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**ORIGINAL ARTICLE**

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# Health-Related Quality of Life during Pregnancy of Filipino Patients with Antiphospholipid Syndrome in Philippine General Hospital: A Qualitative Study

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## ABSTRACT

**Objective:** This study aims to provide qualitative data on the health-related quality of life (HRQoL) during pregnancy of Filipino patients with antiphospholipid syndrome (APS).

**Methodology:** This study utilized focus group discussions (FGDs) to gather experiences, perceptions, and behaviors of patients with APS during their pregnancy. Participants included pregnant patients or patients who delivered in the past 6 months, diagnosed with APS, whether classified as Secondary APS, Primary APS, or Non-criteria APS. This is a qualitative study that underwent five stages in data analysis: 1) data collection, 2) familiarizing and identifying thematic framework, 3) indexing, ranking, and listing of statements per theme, 4) rearranging context under appropriate thematic content, and 5) mapping and interpretation.

**Results:** A total of 5 FGDs were conducted, with 15 participants in all. The majority (93%) had poor overall quality of life. The most common factor was the medication's financial implications. Most had limitations in daily activities (87%) and sleep disturbance (67%). All participants expressed satisfaction with access to healthcare and with the services they received at the hospital. Support from the partner and family, and following the doctor's advice, were the most common coping mechanisms for the disease and its management.

**Conclusion:** The majority of patients demonstrated understanding of the basic knowledge of APS. Despite satisfaction with access to health services and information from physicians, there was dissatisfaction with overall quality of life, mainly due to the financial burden of medication, which also caused physical and psychological dissatisfaction. In contrast, financial support from family fostered social satisfaction.

**Keywords:** health-related quality of life, antiphospholipid syndrome, pregnant

## INTRODUCTION

Based on the 2022 demographic and health survey by the Philippine Statistics Authority, 12% of all pregnancies in women aged 15-49 resulted in pregnancy loss, 11% of which were miscarriages.[1] Worldwide, there are 23 million miscarriages estimated every year, which translates to 44 pregnancy losses every minute.[2] A previous miscarriage is one of the risk factors for another miscarriage.[2] Obstetric Antiphospholipid Syndrome (APS) is the most identified cause of recurrent pregnancy loss and late-pregnancy morbidity related to placental injury.[3]

APS is a systemic autoimmune disorder. According to the Sydney criteria, it is characterized by the persistent presence of autoantibodies against phospholipid-binding proteins leading to thrombosis and other obstetrical complications.[4]

Obstetric APS is a condition that brings serious morbidity at any time during pregnancy. However, with emerging therapeutics, full-term pregnancies are achieved in most cases, with treatments directed towards reducing inflammation, antiphospholipid (aPL) antibody levels, and complement activation.[5]

Equally important in understanding the disease's pathogenesis is the patient's quality of life, defined as the subjective perception of living with the disease.[6] Health-related quality of life (HRQoL) is a subjective, multidimensional concept demonstrating an individual's satisfaction with functional capacities related to health.[7] Several studies on the elements affecting HRQoL have focused on financial status, education level, occupation, emotional state, which includes depression, anxiety, stress, and physical health, including body pain and discomfort.[8,9]

In relation to the disease's morbidity and effective preventive and therapeutic measures, the assessment of QoL includes the ability to cope with everyday tasks and the level of satisfaction with new life circumstances. It is an essential tool for evaluating the impact of a disease and its interventions.[10]

HRQoL has not been fully explored in APS. As of this writing, no study has been found on the HRQoL of pregnant patients with APS. Assessing QoL is an important factor in understanding and managing disease. The World Health Organization (WHO) has included it in the Sustainable Development Goals (SDGs), specifically in the third goal "health and well-being". With the advent of reproductive immunology, assessment of QoL of pregnant patients with APS will also impact the emerging management of these patients.

Focus groups have been used to assess a broad range of health- and medical-related issues, including the identification of patients' psychosocial issues.[11] The element of interaction in focused group discussion (FGD) makes it ideally acceptable in exploring issues related to medical and health research.[12] It has been highlighted that FGDs are used to obtain knowledge, perspectives, and attitudes of people about issues, and to seek explanations for behaviors that are less easily accessible through surveys and direct questions, such as in one-to-one interviews.[13] During FGD, the moderator would facilitate all informants in active participation, hence would enable real feelings and issues to surface, providing higher quality answers than personal interviews or surveys. The dynamics of a group would lead to more developed answers and provide non-verbal cues, such as excitement, doubt, and stress, which informants observed during the discussion and that surveys cannot elicit. Focus groups assist in understanding causality.[14] One of the strengths of FGD is its ability to bridge research and policy. It is a useful tool in providing a venue for awareness of different opinions on anticipated situations. The method of gathering data through FGD is an important tool for qualitative evaluation, providing a deeper understanding of a circumstance, such as a disease or outcome. It facilitates the surfacing of an individual's feelings, experiences, insights, and understanding, and helps clarify the multiple realities of a difficult situation.[15] A study by Leung used focus groups in evaluating quality of life among elderly Chinese people, which showed that focus groups can be a practical method for gathering information.[16]

This study provides qualitative data on the HRQoL during pregnancy of Filipino patients with APS, the factors affecting it, and their perceptions of the disease and coping mechanisms.

## METHODOLOGY

### Study design

This is a qualitative study that utilized focus group discussions (FGDs) to gather experiences, perceptions, and behaviors of patients with APS during their pregnancy as a basis for their quality of life and the impact of the disease course and management on their QoL. The institution's research ethics board approved the study before recruiting participants. Informed consent was secured from each participant before participation

A pilot FGD was done and was followed by four sessions of FGD with pregnant patients or patients who delivered in the past 6 months, diagnosed with APS, whether classified as Secondary APS, Primary APS, or Non-criteria APS with or without concomitant alloimmunity, with or without history of recurrent pregnancy loss.

*Inclusion criteria*

- Pregnant patients in the first, second, or third trimester or puerperium, or those who have delivered within the past 6 months (from the time the protocol was approved)
- 18 years old and above
- Diagnosed with antiphospholipid syndrome
- Regardless of presence or absence of comorbidities such as hypertension, diabetes mellitus, thyroid disease, structural reproductive abnormalities

*Exclusion criteria*

- Those diagnosed with anxiety, depression, or psychiatric illness before they experienced recurrent pregnancy losses
- Those with a language barrier, particularly those who are deaf and mute
- Those who cannot understand English or Tagalog.

