

## Networks of Participation and Influence: Attitudes and Behaviors of a “High Threshold” Person Living with HIV-AIDS

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### ABSTRACT

This study looked into the networks of participation and influence (NPI) of a person living with HIV-AIDS to unfold the ways by which attitudes and behaviors after diagnosis are potentially influenced by them. Using a single case study approach and qualitative research design, an anonymized interview transcript was used for document analysis as it featured a person living with HIV-AIDS (PLHIV) who is unbothered by his HIV-positive diagnosis. Narratives were broken down into smaller units that highlighted relationships that played a crucial role in his experiences as he coped with the knowledge of his diagnosis and thereafter. Through thematic analysis, the study found that building a network of a variety of health-related professionals dealing with HIV-AIDS helps a PLHIV deal better with his HIV-positive diagnosis. Findings suggest that creating a culture where empathic and ethical health professionals dealing with stigmatized illnesses due to HIV can become part of a primary network of support for populations vulnerable to HIV. Creating a NPI may be key to alleviating anxieties that result from HIV infection.

## INTRODUCTION

In 2018, the National Research Council of the Philippines engaged Bantugan (2023) to conduct research focusing on digital technologies and HIV-AIDS artist-advocates who were leading the way in helping HIV-vulnerable populations and misinformed audiences to positively cope with the HIV epidemic in the Philippines. His study showed that networks of participation and influence (NPI) built by artist-advocates contribute to the mainstreaming of positive discourses about HIV in the country. Another researcher, Marzan, and her colleague, Distor, linked up with Bantugan, after knowing about his project and the availability of Distor's interviews with selected persons living with HIV-AIDS (PLHIV). They agreed to explore other ways of understanding experiences of PLHIV after learning about their HIV-positive status.

Their first paper, a study on direct and indirect power blocks and empowerment pathways of a selected PLHIV, was borne out of the realization that some of the disempowered PLHIV suffer from socially constructed relational structures that are often not addressed due to the undue emphasis on medical perspectives, sometimes at the expense of studies that investigate personal experiences. Marzan, Bantugan, and Distor (2023) revealed that given a case, one can draw from it questions for reflection that can be used for community-based workshops that are likely to elicit solutions beyond surgical and pharmacological interventions.

Another interesting transcript from an anonymized set provided by Distor underscored the lived experience of a young adult male who, despite his HIV-positive status, reacted more positively to his situation. Stories of discrimination and anxieties were also found in the said transcript; however, what stood out was how unbothered the interviewee was given his HIV status, which is unusual in narratives presented in mainstream media in the Philippines. His experiences, instead, highlighted a network of professionals he kept whose engagement in the HIV epidemic appeared front and center. This became the foundation of this study in investigating the NPI (Bantugan, 2023) that seemed to influence the interviewee's attitudes and behaviors related to HIV.

Filipino drama serials in the past highlighted the struggles and pains of persons who find out about their HIV infection. *Maalaala Mo Kaya*, a once-a-week drama series from ABS-CBN, annually showed the life story of a PLHIV (IMDb, 2012) to commemorate World AIDS Day every December. Rival GMA-7 did the same with a similar drama series titled *Magpakailanman* (IMDb, 2013). A more recent player in the TV industry, TV5 created its drama series titled *Positive* (The Philippine Star, 2013) revolving around a male heterosexual's struggles with HIV. Mainstream movies on HIV-AIDS were produced much earlier, going as far back as 1993 with the movie *Dahil Mahal Kita: The Dolzura Cortez Story* (IMDb, 1993) featuring the first publicly known HIV case and starring a major film star. Independent filmmaker Cris Pablo launched *Doubt* ten years after (IMDb, 2003). And yet, despite available audiovisual materials on mainstream television, online, and in underground indie film markets,

narratives on HIV were always depressing and lacked the hopefulness that PLHIV find very little of (Casper, 2019).

In 1992, an indie comics publisher Image introduced the first superhero with AIDS - ShadowHawk - who was infected with HIV through a syringe (D'Angelo, 2004). The first to be diagnosed with HIV, however, was Speedy, the female sidekick of DC Comics superhero Green Arrow. D'Angelo clarified that characters in comic books who were HIV-positive were mostly non-lead characters. Nevertheless, having such characters in comics helps facilitate dialogue beneficial to PLHIV (Czerwicz, 2018). Unfortunately, no such heroic characters with HIV are found in Philippine culture.

Thus, the case in this study immediately looks like an outlier in the country. In the absence of mediated messages, social networks might present alternative sources. Bantugan (2023) found that among artist-advocates in the Philippines, conversations about HIV-AIDS are like to be facilitated by a NPI, constituted by, namely, artistic affiliations, educational affiliations, professional affiliations, and government affiliations, some of which overlap. These affiliations stem from "connectedness", one of the four ideas shaping advocacy materials of Filipino artist-advocates. Connectedness was expressed as digital connections, activity connections, organizational connections, and advocacy connections.

## **THEORETICAL REVIEW**

### ***Social Network Theory***

This study abides by the notion of Social Network Theory which asserts that social relationships have a role in "transmitting information, channeling personal or media influence, and enabling attitudinal or behavioral change" (Liu, Sidhu, Beacom, & Valente, 2017, para. 1). While social networks have become more associated with computer-mediated networks, this study finds value in the Two-step Flow of Communication Hypothesis (TFCH) which has a significant influence on its development.

