

EXPLAINING UNEXPLAINED LOSS: WOMEN'S EXPERIENCES OF ONE OR MORE  
PERINATAL LOSSES ASSOCIATED WITH ANTIPHOSPHOLIPID SYNDROME

A DISSERTATION

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## DEDICATION

To my two precious miracle children, Sharath and Thushara,

When you grow up, you will know....

To my husband, Sam Mathew,

Thank you for your continuous support, and patience.

## ACKNOWLEDGMENTS

I acknowledge the coordinators of online perinatal loss support groups for giving me permission to recruit potential participants from these groups. I also acknowledge the women who willingly participated in this dissertational research by sharing their personal experience of perinatal losses and antiphospholipid syndrome.

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## ABSTRACT

SUSAN MATHEW

### EXPLAINING UNEXPLAINED LOSS: WOMEN'S EXPERIENCES OF ONE OR MORE PERINATAL LOSSES ASSOCIATED WITH ANTIPHOSPHOLIPID SYNDROME

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Perinatal loss or pregnancy loss can be a devastating experience for a woman and her family. When the loss remains unexplained and occurs once or more, it can be life changing. Unexplained perinatal loss is the loss of a pregnancy for which a cause is not identified. Perinatal loss in general, is a well researched area in nursing. However, antiphospholipid syndrome (APS) related perinatal loss is not well understood among health care professionals. Therefore, the purpose of this study was to explore women's experiences of one or more perinatal losses associated with antiphospholipid syndrome.

Two research questions guided this study: (a) What are the perceptions, thoughts, and feelings of women with one or more perinatal losses associated with antiphospholipid syndrome? (b) Do women who have experienced at least one perinatal loss have a different outlook on subsequent childbearing, after receiving a diagnosis of antiphospholipid syndrome?

The research design chosen for this study was qualitative, descriptive phenomenology. The data was collected from online perinatal loss support groups using convenience and snow ball sampling. Semi-structured email interviews of 38 participants

provided in-depth description of their experiences of perinatal losses and the related diagnosis of antiphospholipid syndrome. The sample size was determined by data saturation. The trustworthiness of this qualitative research was maintained during data collection, analysis, and interpretation using Lincoln and Guba's criteria.

The data were analyzed using Colaizzi's phenomenological method, and two overarching themes emerged. They were Existence in Bewilderment and Persistence in the Quest for Knowledge and Information. The first major theme had two sub themes. They were Delayed Diagnosis and Living in Uncertainty. Women in this study described their experience as having to exist in a somewhat confused state of mind, mixed with a perplexity of psychosocial emotions. These women had the unique experience of grieving not only the loss of their pregnancies but also the perceived loss of total personal well-being once they were diagnosed with APS. From their description, it was evident that their losses and the diagnosis had great physical, emotional, social, spiritual, and economic impact on their personal well being.

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## CHAPTER I

### INTRODUCTION

#### Problem of Study

Perinatal loss or pregnancy loss can be a devastating experience in the life of a woman and her family. When such losses occur more than once and remain unexplained, these can be life changing experiences for many parents (Adolfsson, Larsson, Wijma, & Bertero, 2004).

Perinatal loss is defined as the loss of an embryo or fetus, stillbirth, or neonatal death. Unexplained perinatal loss refers to the loss of a fetus or a baby for which no explanation or cause could be identified (American College of Obstetricians and Gynecologists, 2001).

Depending upon the gestational age in which the loss occurs, perinatal losses are classified as early or late miscarriage (spontaneous abortions) and intrauterine fetal death, stillbirth, or neonatal death. For diagnostic or therapeutic purposes, recurrent perinatal loss is defined as three or more losses of a developing embryo or fetus, stillbirth, or neonatal death within the first 28 days of the postpartum period (American College of Obstetricians and Gynecologists, 2001).

Approximately 10% to 15% of all clinically recognized pregnancies end in miscarriage, and the majority occur early, before 8 weeks of gestation (Lowdermilk, Perry, & Bobak, 2000). Sixty percent of recurrent spontaneous abortions are unexplained, and 7% to 25% of unexplained recurrent spontaneous abortions have antiphospholipid syndrome (APS) as the main risk factor (Vinatier, Dufour, Cosson, & Houpeau, 2001).

"Association not being synonymous with cause," the proportion of abortions due to APS is difficult to estimate for several reasons: the definition of recurrent abortions is variable, the laboratory assays for antiphospholipid antibodies (APLA) are not well standardized, and inclusion of patients in the study group according to the antibody titer is investigator-dependent (Vinatier et al.). Therefore it is quite a challenge for these women to be diagnosed with APS as a causative factor for their recurrent perinatal losses.

APS, first described in 1983, is an autoimmune, prothrombotic disease characterized by recurrent arterial and or venous thrombosis and pregnancy morbidity manifested by early or late fetal losses associated with aPLAs (Bertolaccini & Khamashta, 2006; Hughes, 1983; Tincani, Bompiane, Danieli & Doria, 2006; Vinatier et al., 2001). According to Bertolaccini and Khamashta, many epidemiological studies now focus on APS as a cause of recurrent spontaneous abortion. Autoimmune diseases such as APS have a high prevalence in women, especially during their childbearing years (Tincani et al.). For many years, the general advice to these women was to avoid pregnancy, as there was an increased risk of maternal and fetal morbidity and mortality (Tincani et al.). According to these medical researchers, recurrent pregnancy loss associated with the presence of circulating APLA is now considered a treatable clinical condition.

