

Journeying with a Person Living with HIV: Direct and Indirect Power Blocks and Empowerment Pathways as Inputs to Empowerment Workshops Providing Solutions from the Ground

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Abstract: *The study aimed to surface questions arising from the experiences of a young gay Filipino man who engaged in sex work as a minor with respect to direct and indirect power blocks and empowerment pathways which were used to create modules for a workshop that can facilitate greater empowerment of persons living with HIV. Using an anonymized interview transcript of a single case and analyzing it using thematic analysis guided by Empowerment Theory, the study identified 11 questions that were drawn from the themes that may be answered by several stakeholders in the community.*

Keywords: *HIV, Empowerment, Power Blocks, Empowerment Pathways, Empowerment Workshop*

I. Introduction

The HIV/AIDS & ART Registry of the Philippines (HARP) documented in February 2022 1,054 newly confirmed HIV-positive individuals resulting in a total of 96,266 cases to date (since 1984). COVID-19 has put these individuals at greater risk of dying (Gavi, 2021), especially those "with advanced HIV or people with HIV who are not on treatment" (MHAF, 2023). However, HIV-related service delivery, specifically those directly related to medication adherence and clinic appointment attendance, suffered due to the COVID-19 pandemic (SeyedAlinaghi, et al., 2023). If such were the case in the global north (Sun, et al., 2020), the situation is far worse in the global south, including the Philippines (Department of Health, 2020). According to the Department of Health, "the limit in social mobility created a variety of barriers for the access of the community to HIV prevention, testing, and treatment services" in the Philippines (p. 1).

Before the pandemic, governments already keep a registry of persons living with HIV (PLHIV) to help monitor the HIV spread (Lin & Liang, 2005). Reporting of new HIV infections varies across states in the US. Lin and Liang wrote that reporting systems are either name-based, code-based, or name-to-code-based. The first system is self-explanatory. The code-based system uses code identifiers instead of actual names while the name-to-code-based system has a two-step process - initial reporting by name and later conversion to code after patient processing and data collection. In the Philippines, the Philippine National AIDS Council was tasked, through Republic Act No. 8504, otherwise known as the "Philippine AIDS Prevention and Control Act of 1998", to ensure that programs pertinent to HIV and AIDS are implemented given the case monitoring system in place.

Amid the continuously rising incidence of HIV infections (Baclig, 2022), the depersonalization of PLHIV as a result of mandatory de-identification of patient's health information (Rafelson, Bruno, & Dizon, 2019) in compliance with data privacy laws, quantitative bias on HIV-reporting (Wilson, et al., 2016), and the drop on HIV awareness among young people (University of the Philippines Population Institute, 2022), PLHIV lives are reduced to codes and statistics, devoid of context that make it difficult for people to empathize with and easy to stigmatize others. HIV stigma, defined as "irrational or negative attitudes, behaviors, and judgments towards people living with or at risk of HIV" (MHAF, 2020, para. 1), has been around since the 1980s when HIV was first reported and remains a social problem that the medical establishment was not ready to address. Hence, artist advocates in the Philippines have initiated steps to address the stigma beyond the confines of the health profession (Bantugan, 2023; Bantugan, 2022).

For the most part, HIV has been studied as an infectious disease and epidemiological phenomenon. It is mostly studied from the vantage point of virology and pathogenesis (Fanelis-Belasio, et al., 2010), epidemiology (HIV.gov, 2022), drug (Maeda, Das, Kobayakawa, Tamamura, & Takeuchi, 2019) and vaccine development (Kim, Vasani, Kin, & Ake, 2021), mental health (World Health Organization, 2022) and service delivery (Ford, et al., 2021), experimental breakthroughs (University of Nebraska Omaha, 2023), media representation (Chanda, Mchombu, & Nengomasha, 2008), and stigma (Tran, et al., 2019). Mostly coming from the positivist lens, knowledge generated from them capitalizes on numbers and leaves a lot to the imagination when it comes to individual experiences. Qualitatively, they look into common experiences and narratives as they seek to arrive at knowledge with greater community impact. For other qualitative researchers, case studies open doors to outlier narratives that bring to the foreground marginalized stories that also need to be understood to be addressed more compassionately. It is this principle that this paper hopes to follow and amplify

II. Theoretical Framework

Given these situations, it is deemed that the PLHIV must be "empowered" so that he/she/they can better manage his/her/their condition and deal with stigma. Guided by the Empowerment Theory in social work, this paper is focused on identifying areas where the PLHIV experiences a lack of autonomy and control in his/her/their life so that proper interventions can be proposed toward such end. Empowerment Theory asserts that "oppression is a primary contributor to disempowerment, which is experienced across several marginalized groups..." (and that empowerment involves helping people) "gain personal, interpersonal, and political power to better their lives. (by challenging) systems that hinder... (them) from meeting their needs" (Martinez, 2022, para. 7). Factors that get in the way of empowerment are (1) direct power blocks and (2) indirect power blocks. Direct power blocks are "systems and structures that prevent people from achieving important goals, such as better employment conditions, higher education, or safe housing" (para. 5). Meanwhile, indirect power blocks arise from "internalized oppression" such as "personal and historical experiences of widespread mistreatment" (para. 6) that lead to negative self-worth and mindset. This paper unravels these two factors at play within a case narrative and surfaces circumstances that can be modified toward the achievement of empowerment. This paper considers the opposite as empowerment pathways.

This paper sought to underscore the human experience of a PLHIV in the context of "empowerment" to identify areas in his/her/their journey with HIV that need to be addressed by society, in general, and specific groups, in particular, to help a PLHIV to deal with his/her/their condition despite or because of HIV stigma and power blocks. Using the experiences of a PLHIV as a starting point, the paper surfaces critical questions that can help formulate a multi-layered solution or solutions that can be constructed by a community in the context of a workshop.