The TFCH, proposed by Lazarsfeld, Berelson, and Gaudet (1944) in *The People's Choice*, described personal influence as "largely derived from people's social contacts and friendship networks" (Liu, Sidhu, Beacom, & Valente, 2017, p. 2). Building on the initial development of the TFCH, Katz (1957) elaborated on three of its important aspects. First, he asserted that "the magnitude of personal influence could be greater than that of social media" (Liu, Sidhu, Beacom, & Valente, 2017, p. 3). Second, "in terms of the flow of personal influence, opinion leaders are not always concentrated at certain social strata, nor does personal influence always flow from a higher social stratum to a lower one" (p. 3). Third, "personal influence does not necessarily work in isolation from mass media" (p. 3). For this case under investigation, what seems apparent of the three is the first.

The TFCH underscores the role of the opinion leader, a person who asserts influence in particular fields. Katz explained that the opinion leader's influence stems from "who one is" or his/her/their individual characteristics, "what one knows" of his/her/their competencies, and "whom one knows" or

his/her/their structural position in a network. TFCH's assertions on network centrality are not relevant to this study, however, as it is more appropriate for network analysis. In later research (Valente & Saba, 1998), it was found that mass media opinion leaders had more influence over "low threshold individuals" (Liu, Sidhu, Beacom, & Valente, 2017, p. 4) or those whose networks were not so directly connected to opinion leaders than "high threshold individuals" (p. 4) who were the opposite. In this study, the case was more reflective of the latter.

As such, this study attempted to describe the network within which high-threshold individuals are embedded. By using the connections and affiliations found in the study of Bantugan (2023), Figure 1 illustrates the network that can potentially describe the world of the interviewee that influenced/s his/her/their attitudes and behaviors.

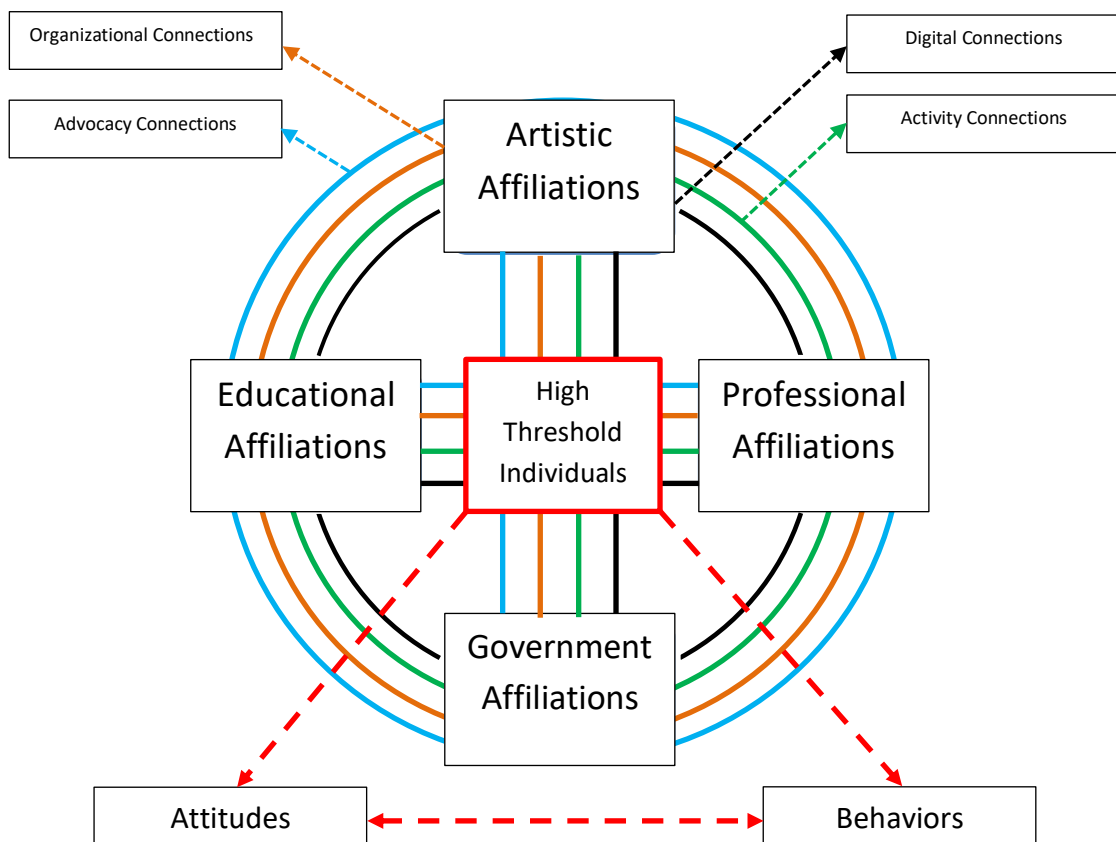


Figure 1. Conceptual Model of the Network of Influence and Participation of High-Threshold Individuals

At the conceptual framework level, the high threshold individual is shown participating in and being influenced by four major affiliations (artistic, educational, professional, and government) that are bound by four types of connections (organizational, advocacy, digital, and activity). This framework helped break down the narrative provided by the transcript through thematic analysis.

## METHODOLOGY

This qualitative study involved data mining and a single case study approach where an already existing and anonymized interview transcript involving a selected PLHIV was analyzed to bring about themes that describe networks of participation and influence. The single case was selected purposively as it highlights experiences with a variety of public opinion leaders. The interviewee in the transcript is male, below 40 years old, a graduate of a bachelor's degree program who has worked with government units doing advocacy-related projects. The social connections of the case present a social complexity beyond the normal person suffering from a viral infection. This case necessarily called for a deductive thematic analysis that helps to uncover the network of a PLHIV that was deemed relevant in telling a story about a person's journey living with HIV. Situations in the journey that constitute affiliations and connections were highlighted. A contextualized model of the Conceptual Model of the Network of Influence and Participation of High Threshold Individuals was created as a result.

