

Development of a Counseling Framework for Mothers of Children with Perinatally Acquired HIV Disease

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Abstract

Globally, the Philippines has one of the fastest-growing rates in increased human immunodeficiency virus (HIV) cases. Mothers and children with perinatally acquired HIV disease (PAHD) have unique special needs that necessitate the development of a counseling framework. As such, this study, based on Straussian grounded theory, sought to explore the needs and experiences of mothers of children with PAHD and construct a counseling framework responsive to their unique context. Utilizing a qualitative research design, this study involved an active interview approach with not only mothers of children with PAHD but also health professionals caring for patients with HIV in the Philippine General Hospital (PGH), a national tertiary university hospital. Individual interviews and focus group discussions were audio-recorded, transcribed, and analyzed using NVIVO, whereas a constant comparative analysis parsed the transcripts. Five thematic processes emerged, namely: (1) reaction of mothers to their own

diagnosis, (2) reaction of mothers to their child's diagnosis and condition, (3) stigma, (4) psychosocial care and support, and (5) HIV counseling. Meanwhile, three core categories—call for help, acceptance, and moving on—explain the theory's fundamental structure. Integrating the experiences of the mothers and health professionals and the related literature supporting them, this study developed a counseling framework for HIV counselors supporting mothers of children with PAHD, providing guidance on engaging with mothers with PAHD relative to their milieu, counseling process, guiding principles, and counseling skills.

Keywords: HIV, counseling framework, mothers, PAHD

Between January 2011 and January 2023, 724 women in the Philippines were diagnosed with human immunodeficiency virus (HIV) during their pregnancy (DOH Epidemiology Bureau, 2023), a reality that puts their children at risk of contracting the same. Mother-to-child transmission of HIV is more likely to occur during delivery, since body fluids (i.e., blood and vaginal secretions) are produced and secreted at a higher and faster rate during childbirth (Smeltzer, Bare, Hinkle, and Cheever, 2010), leading to perinatally acquired HIV disease (PAHD).

Having a child with PAHD is more than just a medical event for a mother; it is an emotional and mental process. In a study done by Walulu and Gill (2011) examining 15 mothers living with HIV and their experience of motherhood using the grounded theory methodology, five themes surfaced: (1) knowing the diagnosis, (2) living with HIV, (3) taking care of oneself, (4) seeking support, and (5) being there for my child. Throughout Walulu and Gill's study and the themes identified, the mothers were mainly motivated by taking care of themselves, understanding their diagnoses, and being a better mother to their children. They also identified that living with HIV is hard—mostly because of the physical strain brought about by the illness and, at times, the medications that they take. However, through the motivation their children give, they can navigate the ups and downs of their situations.

Studies on counselor training in the United States addressing clients with HIV and acquired immunodeficiency syndrome (AIDS) are minimal, according to Joe & Foster (2017), and most studies are focused on the counselor trainees' attitudes and beliefs during training and during their professional practice. Meanwhile, most studies on HIV/AIDS training in the counseling curriculum concentrated on identifying the number of trainings received by the counselors (Britton, 1999). In the Philippines, the Department of Health (DOH) regularly provides HIV orientation and pre- and post-test counseling training through a two-day training program wherein participants are refreshed with updated information on necessary epidemiology, testing, disease mechanisms, holistic treatment and control, and risk-based prevention strategies. These strategies are then employed to provide basic and correct information during patient/client counseling. Current regulations and recommendations for HIV testing in the country are also taught in the training program, aiming for up-to-date patient education. Although the skills the training program seeks to provide are taught in the context of HIV testing, they can also be applied to other aspects of health and social interventions (Research Institute for Tropical Medicine, 2019).

There are even fewer studies on counseling mothers of children with PAHD. Among these, Baker (2018) recommends culturally appropriate guidelines and training for health care providers and caregivers, as these are necessary to support disclosure of children's HIV status and provide ongoing support for children living with HIV. Parents who have been diagnosed as HIV-positive face the difficult choice of testing and disclosing to their children. Furthermore, most studies concentrate on determining the timing and conditions under which children who have been confirmed as HIV-positive will be informed about their test results (Rwemisisi, 2008). In 2013, the World Health Organization (WHO) published a maternal and newborn health care counseling handbook for health care providers to strengthen their counseling and communication skills, allowing them to effectively discuss important issues surrounding pregnancy, childbirth, postpartum, postnatal, and post-abortion care with women, their husbands/partners, and families, as well as their communities. The handbook also included practical activities to encourage reflection,

provoke discussions, build skills, and ensure the local relevance of information. In fact, the handbook dedicated one section to women with HIV/AIDS, with identified skills to be developed, including motivating women to accept HIV testing and counseling; preventing HIV and prevent mother to child transmission (PMTCT); helping women overcome actual or perceived HIV-related stigma and discrimination and other barriers that influence their decision making about HIV prevention and testing and use of PMTCT services; and self-reflecting on their beliefs and attitudes around HIV/AIDS (WHO, 2013). WHO published an updated handbook on maternal health and newborn health in 2017.

Statement of the Problem

Counseling is consistently identified as an integral part of the continuum of HIV treatment; however, there are also limited studies in this area. Given the continued incidence of mother-to-child transmissions in the Philippines and the need for psychosocial care and counseling services specific to mothers of children with PAHD, this study explored the experiences of mothers who have transmitted their disease to their children and aimed to develop a counseling framework for them using the grounded theory approach. Specifically, this study aims to describe the mother's experiences on the treatment used to manage their child's disease, as well as their experiences on managing their own treatment. This also seeks to surface the coping mechanisms of mothers who are diagnosed with HIV and have a child with PAHD.