To increase the number of participants in this study conducted last March 2025, postpartum patients who had delivered in the past 6 months at the time of the FGD were included, given the reliability of maternal recall.[17] All participants were patients from Philippine General Hospital. All FGDs had the same moderator, who asked the questions and facilitated the discussion, and the same observer, who took note of nonverbal cues from the participants.

The primary investigator prepared the FGD questions. Coverage of the questions included overall quality of life, followed by specific domains: physical health, psychological, social, and environmental. These questions were derived from the WHO Quality of Life Scale-Brief domains and questions.[18] Additional focused questions on perceptions of the disease, feelings upon diagnosis and the start of treatment, satisfaction with management, and coping mechanisms were included to conclude the FGD. The questions were stated in English and in Filipino during the FGD.

**Sample size**

Saturation is considered the basis for a rigorous and adequate sample size in qualitative research.[19] Based on Guest et al.,[20] this study conducted four distinct FGDs, in addition to an initial pilot session. Each FGD included study participants at varying stages of pregnancy or postpartum, allowing for diverse topics within the FGD and more discoverable themes.

According to Krueger and Casey, a sample size of 6 to 8 participants is generally accepted.[21] To account for potential attrition and non-attendance, a standard over-recruitment strategy of 10% to 25% was employed,[22] resulting in a target recruitment of 10 participants per session. In this study, each FGD had fewer than 6 participants, rather than the maximum of 10.

**Data collection and analysis**

Descriptive statistics were used for the sociodemographic data, and thematic analysis was conducted on FGD responses. The data set was summarized and organized according to characteristics of the responses collected from the sample population.

In this study, demographic data of each participant and duration of each FGD were documented. Data collection, consisting of participants' responses to the questions, began during the FGD and was recorded via audio recordings saved on a password-protected device.[23,24] Each participant had to mention her assigned participant code before stating her answers to protect her identity and enable tracking of which participant made a particular statement during transcription of the recording. Identifying statements with a corresponding participant code enabled precise frequency accounting for a thematic concept discovered per domain.

The data analysis process was structured around stages established by Ritchie and Spencer for analyzing qualitative data.[25] Data analysis began during the data collection, which included the following stages: (1) familiarizing and (2) identifying a thematic framework while listening to the audio and reading the transcripts as a whole several times, as well as reading the observational notes taken during FGD. The third stage was indexing, which included sifting data, highlighting and sorting statements, and making comparisons, as shown in the listing and ranking of statements by theme. The main thematic concepts were labeled with capital letters in the order of discovery. Sub-themes which pertain to the factors or experiences under a main thematic concept were labeled with the main thematic code letter and a number. The numbers were coded in the order of being discovered.

The fourth stage is charting, which was done by obtaining quotes from the original context and rearranging them under their appropriate thematic content. The fifth stage is mapping and interpretation to examine relationships among quotes or statements, as discussed in the results section. The final stage is content analysis, which includes conceptual analysis to determine the existence and frequency of concepts or themes, and relational analysis to examine relationships among them.

## RESULTS

A total of 58 patients met the inclusion criteria: 20 were pregnant, and 38 had delivered in the past 6 months (Appendix). For the pilot FGD, 10 participants were recruited but only 2 attended. After the pilot FGD, there were no revisions to the prepared questions or to the

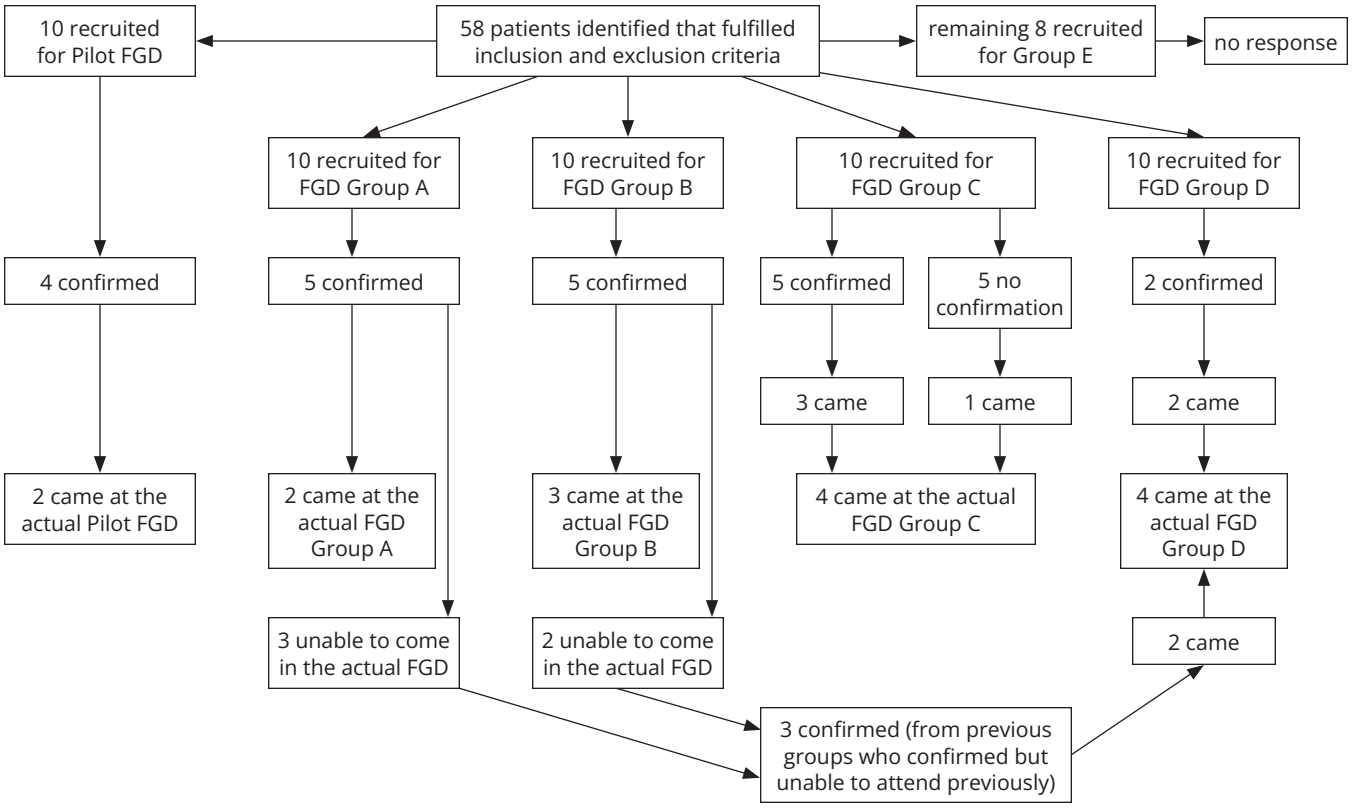


**Figure 1.** Flow diagram on the recruitment of participants and attendance on actual FGD.

manner in which the FGD was conducted. Data from the pilot FGD were included.