## RESULTS

The interviewee is named here as Bobby. He/she/they (made indistinct for political correctness and anonymity) has been HIV-positive since 2017 and as of this writing has a "very open" relationship with a romantic partner who has a graduate degree. Despite his/her/their HIV-positive status, he/she/they remains sexually active and unbothered like most HIV-positive people. He/she/they describes him/her/them-self as falling under a masculine, neutral, androgynous expressive style. He/she/they is not as conservative religiously as many people think because of his active participation in church.

### Attitudes: Unboxed

**"Very Open" Relationship.** Bobby belongs to the relatively conservative religious group called *Iglesia ni Cristo* of INC. But he/she/they clarified that he/she/they is a religious hybrid and confessed that many are shocked by that ("*Marami nga'ng nasa-shock.*"). He/she/they spends time regularly for devotional prayers and yet he maintains a "very open" relationship with a highly educated professional. By very open, he/she/they refer to openness to sexual activities with non-romantic partners. Often, this is frowned upon and labeled as sexual promiscuity by more sexually conservative groups, including INC.

**HIV Testing after Worshipping.** Similarly, he/she/they does not find any contradictions in his/her/their traditional religious beliefs and sexual activities. He/she/they shared that on one occasion, he/she/they got tested for HIV after their morning worship in INC ("*... Ang plano namin (Our plan) after, testing in Malate. Kasi kami ni (Because I and my) (best friend), we're both INC so we attended the morning worship tapos (then)... it's always good to know your status...*"). As in many Christian countries, sexual activity is taboo in the religious talk in the Philippines. Bobby stands out in that his more conservative INC is not big enough a barrier to prevent him to be sexually active as a non-

heterosexual person. The INC is notorious for political 'bloc voting' (Hinosa, 2022) which is often associated with blind obedience to religious leaders.

**Intimacy Without Intercourse.** He/she/they admitted that he/she/they has not stopped having sex since he/she/they learned he/she/they has HIV. Knowing about other HIV-positive people who decided to stop penetrative sexual intercourse after contracting HIV, he/she/they said:

Okay *lang naman kasi may tao talagang* (still, there are people)... they really prefer the touch, *'di ba* (isn't it)? *'Yung mga gan'ung* experience (those experiences matter) ... if you're more on the intimate thing. Although, intimacy, *hindi naman siya palaging* (it is not always about) sex... although sex is (an) important ingredient *naman s'ya ng* (of a romantic) relationship *'di ba* (isn't it)? So, (*walang problema*) (there is no problem if people are) a bit playful.. *paminsan-minsan* (sometimes).

**Benefit of the Doubt for the "Barbaric".** Thus far, he/she/they presented an image of an ideologically eclectic person who is not tied to one belief system. As such, he/she/they has this to say about people who stigmatize PLHIV:

... the ignorance... *ng tao* (of people)... *hindi natin alam 'yung mindset na pinanggagalingan (nila)* (we don't know where their mindsets come from)... *parang ang* (it seems) very very barbaric.

**"Out" but Not "Out There".** In contrast, he/she/they is not bound to a restricted ideological mindset and is empowered to decide to whom he/she/they intends to be transparent about his/her/their HIV status. He/she/they said, "I'm open with my family (and) close friends... *'wag naman sa* (but not to the) community." Bobby calls him/her/them-self "discreetly open", meaning he/she/they is open about his/her/their status to strangers when there is public good coming out of it. He/she/they shared:

I'm discreetly open especially if, *'di ba, sabi ko naman sa students mo* (as I've said to your students) before... I'm discreetly open but when it comes to scholarly studies, it's okay to reveal (my status)... it's different (elsewhere) *kasi* (because) still there is stigma. *'Kita mo naman 'di ba* (You see) how dangerous the stigma is... *nakakaloka* (it's crazy).

**Down but not Dead.** When he learned about his/her/their HIV-positive status while he/she/they was with a friend, the latter reacted more negatively than him/her/their. He/she/they was more level-headed when he/she/they learned about it as he/she/they knows that it was not his/her/their end and that the rapid test still requires a confirmatory test. He/she/they narrated:

... *hindi s'ya nag-sink in (sa akin)*... feeling *ko 'yung friend kong 'yung na-depress sa* (test result). *Parang feeling ko s'ya 'yung tatalon, s'ya 'yung nalungkot. Sabi ko, "Gaga hindi (pa) naman ako end already."* *Kaya lang nga,* the thing is, next day... *parang d'un... s'ya medyo nag-ca-cave in. D'un ako medyo na-alog. Ay, sabi ko... baka kasi alam naman natin na the rapid test (ay) wala pa naman 'yung confirmatory, so there it is. Nalulungkot ako, but sabi ko... "Move on" ... 'Pag nand'yan (na) edi let's have... sick treatment. 'Di ba gan'un lang naman?*

(... it did not sink in... I felt that my friend was the more depressed one regarding the test result. I felt he was the one who wanted to jump, he felt really sad. I said, "Crazy, I am not dying yet." But the thing is, on the following day, that's when I felt shaken. I said, perhaps it is because he did not know that the rapid test requires a confirmatory one, so there it is. I felt sad but I said, "Move on." If it gets to that point, let's have sick treatment. Shouldn't it be like that?)