Specifically, this study answered the following research questions:

1. How did the mothers with children with PAHD cope with their disease and with their child's disease?
2. What counseling framework can be developed based on the results of the study?

Methodology

The study employed a grounded theory approach to generate a counseling framework that explores the experiences and perspective of

mothers of children with PAHD. A grounded theory approach demands that the researcher move beyond describing the domain of study toward a theoretical rendering that identifies key explanatory concepts and the relationships among them (Wuest, 2011). Thus, a grounded theory approach is well-suited to explore the mothers' experiences because of its appreciation for and attention to the data. The study's reliance upon an intensely inductive approach to data assures that the mothers' perceptions and experiences will be highly valued. In particular, this study employed the Straussian grounded theory because of Strauss's willingness to admit the use of a literature review. Hence, this study utilized a comprehensive literature review in the development of a counseling framework for mothers of children with PAHD.

To ensure utmost ethical consideration, the researchers sought permission from the Sexually Transmitted Disease (STD)/AIDS Guidance Intervention Prevention (SAGIP) Unit of the Philippine General Hospital (PGH), a treatment hub for persons living with HIV (PLHIV) in Metro Manila. The SAGIP Unit was chosen as a reference for the study's participants because it has already formally identified and documented the target participants and likewise served as the participants' support group. Subsequently, this study's design and protocol were reviewed and approved by the University of the Philippines Manila Research Ethics Board. Informed consent forms were also explained and secured from the participants.

For the study, the following inclusion criteria were used: (1) mothers of children with PAHD; (2) aged 18 to 59 years old; (3) recommended by the SAGIP Unit; (4) willing to participate in the study as expressed through a signed consent form; (5) must be conscious, coherent, and ambulatory; and (6) diagnosed with HIV, whether or not with comorbidities. Fathers were not included in the study because the study wanted to explore the experiences of mothers who have transmitted their HIV disease to their children. The number of participants was not limited until data saturation was reached.

Six (6) mothers, who satisfied the inclusion criteria, were actively interviewed for the study, whereas eight (8) healthcare providers willingly participated in the study. Three (3) of the health care providers

participated in a group discussion, whereas five (5) preferred to be interviewed individually via Facebook messenger. Table 1 shows the profile of the participants.

Table 1
Profile of Mothers

Mother	Description
1	She is 18 years old and got pregnant at 17. She tested HIV-positive when she was pregnant with her child, who also tested HIV-positive when she gave birth in May 2023. She has a partner who is also HIV-positive.
2	She is 28 years old and was diagnosed with HIV in 2020 when her eldest child, who was five (5) years old then, was tested HIV-positive. She said she got the disease from her previous partner. Her present partner is HIV-negative, as well as her second child.
3	She is 24 years old and was diagnosed with HIV in March 2023 together with her three-year-old child. Her child had been sickly since birth, which prompted their doctors to test for HIV. She also learned that her previous partner died of HIV/AIDS, which then made her decide to be tested for HIV. She is currently married. Her husband is HIV-negative.
4	She is 22 years old with a HIV-negative partner. She was first diagnosed with HIV in 2021, and she became pregnant and gave birth in 2023. Her child is HIV-positive.
5	She is 28 years old, separated from her Japanese husband. She has a three-year-old child who was diagnosed with HIV at the age of one. She works as an entertainer in a Japanese bar.
6	She is 28 years old, with a partner. She was diagnosed with HIV when she was pregnant with her child. Her child was tested last May 2023. She works part time as a cook assistant for an online selling business.

Grounded theory research uses the constant comparative method to analyze data. This method refers to the constant comparison of information or phenomena with another (Merriam, 1988). Developing a theory makes use of coding procedures, creation of categories, and comparison of data and categories. According to Glaser & Strauss (1967), the constant comparative method has four phases: (1) comparing incidents applicable to each category; (2) integrating categories and their properties; (3) delimiting the theory; and (4) writing the theory.

The transcriptions of the interviews and focus group discussion (FGD) were transcribed and translated from Filipino to English. NVIVO, a qualitative data analysis software, was used in the data analysis. Themes and categories emerged after the application of codes in the narratives, which then served as the basis to develop a counseling framework for mothers of children with PAHD. The constant comparative process began with the second participant's interview while analyzing and comparing details of her narrated experiences when she was first diagnosed with HIV and her experiences with her child's diagnosis. However, the constant comparative process began fully with the third participant interview.

After taking notes and writing memos, open coding was done again, comparing elements of the two participant interviews and noting connections between them. The shape of the interviews themselves evolved over time as concepts and meanings emerged from the data. The participant mothers were asked the following questions:

1. How do you feel about the treatment being used to manage your child's disease?
2. How do you manage your own treatment and your child's treatment?
3. How do you cope with: Your own disease? Your child's disease? and
4. What psychosocial care have you received to help you cope with this?

The researchers also explained the relevant concepts to the mothers before they were asked about them, ensuring clarity and full comprehension.

Meanwhile, for the participating health care professionals, these questions were asked:

1. In your experience as a professional handling cases of women with HIV, how do you deal with them?
2. How do you provide psychosocial care?
3. How can we improve/strengthen the provision of psychosocial care and counseling to women in HIV?