III. Methodology

This qualitative study involved the data mining and single case study approach where an already existing and anonymized interview transcript involving a selected PLHIV was analyzed to bring about themes

that describe the direct and indirect blocks and pathways to the empowerment of a PLHIV. The single case was selected purposively as it highlights experiences with several persons, groups, and institutions that manifest in great detail the said direct and indirect blocks and pathways to empowerment. The interviewee in the transcript is male, below 40 years old, a graduate of an associate program who turned to sex work for a time as a minor and, after his recovery from opportunistic infections, was able to work in a non-government organization serving the needs of persons with HIV. He currently works in various companies simultaneously. The multi-dimensionality of the case presents a complexity beyond what statistics often reveal that can help bring light to the need for complex solutions that lead to genuine empowerment, not just treating a viral infection. This case necessarily called for a thematic analysis that helps to uncover the recurring themes shaping the journey of a PLHIV. Situations in the journey that constitute direct and indirect blocks and pathways to empowerment were highlighted and, consequently, needs and opportunities requiring multi-sectoral response were identified by surfacing questions that will help draw them out from a community in the context of a workshop. A series of workshop modules are presented at the end together with corresponding workshop participants and the brainstorming guide questions that arose from the thematic analysis.

IV. Results and Discussion

The interviewee (named in this paper as “Alex”) was orphaned as a child and was adopted informally by a distant relative – a stepmother. He completed a bachelor’s degree despite his circumstances. However, he engaged in sex work when he was 17 years old. This experience must be highlighted since he sought the help of local and foreign “sponsors” when he found himself infected with HIV but could be considered engaging in a criminal offense. He also values a public image as a person living a comfortable life. He did not want to be pitied and the possibility of being looked down upon horrifies him. He faced many direct and indirect power blocks when he started getting sick of complications due to HIV.

Direct Power Blocks (DPB) and Empowerment Pathways (DEP)

Doorway to child sex work. At 17, he found himself engaged in sex work while studying in college. While some people may argue that engaging in sex work is just another kind of work equally respectable as another profession, his being a sex worker at 17 makes him a sexually exploited child. Although he was willing to divulge this part of his life during the interview, he did not engage in sharing the details of his transactions. Even if he did participate willingly in his sexual violation, the act is considered criminal for the offender, and he cannot technically give “consent” since he was a minor. Given this, what is revealed is a doorway to sex work that is easily accessible to minors in Philippine society. One may argue that it was access to an Internet-connected gadget that makes it easy for any child to engage in sex work. Others may counter that a mobile phone does not make a child a sex worker. Whatever drove him to do so, there is an existing doorway he could access at an age where a person is assumed unable to make any free and informed consent.

How are minors protected by immediate family, school, or the government from engaging in sex work?

HIV dark room. He admits not knowing about HIV when he was actively engaged in sex work. At his age, 17, educational materials on HIV and consultations with sex counselors are far from accessible in the Philippines. Hence, he went in blind. His story suggests that there was neither education on HIV from school, his “family”, nor his sex clients. He revealed, “I was forced to suppress my sexuality because they do not approve of me as being gay, so I remember this time when I was trying to out myself to my stepmom and half-sister, they gave me a Bible and a rosary telling me that, ‘it’s just a phase, I should pray it off’. *Babalik din daw ako sa dati* (I will return to my old self).” This reveals that there was no education from his “family” because their religion forbids them to go beyond heteronormativity. Thus, his blindness is partly constructed by

Catholicism, religious dogmatism, and blind obedience. Blindness to HIV, then, means his family's blindness to empathy, as well.

Outside family, school, or illicit sex partners, where can knowledge about HIV be made available to minors?

Holes of Light in the HIV dark room. He, however, pointed out that he had an intense desire to be emancipated from his family because of their homophobia, suggesting that there were other spaces where he learned to listen to himself and fight for his authentic sense of self. This means that he has other sources of inspiration beyond family, school, or church. Alex did not share where this strong sense of self comes from but it was something that persisted even in the most desperate times. He commented that during his confusion, "I researched everything over the Internet, trying to see what I can do for myself. I would chat or text my friends who are in the medical field, telling 'hoy, 'pag ganito ba ang nararamdaman mo, ano ba ang gagawin (hey, if this is what you feel, what should you do)?" This suggests that he has a social circle that served as an alternate support system, or an extension of his socially unaccepted self, light occupying empty spaces, instead of darkness. This social system accepted his homosexuality and strengthened his conviction about being true to himself.

But what will ensure persons like him that such alternative sources of support are adequately informed about HIV and not equally blinded by an ignorant family, school, or religion?

Conditional structures of assistance. Even as Alex was abandoned by his family, several people who were not blood-related came to his rescue, but they did so not knowing he had HIV.

Landlady Incident. For example, when he found himself in a health emergency, his landlady helped him access medical help. He narrated:

I (could not) stand anymore, I (could not) breathe, *tapos* (then), I (was) all alone. *Parang* (it seemed) I (was) really hopeless. *Tapos* (Then), I asked help from my landlady at that time *kung pwede niya akong dal'an ng ganito* (if she could bring me things)... *kasi nga hindi na talaga ko makagalaw* (because I could no longer move)... 'yung(that) landlady ko(of mine), *buti na lang, nagdadala siya sakin ng* (good thing, was bringing me) food that time... and (then) I just... completely blacked out, and then, *nagulat siya* (she was surprised) that I already passed out, so she immediately called an ambulance, so I was rushed by to the nearby hospital.

However, when the landlady found out about his sexual activities before being taken to a hospital, she slowly backed out of the picture. He continued:

... the next thing that came out from the doctor, "*baka may HIV ka na* (perhaps, you already have HIV)..." I was just looking at my landlady at that time and *nakikita ko na parang nandidiri na siya*(I saw that she seemed disgusted) then she just got out of the hospital. *Hindi na niya ako binalikan* (She did not come back for me).