**Moved but not Movie-d.** Given his/her/their level-headedness about his/her/their situation, he/she/they compared him/her/them-self to the hysterics of Filipino movies. Instead of highlighting similarities, however, he/she/they contrasted his/her/their reaction to being HIV-positive to the acting of top actresses in movies. Knowing the state of his/her/their infection and the high likelihood of his/her/their recovery, he/she/they felt there was no need to bother his/her/their family prematurely. He/she/they said:

*'Yun nga, that day itself na... it was unbreakable, carefree... as in hindi s'ya 'yung totally... pinagsakluban... 'yung parang Maricel Soriano feels... laying down on the floor tapos iiyak. Sabi ko, hindi naman (kailangan). 'Kita ko naman si Vilma (Santos), from pneumonia naka-recover si bakla. Eh kasi nga... sabi ko, hindi naman (huli), sabi ko, (it's) early. I know early diagnosis naman... makaka-recover ng bongga. 'Yun yung naisip ko. I wouldn't disclose it to my family until I get the best doctor in the Philippines. So scout, scout, scout, scout ako.*

(Then, that was the day... it was unbreakable, carefree... as in clouds were not completely over my head... like Maricel Soriano feels... laying down on the floor then crying. I said, "It's not necessary." I watched Vilma Santos recover from pneumonia. It's because it is not yet too late. It's early. I know it was an early diagnosis. I can recover big time. That's what I thought. I wouldn't disclose it to my family until I get the best doctor in the Philippines. So, I scouted non-stop.)

The narrative above shows something opposite Alex from Marzan, Bantugan, and Distor's (2023) previous case study in that while Alex was "hysterical" after passing out (before having the HIV test), Bobby is calm and collected (after having the HIV test result), unlike in most mainstream movies, especially those dealing with characters who are PLHIV. Alex knew nothing about HIV before he was diagnosed positive, while Bobby had the vital information that helped him/her/they to not panic.

He/she/they is also not fixated on his/her/their physical appearance like most people nowadays, saying: "I feel confident *naman* with my body. *Alam mo naman 'pag nagkakaedad* (You know that as one ages), *ang mga abs nawawala* (the abdominal muscles disappear." "Studies have found links between social media use and negative body image issues," reported Gallaga (2021), but it does not seem to apply to Bobby. This confirms that he/she/they is not a "low threshold" individual.

### Behaviors: Untied

**HIV-Positive, Sex-Positive.** Bobby remains sexually active despite his/her/their HIV-positive status. Given a choice between abstaining or remaining sexually active, he/she/they chooses to be the latter. He/she/they, as previously mentioned, keeps a very sexually open relationship with his/her/their partner. He/she/they has no guilt in practicing non-heterosexual sex despite INC being conservative in this area. Sex, in other words, is a staple in his/her/their life [“... *hindi naman mawawala ‘yun* (It won’t disappear... *hindi masaya ang love (kung) walang ‘ganun’* (love is not happy if there is none of ‘that’ (sex).”]

He/she/they describe him/her/them-self as sexually naughty especially coming out of a relationship [“... *alam mo naman ako... kasi alam mo naman* when (I am) broken-hearted (I) tend to be playful (you know me when I am broken-hearted, I tend to be playful.)”]. He even went to Thailand to have fun and enjoy life after his/her/their break-up. He/she/they said: “*Nag-Songkran (ako). Alam mo na ‘pag broken-hearted landi-landi ganun.* Enjoy enjoy lang ‘yung life (I went to Songkran. After a break-up I tried to mingle and enjoy life).

**Sex-Moderated, not Deprived.** Bobby, nevertheless, knows how to control him/her/them-self, especially with regards to unprotected sex because he/she/they undergoes life coaching, understands that he/she/they is not yet undetectable, and has other safer alternatives. He/she/they noted:

... the good thing *kasi* (because) when you know how things work with the treatment and *ano kumbaga may* (and you get a) heads-up *ka* on what to do if you’re not yet undetectable or UD so *medyo* (it is quite) risky to (engage in) unprotected one (sex) *‘di ba? ... so ‘yun* (there) *nagba-bath house pa din naman* (I still go to bathhouses)... *tuloy ang happiness, tuloy ang night life* (the happiness continues, the night life remains). But *medyo... bawas* (minimized). *Kung dati* (If before, I do it) every Wednesday to Saturday and even Sunday, (*huwag naman nang gan’un* (it should not be like that anymore). (I) Behave. (Now), *parang* once a week (*na lang*) (only). *Matagal na din* (It has been a while). *Sobrang* seldom *na kasi nga, ito na, nagloloka-lokahan na ‘ko* after three months (It’s been super seldom such that I go crazy only after three months.)

**Seeking More than Second Service.** When Bobby was trying to be sure of his HIV status, he/she/they sought many options at his/her/their disposal. He/she/they went to four institutions to determine his/her/their HIV status. He/she/they narrated:

... *so sabi ko, ah sige, takbo muna ako ng* (Hospital 1). So *tawag ako sa isang friend ko, though parang ano lang naman s’ya parang hindi s’ya doctor d’un* but he’s part of the team, so *may ni-refer s’ya sa’king doctor*. So, I got my screen checked... after a few hours... *wino-workout din ako ni* (Hospital 1). So, *hindi pa rin ako* convinced, so *takbo naman ako ng* (Hospital 2). That week after... I got my diagnosis from (Clinic 1). I even reached as far as (Clinic 2).