For the subsequent FGDs (Groups A–D), 10 participants were initially recruited per group. Actual attendance varied: Group A comprised 2 participants, Group B had 3, Group C included 4 (including 1 unconfirmed attendee), and Group D contained 4 (including 3 rescheduled from previous sessions) (Figure 1).

The duration of the FGDs ranged from 26 to 53 minutes, varying by group size: pilot study (n = 2, 26 min), Group A (n = 2, 43 min), Group B (n = 3, 43 min), Group C (n = 4, 50 min), and Group D (n = 4, 53 min). These durations provided sufficient time to achieve data saturation given each group's participant density.

## Demographic characteristics of the participants

Most of the participants were in the 30-40 age range. The majority of the respondents were postpartum and had delivered a live, term neonate in the past 6 months. Currently pregnant patients who were able to participate were mostly in their third trimester. Six participants had no comorbidities other than antiphospholipid syndrome, while 9 (60%) had comorbidities. Among the comorbidities, hypertension was the most common, occurring in 6 out of 15 participants. Average monthly income was mostly in the range of ₱15,000– 20,000. Forty-seven percent of the participants were college graduates. Forty percent stopped working since pregnancy, and 67% were single but had live-in partners (Table 1).

## Focus group discussion

### *Overall quality of life*

Qualitative analysis of the overall quality of life question yielded three major themes: fulfillment of being pregnant (Theme A), dissatisfaction with health while pregnant with APS (Theme B), and satisfaction with the management that allowed successful pregnancy (Theme C). Theme B comprised 17 recurrent factors (B1–B17), applied consistently across identical response types (e.g., B1 designated all instances of pain, hardship, or bruising from medication injections). Theme C was partitioned into three subthemes (C1–C3).

Most of the participants (14 out of 15) expressed dissatisfaction with their health as pregnant with APS. The most common factor in this dissatisfaction was the financial burden the medication entails. This was followed by traumatic experiences from previous miscarriages, stress from overthinking how they got APS, fears of losing the baby, and treatment requiring injections, which caused pain and bruises. Factors causing dissatisfaction in the

overall quality of life in pregnant patients include not just economic burden (n = 8) but also psychological (n = 15), physical (n = 4), social (n = 2), and environmental (n = 2) issues (Table 2).

Among the 14 participants who expressed dissatisfaction, 7 also expressed satisfaction. This was due to the fulfillment of being pregnant, satisfaction due to the existence of doctors specializing in the management of APS patients, successful outcome of pregnancy despite hardship in the medication, and awareness of how to manage the disease. One participant expressed only satisfaction. This was due to the fulfillment of being pregnant, expressed in a jolly tone that conveyed happiness and excitement.

*Physical health domain of QoL*

Regarding the physical health domain of QoL, inductive thematic analysis revealed five primary themes. Themes reflecting positive or neutral states included "no limitation in daily activities" (comprising one factor), "no sleep disturbance," and "no perceived difference in physical issues pre- and post-APS diagnosis during pregnancy." Conversely, themes capturing negative impacts comprised "presence of limitation in daily activities," which encompassed 19 distinct factors, and "presence of sleep disturbance," which was further differentiated into nine subthemes (Table 3).

**Table 1.** Demographic characteristics of study participants

| | Frequency (%) |
|---|---|
| ***Age in years*** | |
| 18-29 | 4 (27) |
| 30-40 | 9 (60) |
| >40 | 2 (13) |
| ***Pregnant*** | 7 (47) |
| First trimester | 1 |
| Second trimester | 2 |
| Third trimester | 4 |
| ***Postpartum*** | 8 (53) |
| ***Comorbidities*** | 9 (60) |
| SLE | 1 (7) |
| Thyroid disease | 1 (7) |
| Diabetes mellitus | 5 (33) |
| Hypertension | 6 (40) |
| Psoriasis | 2 (13) |
| Asthma | 1 (7) |
| ***Monthly income in PhP*** | |
| below 5,000 | 2 (13) |
| 5,000 – 10,000 | 2 (13) |
| 11,000 – 15,000 | 1 (7) |
| 15,000 – 20,000 | 6 (40) |
| 25,000 – 30,000 | 3 (20) |
| 60,000 | 1 (7) |
| ***Civil status*** | |
| Married | 5 (33) |
| Single, with Live-in partner | 10 (67) |
| ***Educational attainment*** | |
| Elementary graduate | 1 (7) |
| High school graduate | 4 (27) |
| Undergraduate | 3 (20) |
| College/ vocational graduate | 7 (47) |
| Postgraduate studies | 0 (0) |
| ***Occupation*** | |
| Stopped since pregnancy | 6 (40) |
| Housewife | 5 (33) |
| Still working even pregnant | 4 (27) |