Despite these facts, scientific evidence is lacking in nursing research regarding APS-related perinatal loss and its impact on women's lives. Many nurse researchers have explored women's varied experiences of perinatal losses from different dimensions in general. However, a cause-specific perinatal loss and its related experiences of women are not well understood from a nursing perspective. An in-depth understanding of

the phenomenon of APS-related perinatal loss will enhance nurses' and other health care providers' knowledge and skills necessary to better care for these women and their families and thus reduce the devastating effects of such losses. Therefore, the purpose of this dissertation study is to explore women's experiences of one or more perinatal losses associated with antiphospholipid syndrome, using descriptive phenomenology.

### Rationale for the Study

From the extensive literature review conducted to provide a solid background for the study, it is evident that APS-related perinatal loss has been rarely studied in nursing and the lack of knowledge about APS indeed represents a wide gap in perinatal nursing. The barriers to diagnosing APS and to initiating the proper treatment needs further scientific investigation. The risk factors predicting APS needs further exploration so that preventive measures can be undertaken. In order to provide optimum quality care to the expectant woman who is diagnosed with APS and the related losses that once remained unexplained and considered rare, nurses need to learn about (a) the mechanism of perinatal losses due to APS, (b) its controversial diagnostic criteria, and (c) treatment modalities. Importantly, nurses also need to understand what it is like for the woman to live with these APS-related losses. Such learning can take place through hearing about the first-hand experiences of women who lived them.

### Philosophical Perspective

The research design chosen for the dissertation study is qualitative, descriptive phenomenology. This was selected as appropriate for studying women's experiences of recurrent perinatal losses associated with antiphospholipid syndrome (APS). In this study,

the phenomenon of interest is the varied experiences of women who have suffered one or more pregnancy losses due to APS which may have remained undiagnosed for years. The phenomenological approach is especially useful when a phenomenon of interest is poorly conceptualized (Polit & Beck, 2004). This is the case with APS-related perinatal loss, a poorly researched area in nursing.

Exploration using in-depth interviews of women affected by APS should assist in better understanding and conceptualizing this phenomenon. According to Polit and Beck, the topics appropriate to phenomenology are ones that are fundamental to the life experiences of humans. For health researchers, these include such topics as the meaning of stress, the experience of bereavement, and quality of life with a chronic illness. In fact, this study involves all three of these subtopics, as women's experiences of recurrent perinatal loss are associated with the chronic illness, APS, which encompasses stress, bereavement, and impaired quality of life.

Phenomenology is a qualitative research tradition that focuses on the lived experiences of humans and has its roots in philosophy and psychology (Polit & Beck, 2004). Descriptive phenomenology was first developed by Edmund Husserl, and it emphasizes descriptions of the meaning of human experiences. Husserl called his philosophy an archeology of human experience, a search for the ultimate, constitutive foundations of experience of the world 'as' the world of human consciousness (Edie, 1987). Husserl was concerned only with invariant and publicly verifiable constants of experience (Edie). Therefore, the focus of descriptive phenomenological inquiry is the meaning of people's experiences in regard to a phenomenon. In fact, the goal of

phenomenology is to fully describe lived experiences and individuals' perceptions of such experiences.

Phenomenologists believe that lived experiences give meaning to each person's perception of a particular phenomenon (Farber, 1967). According to Farber, they investigate subjective phenomena in the belief that critical truths about reality are grounded in people's lived experiences. The experience of the subject's perceived world is the primary reality. The phenomenological researcher asks the questions: "what is the essence of this phenomenon 'as' experienced by these people?" or "what is the meaning of the phenomena to those who experience it?" (Husserl, 1962). This method illuminates the lived experiences of people - the experiences of individuals within their life-world (Koestenbaum, 1998).

For Husserl, there are two distinguishable intuitive or experiential processes: the perceptual intuition of the individual, particular objects in the real world, and the eidetic intuition of the meanings of such real objects (Levinas, 1973). According to Husserl (1962), perceptual intuition and eidetic intuition are two distinct ways of having the same objects in the same world. In the same way, facts and essences are distinct, but inseparable. The distinction between perceiving and thinking must be stressed because the very ideal of truth requires that we be able to determine the truth or falsity of thought by turning to things as they really are in our experience prior to any thought about them (apriori) (Welch, 1965).

Thinking introduces into experience the ability to turn away from the experienced world of real facts and events to their meanings—to entertain these meanings as such,

and to ask the philosophical question “what does it mean?” (Husserl, 1962). According to Husserl, there is no factual situation which does not exhibit an essential meaning. We do not perceive a chaos, but an ordered world of objects, which, in fact, owe their perceptual structures to the attention, selectivity, and intentional activity of the perceiver (Ricoeur, 1967). Thus, meaning and fact are inextricably bound together, though distinguishable in reflection.