(... so I said, I will run to Hospital 1. I called one friend who was part of the team there and he referred me to a doctor. So I got my screen

checked... after a few hours... Hospital 1 was attending to me still. But I was not convinced, so I went to Hospital 2. The week after... I got my diagnosis from Clinic 1. I even reached as far as Clinic 2.)

The story above is opposite to what Alex (in Marzan, Bantugan, & Distor, 2023) did. Alex wanted to get the HIV test result quickly and when it was given, he immediately surrendered to the verdict of one hospital known for HIV treatment. Again, Alex knew nothing about HIV before his diagnosis. Bobby knew a lot more and yet he/she/they was not satisfied with the test result of only one reputable medical institution. He/she/they wasted no time to get as many possible diagnoses. This is supported by another narrative where he/she/they mentioned that he/she/they would not disclose his/her/their HIV status until he/she/they found the best doctor in the country. Furthermore, he/she/they sourced his/her/their medications from the US, Thailand, and the Philippines. His/her/their network of participation and influence did not leave him/her/them helpless as he/she/they sought all possible help within his/her/their reach.

I got it (my medicine) from (a US Hospital) *kasi* covered *ako ng ano n'ya* (I was covered by my boyfriend's) health card... I was able to go to the US using a fiance visa.

... I have to fly to Songkran *naman* that time (with my friends) ... *kasi* (because) before you could access (medication) from Thailand you (have) to check with the (international health organization) there...

... *sabi ni* (a friend from an HIV clinic said) "You've been helping the organization already for quite some time... why not (give the HIV clinic) a chance to take care of you *naman* (already) in the situation that you need it the most?" ... So *ayun* (there), I submitted all the documents needed *tapos* (then) in less than a month on treatment *na* (already), on trial *na kami*, 2 weeks *lang* (we were on trial for two weeks).

**Seeking Safe Spaces.** With the help of a friend working in a plush hotel in Manila, he/she/they was able to access a room where he/she/they disclosed his HIV status to his family. He/she/they recalled:

I asked them (my family) to have a staycation in (the hotel). *Kasi alam ng Mommy kapag nagpapa-staycation ako may pasabog si mama so 'yun. Pinag-staycation ko sila.* I made sure *na* relax sila, so *'yun lang naman.* Then the next day, *nagbe-breakfast (sila)*, so I discussed (with them). *Sabi ko*, I have lifelong treatment. *Nilabas ko 'yung ER (emergency room) treatment. Sabi nila*, "What is this?" *Sabi ko*, "This is a maintenance medicine but it will help me to live longer just like you..." *Niyakap lang nila 'ko. Naiyak lang si Mommy.* "But the thing is while I'm on my first three months *d'un ako medyo... hindi maayos.*

(I asked them to have a staycation in the hotel. My Mommy knows that when I ask them for a staycation, there is a big reveal for her. I made sure they were relaxed. That's it. Then, the next day, when they were having breakfast, I discussed it with them. I said, "I have lifelong treatment. I put out the ER treatment. They said, "What is this?" I said, "This is

maintenance medicine but it will help me to live longer just like you..." They embraced me. My mommy cried. "But the thing is while I'm in my first three months I will not be alright.)

During his/her/their first three months, he/she/they lived in a condominium unit that allowed him/her/them to access the veranda near the penthouse where he/she/they was able to reflect facing the rising sun and slept after. He/she/they kept this ritual for three months. In his/her/their words:

So I lived in the condo in (a particular area). We were on the 21st floor so *malapit sa* (it was near the) penthouse. So *medyo 'yung* floor unit *ng friend ko* (the floor unit of my friend) meets the sunrise. '*Yung* unit *nila* is facing the east so *parang every night 'and'un lang ako sa* (every night I was just there at the) veranda, *nagpapahangin* (feeling the air), *inaantay kong sumikat ang araw* (waiting for the sun to rise). (*Kapag*) *nakita ko na 'yung araw... d'un lang ako nakakatulog ulit* (When I already see the sun, that's when I was only able to sleep). It went on and went on for three months.

He does the same thing in virtual spaces, particularly on social media, Facebook. He elaborated:

I open... the Facebook page... '*yung* (there) in the positive universe. I think this is not about the posting but reaching out to the people. There's hope after *na parang* (seemingly) it is like... a vlog, an online journal. You share whatever your thoughts are.

**Yoga, Zumba, and Sauna.** Bobby was already doing yoga before he/she/they was diagnosed with HIV. He/she/they is conscious of his/her/their eating too much pastry, drinking too much coffee, and losing his/her/their abs due to aging, but is confident that he/she/they has nothing to worry about. Nevertheless, he/she/they dances and does Zumba to complement yoga before the pandemic happened. He/she/they disclosed:

I am more geared towards low impact-low intensity workouts. *Kaya ayun puro Zumba lang* (That's why it's most Zumba). Dance at least every other day *kung kaya ng schedule* (if the schedule permits) *tapos steam lang ng* (then steaming for) 15 minutes.

With his activities, Bobby noted that after six months, his/her/their health has improved enough to be diagnosed as undetected (UD). He/she/they shared, "... *ang maganda din kasi* (the good thing about it) that time... six months later... and as fast as three months ahh UD *na* (already).

Given the above attitudes and behaviors of Bobby before and after the HIV-positive diagnosis, one can see how he/she/they did not seem to be too bothered about it. He/she/they shows a level of self-confidence not found in Alex (Marzan, Bantugan, & Distor, 2023). He had internal and external resources at his disposal to cope well with being HIV-positive. He/she/they

optimizes those resources when he/she/they most needs them. His/her/their confidence is unbothered by religious restrictions or the worries of loved ones. His/her/their NPI appear to have a significant role in his ability to deal with the challenges of HIV.

