obedience	<p>"Kasi yun yung sinasabi ng Doctor, bawal mag lapse ng gamot kailangan tuloy tuloy."</p> <p><i>[Because that is what the doctor tells me, I should not lapse on my medications.]</i></p> <p>"Unang una sinabi ng doctor, syempre pag sinabi ng doctor dapat sunduin mo yon."</p> <p><i>[First and foremost, that is what the doctor told me, of course I have to abide by what he/she tells me.]</i></p> <p>"Oo sa tamang oras, kasi pag once di mo tinake yung tamang oras yung gamot na binigay sayo ng doctor is malaking tendency na magkaroon ka ng drug resisistance."</p> <p><i>[Yes on the right time, because when you did not take the medicine on the time that the doctor told you, there is a high tendency that you will have a drug resistance.]</i></p>	Obeying the advices and taking medications given to them by their doctors to them.
Prolonging Life	<p>"Gusto ko lang mabuhay ng matagal."</p> <p><i>[I just want to live a long life.]</i></p>	The individual just wants to live a long life.

Table 6 shows the informants' responses on the questions "Who and how would you consider the support you are given to for your health medications and maintenance?" It shows that Pinoy Plus and Phil Healthcare the informants' most common answers when they were asked who supports their health medications.

**Table 6: Health medications and maintenance support**

Name	Medication Support
Jay	Partner, Phil Health, Pinoy Plus
Nigel	Parents, Myself
Gelo	NGO, Phil Health
Bench	Myself, NGO
Kane	Myself, NGO, Phil Health

### *Pinoy Plus Counseling Programs*

Table 7 shows the informants' responses on the question "How do the Pinoy Plus counselling programs affect your overall emotional/psychological and physical well being?" Based on the responses three themes emerged when they were asked the question "How does the *Pinoy Plus* counseling programs affect your overall emotional/psychological and physical well being?" these three themes are support, self discipline and empowerment. Informants responses shows that the counseling programs of *Pinoy Plus* affected their emotional/psychological and physical well being through giving them support, empowerment and self-discipline.

**Table 7: Overall emotional/psychological and physical well-being**

Emerging Themes	Sample Statements	Meanings
Self Discipline	<p>"Sa akin mas naging, yun bang nagpipigil ka sa anung nararamdaman mo. Kunwari dati sige sige lang kung ano yung ginagawa mo."</p> <p><i>[For me I became more self-disciplined. In the past, I just do what I wanted to do.]</i></p> <p>"Siguro, pinagbabawalan na magpuyat, disiplina sa sarili, lalo na sa pagkain. tamang diet, tamang ano."</p> <p><i>[Maybe, avoid sleeping late at night, self-discipline especially on the foods, and right diet.]</i></p>	Self Discipline is the ability of the individual to control oneself for his or her benefit, as well as the benefit of the people around him or her.
Empowerment	"Na empower ako to parang magiging productive pa even though dumaan ako sa pagkarami raming mga ano mga hindrances mga obstructions sa yun malaking naitulong ng counselling."	Empowerment of the individuals through life experiences, and support given by <i>Pinoy Plus</i> , enhances the individuals' capacity and productivity.

Emerging Themes	Sample Statements	Meanings
	<p><i>[The counselling helped me a lot to become empowered even though I went through many hindrances and obstructions.]</i></p> <p>" Kasi unang una doon mo makikita yung mga taong nakasurvive so empowered na"</p> <p><i>[First of all, you can observe there the people who survived (HIV) so you will feel empowered.]</i></p> <p>"Yung nandiyan sila lagi na to offer, to remind yung ano dapat gawin mo para mas maging matatag ka pa sa sarili mo, sa buhay."</p> <p><i>[They are always there to offer you support, to remind you the things that you do to gain strength and courage in your life.]</i></p>	

## SOCIAL WELL BEING

### *Relationship with Friends and Family*

During the interview, when the informants were asked the question "Did the relationship between you and your friends and family change when they found out you have HIV?" it shows that three informants (Jay, Nigel and Gelo) answered that their relationship with their friends and family changed when they found out about they have HIV. Two of the informants (Bench and Kane), however, answered that their relationship with their friends and family did not change.