In this research, women will be interviewed to understand their perceptions, thoughts, and feelings of the unique experience of losing their pregnancies. These women may have different perceptions based on contextual variables such as number of living children, gestational age at losses, number of losses, and the value of the lost pregnancies. According to Husserl (1962), all sound knowledge of facts must include at least implicitly some insight into essences. Once the interview process is over, the phenomenological researcher strives to extract the essence of the themes from particular statements made by the informants using insight to better conceptualize the whole experience.

Four aspects of lived experience that are of interest to phenomenologists are lived space or spatiality, lived body or corporeality, lived time or temporality, and lived human relation or relationality (Polit & Beck, 2004). In a phenomenological study, the main data source is in-depth conversations, with researchers and informants as full co-participants. The researcher helps the informant describe lived experiences without leading the discussion. Through in-depth conversations, the researcher strives to gain entrance into

the informants' world, to have full access to their experiences as lived (Polit & Beck, 2004).

A key concept in Husserl's phenomenology is 'epoché' which is the Greek term for bracketing (Koestenbaum, 1998). Bracketing is the name given to the process of identifying and holding in abeyance any preconceived beliefs and opinions about the phenomenon under study in order to confront the data in its pure form (Polit & Beck, 2004). Husserl considered his phenomenological method a scientific method in which truth is determined exclusively by reference to the structure of experience in the precise and unadulterated form (Farber, 1967).

The method of phenomenology consists in focusing on any part or all of an experience, and then observing, analyzing, abstracting, and describing that experience by removing the researcher from the immediate and lived engagement in it (Levinas, 1973). We must observe the experience in question from a distance, that is, from a state of reflection. Only through distancing, bracketing, and reflecting can we see an object as it is in itself or as it appears in itself (Levinas, 1973). Husserl manifestly distinguishes the experience of the 'fact of certainty' from the experience of the 'feeling of certainty' (Lauer, 1965). Both fact and feeling differs from each other, as facts are objective, and feelings are subjective. However, both fact and feeling are presentations or experiences (Koestenbaum, 1998).

#### Assumptions

1. Antiphospholipid syndrome-related perinatal loss is a poorly conceptualized phenomenon in nursing.

2. A qualitative research tradition of descriptive phenomenology is an appropriate methodology to explore poorly conceptualized phenomenon.
3. In a phenomenological study, the main data source is in-depth conversations, with researchers and informants as full co-participants.
4. Exploration using in-depth interviews of women affected by APS should assist in better understanding and conceptualizing this phenomenon.
5. The topics appropriate to phenomenology are ones that are fundamental to the life experiences of humans.
6. For health researchers, the meaning of stress, the experience of bereavement, and quality of life with a chronic illness are topics that are fundamental life experiences.
7. Perinatal losses can be stressful and in addition, the effects of bereavement and the chronic nature of APS can impair the quality of life of women.
8. Phenomenologists believe that lived experiences give meaning to each person's perception of a particular phenomenon.
9. Critical truths about reality are grounded in people's lived experiences.
10. Women who have had one or more perinatal losses and diagnosed with APS have perceptions, thoughts, and feelings of the unique experience of losing their babies before and after knowing the cause of such losses.
11. Women may have different perceptions of their losses based on contextual variables such as number of living children, gestational age at loss, number of losses, and the perceived value of the lost babies.

12. Based on the perceived value of a lost pregnancy/baby, each woman assigns a meaning to her loss experience.

#### Research Questions

1. What are the perceptions, thoughts, and feelings of women with one or more perinatal losses associated with antiphospholipid syndrome?
2. Do women who have experienced at least one perinatal loss have a different outlook on subsequent childbearing after receiving a diagnosis of antiphospholipid syndrome?

#### Definition of Terms

**Antibody:** Specific protein substance made by the body that exerts restrictive or destructive action on specific antigens such as bacteria, toxins, or Rh factor (Lowdermilk, Perry, & Bobak, 2000).

**Antiphospholipid Antibodies:** Abnormal antibodies the body directs against phospholipids (Novak-McCafferty, & Holloway, 2002).

**Antiphospholipid Syndrome:** An autoimmune disorder characterized by arterial and or venous thrombosis and recurrent pregnancy morbidity manifested by early and or late losses associated with persistently positive antiphospholipid antibodies (APLA) (Hughes, 1983)

**Autoimmune Disease:** Disorders caused by the body's production of antibodies against itself resulting in tissue damage (Lowdermilk, Perry, & Bobak, 2000).

**Email:** Electronic mail; messages sent and received electronically through a computer system (Hartman, & Ackermann, 2005).

**Embryo:** The developing fetus from the 14<sup>th</sup> day of conception until approximately the 8<sup>th</sup> week of gestation in which tissue differentiation, formation of organs, and development of external features take place (Lowdermilk, Perry, & Bobak, 2000).

**Fetus:** A developing offspring in uterus from the 8<sup>th</sup> week after conception until birth (Lowdermilk, Perry, & Bobak, 2000).

**Gestational Age:** The number of completed weeks counting from the first day of the last normal menstrual cycle in fetal development (Lowdermilk, Perry, & Bobak, 2000).

**Intra Uterine Fetal Death:** Death of a fetus weighing 500 gram or more of 20 weeks of gestation or more, in the uterus (Lowdermilk, Perry, & Bobak, 2000).