**Table 2.** Overall quality of life thematic concepts

| Thematic concepts | Frequency n (%) | Mapping and interpretation |
|---|---|---|
| Fulfillment being pregnant (A) | 2 (13) | Satisfaction |
| Satisfaction with the outcome of medication which allowed successful pregnancy (C) | 6 (40) | Satisfaction |
| ***Factors:*** | | ***Aspect:*** |
| Acknowledgement of need of the management for successful pregnancy despite hardship during medication | 2 (13) | Psychological |
| Existence of doctors specializing in the management of APS patients | 1 (7) | Environment |
| Awareness on how to manage the disease | 1 (7) | Environment |
| Dissatisfaction with the health as pregnant with APS (B) | 14 (93) | Dissatisfaction |
| ***Factors:*** | | ***Aspect:*** |
| Financial burden due to medication expense | 7 (47) | Economic |
| Traumatic experience on previous miscarriages | 4 (27) | Psychological |
| Stress from overthinking how she got APS | 3 (20) | Psychological |
| Fears of losing the baby | 3 (20) | Psychological |
| Treatment requiring injection which caused pain, bruises | 2 (13) | Physical |
| Stress from needing others to inject | 1 (7) | Psychological |
| Anxiety on unusual experiences | 1 (7) | Psychological |
| Worries on vaginal spotting | 1 (7) | Psychological |
| Need to be hospitalized for 1 month | 1 (7) | Physical |
| No companion upon check-up | 1 (7) | Social |
| Unexpected diagnosis | 1 (7) | Psychological |
| Family support was also financially limited | 1 (7) | Economic |
| Inability to accept and comprehend diagnosis initially | 1 (7) | Psychological |
| Difficulty in doing the injection | 1 (7) | Physical |
| Accusation by others on being pregnant | 1 (7) | Social |
| Awareness on the seriousness of the disease | 1 (7) | Environment |
| Awareness on the medical explanation of pregnancy loss | 1 (7) | Environment |

Most participants had limitations in daily activities (13 out of 15) and sleep disturbance (10 out of 15). Among the 13 who expressed limitation of daily activities, there were four who expressed having the usual daily activities at the same time: one was able to do usual activities but observed being more careful with doing activities such as avoiding heavy activities; one was able to do household chores except the laundry; one was able to do usual daily activities but unable to go out of the house with ease due to the need to stop anytime and anywhere for the injection of the medicine; and one claimed still being able to do physical activity but expressed limitations in physical health due to financial burden. Among the 6 who reported being able to do their usual daily activities, only 2 reported no activity limitations at the same time.

The top factor limiting daily activities was financial burden. One participant had forehead creases with eyebrows knitting as she shared how her family struggled financially, as they had to choose which one to prioritize - their daily meal or her medication for APS, both of which were perceived as essential for physical health. Next common factors were inability to carry a heavy workload, need to stop going to work, inability to go out of the home with ease, and deliberate bed rest due to thoughts that it may prevent negative pregnancy outcomes.

The most common factor for sleep disturbance was due to injection of medication, which caused pain and bruises. In the observer's notes, it was documented how the word 'sakiiit' (which means pain) was emphasized by prolonging the vowel 'i'. Some also had a shaky voice as details on going through the painful injection were shared. These depicted how real and deep the participants' experience of pain was. The next common factors were the need for help from others with the injection (which implies social relevance to physical health) and worry about how to obtain funds for the medication (which indicates that economic burden is also linked to physical health). Psychological issues were also found to have caused physical burden on sleep disturbance. There was worry about the uncertainty of pregnancy outcome, feelings of depression, worry about physical health, and worry about the need to go to a tertiary hospital for quality health care (Table 3).

### *Psychological domain on QoL*

Analysis of the psychological domain of QoL revealed three primary thematic concepts. Themes encompassing various emotional states and coping resilience included positive feelings and thoughts (differentiated into two subthemes), negative feelings and thoughts (encompassing 13 subthemes), and strategies for overcoming negative feelings and thoughts (comprising six subthemes) (Table 4).

**Table 3.** Physical health domain

| Thematic concepts | Frequency n (%) | Mapping and interpretation |
|---|---|---|
| No limitation in daily activities | 6 (40) | Satisfaction |
| ***Factor/experience:*** | | ***Aspect:*** |
| Felt the need to move and exercise | 1 (7) | Psychological |
| No sleep disturbance | 2 (13) | Satisfaction |
| Presence of limitation in daily activities | 13 (87) | Dissatisfaction |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Financial burden | 3 (20) | Economic |
| Inability to carry heavy workload | 2 (13) | Physical |
| Need to stop going to work | 2 (13) | Physical |
| Inability to attend outing or go out with ease | 2 (13) | Physical |
| Deliberate bed rest as a way to avoid negative outcome | 2 (13) | Physical |
| Doctor's advice for bed rest | 1 (7) | Physical |
| Exertional dyspnea | 1 (7) | Physical |
| Inability to work for straight 8 hours due to BP elevation | 1 (7) | Physical |
| Abdominal cramps from avoidance of food being desired | 1 (7) | Physical |
| Abdominal cramps from heavy activities | 1 (7) | Physical |
| Abdominal cramps upon going up and down the stairs | 1 (7) | Physical |
| Capacity to work affected when time for injection | 1 (7) | Physical |
| Inability to send another child to regular school | 1 (7) | Physical |
| Body weakness due to no exercise (always bed rest) | 1 (7) | Physical |
| Struggle in the need to travel for check-up | 1 (7) | Environment |
| No companion in doing things | 1 (7) | Social |
| Stress from overthinking on previous miscarriages | 1 (7) | Psychological |
| Stress from physical limitation of pregnancy | 1 (7) | Psychological |
| Fears on physical health due to comorbidities | 1 (7) | Psychological |
| Presence of sleep disturbance | 10 (67) | Dissatisfaction |
| ***Factors:*** | | Aspect: |
| Injection of medication caused pain and bruises | 6 (40) | Physical |
| Need for help from others for the injection | 3 (20) | Social |
| Worry on how to get funds for the medication | 3 (20) | Economic |
| Symptom of vomiting | 1 (7) | Physical |
| Worry on uncertainty of pregnancy outcome | 1 (7) | Psychological |
| Feeling of depression | 1 (7) | Psychological |
| Worry on physical health | 1 (7) | Psychological |
| Worry on need to go to tertiary hospital for quality care | 1 (7) | Psychological |
| Worry on injection when fundal height increased | 1 (7) | Physical |
| No difference in physical issues between being pregnant not diagnosed with APS and when diagnosed with APS | 1 (7) | No difference from with APS and without APS |

The majority had negative feelings and thoughts (13 out of 15). The top experience of having negative feelings and thoughts was fear and anxiety about losing the fetus during pregnancy. This was followed by extreme sudden sadness without knowing why, anxiety and hopelessness due to the financial demand of the medication amidst limited fund source, and self-doubt. There was also jealousy of other pregnant patients without APS, abdominal cramps due to sadness, hopelessness, and anxiety, and hopelessness due to wanting to give up during a long hospitalization.