Table 8 shows the responses of the informants on the question "In what ways does your relationship between you and your friends and family change?". Four emerging themes are observable in their responses. These themes are: (1) Stable, which means that nothing changed in the relationship between their family and friends. (2) Self, the changes is not on their family and friends' relationship but it is on their selves. (3) Support, it means that their relationships between their friends and family change through their support. (4) Defect, which means that having HIV lessens their productivity in helping their family and friends.



**Table 8: Relationship with your friends and family**

Emerging Themes	Sample Statements	Meanings
Support	<p>"Hindi katulad dati na hindi ko si-nasabing ganito parang wala lang, ngayon nag-woworry sila. Magagalit sila sa akin... ng isang linggo na hindi ako makatawag magtext na para sabihin na okay ako."</p> <p><i>[Compared to the past, they now worry more about me. They will get angry at me when I don't call or text them to say that I'm okay.]</i></p> <p>Ano kasi, nandiyan lang din naman sila e</p> <p><i>[Because, they are there.]</i></p>	The informants associate their relationship with their family and friends through how they support them in relation to their illness.
Stable	<p>"Nung nagdisclose ako wala naman nagbago."</p> <p><i>[Nothing changed when I disclosed to them.]</i></p> <p>"Siguro ako yung nagbago eh kasi inisip ko hindi naman yata sila dapat sa lahat ng oras sabihin mo nangyari sayo eh,"</p> <p><i>[Maybe I am the one who changed, because I think not all the time it's my responsibility to update them on what's happening to me.]</i></p>	The definition of stable in this sample statements means that disclosing to the family and friends did not change their relationship with the individual.
Defect	<p>"Wala ng pag aasa, paano ka maging productive, makatulong sa kanila kung may karamdamang ganito."</p> <p><i>[There is no hope, how will you be productive, how will you help them (family) if you have an illness like this.]</i></p>	The individual's perception of his own productivity is seen negatively due to his illness.

*Sense of Being Safe and Secure*

Table 9 shows that there are three emerging themes when the informants were inquired about their perception on their self being safe and secure. The emerging themes were Defect, Contagion and Empowered.

**Table 9: Perception on Being Safe and Secure**

Emerging Themes	Sample Statements	Meanings
Empowerment	"Normal, normal pa rin. Siguro dahil empowered na ako." <i>[Normal, still normal. Maybe because 'm now empowered.]</i>	The PLHIV's perception of being safe and secure is the same in comparison with the people without illnesses because of the <i>Pinoy Plus</i> programs that gives them sense of empowerment.
Defect	"Yung safeness, kasi ang hirap pag pera yung wala sa iyo o trabaho napakahirap hindi ko masuportahan." <i>[On safetiness, it is hard when you do not have money or work. It is really hard I can't support myself.]</i>	The individual perceive his low capacity and productivity to work as something that is associated with the sense of being safe.
Contagion	" ... feeling ko safe naman din at times na rin na minsan pagkamay may kunwari pumunta ako sa mall tapos may nakasabay ako na parang umubo siya sa harapan ko automatic na mag-atakip na ako ng bibig kasi nga immune compromise nga ako, madali akong mahahawa kung baga kung sa isang normal na tao" <i>[... I feel I am safe, at times when I go to the mall and someone coughed in front of me, I will automatically cover my mouth because I am immuno compromise. I get easily infected compared to a normal person.]</i>	Being vulnerable to simple illnesses such as flu is associated with the individual's perception of being safe and secure.

When the informants were asked on the activities and organizations that they are joining, four of them (Gelo, Jay, Kane and Nigel) are only affiliated with *Pinoy Plus* and its activities. However, Bench is not just affiliate himself with *Pinoy Plus* but he is also an active member of a support group called *Cavite Support Group (CSG)*.