### *Connections*

#### **(1) Organizational Connections**

**Government Organization.** Bobby was employed in one of the cities in Metro Manila.

**Religious Organization.** He/she/they mentioned a couple of times during the interview that he/she/they is a member of the INC community. He/she/they finds nothing contradictory with his/her/their religious beliefs and norms and his/her/their sexual orientation and practices.

**Volunteer and Health Organization.** He is also connected to a well-known advocacy group focused on HIV testing and treatment delivery through one of its founders. This means he/she/they has high-level access to the organization. This also explains why he is well-informed about HIV and the care delivery it requires. He/she/they is also connected to members of its constituent volunteer groups. His/her/their link to this advocacy organization is more influential to him/her/them than his Church organization because he/she/they is not bound to the latter's sexual norms. Thus, he/she/they is not overpowered with shame given that he/she/they is not heterosexual, sexually active, and keeps a circle of friends who live the same way. His/her/their being part of a mental health care circle in the advocacy group sustains his/her/their positive well-being despite his situation. He shared:

*... ang maganda kasi (the good things before) before... nagkaroon tayo ng... (we had a) circle (in the advocacy organization) ... na nag-address ng (that addressed) mental health (issues). Meron kasi 'yung (It has) positive connections... when I met si nanay-nanayan ko sa (my mother figure in the) (advocacy organization) ... d'un kami kasama ng ibang mga pusit (we were there together with the other PLHIV). Kaya ako before ako nag-(member in the advocacy organization) (So, before I became a member of the organization), I was a supporter na (already) (of the advocacy organization).*

He/she/they was also a part of another HIV-related advocacy group that showed him/her/them the magnitude of the HIV problem. He/she/they confessed to knowing its top management executives. He/she/they recalled:

*Nag-(name of the advocacy group) ... muna 'ko... (I became a member of another advocacy group before). Sabi ko (I said), "Beh, pa-sit-in nga ko d'yan sa mga training eme eme mo (Dear, may I sit-in your training)?" ... Tapos (Then, I) got to see the real magnitude (of the problem) na talagang hindi lang naman kasi (that truly the problem was beyond) ... the LGBT community. It's really an eye-opener when you try to immerse and open yourself to other organizations. Kaya ayon, naging friends ko sila (name of founder and others). (One of them) kasi... (One of them was the)*

bestfriend *ni* former partner *ko* (of my former partner) ... *kaya lumaki ang network nang bongga sa* advocacy (that's why my network in the advocacy grew so big).

## **(2) Advocacy Connections**

**HIV-AIDS-Related Advocacy.** His/her/their organizational connections were also advocacy connections, mostly dealing with HIV-AIDS.

**Cultural Advocacy.** But beyond the advocacy groups he/she/they joined, he/she/they was also involved in projects that dealt with cultural advocacy where he/she/they was much appreciated. He noted:

... because we established in (name of city), *'yung* first (name of province) museum there. *Tapos may isang...* institution there... *'yon!* ... *inawardan lahat ng* technical working group *na nag-establish n'ung...* cultural advocacy - promoting the culture of peace and preserving the heritage of the... people, *kaya... kasama ang lola mo... may* award.

(... because we established in the city, the first provincial museum there. Then there was one institution that gave each member of the technical working group who established the cultural advocacy - promoting the culture of peace and preserving the heritage of the people, so, I was also given an award.)

Given the above, one can see that Bobby has time and interest in two very different types of advocacies. While it is convenient to stay in one advocacy organization, he/she/they does not limit him/her/them-self to one.

## **(3) Digital Connections**

He mentioned digital technology during the interview only in the context of coping with his HIV status. This does not mean that he has a very limited connection to digital worlds; if any, this should be read as the digital link that is relevant to the contexts he/she/they told stories of. While he/she/they did mention that he/she/they made calls to different doctors in several hospitals/clinics, he/she/they did not elaborate much on the digital connections he/she/they accessed. These digital connections seem to be his/her/their access to safe spaces.

## **(4) Activity Connections**

Bobby, as mentioned earlier, spends time with other people in worship and HIV testing, advocacy-related activities, and work-related tasks. He/she/they also spoke about the experience of being treated for HIV as the experience of a PLHIV in treatment was shared with him/her/them by the interviewer. He elaborated:

... *'yung* physical appearance *mo*, if you see yourself deteriorating *na talagang parang* you don't want to continue with the treatment *kasi parang nakikita mo kasi* physically you're deteriorating so *parang alam mo 'yun?* *Parang pasasaan pa? Masakit ang* chemo(therapy) *'di ba?* (your physical appearance, if you see yourself deteriorating you think that don't want to continue with the treatment because you see that physically you're deteriorating so you know where it's going? Where is it going to lead? Chemotherapy is painful, right?)

On a positive note, Bobby also spends time having coffee and watching movies with friends. He does get help from coaching and training, and seeks

other forms of help from people he/she/they knows, mostly from higher positions in society or those who immediately belong to his/her/their social circle. He tries to help him/her/their-self by exercising with peers in the gym. He tries to help his/her/their family to cope with the reality of him/her/their being HIV-positive. Overall, the activities that surfaced in his narratives as he shared his experiences dealing with HIV during the interview are those that present him as equal with friends, a person who seeks help, and a helper – a social person who remained so even after his/her/their HIV diagnosis.