Results and Discussion

Eighteen (18) concepts emerged from the interviews and group discussions:

1. Awareness of disease from other people;
2. Current experience in coping with own disease;
3. Managing treatments;
4. Experience in managing child's disease;
5. Current experience in coping with child's disease;
6. Psychosocial care;
7. Suggestions for people with similar case;
8. Experience in managing own disease;
9. Sociodemographic profile;
10. Experience in counseling patients;
11. Strategies in counseling;
12. Testing;
13. Experiences as a life coach;
14. Suggestions from healthcare professionals;
15. Process in HIV counseling;
16. Psychosocial support;
17. Contents of counseling; and
18. Financial instabilities.

From the eighteen (18) original concepts that emerged, the researchers drafted a rudimentary set of five (5) themes to begin the process of analyzing and breaking down into properties through axial coding:

1. Reaction of mothers to their own diagnosis;
2. Reaction of mothers to their child's diagnosis and condition;
3. Stigma;
4. Psychosocial care and support; and
5. HIV counseling.

Reactions to Own Diagnosis

All of the participant mothers had varied reactions when they first learned that they tested HIV-positive: shocked, fearful, denial, confused, scared of death, and afraid of the stigma. Their fear and worry may be triggered by not knowing what to expect when a person has been diagnosed with HIV or how others will treat a person once they learned that they are HIV-positive. As Mother 5 said:

Yes, they also tested me. Then, I did not know if that kind of test was accurate, and I did not believe it. I continued working since I am the only one who works in our family, [as] the breadwinner. I am also a single parent. After two years, I did not take any medicines from them [the testing center]. It's just now that I realized that I cannot take it [the treatment] for granted since I have a child that I need to prioritize. I need[ed] to prioritize that we [are] both okay.

Many people react strongly when they find out they have HIV, with some feeling scared, angry, or overwhelmed. Often, they may feel helpless, sad, and anxious about the illness, despite knowing that HIV can be effectively treated. This is recognized by Kubler-Ross's model of grieving (1969), more popularly known as the Five Stages of Grief. This model outlines the common emotional stages experienced when dealing with the loss of a loved one or, in this case, facing impending mortality. It is pertinent to note that these stages are not strictly linear or universally

experienced, as each person's grieving process is unique, with varying durations and potential skipping of stages.

The mothers also have to immediately cope and manage their situation when they find out about their disease, so that they can adapt to their situation as soon as possible. These tactics are typically used to *get through* situations and are typically learnt informally (Wilkinson, 2021), and they also necessitate a more proactive engagement with the surroundings. In addition to self-efficacy—the conviction that one can succeed—and management strategy or self-management expertise, people typically require support, information, and knowledge.

Mother 2 stated that she initially did not know that she had HIV. She had been pregnant and unaware of what she was going through. However, when she lost weight and did not have any appetite to eat, she then became concerned.

... That's when I started to feel that something is different, [since] I am always feeling weak. Then I went to health centers for check-ups and they always wondered why I am thin. [...] 'Why is it like that? Just eat and eat,' [they said.] [But] I ate well. Then someone prescribed me to have a test for this and that... the usual tests for pregnant women...

Mother 1 was honest, saying that she wanted to die when she learned she had HIV. She felt scared of what people say and how they would hate her for it. Getting an HIV diagnosis can be life-changing news. As with other chronic health conditions, people may have many different feelings—both positive and negative—when they learn they are living with HIV.

Reactions to Child's Diagnosis and Condition

Given the advances of HIV treatment programs, a child with PAHD is no longer faced with a death sentence; children with PAHD now grapple with a chronic disease rather than a progressive, fatal one. Despite this, the successes of advanced HIV treatment pose new challenges as youth with PAHD survive into adulthood, such as adhering to long-term—likely life-long—therapy; selecting successive antiretroviral drug regimens, given

the limited availability of pediatric formulations and the lack of pharmacokinetic and safety data in children; and overcoming extensive drug resistance in multidrug-experienced children. Successes in high-resource countries also help low-resource countries, where most HIV-infected children live. For instance, in high-resource countries, children with PAHD's survival into adulthood encourages expansion of pediatric treatment programs in low-resource countries and provides important lessons about how the epidemic changes with increasing access to antiretroviral therapy (ART) for children (Hazra, 2010).

Mother 2 got depressed when she first learned that her child tested positive for HIV. She feared that she might not be able to be there for her child when she dies.

I'm super down. I did not expect that it would happen to him. It hurts.

Meanwhile, Mother 5 was in denial when she learned that her baby tested HIV-positive.

It's just... it started with my baby last 2021 when my child got sick then he was confined in this hospital. After that, I did not know that he was tested by the doctors, since they did not tell me that it was needed. [A]fter that, it was found that my baby is positive [...].

Catz, Gore-Felton, & McClure (2002) found that women living with HIV had elevated levels of stress and anxiety. Although analyses indicate that while HIV-positive women found motherhood to be their most important role and their children to be their greatest source of motivation, child-rearing and their relationships with their children were also significant sources of stress (Van Loon, 2000). Additionally, other studies indicate that the declining health status of HIV-positive mothers negatively affected their performance of certain parenting tasks, such as including disciplining and physically caring for their children and being involved in their children's activities (Tompkins, 1999; Van Loon, 2000). Mothers living with HIV report compromised parenting skills across

a variety of parenting domains (Murphy, 2011), as mothers living with HIV had maternal anxiety and stress, which, in turn, had a direct effect on their parenting skills.