**Miscarriage:** The lay term used for spontaneous or missed abortion (Lowdermilk, Perry, & Bobak, 2000).

**Neonatal Death:** Death of a newborn within the first 28 days after birth (Lowdermilk, Perry, & Bobak, 2000).

**Online:** Connected to, served by or available through a computer or telecommunication system; the Internet (Hartman, & Ackermann, 2005).

**Perinatal Loss:** The loss or death of an embryo or fetus, stillbirth, or neonatal death (Lowdermilk, Perry, & Bobak, 2000).

**Placental Infarction:** Condition of deficient blood supply to the afterbirth, the specialized vascular disk-shaped organ developed during pregnancy for maternal-fetal gas and nutrient exchange (Lowdermilk, Perry, & Bobak, 2000).

**Primary Antiphospholipid Syndrome:** APS occurring in patients without clinical evidence of another autoimmune disorder (Levine, Branch, & Rauch, 2002).

**Prothrombotic Diseases:** Diseases that give rise to systemic thrombosis or formation of blood clots in the vessels and organs; inherited thrombophilias (American College of Obstetricians and Gynecologists, 2001).

**Recurrent Perinatal Loss:** Three or more losses of a developing embryo or fetus, stillbirth, or neonatal death (American College of Obstetricians and Gynecologists, 2001).

**Secondary Antiphospholipid Syndrome:** APS occurring in patients in association with other autoimmune diseases (Levine, Branch, & Rauch, 2002).

**Spontaneous Abortion:** Loss of pregnancy that occurs naturally without interference or with no known cause (Lowdermilk, Perry, Bobak, 2000).

**Stillbirth:** The birth of a baby after 20 weeks of gestation and 1 day, or weighing 350 g that does not show any sign of life (Lowdermilk, Perry, & Bobak, 2000).

**Support Group:** Group that provides social networks and support to people with similar issues and concerns by creating a supportive environment (Schopler & Galinsky, 1993).

**Thrombophilias:** Inherited or acquired conditions which predispose an individual to thromboembolism or blood clot formation followed by the dislodging of the clot in the blood circulation (Kupfermine, 2003).

**Trophoblast:** The outer layer of cells of the developing fetus (Lowdermilk, Perry, & Bobak, 2000).

Unexplained Perinatal Loss: The loss or death of an embryo, fetus, or a baby for which no explanation or cause could be identified (American College of Obstetricians and Gynecologists, 2001)

Webmaster: A person responsible for the creation or maintenance of a website especially for a company or organization (Hartman, & Ackermann, 2005).

Website: A group of world Wide Web pages usually containing hyperlinks to each other and made available online by an individual, company, educational institution, government, or organization (Hartman, & Ackermann, 2005).

### Limitations

The dissertation is limited as it uses women who can read, write, and understand English; who are 18 years or above; who have access to a computer, and the Internet; who are knowledgeable in using a computer to compose and receive electronic messages; who have a total time commitment of 4 hours to spend to participate in the study; who have an established diagnosis of antiphospholipid syndrome and related perinatal losses at any gestational age of pregnancy or in the first 28 days of postpartum period and who are members of an online perinatal loss support group. Women are interviewed via emails exclusively and are contacted via phone for clarifying the information provided in the emails. Electronic interviewing does not allow the researcher to see the participant and may not be able to establish rapport as in the case of face-to-face interviews. For the same reason, the researcher may not be able to elicit the participants' non-verbal cues to add to the data.

## Summary

In summary, this dissertation is an exploratory study of women's experiences of one or more perinatal losses associated with APS. Descriptive phenomenology is an appropriate methodology to better understand this poorly researched area in nursing using in-depth interviews electronically. An online support group may be an appropriate setting to recruit informants without any geographic boundaries, and without discrimination against race, religion, education, income, and marital status. Electronic interviews provide the participants with the advantages of writing about their unique and sensitive experiences at their own pace and without reluctance. An evidence-based knowledge of APS and its impact on women's lives obtained from the first-hand experiences of these women is essential for nurses and other health care professionals to better care for APS women and their families.

## CHAPTER II

### REVIEW OF LITERATURE

The dissertation explores women's experiences of recurrent perinatal losses associated with antiphospholipid syndrome. For the ease of reading, the literature review is divided into four sections. In the first section, literature on perinatal loss in general, is discussed. The second section is devoted to literature on antiphospholipid syndrome. This section is followed by a discussion of the only "known" nursing study on thrombophilia-related perinatal loss. In the last section, the pilot study that was conducted to test the feasibility of the dissertation research is discussed.

The research and inquiry for the literature review was done using the electronic databases such as Medline, CINAHL, Academic Search Premier, Web of Science, Cochrane Database of Systematic Reviews, PsychInfo, Science Direct, and Dissertation Abstracts Online & ProQuest Digital Dissertations. In addition to these, the investigator did hand searching of some peer reviewed specialty journals and used the references cited in retrieved articles. Relevant articles were retrieved using the keywords and phrases pertaining to perinatal loss and antiphospholipid syndrome.

The keywords and phrases used for perinatal loss literature include pregnancy loss, perinatal loss, recurrent perinatal loss, high risk pregnancy, nursing research and perinatal loss, loss and grief in perinatal loss, women's experiences of perinatal loss. Added to these were the MESH terms miscarriage, stillbirth, spontaneous abortion, fetal death, neonatal

death, and missed abortions. APS literature was retrieved using the keywords and phrases, antiphospholipid syndrome, Hughes' syndrome, and autoimmune diseases and perinatal loss.