#### Pinoy Plus Counseling Programs

Table 10 shows the responses of the informants when they were asked on how to they perceive their social lives after joining *Pinoy Plus*. Four themes emerged these are Support, Optimism, Involvement and Stigma.

**Table 10: Perceived social life after joining the Pinoy Plus**

Emerging Themes	Sample Statements	Meanings
Support	"Dahil nandiyan silang sumusupporta." [Because they (Pinoy Plus) are there to support.]	The informants associate their perception of their social life through the support given to them by the <i>Pinoy Plus</i> .
Optimism	"Sabi nga nila hindi daw sa kung sa paano kung namatay, kung paano ka mabuhay." [You know what they say, it is not how you die, but rather it is how you live your life.]	The individual states that what matters most is how you live your life.
Involvement	"Kasi naging involve ako naging aware ako.... Motivated ako pagdating sa positive community." [Because I got involved and became aware... I am motivated when it comes to the positive community.]	Being involved in the <i>Pinoy Plus</i> , improved and motivated the individual on how he/she perceives his/her social life.
Stigma	"Kasi hindi ako..nagtatago ako, hindi ako masyado lumalabas." [In the past... I hid myself... I do not usually go outside.]	The social life of the individual in the past had been hampered because of the stigma of his illness.

## DISCUSSION

This case study research gave voice to the perceived quality of lives of five *Pinoy Plus* members through exploring their life transitions from "Bare Survival" to "New Life". It gives insights on the factors that affect the perceived quality of life or QoL of PLHIV through counseling programs. The different dimensions of related to the QoL, like the stigma, contagion, defect, quality of life, such as health and social well being were inquired in this research.

The discussion for this study consists of four themes, and these are: (1) Health and Counseling Programs, (2) Social Well Being and Counseling Programs, (3) Economic Satisfaction, and (4) Quality of Life and Counseling Programs.

### Self Perceived Health

This research inquires the PLHIV informants' self-perception of their health through its two variables, psychological and emotional/psychological health. The data that were

gathered suggest that their perception of their own health have improved through joining and participating in the *Pinoy Plus* counseling programs.

Studies suggest that counseling programs have been important in health related interventions and life development to the people with illnesses like PLHIV (Maman, et al., 2001; USAID, 2012; Menzies, et al., 2009; Laos Red Cross, 2014). It is clear that the informants' "New Life" from "Bare Survival" have manifested positive outcomes when it comes to their perceived QoL through the aids of the programs offered by *Pinoy Plus*.

This study shows that when it comes to their emotional/psychological health majority of them approach their problems in life positively through acceptance, faith and avoidance (see Table 2) once they go through their "New Life" as a *Pinoy Plus* member. However, despite these positive approaches when it comes to their problems, some of them stated that they are preoccupied with problems due to how they perceive their future selves, job limitations, and discouragements they have. These negative views were possibly be carried out from the informants' "Bare Survival" to "New Life".

"Mahirap kasi parang iniisip ko may pag asa pa ba ako na makapgtra-baho, may pag asa pa ba ako na mabuhay ng matagal, may pag asa pa ba akong matupad mga pangarap ko. Mahirap kasi, ako wala akong work ngayon, nagrerenta ng bahay, ang daming problema...Tapos nung nala-man nila napakahirap sa akin kasi parang dinidiscourage ka nila"

*[It is hard, because I ponder on my things like: Is there a chance for me to get a job? Is there a chance for me to live a long life? Is there a chance for me to materialize my dreams? It is hard because I do not have a job at the moment, I'm renting a house, there a lot of problems... It has been really hard for me when they (family) found out about my illness, because I feel like they are discouraging me.]*

-Gelo, 27

"... pero hindi ko namang sinasabing lahat ng pangarap mo mawawala kasi pwede ka naman magtrabaho pero limit na lang siya. Yun lang mas kinadepress ko ng almost kulang kulang na isang buwan."