**Table 4.** Psychological domain of QoL

| Thematic concepts | Frequency n (%) | Mapping and interpretation |
|---|---|---|
| Occurrence positive feelings and thoughts (A) | 3 (20) | Satisfaction |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Happiness for the chance of getting pregnant as APS | 2 (13) | Outcome |
| Gratefulness for having a baby | 1 (7) | Outcome |
| Sense of motivation due to hope in the management | 1 (7) | Management |
| Occurrence of negative feelings and thoughts (B) | 13 (87) | Dissatisfaction |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Fear, and anxiety on losing the fetus | 8 (53) | Psychological |
| Extreme sudden sadness without knowing why | 5 (33) | Psychological |
| Anxiety and hopelessness due to financial burden | 4 (27) | Economic |
| Self-doubt | 3 (20) | Psychological |
| Jealousy of other pregnant patients without APS | 1 (7) | Psychological |
| Abdominal cramps due to sadness, hopelessness, anxiety | 1 (7) | Physical |
| Inability to understand APS and why she got APS | 1 (7) | Psychological |
| Hopelessness, wanting to give-up during hospitalization | 1 (7) | Psychological |
| ***Occurrence:*** | | |
| When alone | 2 (13) | Social |
| When others could not understand APS and the situation | 2 (13) | Social |
| When previous miscarriage was recalled | 1 (7) | Psychological |
| When other family members unaware of the problems | 1 (7) | Social |
| When admitted for 1 month | 1 (7) | Physical |
| Overcoming negative feelings and thoughts (C) | 10 (67) | Growth and maturity |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Sense of need to be optimistic | 5 (33) | Psychological |
| Encouragement from others | 3 (20) | Social |
| Acceptance of management for desire of having a baby | 3 (20) | Psychological |
| Presence of physicians who can manage the APS | 2 (13) | Environmental |
| High spiritual growth | 2 (13) | Psychological |
| Surpassing usual age of gestation of miscarriage gave hope, strength and ability to see life as meaningful | 2 (13) | Outcome |

Negative feelings and thoughts would occur when alone, when others could not understand APS and the situation, when a previous miscarriage was recalled, when other family members were unaware of the problems the disease caused, and when hospitalized for 1 month. Participants mostly got teary-eyed as they narrated these situations.

There were three who expressed positive feelings and thoughts, but all also expressed negative ones during the pregnancy. The occurrence of positive thoughts and feelings was due to happiness at having the chance to get pregnant despite APS, gratitude for having a baby, and a sense of motivation from the hope the management gives.

There were 10 who showed psychological growth and maturity by overcoming the negative feelings and thoughts. Among these 10, 8 belonged to the majority and expressed negative feelings and thoughts. Psychological growth and maturity were due to sense of need to be optimistic, encouragement from others, acceptance of the management for the desire to have a baby, presence of physicians specializing on the management of pregnant with APS, high spiritual growth manifested through praying and surrendering to the Supreme Being, and the surpassing of the usual age of gestation of miscarriage which gave hope, strength and ability to see life as meaningful.

Aside from the psychological aspect, factors that cause negative feelings and thoughts include economic burden (n = 4), which ranks next to psychological, followed by physical (n = 1). The occurrence of negative feelings and thoughts is also linked to social and physical factors, in addition to psychological factors. Positive feelings and thoughts arise from the positive outcome of management and pregnancy. Psychological growth and maturity were supported by psychological, social, and environmental factors, as well as outcome satisfaction (Table 4).

*Social domain of QoL*

There were three main concepts identified for the social domain of QOL: satisfaction with support from personal relationships (14 sub-themes), dissatisfaction with support from personal relationships (7 sub-themes), and the expression that both satisfaction and dissatisfaction with relationships occurred simultaneously but among different groups of persons (Table 5).

There was more expression of satisfaction with a personal relationship than of dissatisfaction. There were 10 who expressed both satisfaction and dissatisfaction, such as being satisfied with support from husband and family,

**Table 5.** Social domain of QoL

| Thematic concepts | Frequency n (%) | Mapping and interpretation |
|---|---|---|
| Satisfaction with personal relationships | 13 (87) | Strong social ties |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Support from husband and family | 4 (27) | Social |
| Financial and emotional support from partner, family | 4 (27) | Economic |
| Encouragements and direction from family | 3 (20) | Social |
| Ability to understand the situation of APS | 2 (13) | Social |
| Sense of being loved and cared by partner and family | 1 (7) | Psychological |
| No discrimination | 1 (7) | Psychological |
| Companion for check-up and providence of food | 1 (7) | Social |
| Sense of belongingness | 1 (7) | Psychological |
| Consultation with physician explaining management | 1 (7) | Environmental |
| Loyalty from partner despite previous miscarriages | 1 (7) | Social |
| Dedication to give time to listen during times of stress | 1 (7) | Social |
| Partner's effort to research on the cause and what to do | 1 (7) | Social |
| Partner's availability to be there when needed | 1 (7) | Social |
| Sister's effort to visit in the hospital, taking away sadness | 1 (7) | Social |
| Thankfulness to a friend who is a nurse who can understand the situation, give advices and spend time to eat out and chat | 1 (7) | Social |
| Dissatisfaction with personal relationships | 12 (80) | Weak social ties |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Information on pregnancy kept secret from friends | 7 (47) | Psychological |
| No support from friends | 4 (27) | Social |
| Sense of being disvalued and misunderstood by friends | 3 (20) | Psychological |
| Inability to open up to friends | 3 (20) | Social |
| Inability to bond with friends and do what friends do | 1 (7) | Physical |
| Sense of boundary from friends | 1 (7) | Social |
| Insensitivity with neighbors | 1 (7) | Psychological |
| Unawareness of other family members due to distance | 1 (7) | Environment |
| Both satisfaction and dissatisfaction with personal relationships | 10 (67) | Social ties different among different other individuals |
| Only satisfaction with personal relationships | 3 (20) | Strong social ties |
| Only dissatisfaction with personal relationships | 2 (13) | Weak social ties |

but not satisfied with friends who showed no support. There were three who expressed only satisfaction with relationships, and two who expressed only dissatisfaction.

The top factor for dissatisfaction in relationships with others was information on pregnancy kept secret from friends. There was a pained expression as one narrated how she did not want to share with other people who are not family that she was pregnant, as they tend to tease her for her past unsuccessful pregnancies.