Articles were mostly limited to those written in English, published between 1999 and 2006, and those with abstracts. A few landmark studies retrieved were published earlier than the 1990s. A total of 87 articles retrieved were narrowed down to 36 relevant articles, the majority of them research and a few were reviews and clinical reports on the topic of interest. Studies on voluntary termination of pregnancy or elective abortion, abortion due to abuse, anatomic and structural abnormalities, ectopic pregnancies, and chromosomal anomalies were excluded from the review as these are irrelevant in the case of APS-related perinatal loss. Women's experiences of perinatal losses at any gestational age, namely embryonic loss, early and late miscarriage, fetal death, stillbirth, and neonatal death were included in this review as APS can cause losses at any time during pregnancy. Since perinatal loss is a universal problem, articles written by authors from all over the world and those focusing on multicultural issues related to perinatal loss were also included in the review.

### Perinatal Loss

Perinatal loss is a global issue because it does not discriminate against age, race, socio economic status, education, marital status, or the overall health of women (Bennett, Litz, Lee, & Maguen, 2005). Research related to perinatal loss has transcended disciplines within and around health care because of its impact on the holistic well being of women and families across nations. Researchers from medicine, psychology and psychiatry, nursing and midwifery, and sociology have studied perinatal loss from different perspectives. For example, Theut, Pederson, Zaslow, and Rabinovich (1988) have studied stillbirth as a risk

factor for depression, anxiety, and post-traumatic stress disorder in subsequent pregnancies from a psychological perspective. From the medical perspective, physicians have studied the medical management modalities after perinatal loss (Bennett et al., 2005). Others have studied the psychosocial aspects of loss such as anxiety (Janssen, Cuisinier, & de Graauw, 2004), depression, grief, guilt and emptiness as women's experiences of miscarriage (Adolfsson et al., 2004), and women's postnatal experiences following a medically complicated pregnancy including thrombosis (Thomas, 2004).

In nursing research, investigators have studied the magnitude of the impact of perinatal losses from many different perspectives. Using interpretive phenomenology, Adolfsson et al. (2004) examined the lived experiences of a sample of 13 Swedish women who experienced miscarriage. The impact of their losses on self, were feelings of guilt and emptiness after the initial shock. To these women, miscarriage was not the loss of an embryo or a fetus, but a child of their own, a part of themselves. They felt they were the cause of their miscarriage and felt abandoned (Adolfsson et al., 2004).

A review by Bennett et al. (2005) corroborated the findings in the Swedish study in which women felt guilty and empty after perinatal loss. These authors, in their review on the scope and impact of perinatal loss, have suggested areas for future research on variables that can cause increased emotional and psychological impact on women's lives. One priority area they suggested is to examine the acute context of the loss, including the suddenness of the crisis, what is known about the cause of the loss, and the mother's perceived responsibility for the loss, such as self-blame and feelings of guilt. This review indicates that knowing the cause of the loss can prevent women from self-blaming and feeling guilty and responsible for

the loss. Yet another suggestion for future studies was to explore the impact of culture and religion as potential mediators of outcome from perinatal loss. The expectations about having children, the notions regarding the meaning of parenthood, and the role of the woman in a family structure may differ from one culture to another. To a great extent one's culture, language, and religion play a role on the impact of perinatal loss on a woman's view of her own self (Bennett et al., 2005).

Swanson, Karmali, Powell, and Pulvermacher (2003) using a secondary analysis of data gathered from a non-randomly selected sample of 185 women, examined women's perceptions of the miscarriage effects on couples' interpersonal and sexual relationships during the first year after loss. Inductive content analysis techniques were used to analyze women's responses to open-ended questions regarding these variables. The findings of this study provide evidence to support the claim that miscarriage affects women's relationships with their partners.

The findings of the above study are similar to that of earlier research on familial consequences of perinatal loss. According to deMontigny, Beaudet, and Dumas (1999), perinatal loss can cause strain on a marriage as each member of the dyad is coming to terms with the loss in his or her own way. Both of these studies have clinical implications, suggesting couples experiencing perinatal losses should be counseled and coached on the importance of supporting each other to avoid more serious emotional trauma for both partners.

Studies that focused on the impact of perinatal loss on family social networks found that the quality and quantity of ties with the couples' social networks were profoundly

affected by the loss (DeMontigny, Beaudet, & Dumas, 1999). Studies that explored women's experiences of pregnancy after perinatal loss (Armstrong, 2002; Cote-Arsenault, Bidlack, & Humm, 2001; Cote-Arsenault & Mahlangu, 1999; Theut et al., 1988) found that women have increased anxiety and depressive symptoms. Theut and colleagues' landmark study on women's experiences of subsequent pregnancies after perinatal losses was the first empirical study that examined the nature and extent of anxiety and depression in subsequent pregnancies after losses, and evaluated whether such reactions occur in all or most women who had such losses. The specific purposes of this study were to assess if anxiety and depression were heightened in mothers with loss, relative to those without the history of a loss, and to determine if the anxiety and depression, if heightened, were generalized or focused (pregnancy-specific anxiety).