Health Care Facility Incidents. In another incident, while he was staying bed-ridden in the RITM (Research Institute for Tropical Medicine) and had no one visiting him and attending to his personal needs, the nurses were at his service. He recounted:

parang naaawa na sakin 'yung ibang nurses. Ang haba na ng balbas ko na ganyan. Hindi ko man lang maiangat 'yung buong kamay ko kasi parehas siyang may nakasalpak na ano, so parang, habang

'yung mga nurses na nagse-shave sa 'kin, naiiyak ako kasi sabi ko (noon), "I don't know why I'm... here, bakit ako nandito ngayon. Thanks for being the family na wala ako ngayon."

(... it seemed the nurses pitied me. My beard was getting too long. I could not even raise my hands since both had something, so while the nurses were shaving me, I was teary-eyed as I was telling myself, "I don't know why I'm here... Thanks for being the family I do not have now.")

Earlier, however, when he was sent to the intensive care unit (ICU), the nurse in charge was far from being empathetic. Alex recalled:

"I was diagnosed with 10 or more opportunistic infections... I have tuberculosis, pneumonia, I have dermatitis, I have gastroenteritis, the greatest challenge that I had was, siguro 'yung (perhaps was) how I would support myself inside the hospital without anyone beside me... I can't ask someone to throw the urine... that's why *kahit igapang ko na papunta ng CR gagawin ko* (even if I had to crawl to the washroom I would do it). I had to do it *kasi*(because) no one's gonna take care of me. *Sinisigawan na ko ng head nurse na* (The head nurse was shouting at me saying,)," *Ano? Hindi ka pwede dito sa ICU nang walang nagbabantay sa 'yo.* (What now? You can't stay here in the ICU without someone looking after you.) You need to ask someone to be here for you *kasi* (because) no one's gonna do this and do that." But I cannot...

This happened even if, at the beginning, during a similarly critical situation, he was told: "... *nandito kami. Kami na lang muna isipin mo, 'wag mo na isipin 'yung sasabihin ng ibang tao* (we are here. Just think about us instead of what other people will say). Let us help you and you need to help yourself to become well."

Boyfriend Incident. His boyfriend, after seeing the sorry state that he was in while undergoing treatment, left him as he was unable to deal with Alex's situation. He shared:

... sobrang shocked siya na. Bakit ang payat ko? Bakit ang itim-itim ko na (he was so shocked. Why was I so thin? Why did my skin turn so dark?). And then, *sabi niya* (he said), "*May AIDS ka ba?*" "*Ba't ka nandito sa RITM? May mga AIDS lang 'yung mga nandito* (Do you have AIDS? Why are you here at the RITM? Only those with AIDS are here.)" *Ginaganyan niya ko* (He treated me that way)... And then, *sabi niya* (he said), "You know what? We need to stop this. *Parang ayoko madamay kung ano mang meron ka* (I don't want to get dragged into your problem.). *Parang 'yung* meaning *n'ung sinasabi niya* (what he meant) ...*'di ko ma-digest lahat eh* (I couldn't digest everything). *Sobrang sakit n'ung time na 'yun* (It was so painful during that time). *Pero 'yung* (But the) main point is *parang gusto niyang sabihin sa 'kin na parang bulok na ko* and that *parang ano pa 'yung makikita niya sakin* (it seemed he wanted to say to me that I was rotting and he did not know what else he would see in me).*Parang gan'un. Parang gan'un 'yung feeling na pinaparamdam niya sa 'kin* (He made me feel that).

Sponsors Incident. Alex, in his better days, was able to meet people who would support him financially. He did not expound on the nature of the sponsorship but based on his story, he did not want them to know his health status so he could entice them to send him money in a time of need. His strategy involved teasing and taking them for a ride and talking to them occasionally, mentioning his being in the hospital without revealing his HIV infection. Otherwise, they would not give money. He revealed:

... since *konti lang 'yung savings ko* (since my savings were running out), I have what I called "sponsors" - *mga* (they are) gay men or people abroad both Filipino and foreign (who) give financial help *sa 'kin* (to me)... partly *kinakausap ko sila, parang alam mo 'yun* (I talk to them, somewhat like,

you know) they like giving me money, so *parang binobola bola ko pa sila* (I somewhat fool around with them), *kinakausap ko pa din sila* (I converse with them) from time to time. I would make some reasons why I'm in a hospital. *Sasabihin ko na* (I would tell them) I'm sick and I need help and (the reason) why I'm in a hospital is that (I) ate something and my tummy hurts.

Friends Incident. His experience with people he considered friends were similar to what he had with his boyfriend. They turned their backs quietly when they learned of his HIV status. After being abandoned by his boyfriend, his friends did similarly. He described:

And, so I had no choice. I had to contact my friends. I have friends, there were 12 of them. *Parang n'ung una parang sinasabi nila*, "okay lang" (It seemed at the beginning they were saying, "it's okay"). Slowly, *hindi sila nagpaparamdam* (they disappeared). *Alam mo 'yun, parang nararamdaman mo na, evasive na sila sa 'yo* (It seemed they were becoming evasive of you, you know?).

Family Incident. During his release from the treatment facility, his family fetched him. Unfortunately, they could not take him in completely after bringing him to their home.

Then, *parang* one day, *hindi nag-message sa 'kin*, and then the next day (they messaged me, saying) "me and mommy (are) going there." Then, *dumating siya* (she arrived). She was wearing five gloves. Then, *ang dami niyang mask na suot, patong patong* (she was wearing masks on top of one another). Then, *ayaw niyang lumapit, sa may door lang siya* (she does not want to come closer, she stayed by the door).