Specific factors that caused ability to sustain strong social ties were as follows: financial and emotional support from partner and family (ranking the highest), encouragements and direction from family, ability of others to understand the situation of APS, sense of being loved and cared by partner and family, sense of not being discriminated by others, sense of being accompanied during check-up and of being provided with food, sense of belongingness, consultation with physician explaining the management which gave hope for the partner to give support on the pregnancy, loyalty from partner despite previous negative outcome of pregnancy, dedication of others to give time to listen especially during times of being stressed, partner's effort to research on the causes and things to do, partner's availability when needed, sister's effort to visit in the hospital to give messages that would take away sadness, and presence of a friend who is medically related (a nurse) and could understand the situation, give advices and spend time to eat out and chat.

Aside from social attributes that mostly support satisfaction with personal relationships, economic relief (n = 4), which ranks highest next to the social aspect, as well as psychological and environmental factors, were also found to be involved. For dissatisfaction in relationships with others, psychological issues caused by other people, particularly friends, were the most common factor. Physical and environmental factors were also noted to contribute to the inability to sustain strong social ties (Table 5).

*Environmental domain of QoL*

There were four main themes identified for the environmental domain of QOL: satisfaction with access to and service from healthcare (7 sub-themes), satisfaction with access to information (3 sub-themes), difficult situations experienced in obtaining access to healthcare, and the belief that the right information access is through doctors only (Table 6).

All participants expressed satisfaction with access to and the quality of healthcare at the tertiary hospital where they were managed. There was satisfaction with being able to access medical help through Viber, email and messenger when they could not physically go to the hospital, with

**Table 6.** Environmental domain of QoL

| Thematic concepts | Frequency n (%) | Mapping and interpretation |
|---|---|---|
| Satisfaction with access and service of health care | 15 (100) | Management and outcome |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Being able to access medical help through Viber, email and Messenger | 5 (33) | Environmental and Social |
| Being able to avail cheaper laboratory and services in PGH | 3 (20) | Economic |
| Having trust on the quality of care from the hospital | 2 (13) | Perception |
| Having good outcome on management through its help | 2 (13) | Perception |
| Having physicians who know how to manage APS | 2 (13) | Environmental |
| Being able to have check-up without waiting for long line | 1 (7) | Environmental |
| Knowing PGH is open despite many patients | 1 (7) | Environmental |
| Satisfaction with access to information | 6 (40) | |
| ***Factors and experiences:*** | | ***Aspect:*** |
| Access of information through doctors | 4 (27) | Environmental |
| Available through joining group in Facebook | 2 (13) | Social |
| Available through focus group discussion | 2 (13) | Social |
| Right information access through doctors only | 1 (6) | Perception |
| Difficult situations despite satisfaction on access | 3 (20) | |
| ***Factors and experiences:*** | | Aspect: |
| Need to go to hospital very early and still with long lines | 3 (20) | Environmental |
| Difficulty and need in traveling far | 2 (13) | Environmental |
| Need to go to different rooms for multiple subspecialty | 1 (7) | Physical |

*PGH (Philippine General Hospital), the tertiary government hospital where the participants were being managed*

being able to avail cheaper laboratory and services, with having trust in the quality of care of the tertiary hospital, with having good outcome on the management due to emotional support and right management from the doctors, having physicians who know about APS, with being able to have check-up without waiting for long (this pertains to the polyclinic policy in the Immunology department), and with knowing that the health care in the said hospital is open despite many patients coming in.

Despite this satisfaction, there were environmental difficulties, such as the need to go to the hospital very early and the difficulty and need to travel long distances. There was physical difficulty when going to different rooms for multiple subspecialty visits.

Satisfaction with access to information was based on access to information through doctors, joining a social media group (on Facebook), and FGDs. One emphasized that the right information on APS and its management came only from doctors. Some participants nodded vigorously as one participant shared that she was 100% grateful for the institution's services and its doctors' patience and willingness to educate about APS (Table 6).

### Perception of the disease and its management

Most participants expressed a perception of the disease as its basic knowledge stated as “sakit sa dugo” (a disease in the blood), autoimmune disease, blood clot, recurrent miscarriages, and a serious illness. Four perceived the disease as physical, stated as being a hassle, having headaches and spotting, and visual symptoms. Two perceived the disease as “for the rich,” stated as “sakit ng pang mayaman”. It means that the medication was expensive, which only those with high socioeconomic status can afford. Two perceived the disease as an emotional burden, expressed as ‘mahirap’ (which means hardship). One perceived it as a danger, which implies a well-being issue. All the feelings upon diagnosis were negative, the majority of which was sadness. Feelings upon start of management were varied. The majority had positive feelings (n = 10). The most common were a sense of hope, followed by satisfaction, high spiritual growth (which means holding on to prayers), happiness, relief, and a sense of endurance. Fewer had negative feelings (n = 5), including nervousness, indifference, worry, fear, and uncertainty, which was quoted as “Mental block. Wala akong alam kung magiging successful ba yung ginagawang gamutan.” This means there was uncertainty about whether the management would be successful.

All the participants expressed satisfaction with the management. The most common coping mechanisms for the disease and its management were support from partners and family (n = 7) and following the doctor’s advice (n = 7). This was followed by a sense of need to endure, high spiritual growth (resorting to prayers), sense of acceptance, and injection of medication by the participant herself, which was quoted as “mas okay po na ako yung nag iinject.” (Table 7)

### Content analysis across domains

Based on the participants' demographic characteristics, the estimated average monthly income was mostly below ₱30,000 (14 out of 15). Economic burden was a consistent factor in dissatisfaction with overall quality of life, physical health limitations, and negative feelings. Relief from the economic burden through access to cheaper laboratories and free services within the institution was a factor in satisfaction in the environmental domain related to access to health services. The top factor for social satisfaction was