*[..... I am not saying that all your dreams will be gone, because you can always find a job but it is limited. That made me depressed for almost one month.]*

-Jay, 28

The negative views of some informants when it comes to their preoccupations in their problems can be associated with Veena Das' Stigma and Defect. Based on the given statement above Jay are preoccupied with his problems concerning his job limitations.

The statement of Jay can be associated with Defect, since it shows that due to Jay's illness his job and productivity are hampered and limited. Gelo's statement, on the other hand, present's Das' concept of Stigma. It shows from Gelo's statement that his preoccupations concerning his problems are because of the feeling of discouragements he receives from his family when they found out about his HIV status.

Another topic that was inquired in relation to the informants' health is their emotional/psychological health after joining Pinoy Plus. It is observable in the data that as inform-ants' transition from "Bare Survival" to "New Life" manifested positive outcomes as they joined Pinoy Plus. Their responses show significant improvements as they joined the Pinoy Plus (see Table 3). The reasons for these improvements were the support, em-powerment, and belongingness they receive from the Pinoy Plus. Through this inquiry regarding their emotional/psychological health after joining Pinoy Plus, two concepts of Veena Das emerged and these are Stigma and Contagion.

...kasi may nalaman ako na ganito pala... pagka may kapartner ka mahahawa yung kapartner mo."

[... because I found out that when you have a partner you can transmit (HIV) to your partner.]

-Gelo, 27

"Parang nadodown ka na sa sarili mo, parang nadidiscriminate ka na kunwari may koting hindi pag kakakintindihan sa magkakapatid o pami-lya, minsan nauungkat sa yung sakit."

[I feel so down. I feel like I am being discriminated. For example, when there is an argument with my brothers and sisters or with my family, sometimes my illness was brought up.]

-Gelo, 27

The first statement of Gelo above shows the concept of Contagion. In this statement, Gelo perceive himself as very contagious due to his illness, which is why it can be associated with Das' concept of Contagion. The second statement can be associated with Stigma, because as stated by Gelo there are times when his illness is bringing brought up as an issue when there is an argument in his family.

The physical health of the PLHIV informants are inquired as well to be able to understand better their health well being. When the informants were asked on how they view their

physical health after joining the *Pinoy Plus*, their views have inconsistencies (see Table 4). Some view it positively because of the involvement to the *Pinoy Plus* programs, and becoming knowledgeable about the treatment processes and lifestyles for them. This shows that the informants have different transitions when from their "Bare Survival" to their "New Life". One informant associates his physical health based on the symptoms of his illness. He responded that there is no change when it comes to his health before and after joining the *Pinoy Plus*, his reason is that he did not feel any symptoms of his illness. Veena Das' concept of Defect is observable in one of the responses. The informant stated that he perceives himself as not 100% normal compared to the people with no HIV.

"Ayon napapagod kasi hindi siya 100% na normal ganon"

[I get tired. It's not 100% normal.]

-Jay, 28

#### *Self Perceived Social Well Being*

Social well being, according to the United Nations Institute of Peace (n.d.) " is an end state in which basic human needs are met and people are able to coexist peacefully in communities with opportunities for advancement. " It is also an important aspect in determining the overall QoL and health well being of people (Aked, et al., 2008). Social well being in relation the the life transitions of the informants from "Bare Survival" to their "New Life" was inquired in this study through the informants' relationships with other people, perception of being safe and secure, and the overall view on the perceived social life.

When the informants where asked the changes in their relationships with friends and family when they have been disclosed, their responses show some inconsistencies (see Table 8). Some informants show that their relationships with their friends and family changed in a positive way because they became more supportive to them. Others viewed their relationship as stable, meaning nothing has changed in their relationship with friends and family. Also, one informant associates his relationship with his friends and family with how he could help them, he perceives himself negatively when it comes to productivity due to his illness. It can be observed that when it come to the development of the informants' life transitions from "Bare Survival" to "New Life", relationships with their

family and friends are important.