According to Theut et al. (1988), clinicians have reported that mothers with a history of loss are at increased risk for anxiety and depression during a subsequent pregnancy. This could be because such women might have exhibited a variety of responses including somatic symptoms, subjective distress, and uncertainty about the outcome of the pregnancy after loss, or because they merely expressed concerns about their reproductive efficacy (Theut et al.). In their study, Theut et al. developed an instrument to measure pregnancy-specific anxiety and established its psychometric properties and found high correlation by comparing with the standardized measures of anxiety and depression such as Spielberger's State-Trait Anxiety Inventory and Beck's Depression Inventory (BDI). The Pregnancy-Specific anxiety instrument differentiated between the two groups of mothers as the mothers with loss had significantly higher anxiety scores than the first time mothers who never had a loss. This

difference indicated that perinatal loss in this sample was associated with specific rather than generalized anxiety during a subsequent pregnancy.

The authors of this study (Theut et al., 1988) recommended that all health care providers develop a deeper understanding of the emotions women exhibit during a pregnancy which follows earlier pregnancy losses before labeling the women with trait anxiety or clinical depression. If persistent anxiety and depression are present in such women, clinicians should consider other psychological stressors as primary contributors (Theut et al.).

Similar findings were discovered in another study in which couples with a history of loss had higher levels of depressive symptoms and pregnancy-specific anxiety than did couples with past successful pregnancies and no losses (Armstrong, 2002). In this study, Armstrong evaluated not only pregnancy-specific anxiety and levels of depressive symptoms, but also prenatal attachment of mothers to their growing fetus in subsequent pregnancy. The reason for the inclusion of the latter variable is that previous studies (Cote-Arsenault & Mahlangu, 1999) have found that women who have had losses may deliberately detach from their fetus to save themselves from extreme grief because of the uncertainty of perinatal outcome. Some women felt that they could not afford another loss because of the devastating and traumatizing emotional effects of a previous loss. However, Armstrong's findings indicated that depressive symptoms and pregnancy-specific anxiety did not affect subsequent parent-infant attachment after a prior loss. Families, though, might have long-term emotional distress resulting from previous perinatal losses (Armstrong, 2002).

Cote-Arsenault and Mahlangu (1999) found that the women in their study reported feelings about why and how the previous loss had changed their inner-self: who they had

been, who they had become, and their attitudes and beliefs. The women explained how the loss experience helped them ‘develop a deeper trust in the Lord.’ They shared their experiences of gaining greater trust in their abilities as wives and mothers and increased abilities in broadening their support system (Cote-Arsenault & Mahlangu). In this study, women had varied responses about their ways of coping with the loss. Some women were able to hear the stories of other women who had miscarriages, listen and console, or help them in any way possible. In contrast, others discussed the fears caused by talking about miscarriages and hearing about others’ stories. A few women commented that their faith in God enabled them to get through the fear of the unknown in the current pregnancy.

Cote-Arsenault, Bidlack, and Humm (2001) investigated the specific emotions and concerns of women in subsequent pregnancies following perinatal losses using a convenience sample of 73 women who were enrolled in two separate “Pregnancy after Loss” (PAL) support groups in the United States. These authors stated that women joined perinatal loss support groups but switched their memberships to PAL groups as they did not feel comfortable being with other women who were still grieving and not pregnant again. Women in this study had from one to nine losses. Many women with more than one loss have had losses at different gestational ages, and some had successful pregnancies in between. Cote-Arsenault et al. in this study found that the most dominant emotions were anxiety, fear, and nervousness. For the majority of women positive emotions were intermingled with intense concerns and worries about the possibility of losing another baby. The pregnant women were scared of again hearing the bad news that the fetus was not alive and indicated mistrust of self and care providers. They worried whether their doctors would be able to ‘catch any red

flag' or if 'my body will fail me again' (Cote-Arsenault et al., 2001). The presence of live children did not negate women's fears or lessen the emotional bonds with babies who were dead. Having a miscarriage or loss in later gestation did not decrease or increase the emotional pain, but the personal meaning of each loss for each woman determined the impact of it (Cote-Arsenault et al., 2001).

Women's membership in support groups is both the strength and the limitation of this study. The strength is that, because of the support they received from the group, they were able to articulate their emotions and concerns without reluctance, thus contributing to the richness of information the investigators could gather from them. The limitation is that, since the study used only women who were in support groups, the findings may not be transferable to other populations (Cote-Arsenault et al., 2001).

Finally, several researchers across disciplines have investigated the social and professional needs of families bereaved with perinatal loss (Cote-Arsenault & Freiji, 2004; Hutt, 2005; Lundqvist, Nilsson, & Dykes, 2002; Wong, Crawford, Gask, & Grinyer, 2003). In their study, Lundqvist et al. examined the perceptions of the care given to women in prenatal clinics while facing the threat and the reality of losing their babies. They interviewed 16 Swedish mothers about two years after the death of their newborns and the responses were analyzed using a hermeneutic phenomenological method. These investigators identified the primary theme as mothers' feeling both empowered and powerless. The sub-themes to feeling empowered were a sense of nearness, encouragement, and empathy; those related to feeling powerless were a sense of distance, helplessness and despondency, and disconnection leading to insecurity and discouragement (Lundqvist et al., 2002). The findings reflected

these women's experiences of both competent and inhumane treatment from the professionals when they needed the most humane care in an empathetic manner.