**Table 7.** Perception of the disease and its management

| Perception of the disease and its management | Responses | Frequency n (%) |
|---|---|---|
| ***Perception of disease*** | Basic knowledge of the disease | 6 (40) |
| | Physical burden | 4 (27) |
| | 'For the rich' perception | 2 (13) |
| | Emotional burden | 2 (13) |
| | Well-being issue | 1 (7) |
| ***Feeling upon diagnosis*** | Sadness | 8 (53) |
| | Fear | 4 (27) |
| | Nervousness | 2 (13) |
| | Worried | 1 (7) |
| | Anxiety | 1 (7) |
| | Disbelief | 1 (7) |
| ***Feeling upon start of treatment*** | Sense of hope | 3 (20) |
| | Satisfaction | 2 (13) |
| | High spiritual growth | 2 (13) |
| | Happiness | 1 (7) |
| | Relief | 1 (7) |
| | Sense of endurance | 1 (7) |
| | Nervousness | 1 (7) |
| | Indifference | 1 (7) |
| | Uncertainty | 1 (7) |
| | Worry | 1 (7) |
| | Fear | 1 (7) |
| ***Management satisfaction*** | Yes | 15 (100) |
| | No | 0 (0) |
| ***Coping with the disease and management*** | Support from partner, family | 7 (47) |
| | Following of doctor's advice | 7 (47) |
| | Sense of need to endure | 4 (27) |
| | High spiritual growth | 3 (20) |
| | Injection of the medication | 1 (7) |
| | Sense of acceptance | 1 (7) |

financial and emotional support from partner and family. Each domain showed factors in the aspect belonging to other domains. This means that each domain of quality of life may also be affected by the other domains.

Most of the participants were college graduates. The majority of the disease showed basic understanding of the disease. The top coping mechanism with the disease and management was through support from partner and family, which is a social aspect, and through following the doctor's advice, which includes compliance with the medication. However, the medication is expensive under financial constraints. This creates a cycle of events leading to the main factor of dissatisfaction with overall quality of life in pregnant patients with APS.

## DISCUSSION

In this study, dissatisfaction with overall quality of life was reported by the majority of participants. In a systematic review on quality of life during pregnancy by Boutib A. et al., pathological pregnancies were shown to have a negative impact on the HRQoL of pregnant women. It showed that low back pain, uterine fibroids, asthma, anemia, maternal obesity, and gestational diabetes mellitus impact the quality of life of pregnant women as well as pregnancy outcome.[26] However, there was no review on pregnancy with APS. In this study, only 5 of 15 had concomitant diabetes mellitus, and only 1 of 15 had asthma. This may mean that the dissatisfaction with the overall quality of life among the participants was indeed related to their disease, APS. In another systematic review by Lagadec N et al., which included studies that used surveys to measure HRQoL, pregnant women had significantly lower quality-of-life scores than non-pregnant women of the same age. This was documented especially during the third trimester.[27] In this study, most of the pregnant patients who were able to attend were in their third trimester, but were only 4 out of the total 15 participants. Most of the respondents were postpartum women who delivered a neonate in the past 6 months (8 out of 15). In a study by Amana I et al,. on the HRQoL of postpartum women, which used a pretested, standard, structured questionnaire for data collection, HRQoL was very low, especially among those with low socio-economic status and inadequate maternal health utilization.[28] But for this study, postpartum participants were asked to answer the questions as recalled during their pregnancy. Nonetheless, the participants were mostly of low socioeconomic status.

The most common factor contributing to the participants' poor overall quality of life was the economic burden associated with the medication. One of the main treatments in pregnant patients with APS is anticoagulation using Tinzaparin which is about ₱892 per one vial of 10,000 IU/2mL or using Heparin which is about ₱628.35 per one vial of 1mL at 5,000 IU/mL or ₱1,499 per one vial of 5mL with same concentration of 5,000 IU/mL (based on the current standard price in a pharmacy). For the lowest possible dose of Tinzaparin, a prophylactic dose of 4,500 units subcutaneously once a day, equivalent to 0.45mL once a day,[29] one vial of 2mL Tinzaparin can suffice for 4 days of treatment. This means that over 4 days, a pregnant woman with APS needs about ₱892, which is equivalent to ₱6,690 per month, at least ₱70,245 for the whole 9 months of pregnancy and 6 weeks postpartum. However, some of the pregnant patients would require an increase in anticoagulation dose depending on the fetal status and Doppler studies monitoring. This would require more vials and increase expense. For heparin, the lowest prophylactic dose during the first trimester is 5,000 units subcutaneously twice daily.[27] This means that twelve vials of Heparin 5,000 IU/mL at 5mL/vial are needed in a month, which is equivalent to ₱17,988 per month or about ₱600 per day. And the dose of heparin increases as pregnancy progresses to the 2nd and 3rd trimester and as a therapeutic dose would be needed. This means that an estimate of at least ₱269,820 would be needed throughout pregnancy up to 6 weeks postpartum, when heparin in a 5 mL vial at a 5,000 IU/mL

concentration will be used. Based on the demographics data of this study, most of the participants' monthly family income ranged between ₱15,000 to ₱20,000. There were two with average monthly income below ₱5,000. Only one had an average monthly income of ₱60,000, and the rest had ₱30,000 or less per month. As of this time of writing, pregnant patients with APS are not among the list of those who can avail of the PWD (persons with disabilities) identification card in the Philippines. Under Republic Act No. 10754 and Administrative Order 2017-0008, there is a 20% discount and VAT exemption on the purchase of medicines for PWDs.[30] Under Republic Act No. 11228, PWDs are automatically enrolled in the National Health Insurance Program of PhilHealth. For the hospitalization frequency of pregnant patients with APS, it depends on several factors such as presence of co-morbidities and severe complications such as pre-eclampsia, eclampsia, HELLP syndrome and placental insufficiency which can lead to hospitalization.[31] There are PhilHealth package that covers eclampsia under the Maternity Care Package and Benefits for premature and small newborns, and a package that covers antiphospholipid syndrome. But there is no specific PhilHealth coverage for pregnant patients with APS. PhilHealth has raised awareness that expecting mothers, in general, are entitled to essential health services during the antenatal period, labor, normal delivery, and the postpartum period, which are set at ₱6,500 if availed in accredited hospitals and ₱8,000 if availed in infirmaries and birthing homes. For cesarean section deliveries, it covers ₱19,000. These are for pregnancy and delivery in general.[32] This study may serve as the basis for policies in the public health sector about reinforcement of support necessary in the management of pregnant patients with APS, particularly in addressing financial burden among pregnant women with APS due to the expensive and extensive medications throughout pregnancy and 6 weeks postpartum. This study also raises awareness of how society can support this particular group of patients by understanding the situations that affect each domain of quality of life.