Despite the presence of negative perception with regards to the informants perception of being safe and secure (see Table 9), some responses manifested that through the empowerment given to them by the Pinoy Plus programs their social lives improved. It is clear that empowerment given by the programs of the Pinoy Plus greatly affects the informants' transition from "Bare Survival" to "New Life".

The perceived social life of the PLHIV after joining the Pinoy Plus, was also inquired. Based on the responses of the informants (see Table 10), it shows that Pinoy Plus greatly improved their social lives through the support, counseling, and activities the NGO gives.

#### *Economic Satisfaction*

When dealing with the two aspects of QoL, health and social well being, based from the conceptual framework, a new aspect which is disparate from the two has been discovered. This is the economic satisfaction, also known as economic utility. It is de-fined as "the total satisfaction in consuming a good or service" (Investopedia, n.d.)

The economic satisfaction has been taken into consideration in the QoL for this study. As studies suggest the economic satisfaction plays a vital role in measuring and understanding the QoL of people especially people with illnesses (Misajon, et al., 2005; Richardson, et al., 1998; Feeny, 2000; Reichardt, et al., 2012).

Employment status is one of the factors that determines the economic satisfaction, and also the QoL of PLHIV (Odek, 2013). Based on the employment statuses of the informants of this study, four of them are self-employed and one is unemployed (see Table 1). All of the informants show dissatisfaction with their employment statuses. Their productivity to work, salary and HIV status are some of the given reasons of the informants why they view their economic satisfaction as such. The perceptions the informants have on their economic satisfaction might have been carried out from their "Bare Survival" to their "New Life". It is observable that they attribute it to Veena Das' concept of Defect, for they relate their negative views productivity and job availability to their HIV statuses. Some of the supporting responses for this are the following:

"Wala ng pag aasa, paano ka maging productive, makatulong sa kanila kung may karamdamang ganito."

*[There is no hope, how will you be productive, how will you help them (family) if you have an illness like this.]*

-Gelo, 27

"..... pero hindi ko namang sinasabing lahat ng pangarap mo mawawala kasi pwede ka naman magtrabaho pero limit na lang siya. Yun lang mas kinadepress ko ng almost kulang kulang na isang buwan."

*[..... I am not saying that all your dreams will be gone, because you can always find a job but it is limited. That made me depressed for almost one month.]*

-Jay, 28

When the informants were asked about their income satisfaction, it shows that they have dissatisfaction on their income. Their responses are:

"Hindi masyado, compared dun sa meron kang stable job."

*[Not really, compared to if you have a stable job.]*

-Nigel, 27

"May income pero hindi 100% na enough.... pasok ko minsan Biyernes, Sabado, Linggo. Kung minsan sa dalawang linggo wala."

*[I have income, but it is not 100% enough.... I go to work sometimes Friday, Saturday, Sunday. Sometimes in two weeks I do not have any work.]*

-Jay, 28

"Hindi masyado, compared dun sa meron kang stable job."

*[Not really, compared to if you have a stable job.]*

-Nigel, 27

"Hindi, kahit nga yung regular na trabaho hindi satisfied sa ano nila e pati pa kaya yung ano"

*[No, even the ones with regular jobs are not satisfied.]*

-Bench, 30

"Sa ngayon hindi, kasi matumal, kasi sa gulayan ako sa palengke, sa ngayon kasi medyo matumal ang paninda lalo na sa mga gulay"

*[For now, I am not satisfied. Because the business I have in the market is slow especially on the vegetables.]*

-Kane, 40



Based on the responses of the informants, it clearly shows that their economic satisfaction is an aspect to be considered when determining the QoL of PLHIV. Studies suggest that economic satisfaction through the employment status of people with illnesses has been associated with their perceived QoL (Orbon, et al., 2005; Rueda, et al., 2011; Lund, et al., 2010; Carlier, et al., 2013; Velcu, et al., 2005).