Mother 1 stated that she finds her strength from her child, as she needed to be strong for him. She also sought guidance and energy from her family. Meanwhile, Mother 5 believed that her firm faith in God will carry her through challenges in life. These instances evince the coping mechanisms that the participants have developed, a necessary tool to reduce the psychological suffering of PLHIV, arising from the difficulties related to the disease. Coping strategies or mechanisms are usually internal cognitive strategies to control one's thinking, usually using reappraisal of the situation. People using coping mechanisms also employ positive self-statements they have informally learned and usually deployed to *get through* their stressful situations. These mechanisms consist in thoughts and behaviors that people use as a strategy to organize a particular stressing event or factor's internal and external demands. They also depend on resources that may either be personal (e.g., health status, morality, religiosity, intelligence and individual peculiarities) or sociological (e.g., family characteristics, social networks, economic situation, conjugal relationship, and so forth) (Mohanraj, 2015).

Health care providers encounter challenges in diagnosing HIV in children during their first year of life. Infants may have initial symptoms such as inadequate weight gain, intermittent diarrhea, and pneumonia. Later, these symptoms may involve a broad array of health issues, depending on the severity of the HIV condition. Since children do not have fully developed immunity, those with HIV become more severely ill from common pediatric infections than those who are HIV-negative (Vinetz, 2021).

Mother 3 also shared her experience when her son started having HIV symptoms—during which she had no idea about the disease.

He started getting sick with pneumonia when he was a year old. My child got admitted to the hospital several times, until his second year. Then, the pediatrician decided to test for tuberculosis

(TB), [for which] my son tested positive. [He] was treated for TB for six (6) months. But then, he still had recurring blood infections, so the doctor decided to have him tested for HIV and was found [to be] positive. I also got tested and was found HIV-positive too.

Children with HIV infection are at risk of developmental and behavioral challenges. They are affected by the adverse impact of HIV and ART. Environmental factors also have known consequences on the cognitive development of children with HIV, such as reduced stimulation, which is a predictor of poor cognitive performance. In households where poverty and illness occur, parental responsiveness and environmental richness may be reduced. Roversi (2022) found that a higher viral load was often associated with fever, exposure to SARS-CoV-2 (the virus that causes COVID-19), and respiratory symptoms in children, especially infants, whereas age, the presence of nonrespiratory symptoms or the absence of any symptoms were associated with a lower viral load.

Stigma

Both the mothers and health care providers described the stigma that the former has experienced and are still experiencing borne by HIV. According to the Philippine PLHIV Stigma Index 2019, a study conducted through the joint effort of the Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV (ICW), International Planned Parenthood Federation (IPPF) and Joint United Nations Programme on HIV (UNAIDS), one in every five people experienced stigma and prejudice in the previous year, primarily because of gossip from friends and/or family. Their work environments are also affected. For instance, there have been cases of coworkers disclosing their HIV status without their consent. One-third of the study's participants said that their HIV status had a negative impact on their self-efficacy, most notably in the loss of desire to have children. There have also been reports of worthlessness, humiliation, remorse, and self-exclusion (Laguna & Villegas, 2019).

Mother 1 said that she was hurt when her family separated all her things from them, especially her plates, utensils and glasses—which her family still did even at present. However, she cannot do anything about it, instead wishing for more compassion:

Of course, other people are judgmental if you have something like this. [T]hey look at you differently. We cannot change if that's what they think of us, but I wish that [they] understand that we have different views in life. I wish they [were] not like that.

Stigma is committed by multiple perpetrators, including the public, employers, health care staff, or even oneself, friends, and family, through various forms of discrimination, which ranged from victimization and assault to macro- and micro-aggressions (Dale & Saffren, 2020). Despite their need for assistance, many persons are afraid of disclosing their HIV status to family or friends for fear of stigma and rejection that even if they did reveal their HIV status, they would not receive the necessary emotional support and information. They may be overcome by thoughts and anxieties about the future, the potential ramifications for themselves and others, as well as feelings of guilt, wrath, shock, and despair. People may require assistance in telling family members about their HIV status, and conversely, the family may also require assistance in dealing with their reactions to the news.

Attitudes toward HIV-positive individuals are also stigmatized, as HIV infection is often equated to sin and immorality. Strong roots in Catholicism coupled with poor HIV education are some of the main drivers of both HIV and sexual orientation–related stigma in the Philippines (Alibudbud, 2021). This is confirmed by one of the health care workers interviewed, stating that:

It's still the culture. Because of one of the families I've talked to, I experienced one patient when she was diagnosed a long time ago. Her family themselves, when she cooked at their house, the family did not eat. I said, "Okay, who do you want to refer [them] here? Let's talk to them." But it's still the same. Her siblings quite [understood], but I said that I wish[ed] I could talk to your parents.

Psychosocial Care and Support

Psychosocial care refers to the health care services provided to the mothers while their disease is being managed by health care professionals. This includes testing, pre- and post-test counseling, medical consultations, laboratories, diagnostics, among others.

The SAGIP unit is the treatment hub and testing facility in PGH. They provide services for CD4¹, viral load, and genotyping. They also provide HIV screening, access to lifesaving ART, and they are the only ones who provide HIV consultation for children, aside from the adults with HIV. As one health care provider stated:

In SAGIP, we recognize [that] it's really important to have a support group where they can be with each other, they can tell each other their experiences. Actually, it's in the plans of Dr. Lim,² to have a lounge for the patients. So, what is needed is the space.

Most of the mothers also raised their financial concerns, especially in their children's treatment. In particular, they were concerned with their daily expenses, especially those they incur every time they travel to PGH for consultations. Some mothers also lived far, with some from Cavite, Quezon City, Rizal, and Laguna, so they needed to find financial resources for transportation and food costs, laboratory fees, and others. For instance, Mother 5 experienced difficulties when she and her child have to travel to PGH for their regular check-up, since this necessitated a lot of logistical considerations (i.e., taking leave from work, budgeting for transportation, food expenses, and laboratory fees).