### *Affiliations*

#### **(1) Artistic Affiliations**

Bobby mentioned a name of a friend (that cannot be disclosed for confidentiality reasons) in the HIV-AIDS advocacy group he/she/they is part of, a rare name, which is familiar to one of the researchers of this study as he has had a personal encounter with said friend in a project. That friend is an artist. Bobby never mentioned any artistic organization or any art-related group they had a chance to work with in the past. This means that in the context of his/her/their story as PLHIV, artistic connections mattered marginally, if at all.

#### **(2) Educational Affiliations**

Bobby mentioned educational institutions thrice during the interview. First, he/she/they mentioned the school where he/she/they earned his/her/their Bachelor's degree. Second, he/she/they mentioned being conferred an honorary degree of Doctor of Humanities after he/she/they worked to establish a city museum. He/she/they never uses the degree for public recognition, he/she/they admitted (slightly expressing a feeling of not deserving it) – and yet, only a higher educational institution can confer such a degree. The name of the institution was not mentioned during the interview but his/her/their work may have been so significant that the institution saw it fit to give him/her/their such an honorary title. Third, he/she/they mentioned that his/her/their romantic partner (as of this writing) is working as a professor (school undisclosed in the interview). Those affiliations did not figure significantly in his/her/their journey as a PLHIV as much as hospitals and clinics.

#### **(3) Professional Affiliations**

Bobby works as a particular kind of specialist which is considered a cultural worker. He/she/they also works as an exhibit designer so he/she/they admits to having many side hustles. In these circles, he/she/they likely has other professionals from different fields. He/she/they does not mention them in the interview, however, as they may not be relevant to his/her/their journey as a PLHIV.

However, he/she/they mentioned many times that he/she/they knows medical professionals personally – his/her/their former partner in the US, a doctor in one hospital who referred him/her/their to another doctor, a doctor in the social hygiene clinic handled by the advocacy group he/she/they is part of, and health counselors. Bobby also recalled during the interview that he/she/they knows of a doctor and psychologist who referred him/her/their

to a local mental health facility that could serve his/her/their mental health needs.

He/she/they also mentioned a friend, a hotelier, who gave him/her/them access to a room in the hotel where the latter works. This allowed him/her/them to bring his/her/their family to a relaxing place where he/she/they can disclose his/her/their HIV status. He/she/they also mentioned a relative who is a Human Resources specialist who took care of certain documents he/she/they needed. He/she/they also revealed his/her/their being a BPO (business process outsourcing) professional sometime in the past; hence, it can be surmised that he/she/they built a network with professionals in that field while he/she/they was there. These professionals, while not in the field of health, were people Bobby considered relevant in his/her/their journey as a PLHIV. These professionals who helped him/her/them inspired him/her/them to say, "*Kaya nga sabi ko, 'ay 'nako, yaman ko talaga sa mga kaibigan. Sila talaga ang aking yaman.* (That's why I can say, 'Goodness, I am so rich with friends. They are truly my treasures.')." "

#### **(4) Government Affiliations**

There were three instances where Bobby revealed his/her/their connections to the government. First, he/she/they works in a local government unit. Second, he/she/they stayed at a friend's place who was the grandchild of a former mayor. Third, through his/her/their advocacy organization, he/she/they has had a minor encounter with the Department of Health. The first two connections were more relevant to his/her/their journey as a PLHIV.

## **DISCUSSION**

Data reveal that not all connections and affiliations were activated in the selected PLHIV case. Out of the four connections, three were highlighted most by Bobby's narratives. Out of the four affiliations, only two were key in his/her/their story as a PLHIV. Surprisingly, digital connections were not highlighted enough; they paled relative to the other connections at play. One would expect digital connections to be critical in a highly connected individual like Bobby. However, as stated in the theoretical discussion above, mass-mediated opinion leaders do not affect high-threshold individuals who are more vulnerable to directly affiliated opinion leaders (Liu, Sidhu, Beacom, & Valente, 2017). The data suggest that mass media or networked media opinion leaders do not affect low and high-threshold individuals the same way, at least in the case of Bobby. High-threshold individuals like Bobby are more affected by the guidance and assistance provided by opinion leaders coming from professional and government affiliations. Whether digital connections would play a bigger role in artistic and educational affiliations in the life of a PLHIV like Bobby remains to be seen.

Figure 2 illustrates that despite certain connections and affiliations not figuring prominently in the narratives of Bobby, the synergistic impact of those connections and affiliations that were highlighted creates a strong network of participation and influence. In a less-than-perfect world, we cannot expect all connections and affiliations to work in all, or most cases. Given that and Figure 2,

the influence of connections and affiliations on a high-threshold individual is hard to ignore.