And then she (was) telling me, "*si mommy nasa guard house lang sa baba. ayaw pumasok kasi mahawaan mo daw siya. And parang siya din parang ayaw niya. Sobrang malayo siya sa 'kin* (Mommy is at the guard house downstairs. She does not want to come in because you might infect her.)

And then like, *sabi ko, "hindi naman nahahawa sa ganito, ganyan ganyan* (it is not contagious that way, like that)".

(She responded) "*Hindi, marami kang sakit eh sabi ng doctor ganyan ganyan* (No, the doctor said you have a lot of infections)." So *parang wala akong* (it seemed I had no) choice. I had to (be quiet), *kasi* that time *iniisip ko na kasalanan ko* (I was thinking that it was my fault), *parang deserve ko 'yun kasi nga hindi ako nag-ingat* (it seemed I deserved it because I did not take precautions).

Sinasabi niya nga na (She also said), "*Ano na naman tong ginawa mo? Parang lahat na lang (ng problema binigay mo sa 'min* (What did you do again? It seemed you have given us all the problems) ...*So parang sobrang ang down ko n'un* (I felt so down then).

Inside the car and at home, after Alex was released, his maltreatment did not stop. He recollected:

So, I thought that's going to end there but *hindi pa pala* (not yet apparently). The worst is yet to come *pa pala* (still). So aside from the physical hurt that I got because of my condition is *'yung* (the) emotional pain *na nare-receive ko* (that I received) from my own family...

Tapos 'yung pagdating ko sa kotse, 'yung buong seat may mga Manila paper ta's may plastic cover. Sabi n'ung half-sister ko, "Buksan mo lang 'yung window ah. Baka 'yung paghinga mo dito sa loob (umikot). Tapos make sure hindi ka magle-lean sa seat... Diyan ka lang sa dulo, Kailangan 'wag daw ako gumalaw... (When I got into the car, the car seats were covered with Manila paper and overlaid

with plastic cover. My half-sister said, "Open the window. Your breath may circulate inside the car. Then, make sure you don't lean on the seat... Keep yourself at the edge of the seat." I was told not to move.)

Tapos pagdating ko sa bahay gan'un 'yung nakita ko sa bahay, lahat naka-cover, tapos parang ayaw ako kausapin ng step-dad ko (who) is a foreigner, ayaw niya kong kausapin. Tapos 'yung step mom ko parang, "D'un ka na, dumiretso ka na d'un sa labas. D'un ka na sa may kitchen. 'Wag ka na dito. 'Wag mo na ko kausapin." Ginaganun nila ko. (Then, when I arrived at home, I also saw that everything was covered inside the house, and my step-dad refused to talk to me. He did not want to talk to me. Then, my step-mom was saying. "There, you have to go straight out the door towards the kitchen. Don't stay here. Don't talk to me." They were treating me that way.)

Tapos kapag may gusto silang sabihin sa 'kin, 'yung katulong kumakausap sa 'kin. Sasabihin (n'ya), "Sabi n'ung mommy mo 'yung kutsara mo, tinidor mo, ganyan, ito naka-plastic. Dito lang siya ah. Ikaw lang daw pwede maghugas niyan. Huwag mo daw ako pahugasin ng plato mo kasi baka daw pati ako madamay, parang mahawaan...I would eat separately from them. Sobrang hirap, even (my interaction with) the dogs. (I was told), "Hoy, huwag mo hayaan lumapit sa 'yo 'yung aso baka dila-dilaan ka niyan," (When they want to tell me something they course it through the helper. The helper said, "Your mommy said, your spoon and fork are inside the plastic. Keep it there. You need to wash it on your own. I should not wash it because I might get infected... I would eat separately from them. It was so difficult. Even my interaction with the dogs. I was told, "Hey, don't let the dog come close to you because it might lick you.)

He was also told painful words that drove him to move out and live independently:

Kasi lagi nila sasabihin sa 'kin na inutil na ko. Wala na 'kong magagawa sa buhay ko na parang forever na 'kong imbalido, parang ganun. Gan'un tingin nila sa akin. (They also said,) "Hindi ka na makakahanap ng trabaho niyan. P'ano yan? Magiging pabigat ka na samin." Alam mo 'yun? Gan'un 'yung iniisip nila sa akin so I had no choice. I had to move out. (They always told me that I was helpless. I can't accomplish anything in life anymore, as if I were a paralyzed. That was how they saw me. They also said, "You will not be able to find work anymore. How about that? You will just be a burden to us." You know? That's what they thought about me so I had no choice. I had to move out.)

Given the above incidents of conditional acceptance and assistance, what less judgmental support structures can be provided for persons living with stigmatized illnesses?

Data Privacy Breaches. As Alex spoke about his experience being admitted to healthcare facilities, the issue of healthcare professionals not observing data privacy protocols stood out as rendering Alex more vulnerable.

Admission Breach. When he passed out and was sent to the hospital, his first encounter with a sick care professional made him more uncomfortable when he was already in grave discomfort. He noted:

I was rushed to the nearby hospital. the first hospital that I had been to. *Hindi... gan'un ka-friendly sa 'kin 'yung doctor (The doctor was not so friendly to me). Parang (It seemed) she was really straightforward to the point na she asked me immediately, "Ano bang sexuality mo? Bakla ka ba? (What is your sexuality? Are you a homosexual?) Ganyan (Like that) ... she asked me, "Are you sexually active?*

He was asked such very personal questions while his landlady was beside him and when he was barely conscious after passing out. He questioned the nature of the line of questioning by the emergency doctor because it made him so uncomfortable. In his own words:

... the landlady was beside me so I could not speak up. Feeling *ko* (I felt) it was not a safe space for me just to blurt out everything *kasi* (because)... (I was) around other people *sa loob ng* (inside the) emergency room.