¹ CD4 T lymphocytes are a part of the human T-lymphocyte cells produced in the bone marrow. They circulate the body to fight against bacteria and viruses. When HIV is untreated, the virus enters the cell and causes CD4 cells to die. Thus, for decades, measuring CD4 cell count has been a means to track the progression of a person's HIV (Garcia & Guzman, 2023).

² Dr. Jodor Lim is the Head of the University of the Philippines–PGH Infectious Diseases Section. She is the HIV AIDS Core Team Leader and the main contact person for the SAGIP Unit.

The health care workers that participated in the study also discussed the patients' financial constraints, the recourses available, and, ultimately, their inadequacy to address the patients' needs. According to them:

PGH has a MALASAKIT Program. However, it is only for admitted patients. But the patients in SAGIP can ask for financial assistance from our Medical Social Service (MSS) in case they need it. The MSS gives them a blue card or white card. Both have discounts in PGH services: the white card has a bigger discount on medications and sometimes they can get free laboratory [testing] and diagnostics from it.

At present, PGH's SAGIP Unit has yet to establish its own support group. Being in a support group has proven to be tremendously helpful towards helping many PLHIV face and move through the difficult points in their lives. PLHIV may experience social isolation and stigma, as they learn to adjust to their diagnosis and lifelong treatment. Thus, social support is essential, as it plays an essential role in managing their stress and provides better psychological and physical health outcomes (Turner-Cobb et al., 2002, as cited in Coulson & Buchanan, 2022). These groups allow PLHIV to share their experiences, provide mutual support, and ask questions from each other (Coulson & Buchanan, 2022), as members of the group, mostly those undergoing similar conditions, offer not only authentic empathy, emotional comfort, and moral support but also practical advice and suggestions to help their co-members cope with the situation.

HIV Counseling

The mothers mentioned that they received counseling when they had their pre- and post-HIV tests, but they did not receive much after they have been diagnosed with HIV. Counseling of HIV persons should be highly individualized, including interpretation of the test result and discussion on the biomedical and psychosocial implications of the diagnosis. Individuals with positive HIV test results should be instructed

to notify their sexual partners or those who share needles with them. Counseling these other individuals whom the HIV-positive person has been in contact with should also be suggested. The physician may, alternatively, inform the partner/s of the person with HIV of their partner's condition and suggest HIV testing as well for them in case the person with HIV is reluctant to tell the partner.

Mother 4 mentioned that there was a doctor in the SAGIP Unit who will assist patients and answers all questions and concerns, which was why the patients always went to that doctor for inquiries on what medicine or vitamins to take. However, Mother 4 also mentioned that she has not yet received counseling from the HIV counselors.

Most of the health care providers interviewed mentioned that they do individualized counseling because their clients have individualized needs and issues. They also mentioned that they counseled more men than women. One narrated his experiences with counseling women, stating:

....Women are more dramatic, sorry. Since I handled two recently, I think I did secondary counseling since I was assigned to them. I asked them if they [had] a job. Their economic status [their employment] was somewhat stopped because they were diagnosed with HIV. So, two of them were deported from the Middle East. They do not want it [the disease]; they were infected by their partners. So, they asked me, "Why is it like that? I don't deserve it."

Almost all of the participant mothers were diagnosed with HIV when they were pregnant or when their child got sick and was found HIV-positive. As discussed in WHO's 2013 handbook, this is why identifying women with HIV and their partners is a "gateway" to helping women, partners, and children to receive HIV treatment and care. WHO recommends that all women in high-prevalence countries, particularly pregnant women, should receive HIV testing and counseling. Specifically, HIV counseling during routine antenatal and postpartum care can benefit women by providing them HIV/AIDS information and, ultimately,

encourage HIV testing. Getting essential HIV/AIDS information at the first antenatal care visit is primordial to ensure that as many women as possible receive the necessary information (WHO, 2013). One health care provider remarked:

Women are more expressive with their feelings. If they want to cry, they cry. They are also loyal to their partners even if their partners are not.

Research has suggested that women express emotions more frequently than men on average. Studies have found that women cry more frequently and for longer durations than men at similar ages (Madison, 2019). Health care provider 5 noted:

I have a case of [...] a male diagnosed with HIV. He has a wife who is pregnant. Then, he was diagnosed HIV-positive. He told me not to disclose it with his wife because he is afraid that they will separate [...] something like that. But I counseled him that he needed to disclose [his HIV status] because his wife is pregnant. If not, the unborn child may be infected. So, he thought about it and [agreed that he should disclose].

Disclosure means telling someone that you are living with HIV. Sharing your HIV status can help with the stresses of living with HIV. However, deciding whom to tell and how to tell them can be complicated and difficult. Despite their need for support, many people feel that they cannot tell relatives or friends about their HIV status, scared of stigma and rejection. Even if they do reveal their HIV status, they may not receive the emotional support they require and deserve. Both sides need support in this situation: PLHIV may need support to tell family members about their HIV status, and their families as well may need support to cope with their feelings about the reveal. Although disclosing HIV status is usually advocated to reduce stigma and protect uninfected partners, this is a complex situation. Many factors should be considered before disclosure takes place—precisely why counseling is essential.