#### *Self Perceived Quality of Life and Counseling Programs*

Based on the data, capacity building and counseling programs are two of the programs that helped the informants improve their QoL. Studies suggest that counseling programs for people with illnesses improve their self-capacities and well being (Thomas, et al., 2009; Lutgendorf S., et al. 1994; Raddi, Prakash, & Dandagi, 2014; Vigneshwaran, Reddy, & Devanna, 2013).

Counseling program for PLHIV is an effective process in improving their QoL (Laos Red Cross, 2014). Inquiring the perceived QoL of the Pinoy Plus informants for this research, the concepts of Veena Das on illness-- stigma, contagion and defect, have been observed through gauging their life transitions from "Bare Survival" to "New Life". The concepts have manifested themselves through inquiring how the informants perceive their social and health well being before and after joining the Pinoy Plus. One of the programs offered by Pinoy Plus that greatly developed and redefine how the PLHIV view their perception of their QoL is the counseling programs.

"Malaki yung effect noon kasi nag iba yung pananaw ko sa buhay mas nag-ing positibo. I see things in a positive way."

*[Because of the counseling programs offered by Pinoy Plus, I see things in my life in a positive way.]*

-Nigel, 27

"Nabago yung pananaw ko sa buhay. Parang... yun bang ano... wag mawalan ng pag asa."

*[My view on life changed... I should not lose hope.]*

-Gelo, 27

The life transitions of the informants from their "Bare Survival" to the "New Life" have been significantly developed and aided by the programs offered by *Pinoy Plus*. The programs that were offered helped the informants redefine their QoL, as they were aided

in creating a positive outlook on the life they have in relation to the social stigmatizations, defect and contagion that they have experienced.

### **CONCLUSION**

The case study focuses on how the Pinoy Plus' programs, especially counseling programs, affect the perceived Quality of Life of its PLHIV members. The perceived QoL of five Pinoy Plus members were inquired through the various dimensions of QoL, these are health, social well being and economic satisfaction. Based on the data gathered through the in depth interviews on the five informants, it can be assessed that the programs offered by Pinoy Plus, most especially the counseling programs and capacity building programs, are vital tools in redefining how PLHIV perceive their QoL.

The concepts of Veena Das have manifested on the lives of the PLHIV informants of this research, through inquiring their health and social well being. The informants responses gave an insight on how they redefine and identify their QoL through their shared experiences on the Stigma, Contagion and Defect. By establishing relationships, empowering, rapport building and educating its PLHIV members show significant impact on redefining their past in perception of their QoL.

It has been observed that the experiences of the informants with Stigma, Contagion and Defect from their "Bare Survival" have hampered them in coping up with their illnesses and having a better QoL. Despite this fact, as they joined and participated in the programs of Pinoy Plus, they were able to redefine in a positive way not only their QoL, but also how they perceive the Stigma, Contagion and Defect that they have experienced. Their life transitions from "Bare Survival" to "New Life" helped them cope with their health, social well being and quality of life; and one of the factors that aided them to their "New Life" were the Pinoy Plus and the programs they offer to the PLHIV.

### **RECOMMENDATIONS**

Based on the data, it shows that the health and social well being of the informants improved through the counseling programs offered. However, some respondents show pessimistic perceptions when it comes to their economic satisfaction/utility. For the counseling program practitioners, it would be essential to have an in-depth attention and

support on dealing with the PLHIV's view on their productivity and economic satisfaction. For the counseling programs, one of the informants suggests that age and gender specifications should be taken into consideration. As the informant stated, sharing of life experiences from same age groups and genders would be more effective, than from different age groups and genders.

Considering that the researcher for this study had limited time and budget, for future research, a series of longitudinal studies would be advantageous and possibly document a more in depth perspective and understanding on how Pinoy Plus programs help integrate and redefine the Quality of Life of its PLHIV members. Quantitative and mixed method research study related to the QoL of the Pinoy Plus members would also be beneficial and advantageous in gauging how counseling programs redefine the QoL of PLHIV.

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