A similar study explored women's experiences of care after a miscarriage that impacted on the ability of the primary health care team to detect psychiatric morbidity after a miscarriage (Wong et al., 2003). According to these authors, questionnaires were sent to the women following discharge, both at 1 week and at 8 weeks after miscarriage. The time scale of 8 weeks was chosen to identify probable psychiatric cases because, according to DSM-IV criteria, 8 weeks after a loss is the time threshold after which the depressed mood of bereavement can be considered to be part of a major depressive disorder. The authors also interviewed health professionals in focus groups. In this study, women expressed a need for a formal follow-up plan after discharge from the hospital as they felt that the medical professionals left it up to the patients to seek further consultation and medical attention if it was required. Women regarded this approach as quite inadequate. Another finding indicated that these women felt it inappropriate for them to receive information when they were devastated as they could not comprehend and receive anything in the immediate post-loss period (Wong et al.). Women also needed more information and specific answers to the questions pertaining to miscarriage despite the availability of written and verbal information given at discharge.

According to Wong et al. (2003), the women in this study complained that no one gave them an 'explanation' for their loss, preventing them from coming to terms with the loss and moving on in life. Also, women felt that the health professionals did not validate their losses and considered these as everyday occurrences. Such normalization of miscarriage

reduced its impact on their lives when in fact it has been a life-changing event. Both the focus groups of professionals and the women addressed the educational needs of the professionals to develop the skills to manage the emotional impact of miscarriage in these women. Health care workers were acutely aware of their own lack of experience and vulnerability when dealing with miscarriages (Wong et al.). Implications for future research identified were the need for interventional studies based on the findings that there was a significant discrepancy between women's perceived needs and the service that was provided.

#### Antiphospholipid Syndrome

APS was discovered by Dr. Hughes at St. Thomas Hospital, London and was known as Hughes' syndrome until Dr. Asherson, who conducted more studies into the antibodies that caused this syndrome, named it the Antiphospholipid syndrome (APS) (Bertolaccini & Khamashta, 2006). APS is classified as primary APS if it is not associated with any disease and secondary APS if it accompanies an autoimmune disease such as Lupus, Rheumatoid arthritis, or a thyroid disorder. The obstetrical complications, mainly recurrent perinatal loss, are at the origin of the description of the syndrome (Vinatier et al., 2001).

The mechanism of recurrent abortions or fetal deaths associated with APS is described as either due to the thrombogenic effects, or due to a direct, non-thrombogenic effect (Vinatier et al., 2001). Mechanism due to thrombogenic effects is described as follows: During pregnancy, in women diagnosed with APS, the coagulation system is abnormally activated. The first detailed histological examination of the placenta obtained from a woman with intrauterine fetal death (IUFD) in association with lupus anticoagulant (LA) has been reported as having widespread infarction that involved more than 50% of the placental

substance. Researchers started routine examination of the placenta from women with IUFD and have observed thrombosis and infarction more often in women with APS than women with negative APS (Hughes et al., 1983).

Histological examinations of placenta have shown that not all miscarriages are accompanied by thrombosis and infarction. Some authorities believe that the Antiphospholipid (APL) antibodies have a direct effect on the trophoblast functions as these bind to the surface of phospholipids, and result in direct cellular injury, leading to placental dysfunction (Vinatier et al., 2001). Others reported a slightly different theory about the mechanism of loss due to APL antibodies (Tincani et al., 2006). According to them, early pregnancy loss may result from a failure of placentation owing to the direct effects of APL on trophoblasts (the embryonic cells), but the second and third trimester losses are more likely to result from thrombotic damage to the utero-placental vasculature. So there are controversies and more research into the pathophysiology of APS in causing perinatal losses (Vinatier et al.).

The issue of diagnostic criteria for APS remains a challenge for both the patients and the physicians. Diagnosis of this disorder is made based both on clinical manifestations and laboratory tests of APL antibodies. The detection of these antibodies is subject to wide spread laboratory variation. Only Lupus anticoagulant (LAC) and anticardiolipin antibody (ACL) assays are sufficiently standardized to be usable in routine practice (Vinatier et al., 2001). Several investigators advocate testing for other APL antibodies, but their assays remain investigational. This could be the reason why the treatment for some women with unexplained recurrent losses, leads to a positive perinatal outcome, in spite of getting a

negative test using the standardized markers. It is also important that before a diagnosis is made, a patient must be tested positive on at least two occasions more than six to eight weeks apart.

Another controversy is about the treatment modalities of APS. Noble, Kutteh, Lashey, Franklin, and Herrada (2005) conducted a randomized, multi-center, controlled, pilot study to compare the adequacy and effects of two such modalities in the treatment of APS-related pregnancy loss. They compared low-molecular-weight-heparin (LMWH) in combination with low dose aspirin (LDA), and un-fractionated heparin (UFH) with LDA. The patients had three or more perinatal losses associated with antiphospholipid (APL) antibody. Twenty five out of 50 women were treated using LMWH plus LDA, and the rest with UFH plus LDA. The researchers found that the fetal outcome and maternal complications from either treatment modality were comparable. Both the modalities were found to be safe. The results of this study are consistent with that of Empson, Lassere, Craig, and Scott (2005) who conducted a meta-analysis of 13 randomized or quasi-randomized, controlled trials involving 849 participants. However, the investigators in both these studies suggested large randomized trials in the future since small studies are not sufficient to resolve uncertainty about the benefits and risks of different treatment plans.