The health care workers discussed the different strategies they use in counseling, with some ensuring accessibility in their language:

I use simpler words so that they can understand better and they can remember. Then in [the] post-tests, it is still the same [...] I am more on assessment with them, [on] how they will take those things. There is [procedure] that needs to be followed, but I really prioritize the needs of the patient, the knowledge, and their feelings.

Another health care worker employed the same strategy, stating that:

In my opinion, I would first do an assessment of the patient, [on] how she is taking the word [of the test results], since there are those who will take the test that of course cannot understand [the results completely]. In DOH, this is what you need to say. Most of the patients who take the test are not really educated, so I have to use simple words.

There are many ways and strategies in HIV testing and counseling. The most common are the 5 Cs, which are essential for all HIV testing services (HTS): consent, confidentiality, counseling, correct test results, and connection to HIV prevention, treatment and care. People who test HIV-negative will usually need only brief health information about their HIV status report, particularly how to prevent acquisition of HIV in the future and where and how to link to HIV prevention services, as appropriate. Meanwhile, people with significant ongoing risk may need more active support and linkage to HIV prevention services. Thus, those diagnosed HIV-positive should receive post-test counseling, including couples where one or both are diagnosed HIV-positive (WHO, 2015).

Receiving an HIV diagnosis empowers individuals to make informed decisions about HIV prevention, treatment, and care that will affect both HIV transmission and their health and survival. Therefore, linkage to appropriate services following diagnosis should be regarded as a key component of effective and comprehensive HTS. Some structural

hurdles to HIV testing include a lack of community-based HIV counseling and testing services for children, as well as challenges recognizing HIV-infected babies (Madiba & Mokgatle, 2017).

According to Flick (2009), a greater degree of abstraction is reached via selective coding through acts resulting in an extension or formulation of the case story. Selective coding is the third and last step in the grounded theory approach. It connects categories that have been developed from the qualitative data in previous coding cycles, such as axial coding. The core category developed in selective coding may come from elevating one of the categories from the axial coding stage, or it may even be a new category that was derived based on other categories.

In this study, as the researchers worked through the themes, three meanings emerged from the process:

1. *Call for help*, which we refer to as *the why*;
2. *Acceptance*, the core category around which everything else revolves, and we refer to as *the what*;
3. *Moving on*, which puts emphasis on self-care.

These meanings emerged from the related literature and data interviews from the mothers and health care providers.

Call for Help

This category was not among those concepts first considered, but it underlay nearly every discussion. Call for help refers to why persons with HIV submit and admit themselves to a testing center or health care facility to be treated and managed with their disease. During the interviews, the health care providers were unanimous in saying that most patients get admitted in the hospital because of the physiological signs and symptoms arising from HIV complications. The health care workers manage and prioritize the patient's physiological signs and symptoms when they are admitted. If the patient needs to be isolated because of a communicable infection, the patient is then assigned to an isolation room. With regard to their response, the health care providers agreed that they conduct health education to their patients

with HIV, especially on HIV and how it will progress to AIDS. Their educational sessions also cover on the primary effects and side effects of antiretroviral medications and how important monitoring their CD4 levels is. Literature supports this strategy, with Stonbraker (2019) identifying that the most significant topics for effectively educating PLHIV about their health are medication usage and adherence, transmission risks and prevention strategies, mental health management, and overall understanding of HIV. Stonbraker (2019) also pointed out that prioritizing evidence-based health education provides health care providers with a comprehensive guide to assist PLHIV in effectively managing their health.

WHO (2013) noted that in many countries, the prevalence of HIV/AIDS is rapidly increasing among women of reproductive age, making it a significant contributor to high maternal morbidity and mortality. Thus, WHO suggests that all women should know their HIV status and understand the importance of HIV prevention. Their knowledge, through HIV testing and counseling, is crucial during the early stages of motherhood, such as during pregnancy, childbirth, and breastfeeding, when women with HIV can directly transmit the virus to their infants. In the Philippines, the PGH is the only tertiary hospital who delivers babies from mothers with HIV. Most of the participants disclosed their HIV status to their families to seek help and financial assistance. This is especially true to one of the mothers:

“When I was pregnant, I have actually [gone] to several hospitals already, since they refuse to accept me [because] they said that they cannot assist me in giving birth [...]. So, I don’t have any choice but to go to PGH.” (Mother 6)

Acceptance

Even when the mothers were diagnosed with HIV for the first time, over time, they accepted their condition. One health care provider mentioned going through the process of grieving: denial, anger, bargaining, depression, and acceptance. Another healthcare provider also mentioned

that his friend eventually accepted his condition and got actively involved in the management of his disease.

...[H]is journey was long before he accepted that he is HIV-positive. Before, he was able to change his behavior; now, he is focused on the church.

This is recognized by Kubler-Ross' model of grieving (1969), also known as the Five Stages of Grief. The stages are *denial*, where individuals resist accepting the reality of the situation; *anger*, involving frustration and resentment toward the deceased or circumstances; *bargaining*, attempting to negotiate or find ways to change the outcome; *depression*, marked by profound sadness and withdrawal; and *acceptance*, the recognition that life can move forward despite the pain. It is pertinent to note that these stages are not strictly linear or universally experienced, as each person's grieving process is unique, with varying durations and potential skipping of stages.