In general, physical wellness has been defined as the ability to recognize the need for physical activity, healthy foods, and sleep, which help prevent illness and chronic health conditions and reduce depression and anxiety.[33] In pregnancy, more physical activity, fewer sedentary behaviors, and higher physical fitness have been shown as promising targets to reduce psychological ill-being and improve psychological well-being,[34] which is desirable for maternal and fetal health during pregnancy.[35] In this study, there was physical activity limitation in the majority, which may mean there would be increased psychological ill-being, which would not be beneficial for maternal and fetal health during pregnancy.

There are indeed psychological issues in a pregnant patient with APS to deal with. In this study, the majority expressed negative feelings and thoughts. It is important to note factors causing negative psychological health in pregnant patients with APS, as well as distinguish such from neuropsychiatric manifestations in women with APS caused by the effect of antiphospholipid antibodies on neurons and glial cells.[36] In this study, some of the participants overcame negative feelings and thoughts mostly with the help and support from their partner and family. Poor psychological health is shown to have a significant impact on the management of chronic diseases, since patients may not be able to adhere to treatment well.[37] Hence, the importance of knowing psychological health and its factors.

In a study by Anita Setyawati et al. on the quality of life among women with preeclampsia: a pilot descriptive study, it was shown that women with pre-eclampsia have high quality of life in all domains, including physical, psychological, and social. This was positively correlated with participants' characteristics, including age, education, occupation, family income, pregnancy stage, gravida, and medication adherence.[38] In this study, the quality of life of pregnant patients with APS was poor in the physical and psychological domains. Demographic data from this study showed low family income, and the majority had no occupation at the time of pregnancy.

According to Stansfeld, social relationships and social support are linked to positive physical and mental health outcomes.[39] According to Berkman and Glass, social relationships and social support are linked to better prognosis and survival following major illnesses[40] which may apply to APS which is a debilitating disease. In this study, the majority were able to maintain good relationships with others, more commonly with the partner than with family, and least with friends and co-workers. In a study by Debra Umberson et al., there was evidence that social ties influence health behavior.[41] This may explain the top coping mechanism of the disease and management in this study, which was support from partner and family aside from following the doctor's advice.

In a study by Rachel Zachariah on social support, life stress, and anxiety as predictors of pregnancy complications in low-income women, anxiety and social support were shown to be discriminating factors for prenatal complications.[42] In this study, the results showed higher satisfaction with personal relationships and 100% satisfaction with management, which implies a good outcome. Social support may have indeed contributed to the overall satisfaction in the management and outcome of pregnancy with APS.

For the environment domain, all participants were satisfied with health access and services, despite some having environmental difficulties, such as needing to travel far, needing to go early, and needing to go to different rooms for multiple subspecialty visits. The quality of service received at this tertiary institution outweighed some of the hardships they endured. Participants were satisfied with lower laboratory expenses and the services provided by physicians. There may be other hospitals near their location, but some would still choose to travel to this tertiary institution because they trust its quality of service. Some had to experience many miscarriages before knowing about APS. And they were satisfied with the information and education provided by the physicians at this institution. In a cross-sectional descriptive study among newly delivered mothers in Nigeria by Bello CB, it showed that 41.6% of the participants had inadequate maternal health literacy, moderate utilization of maternal healthcare with only 55.7% registered for antenatal care and 49.2% had poor pregnancy outcomes. This means that access to information and health care services impacts pregnancy outcomes.[43]

## CONCLUSION

Improving a patient's overall well-being should be emphasized rather than just treating the disease. This study shows that pregnant patients with antiphospholipid syndrome deal not only with the disease itself but also with physical health, psychological well-being, social health, and environmental factors, which are domains that affect health-related quality of life. Hence, they should be taken into consideration when managing pregnant patients with APS for a holistic approach towards better outcomes of pregnancy.

This study gathered enough information and experiences during pregnancy in women diagnosed with APS, which enabled a deeper understanding of their health-related quality of life. Despite satisfaction with access to health services and information from physicians, there was dissatisfaction with overall quality of life, mainly due to the financial burden imposed by medication. The financial dilemma also caused physical and psychological burden, while financial support from partner and family fostered social satisfaction. The majority of patients showed basic understanding of APS. Support from the partner and family, and following the doctor's advice were the most common coping mechanisms with the disease and its management.

### Limitations of the study

This study included only patients seen at a single tertiary government hospital and may represent only a particular class of the population. Nonetheless, this particular representation is a concern for the country and its medical service. This study had only 15 participants, which may have satisfied saturation for the FGD in a descriptive study. Still, it may not be enough to be representative of the general population for statistical analysis.

This study involved pregnant patients of different trimester stages and postpartum period who delivered a neonate in the past 6 months. Variation in patients' pregnancy stages could contribute to variability in responses, providing more discoverable themes in the FGD. However, due to the small sample size, meaningful comparisons cannot be made across these stages. Future research may be done to provide more nuanced insights into the experiences of women in different stages of pregnancy.

This study also did not include characterization of the presence and frequency of having arterial or venous thrombosis, which may be a factor in the poor quality of life since those APS patients with arterial thrombosis tend to have impaired QoL based on a study by Desnoyers, M.[44] One analyst, the primary investigator, did content analysis.

### Recommendations

Further studies with more extensive FGDs, including participants from a wide range of socioeconomic status, are recommended. Further study may focus on a specific trimester of pregnancy or the postpartum period to enable further comparison of HRQoL and to assess possible correlations in the results. Documentation of the presence and frequency of venous and/or arterial thrombosis among participants should also be included in future studies. For the content analysis, an independent analysis from a second investigator may be recommended.

### Statement of Authorship

The authors certified fulfillment of the ICMJE authorship criteria.

### Author Disclosure

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# APPENDIX

**Inclusion and exclusion criteria**

| | |
|---|---|
| ***Inclusion criteria*** | • Pregnant patients in first, second or third trimester or puerperium, or those who have delivered within the past 6 months (from the time the protocol was approved)<br>• 18 years old and above<br>• Diagnosed with antiphospholipid syndrome<br>• Regardless of presence or absence of comorbidities such as hypertension, diabetes mellitus, thyroid disease, structural reproductive abnormalities |
| ***Exclusion criteria*** | • Those diagnosed with anxiety, depression or psychiatric illness before they experienced recurrent pregnancy losses<br>• Those with language barrier particularly those who are deaf and mute<br>• Those who cannot understand English or Tagalog. |