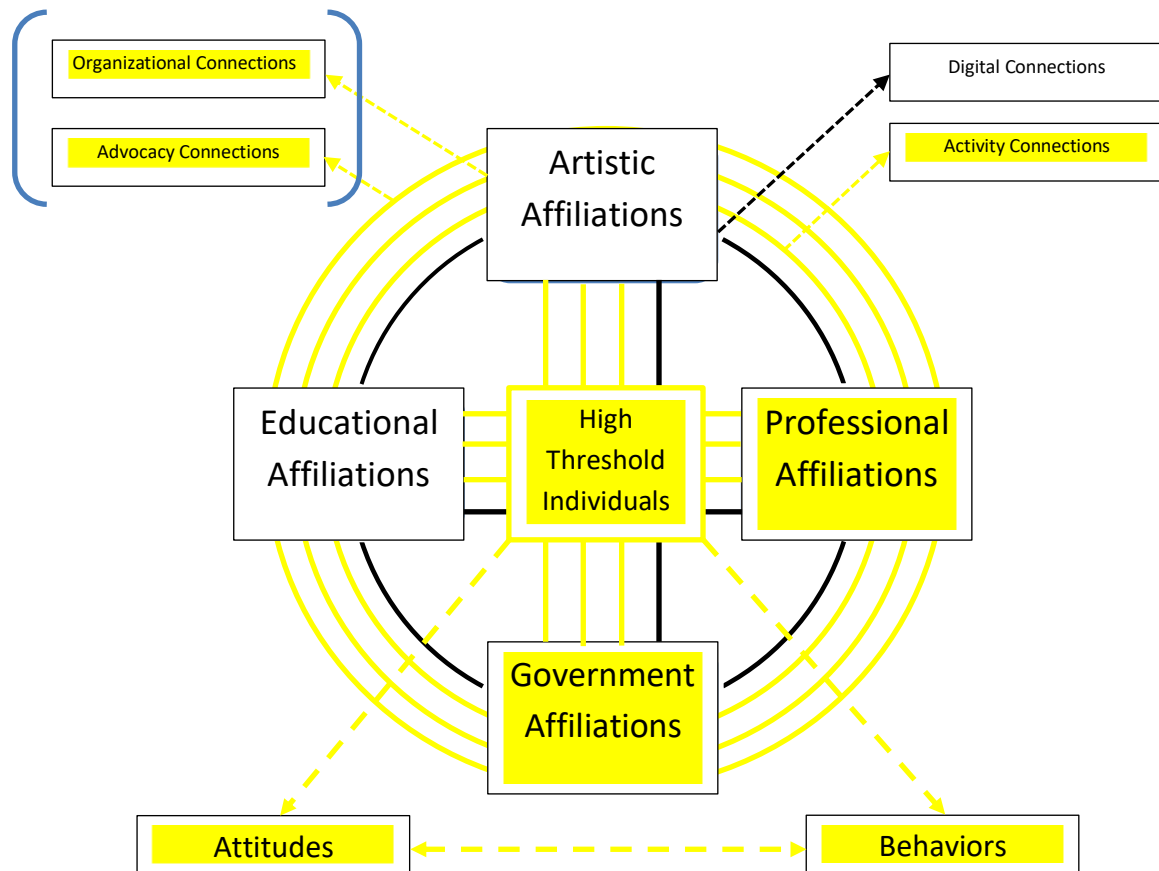


Figure 2. Contextualized Conceptual Model of the Network of Influence and Participation of a High Threshold PLHIV Case

Figure 2 also presents the significant overlap between organizational and advocacy connections reflected in the experiences of Bobby. This connection ties in strongly with the professional organizations affiliated with Bobby – mostly health professionals. Given the out-of-the-box attitudes of Bobby and his/her/their behaviors untied to social norms influenced by religious restrictions and social pressure, it can be posited that much of the influence in those two areas of his/her/their life would likely come from organizational-advocacy connections and professional affiliations that have very little to do with religious restrictions or stigmatizing beliefs. Although the medical field cannot be completely excused from contributing to the stigmatization of HIV-AIDS (Marzan, Bantugan, & Distor, 2023), it relatively has less to do with social discrimination when compared to the rest of society given its greater knowledge of HIV.

Figure 2 suggests that while artistic affiliations will have very little influence on high-threshold persons like Bobby, they may have some more influence over most of the population who are tied to their mobile phones and yet not sufficiently educated on HIV – the youth who are most at risk. The challenge, then, is to develop the youth to become high-threshold individuals

like Bobby who is more empowered to make better decisions when facing the threat of HIV. While not much can be done with the proliferation of digital technologies and the growing dependence of the young on them, the youth can be helped by expanding their networks to include those of Bobby's. Exposing them more to caring and more empathic connections and affiliations will help them to be less dependent on digital technologies, especially at this time when it is becoming more and more challenging to do so.

## **CONCLUSION**

In a society where PLHIV and sexual positivity are not well-received, the case of Bobby shows that developing a NPI composed of non-prejudicial and judgmental affiliations and connections help create a safe space that PLHIV need to bring about less-stressful environments beneficial to one's personal healing process. Not all people are as sociable, open-minded, and financially capable like Bobby who finds it easier to establish a NPI. In a religious country like the Philippines where people seek the blessings of the Church or the religious to feel supported, finding communities that are not affected by them and intent on building safe spaces accessible to sexually marginalized individuals and groups are few. They are mostly known about by people who are already in such networks. Those who are not brave enough to explore and find such networks will likely find themselves anxious and with limited options. Thus, finding access points to educational and artistic affiliation with low barriers to entry will be valuable. Without them, concerned groups must organize the NPI on behalf of those less capable of doing so.

Although artist-advocates have found ways to make digital connections work in favor of PLHIV (Bantugan, 2023), their impacts have yet to reach communities that are geographically and economically marginalized. While theoretically, digital technologies may have made access to support groups easier and more convenient, a person who has not built his/her/their NPI will continue to grope in the dark not knowing it is vital for his survival. For most people, building a personal NPI is a life work. Some people do not have the time and other resources for it. HIV-AIDS-related advocacy groups, then, should expand their NPI and other concerned groups must ask how they can help towards said expansion. Student groups intended to help minimize social exclusion, will find themselves in a privileged position to create NPI in the various spaces they are able to penetrate, especially the ones that render people like them most vulnerable to HIV; thus, the creation of said NPI in schools must be incentivized and recognized as critical to addressing the challenges of PLHIV and those with other stigmatized conditions.

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