One is finally able to accept the reality of what has happened and begin to look for avenues to move on. During this stage, it is important that the mothers accept how their situation has changed their lives and stop wishing for everything to go back to how it used to be. Their life has been forever changed, making this the time to seek new meaning. For caregivers and health care providers, this stage may be less emotionally draining, but it is still crucial to keep in mind that it is not always healthier than the previous stages. Understanding the phases—denial, anger, bargaining, and depression—involves more about anticipating patients' experiences to increase empathy and support for their struggles than about advocating a set process. This is best reflected by Mother 5:

For those like me who is a mother and who have this illness, it's not really easy for us, especially if we don't have enough ability to go back and forth to the hospital, [since being unable to go] will really stop [...] [the] treatment... [Thus], it's best to continue and adhere to the treatment given to us.

Moving On

Moving on is directly related to loss and how an individual reacts to it. Resilience amid grief and established support networks to assist during difficult times are important as well. Although the order and experience of the stages of grief vary for each individual, they remain equally important. After accepting their condition, all the interviewed mothers narrated that they have moved on or are moving on with their lives. Mother 6 articulated that she is now compliant with her medications and very cautious when outside her home to minimize infections.

...[A]ctually, the nurse there told us that every six months, we will be tested again [...]. [They also told me that] I have to continue taking my medications even if my viral load is undetected already. I am taking my medications religiously, do not want to expose myself outside often... rather stay at home.

Most persons with HIV joined HIV test hubs such as the SAGIP Unit in PGH, LoveYourself, Inc., and others. The mothers who were interviewed were all recipients of the SAGIP Unit's services. This hub also served as one of their support systems, where they can avail their supply of antiretroviral medications, as well as their offered services. One health care provider shared about his friend's experience of receiving medications from various sources, stating that although there are many places in the country to get antiretroviral drugs, the medication available in the Philippines is considered obsolete in other countries. Mother 5 was initially suspicious before taking the medications from the HIV hub center, doubting whether they could help her condition. Later on, she realized that having a child with HIV changed her perspective in taking her medications, since her child's treatment now became her priority.

After two years, I did not take any medicines from them. It's just now that I realized that I cannot take it for granted, since I have a child that I need to prioritize. I need[ed] to prioritize that [both of us are] okay.

Moving on explains a five-stage process of making voluntary change. The five stages are: becoming aware of a need for change, seeking a right fit, reaching a tipping point, journeying, and drawing to a close (Goldberg et al., 2020). The first stage, which emphasizes awareness, begins with realizing that a person is moving toward or away from something and decides to do nothing, remain stagnant, or persevere. In seeking a right fit, the person explores avenues for change and uses value-based decision-making to find the best choice. Acting upon that right fit does not happen until a tipping point is reached, or the third stage. Deciding whether or not to is a decision made when a person either spontaneously upon receiving new information or after careful deliberation. The fourth stage explains the journey, decisions made, and the factors affecting decision making, and coping strategies. The fifth stage explains how moving on concludes by evaluating the success, or lack thereof, of moving on.

Development of a Counseling Framework for Mothers of Children with PAHD

Based on the data from the individual interviews and the focus group discussion (FGD) from health care providers who have experienced counseling and taking care of PLHIV, and literature reviews and related studies, this study developed a counseling framework that would help HIV counselors in dealing with women living with HIV, specifically mothers with perinatally HIV-infected children, by focusing on the mothers' experiences and perspectives. WHO's framework on Counseling for Maternal and Newborn Health Care (2013) was used as the basis for this study, modified accordingly based on this study's results.

Figure 1 provides an overview of the counseling framework for mothers of children with PAHD. The counseling framework takes place within a counseling milieu, which is why the counseling milieu is in the outer circle. It is important for counselors to be familiar with the environment as this will give them guidance on how to act, determine what is appropriate depending on the situation, culture, and norms of the women and families they are counseling. Numerous guiding principles support the counseling framework. Thus, it is important to approach this framework with sensitivity, empathy, and a focus on

Figure 1
Counseling Framework for Mothers of Children with PAHD



both the physical and emotional well-being of the mothers and their children.

The counseling milieu is composed of the socio-economic conditions of the mothers, social and cultural norms that influence them, their gender roles, and household decision-making processes. Gender roles are the product of the interactions between individuals and their environments, and they give individuals cues about the “appropriate” behavior for each sex. Appropriate gender roles are defined according to a society’s beliefs about differences between the sexes. In this study, the concept of gender roles may not have been emphasized in the interviews and group discussions extensively. However, some studies, such as Hunt’s 2008 study

on understanding gender stereotyping and its impact on clients and Enns' 2012 study on gender issues in counseling, established gender roles as one of the primary contexts in counseling.

The counseling process, guiding principles, and counseling skills are interconnected with each other. The process can be done efficiently, as counseling skills and guiding principles underpin the six key steps, with their respective guiding suggestions, in the counseling process (Blackstone, 2003):

1. **Needs assessment.** Engage the mother in interactive discussion. Begin by conducting a thorough needs assessment to understand the specific challenges and concerns of each mother and child. This may involve medical, psychological, social, and economic aspects.
2. **Identify problems, needs and information gaps.** Review with the mother what it is about her situation that prevents her and her family from addressing her needs or those of her child with HIV.
3. **Generate alternative interventions.** Review with the mother or couple how she/they and the family can better address their needs by looking at what is currently being done, and what else could be done. Identify what other information, resources or support is needed.
4. **Prioritize interventions.** By reviewing the advantages and disadvantages of the various alternatives, work out with the mother which of the alternatives are most feasible to address the problem and/or meet the mother's and family's needs. Assist the mother or couple to work out how to overcome potential disadvantages.
5. **Develop a plan.** Make a plan together, including how to discuss the problem and solution with her partner and with others in the household.
6. **Review and evaluate.** In subsequent counseling sessions, review implementation of the plan with the mother. Is the plan working or should another alternative be sought?