Given his vulnerability, Alex thought not answering will jeopardize the delivery of the medical service he needed at that time, especially because of the non-verbal communication of the sick care professional before diagnosis. He intimated the undue pressure of the doctor when he encountered the inappropriate line of questioning that led him to not be truthful (and in his condition, he was likely not in the right disposition to answer properly such a sensitive question in front of his landlady):

... the look from the doctor *kasi, parang* (it seemed) I was overpowered. *Parang* (it seemed) I had to answer *kasi kung hindiwala siyang gagawin* (because if I won't, she won't do anything). So, *sabi ko* (I said), actually *po, may naka-sex po akong same sex mga 5, 10* (I had same sex intercourse with five, ten people). '*Yung totoo* (In truth), 20, I don't know. More '*ata* (I suppose). *Hindi ko na talaga alam* (I don't really know).

Based on that alone, the doctor responded, "... *baka may HIV ka na* (you probably have HIV)." Hence, over and above the inappropriate question and intimidation, was suspicion that sounded like a proxy for diagnosis on a person who has yet to undergo HIV testing, which worried Alex further. Furthermore, a bystander doctor approached him saying, "Son... this is not the place you should be in. You need to go to the RITM and, if you want, we can arrange an ambulance for you to be brought (there)." This rendered the suspicion a prediction at a time he was not sure what was happening to him. Alex had to take this all in upon admission to the hospital.

It took him a few more hours before he arrived at the RITM (and it can be assumed that he did succumb to the pressure or undue influence). He said, "a few hours later *dinala na ko sa* (I was brought to the) RITM, and from there *parang hiniga na nila ko dun sa parang* (it looked like they made me lie on a bed inside what seemed like the) ER (emergency room). And then, *tinatanong ako ng* (I was asked by the) doctor if I wanted to get myself tested for HIV." While it is expected that doctors should ask patients if they would agree to any diagnostic test, the test was the reason why he was sent to RITM in the first place. For a patient who has waited hours to get the proper medical attention, such a question would be ridiculous at that point. This means the protocols have the effect of further stressing out the patient. True enough, Alex admitted, "I just said, *sige po* (alright) Doc. *Kayo na po bahala* (It's all up to you). *Wala na akong pakialam* (I don't care anymore). *Mamamatay na din naman 'ata ako ganyan* (I am about to die anyway). *Parang* (It seemed) I (was) losing, I (was) losing the will to survive that time." Being so exhausted, he just surrendered his agency. It would have been the end of his agony after agreeing to the test, but he had to undergo more suffering (including being revived in what sounded to him was a rabies treatment facility which he resented), the most difficult was waiting for the test result that came only the next day.

How are sick care professionals trained to be sensitive and more empathetic to PLHIV? How are they to be made strict enforcers and followers of data privacy in their professional practice?

Release breach. When he was about to be released from the RITM, his encounter with his step-sister led to another data breach committed by the latter. He narrated:

... what she did, was she got my phone and texted everyone on my contact list that I have HIV. *Ang* (The) reason *niya daw kasi, para daw ma-inform baka may naka-sex daw ako o naka-contact...* and she just means well for them *para magpa-test din* if ever *nakasalamuha daw nila ako* (Her reason was that she wanted those who had contact or sex with me to be informed so that they could get tested for HIV).

While the doctors intervened as she was on Alex's phone, it is more apt that the doctors briefed his family earlier about the right way to proceed in helping Alex manage his situation outside of the hospital, including managing information. This means it would have saved Alex from undue stress upon his release if the doctors intervened earlier and sufficiently. However, they did not.

It is good to note that this kind of information dissemination work on behalf of the PLHIV also happened to Alex's deceased ex-boyfriend. Alex was informed by his ex-boyfriend's sister that his ex-boyfriend had died of tuberculosis. "His sister called me on the phone and said I should get tested for HIV and that my ex... died of tuberculosis," he revealed at the beginning of the interview. Unlike Alex's step-sister, this kind of information dissemination did not overstep the PLHIV's privacy needs. However, having done so too late may not be to the benefit of those receiving the information. Thus, PLHIV must be advised promptly when and how they should advise people concerned about their HIV status. For Alex, dealing with his status is overwhelming enough; informing others about it is beyond him. He admitted his overwhelming fear of HIV:

... *natatakot ako* (I was scared). What else can this virus do? *Parang sobrang payat ko na, naglalagas 'yung buhok ko* (I was so thin and I was shedding my hair). And then *ang dami kong spots sa katawan* (I had so many spots on my body). *Parang alam mo 'yun?* (You know that?) *Diring diri ako* (I was disgusted) looking at myself. But I cannot do anything about it. *Ang hina ko* (I was weak). *Hindi man lang ako makatayo* (I could not even stand). *Hindi ko man lang ma-balance 'yung sarili ko* and *sobrang natatakot ako* (I could not even balance myself. I was so scared). What else is going to happen with me? And *lagi kong tinatanong sa doctor ko* (I walyas ask my doctor), "how (much) chance would I (have to) live? *Kaya ko pa ba* (Can I still bear it)? I would question my own self, *'yung kakayanan ko* (my capacity) ... to survive.

He was always hesitant to divulge his HIV status. It seems it is not when or how he would inform others, but whether he would given that he does not want to be pitied. He remembered:

Kasi natatakot talaga ko na parang (I was so scared that a) single information will come out so *ayaw ko talaga* (I didn't like it really). *Sobrang laki talaga ng walls ko na parang* my pride is so high *na parang hindi pwede malaman ng iba* that I'm struggling (My walls and pride are so high I could not allow anyone to see that I am struggling).

He also preferred to remain quiet about his status, neither announcing nor denying anything, for fear of negatively affecting family members to whom he wanted to prove himself upright. The quote below also connects tightly with indirect barriers to empowerment, which will be discussed later.