To be able to effectively utilize these six steps, it is important that counselors understand their foundation: the guiding principles. Adhering to the guiding principles will enhance the effective implementation of the six steps. Additionally, a solid understanding of these principles is essential for improving counseling skills in:

1. **Establishing trust and rapport.** Build a strong foundation of trust by creating a safe and non-judgmental environment.
2. **Empathy.** Counseling for mothers relies on respecting the knowledge and skills of the counseled person, understanding the situation from their point of view, and empathizing with them.
3. **Sensitivity.** Sensitivity involves kindness, compassion, and attentiveness to others' emotions and needs, ensuring that one's actions provide comfort and support.
4. **Physical well-being.** Physical wellness also includes a personal responsibility to understand our body's warning signs and recognize when we are ill and in need of medical attention.
5. **Emotional well-being.** It is the ability to produce positive emotions, moods, thoughts, and feelings and adapt when confronted with adverse and stressful situations.

Considering the guiding principles, the following are the key skills necessary for counseling in mothers of children with PAHD:

1. **Two-way communication.** For instance, facilitating the decision on where to give birth and thinking about how to get there would be conducted through a two-way discussion of options between the counselor and the mother.
2. **Active listening.** Demonstrating that counselors are really listening will increase the mother's trust and confidence in them as counselors, building rapport and lessening her discomfort, thereby forming an alliance between the mother and the counselor. It is important the counselor does not tell

the mother how to solve the problem or suggest solutions for her, but they should try and arrive at the best solution for the mother together through a process of facilitation and two-way communication. The counselor can then support the mother to carry out this solution. Body language and gestures are also an important part of active listening.

3. **Open questioning.** They are useful when counselors are trying to encourage the mother to talk about her situation and explore her emotions, feelings, beliefs, attitudes, knowledge, and specific needs.
4. **Providing information.** As health workers, counselors must provide clear and understandable information, pertinent to the mother, her child, and their situation. Often, health workers routinely—because they are busy—provide the same information in the same way to all the mothers they see. There may not always be sufficient time for mothers to ask questions, resulting in much of the information being unused due to a lack of understanding or relevance to their needs. Providing an opportunity for mothers to seek clarification and share their thoughts enables them, along with their families, to make informed decisions. Additionally, this approach allows for the identification of beliefs and misconceptions, facilitating discussions to address inaccuracies and explore alternative perspectives.
5. **Facilitation.** Counseling involves assisting the mothers and their families to find their own solutions, as well as supporting them to take the action they need. Counselors must employ varied levels of facilitation, depending on their knowledge and skills about the mother and her family.

Conclusion

Based on the study's results, mothers were able to cope with their own disease, as well as their children's, through the help of their families who provide the first line of support in the mother's situations. The mothers managed their situation by making themselves strong for their children and keeping their strong faith in God, to whom they give credit for everything that has occurred to them. The mothers also need psychosocial help and support with their daily concerns, but mainly to support them holistically with childcare. Aside from needing psychosocial support, counseling services are also essential. Although most mothers only rely on the information given by their doctors, they are still very willing to consult for counseling whenever they feel that they need it. All participants said that aside from their children's doctor, they do not have any means of communicating their experiences and emotions to a professional counselor.

The mothers also receive little support from the government aside from the free medications and discounts of their laboratories and diagnostics. Counseling services and other psychosocial support are limited only during the pre- and post-HIV testing. Other psychosocial support needs are also not provided for both mothers and children.

Recommendations

The developed counseling framework for mothers of children with PAHD disease serves as a guide for HIV counselors in providing emotional support, education, and practical suggestions to mothers navigating the challenges associated with their own and their child's HIV diagnosis. Trained professionals can use the framework to provide personalized support, education, and emotional guidance. It involves continuous assessment, tailoring of sessions, collaboration with health care providers, and focusing on both the emotional well-being of mothers and the overall health of their children. It is also essential to establish a system for regular follow-ups to assess progress, address emerging issues, and make necessary adjustments to the counseling plan. Health

care providers, social workers, psychologists, counselors, and other relevant professionals should work and collaborate closely to ensure a holistic approach of care to mothers with PAHD and women living with HIV as a whole.

HIV/AIDS education plays an integral part in ensuring an accepting environment of PLHIV. Integrating HIV/AIDS education into the K-12 curriculum in the Philippines is essential for raising awareness, reducing stigma, and preventing the spread of the virus. Addressing many challenges requires a coordinated effort involving government agencies, educational institutions, civil society organizations, and communities.

Additionally, a comprehensive review of laws and policies specific to HIV/AIDS is essential to ensure that existing legal frameworks are effective, up-to-date, and aligned with the evolving understanding of the disease. Empowerment of these mothers living with HIV together with their children through the government programs sponsored by the Department of Social Work and Development (DSWD) and the Department of Health (DOH) is vital in helping them contribute meaningfully to not only their families but also to society.

More studies in theory generation in the context of HIV/AIDS is also recommended. This involves developing and refining conceptual frameworks that guide research, interventions, and policy and promoting a deeper understanding of the underlying factors influencing HIV/AIDS spread of HIV/AIDS and the effectiveness of prevention and treatment strategies. Moreover, qualitative research studies specifically on HIV/AIDS emphasize the need for in-depth exploration and analysis of qualitative data to inform more nuanced and context-specific interventions.

Acknowledgment

This research was funded by a Research Grant from the University of the Philippines Center for Women's and Gender Studies.

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