I'm still okay *kasi* (because) I don't want them to worry. I don't want them to know or find out what I have... I did not have the strength to message my family, my half-sister, and my stepmom. *Parang 'di ko kaya magsinungaling sa kanila* (I could not tell them a lie) so I just kept quiet... *Sabi ko* (I said), "ano man mangyari, *ayoko madamay sila sa ganito. Ayokong malaman nila*, as much as possible, *maghirap man ako, mamatay man ako* (Whatever happens, I don't want to drag them into this. I don't want them to know, as much as possible, even if I suffer or die). *Dapat hindi nila malaman na nandito*

ako sa ospital ngayon na that I have HIV (They should not know that I am in the hospital now that I have HIV).

The quotes above explain why he reacted violently when his step-sister took his mobile phone and disclosed what he has fought so hard to keep hidden for his self-preservation. Whatever sense of agency, hope, and dignity was left with him was stolen by his step-sister whom he initially trusted with such information. He described his reaction when his step-sister took away from him his authority to disclose his status:

I was pushing her away. I was shouting. I was hysterical. *Parang gusto ko nang mamatay* (I wanted to die) ... *Parang gusto ko na kainin na lang ako ng lupa* (I wanted the ground to swallow me). *Kasi* (Because) how will I face the world after this? Here I am trying my best to be better and then *biglang* (suddenly)... the things that I'm looking forward to like my friends or people around me, my work, *parang* (it seems) now that they know '*di ba* (isn't it)? The rumors, '*yung* (the) discrimination. How would I deal with that? Paano ko gagawin '*yun* (How will I manage)? *Parang sobrang kahihyan, sobrang takot, sobrang wala* (All that shame, fear, and nothingness). I lost hope *talaga* (truly).

Given the above sufferings of a PLHIV like Alex, **how can families be held accountable and committed to observing data privacy, especially of PLHIV related to them?**

Indirect Power Blocks (IPB) and Empowerment Pathways (IEP)

Alex was employed when he was interviewed. He was also able to take part in an organization that serves PLHIV while he remained positive. This means that he realized self-efficacy, critical consciousness, and tool development, enough to remain employed while he still journeys as a PLHIV. However, he expressed that reaching empowerment has not been easy for him from the moment he started suspecting having been infected.

Abandonment and indebtedness issues. Alex battles with having been orphaned by his parents when he was still a child and living with a family not his own. He feels indebted to them and felt he had to abide by their rules to remain part of the family. Thus, he sought their permission to live as a homosexual man. Unfortunately, they refused to accept him as a gay man. Feeling indebted, he tried living as a heterosexual man. He noted:

I had to do everything I can *para 'di sila ma-off sa 'kin* (so they will not be turned off by me) so *ginawa ko lahat*(I did everything). I mean, I studied well. I tried my best to court girls.

After he was found to be HIV-positive, he was hesitant to inform his family about it, saying, "they had helped me graduate, get a decent job, *tapos ganito pa 'yung ire-repay ko sa kanila* (then, I will repay them with my HIV status)."

The narratives above reveal a power dynamic between Alex and his family where he feels obliged to defer to the latter because of their help to him throughout the years, otherwise, he will find himself without a family once again. His having been orphaned early in his life creates an undue attachment and sense of indebtedness to the family that adopted him that prevents him to assert some semblance of independence at the most crucial point of his life. Without the family's blessing, he feels unworthy. He shared, "I was thinking, *may magmamahal pa kaya sa 'kin* (will somebody love me still)?" This worry weighs even more in the face of his HIV-positive status, which he assumes will disgust other people ("*Pandidirihan ako ng tao* (People will be disgusted with me").). Who else will love him if his family will not love him anymore because of his HIV infection?

Thus, he wrote a message reaching out to his family and opening up about his being HIV-positive. He described his letter in this manner:

I composed a text, *parang* (seemingly) it was a three-part text for my half-sister *na lahat sinabi ko na dun* (where I said everything). *Lahat ng* (All of the)... disclaimers *na pwede ko maisip* (that I could think of) (I wrote.). *Sabi ko*(I said), “*wag niyo na muna sana koi-judge* (I hope you don’t judge me yet). *Sana isipin niyo na kahit ganito yung nangyari sa ‘kin, nandito pa rin ako* (I hope you consider that even if this is what happened to me, I am still here). I still love you. *Hindi ko kayo masisisi kung magagalit kayo sa ‘kin* (I can’t blame you if you are angry with me). I’m in the hospital right now. I have HIV.

The message does not apologize but seeks acceptance and understanding - things that he knows are far from guaranteed given how they refused to accept his homosexuality. After all, HIV is easily associated with homosexual intercourse. Not being biologically related to his family is a barrier enough; his homosexuality has already strained their relationship in the past. His HIV status can worsen the damage only he has caused his family. These are layers of vulnerabilities that touch the core of Alex and others who are homosexuals in homophobic households who feel they do not belong anywhere especially when they are HIV-positive.

What cultural structures can help a person form a greater sense of self-worth that is not bound to and can exist separate from authorities in his/her/their life?

Uncertainty and Insecurity. Alex’s hospitalization bill was a huge burden in and of itself, especially after having spent much time in confinement like him which led to his eventual firing from his job in a call center. He recalled:

... *yung* (the) problems had arisen... *p’ano ko babayaran lahat ng bills ko?*(how will I pay all my bills?).*Parang sobrang nagpa-panic ako* (I was panicking a lot). *Ano ba?* (What now?) *Ba’t tumataas yung bill ko every single day?* (How come my bills are rising daily?). And I stayed there for almost three months *sa buong hospital duration ko* (during my entire stay in the hospital).

This may be considered a worry any person would have given a long period of hospitalization without the benefit of a health insurance. But note that his parents died when he was just a child so this may resonate with his experience of uncertainty with life in general. He has no hold on anyone or anything, including money, especially when was fired from work. In short, his rising hospital bills may have intensified an already excruciating loss from his past from which he probably did not recover completely. Growing up, he might have suffered dealing with his anxieties and problems alone, realizing that he is nothing but a burden to his adoptive family (this is reflected in a previous narrative expressing his sense of indebtedness). He should find a way of getting out of his financial problems because he cannot expect his adoptive family to pay for them. After all, to attain more independence, he has to feel less indebted and trapped in them. But how will he be more empowered if he had to depend on them for the payment of his hospital bills? Thus, he could not help worrying whether he can truly find a way out given his mounting concerns when he was contemplating his hospital release. He confessed:

It’s really bothering me *kung paano ko masu-surpass yung problems* (how I will surpass all the problems) that would arise after (my release), *kung ano man mangyari sa ‘kin* (whatever happens to me) ... how my friends would react, my work, *kung may babalikan pa ba kong trabaho* (if I still have work to return to). How are they taking it now? *Sobrang dami* (So many). *Lahat ng* (All) aspects *ng buhay ko naisip ko* (of my life I was worried about). What’s going to happen next?

His uncertainties, make him easily succumb to offers of support, even from persons he hardly knows. For example, he met a person online who learned about his HIV status when they met at his place. Having discovered the medications Alex was taking, this new acquaintance offered to be his boyfriend based on them being both HIV-positive. Hoping to cling to whatever semblance of support he could get, Alex agreed immediately. He narrated:

... *sabi niya parang kung gusto ko ba daw maging kami na lang daw tapos parehas daw kami ng status ganyan ganyan. So parang sabi ko okay, I'll go with this...* [he asked if I wanted us to be partners since we had the same (HIV) status and so on. I somewhat said (to myself), I'll go with this...]

When the new relationship did not work out, Alex down-spiraled in anger which led him to stop taking his medications (“... *tapos* (then), he cheated, *nalaman ko na naman* (I found out). it didn't work out. *Parang galit na naman ako sa mundo* (It seemed I was mad at the world again). So, I stopped taking med(icine)s.). This shows how deeply embedded his insecurities are in being abandoned at his lowest point in life. His words above - “I was thinking, *may magmamahal pa kaya sa 'kin* (will somebody love me still)? - seems to be a melody underlying his life story which goes back to his having been orphaned as a child, and perhaps, being a child sex worker who received money but not the love that he desires.

What cultural structures can help make persons more self-confident and capable of self-love?

Aspirational Facade and Positive Manifesting. At first glance, Alex may be seen as an image-conscious person, and given his circumstances, a pretentious one. He described aspirational images he wants to present to the social media world while he was confined in the hospital:

... *sa social media ko* (in my social media), I will, *alam mo 'yun* (you know), *nag-iisip pa rin ako ng* (I was still thinking of a) way... to make it feel like I'm still around, *na hindi ako naospital* (that I wasn't hospitalized). I would post pictures *na nasa* (that I was in a) coffee shop... but that picture was taken from my previous... *mga* previous pictures *ko* (my previous pictures), *mga* (some) throwback pictures *ko na lang* (of mine) and then, I would still message *'yung* (the) boss *ko*(of mine)*na parang* (something like), “boss, I'm in working right now”.

But a second look would reveal a person, like any other person, imagining a situation he prefers to look forward to. To deal with his helplessness, he imagines himself as a regular person able to do what he wills. He presents an aspirational facade because the other option is to present a situation other people would automatically pity or stay away from. Despite his illness, he continues to communicate with a person whom he was dating before his confinement. In his social media, he projects a normal life he lived before he ended up trapped in a hospital for stigmatized patients. He was manifesting, perhaps, a positive future. He confided:

... I won't allow people to see me on cam(era) and I still (was)... dating someone at that time and he was asking why I (was) still not showing (myself). So, *sasabihin ko* (I said), “I am just here and... i am just busy... I (was) still maintaining this personality... uhm, a picture *na*(that) I'm still okay *kasi* (because) I don't want them to worry. I don't want them to know or (find) out what I have...

The other image, the realistic one, was mired in challenges he has no way of facing, more so, fighting against. In his own words:

... how will I face the world after this? Here I am trying my best to be better and then *biglang 'yung* (suddenly) the things that I'm looking forward to like my friends or people around me, my work... they know, ‘*di ba* (isn't it)? ... the rumors, *'yung* (the) discrimination, how would I deal with that? Paano ko

(*haharapin*) 'yun (How will face that)? *Sobrang kahihyan, sobrang takot, sobrang wala* (So much embarrassment, fear, and emptiness). I lost hope *talaga* (truly).

What cultural structures can help a person realize alternate realities that he can potentially attain despite contradictory messages from the status quo?

Defense Mechanism and Fight for Humanity. Thus, one might consider, alternatively, the positive imaging as a form of defense mechanism, some form of escape, perhaps - something that would pull him out of the rut, out of despair. It is also possibly a way of facilitating faster healing as the body follows the mind. And yet, he admits that he is full of pride that he does not want to be seen defeated ("... *sobrang laki talaga ng walls ko na parang* (my walls were so thick and) my pride is so high *na parang hindi pwede malaman ng iba that I'm struggling* (that I resolved not to let others know I am struggling").

Given his predicament, and the brute force by which he tried to reimagine what would be an obvious defeat, he is better seen as a "fake it till you make it" believer. Despite his sense of abandonment and insecurities, a sense of strength lies within him, nevertheless. This strength is nourished in the belief that despite the odds stacked against him, and his occasional surrender to persistent worrying, he knows he deserves more and refuses to be treated less than what any person deserves. While being resuscitated in RITM, he was still conscious of his surroundings which he strongly believed is less than what he ought to receive as care. He recounted:

... *ang init ng room na 'yun, ta's para siyang room for rabies patients* (the room was so hot, then, it seemed like a room for rabies patients). I can hear people shouting, *'yung mga may rabies* (those who have rabies) ...*ayoko na ganyan, patayin niyo na ko* (I don't want that, just kill me). *Tapos, I felt nasa hell ako n'ung time na 'yun* (I felt I was in hell that time).

After his release from the hospital, he felt offended about being treated like a dog. He said, "... *nasa bahay lang ako n'un* (I was just in the house then) *Parang dinadalhan lang nila ko ng* (They were just sending me) food *tapos iiwan na nila sa labas ng door*(which they will leave out by the door). *Magugulat ako may naka-packed lunch na sa labas* (I would be surprised seeing packed lunch outside), *Para akong aso n'un* (I was treated like a dog then)." The same fighting spirit was expressed when his step-sister took his phone and violated his right to privacy ["I was hysterical, *parang gusto ko nang mamatay* (I just wanted to die). *Parang... gusto ko na kainin na lang ako ng lupa* (it felt like I just want to be swallowed whole by the ground)]. These are examples Alex highlighted showing the intensity of his resistance against maltreatment and the strength of his desire to be accorded dignity even in his lowliest state.

Alex attributes his fight for dignity to his personality. Despite his disabling circumstances in life which were beyond his control, he acknowledges that his reflective and highly self-conscious person is what keeps him alive and his agency intact. He underscored, "I'm the type of person *kasina malakas 'yung self-awareness ko* (whose self-awareness is strong). (Despite)... all of these voices that are in my head, *darating pa rin ako sa* (I am still able to arrive at the) center of focus *ko*(of mine) where I would think, "I'm still here, I'm still breathing, *ano pa (ang) pwede kong gawin* (what else can I do)? This means that there have been instances in his life, despite being orphaned and placed in a state of dependence, that helped form a person who realized that he has to fight for what he desires or no one else will.

What cultural structures help form autonomous agency in a person who has always felt like an outsider?

Workshop Modules and Reflection Guide Questions

Given the above points and insights related to important intervention gaps, the following workshop program is proposed to elicit solutions from community-based participants.

Table 1

Proposed workshop modules with corresponding intended participants and emergent brainstorming guide questions

Module Title	Participants	Brainstorming Guide Questions
Module 1 Never too young: Sex, minors, and sex work	Family Members Law Makers Law Enforcers School Administrators Community Development Workers Mental Health Practitioners	How are minors protected by immediate family, school, or the government from engaging in sex work?
Module 2 Grapevine 911: Finding reliable sources outside conventional circles of trust	Artists Digital Creators Guerilla Advertising Practitioners Marketing Practitioners Peer Counselors Community Development Workers Local Government Officers Community Association Members	Outside family, school, or illicit sex partners, where can knowledge about HIV be made available to minors?
Module 3 Circles of Truth: Building communities of empowered selves	Community Development Workers Mental Health Practitioners Self-Help Coaches Peer Counselors Community Organizers Church Leaders Family Members	What will ensure PLHIV that such alternative sources of support are adequately informed about HIV and not equally blinded by an ignorant family, school, or religion?
Module 4 Least Judgment: Empathy First Aid	Teachers and School Administrators Guidance Counselors Community Development Workers Mental Health Practitioners Self-Help Coaches Peer Counselors Community Organizers Church Leaders Family Members	Given incidents of rejection experienced by PLHIV from people who can only provide conditional acceptance and assistance, what less judgmental support structures can be provided for persons living with stigmatized illnesses?
Module 5 Mind your Care Level: Challenging the Sick	Sick Care Professionals Persons with experience in health care facility services	How are sick care professionals trained to be more empathetic to PLHIV?

Table 1

Proposed workshop modules with corresponding intended participants and emergent brainstorming guide questions

Module Title	Participants	Brainstorming Guide Questions
Care Professionals (Part 1)		
Module 6 Mind your Patient's Business: Challenging the Sick Care Professional (Part 2)	Sick Care Professionals Persons with experience in health care facility services Data Privacy Experts Ethicists Researchers of studies involving human participants	How are sick care professionals to be made strict enforcers and followers of data privacy in their professional practice?
Module 7 Family Affairs: Rated Restricted	Family Members	How can families be held accountable and committed to observing data privacy, especially of PLHIV related to them?
Module 8 Unbounding: The autonomy of the self	Transformative Leaders Self-made Persons Internally Motivated Persons Peer Counselors Youth	What cultural structures can help a person form a greater sense of self-worth that is not bound to and can exist separate from authorities in his/her/their life?
Module 9 Selfing: Undoubting the self	Members of marginalized and stigmatized communities (Women, LGBTQIA+ Members, Senior Citizens, Visible Minorities, Hidden Minorities, etc.)	What cultural structures can help make persons more self-confident and capable of self-love?
Module 10 Alt Self: Visioning, Manifesting, Claiming Self-Worth	Visionaries Innovators Inspirational Leaders Artists Youth	What cultural structures can help a person realize alternate realities that he can potentially attain despite contradictory messages from the status quo?
Module 11 Inside Out: You are your agent	Members of marginalized and stigmatized communities (Women, LGBTQIA+ Members, Senior Citizens, Visible Minorities, Hidden Minorities, etc.)	What cultural structures help form autonomous agency in a person who has always felt like an outsider?

The modules were shaped by the questions that emerged from the experiences of a single PLHIV whose life captures the complexity of empowerment and disempowerment of PLHIV in Philippine society. It is hoped that such a workshop can create a space where different sectors can contribute to the solutions for a complex problem, not just one sector or one group of experts who seem to dominate or claim a monopoly over the field of HIV problem-solving. The modules are not sequentially formalized, meaning, they can be arranged

like Lego blocks, depending on the needs and context of the community that will be implementing it. Hence, it is advised that the actual flow of the modules be a result of community-based collaborative decision-making. It is hoped that those who will use the above-suggested module ideas publish their work openly so that concerned parties can learn collectively through evidence-based empowerment programs, especially for stigmatized persons.

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