Smulian, Ananth, Vintzileous, Scorza, and Knuppel (2002) studied the specific maternal-fetal high-risk conditions on the risk and timing of fetal death. They found that high-risk conditions such as gestational hypertensive disorders (PIH) and others are associated with an increased risk for fetal death particularly in the third trimester. They suggested that delivery should be considered at 38 weeks for high-risk women. These

authorities noted that it would be unsafe to wait until after 41 weeks to induce the high-risk women (Smulian et al.).

#### APS-Related Perinatal Loss

As mentioned earlier, APS-related perinatal loss is not studied from a nursing perspective, and the only study found during the literature search is on the experiences and challenges of pregnant women coping with thrombophilia (Martens & Emed, 2007). This study did not focus solely on APS, but on thrombophilia- related losses in general. Using a qualitative, descriptive phenomenological approach, these authors conducted semi-structured interviews in either the participant's homes or in the thrombosis clinic of a large university-affiliated hospital in Montreal, Canada where they attended for their regular check up. Women diagnosed with acquired or inherited thrombophilia who were prescribed unfractionated heparin or low molecular weight heparin during pregnancy and who were pregnant at the time of the study or had been pregnant within the past 12 months, were eligible to participate. Seven out of the nine participants had antiphospholipid syndrome, the other two had Factor V Leiden and protein S deficiency. The data were collected over four months and analyzed thematically. For all participants, the diagnosis of thrombophilia was made in the context of multiple adverse pregnancy events. Four main themes emerged from the data analysis: the impact of diagnosis and treatment on the pregnancy experience, the need for professional support, a perceived sense of uncertainty, and successful coping strategies (Martens & Emed, 2007).

The above four themes are supported by significant words and phrases from the data collected. The authors found that these women had a negative response to their newly found

diagnosis and their initial reactions were worded as, “very scared,” “hysterical,” “overwhelmed,” “shocked,” and “freaked out.” Five of the nine women had some knowledge about thrombophilia. For example, two women realized that this could have caused the placental abruption they had experienced. Three others linked “thick blood” to an increased risk of stroke, deep vein thrombosis, or pulmonary embolus. One woman developed anxiety attacks based on her belief that she would be unable to conceive as a result of thrombophilia (Martens & Emed, 2007). Interestingly, three women responded to the diagnosis with relief, as they understood that a likely cause and possible solution for their losses had been identified. These women were predominantly concerned with the pregnancy outcome rather than with the possible implications for their own health, noted Martens and Emed.

Women in this study felt that it was a burden to take daily heparin injections as it was difficult to remember it every single day to take it at the same time. But they got adjusted to them as part of a new routine, and felt that in light of having a healthy baby they were “not a big deal.” These women commented that their physicians - including obstetricians, thrombosis clinic physicians, and family physicians - did not take the initiative to investigate the cause of pregnancy complications or losses; rather, these women had to request them to do so. Those who had acquired a knowledge base of possible causes for fetal loss, whether through word of mouth or formal education were able to articulate their requests directly (Martens & Emed, 2007). Some doctors told the participants that miscarriage is “part of nature and could happen without a cause,” noted these authors. Others told the women their test results for thrombophilia were inconclusive and put the burden of decision making about whether to initiate treatment on them. Some physicians were reluctant to initiate treatment

regardless of several losses for some women who had to push their physicians to prescribe medications for treating their diagnoses.

The majority of women in the thrombophilia-related perinatal loss study felt that they did not receive enough information to address their concerns and got confused about how “thick blood” could affect their baby, how it could compromise their own health, and why it was particularly relevant during pregnancy. Many women were concerned about not getting enough information about proper injection techniques, the side effects of heparin, and what to do if a difficult situation arose. In fact a few women had to rely on the information included in the medication instruction booklet, while others got it from a variety of settings such as the community health center and the hospital’s medical outpatient clinic. However, discrepancies were noted, especially regarding which injection sites could be used; and most participants were distressed by the extent of bruising and bleeding that accompanied heparin injections.

The participants also complained about the less frequent blood monitoring and follow-up they received in their clinic and the insecurity they felt as they were aware that women with the same disorder getting their follow-up in other hospitals were monitored more frequently and regularly. In spite of taking the treatment, these women understood that the desired outcome of a successful pregnancy could not be predicted with any measure of certainty as they were constantly worried about their babies. They knew that if their uterine contractions started, they would have to stop taking heparin, as continuing it might cause bleeding during labor. For the same reason, having an epidural was not an option for them to

reduce labor pain. At the same time, stopping the anticoagulant might cause clotting and the baby's survival would be in danger.

Martens and Emed (2007) further state that women took control of their situations to cope with the above challenges as they perceived a lack of professional support. They did it by seeking information as a powerful means to meet their needs. Information was gathered from the Internet, books on pregnancy, health professionals, or word of mouth by sharing stories with other women on-line or on the phone. The women reported that talking to others not only helped them get information, but also was reassuring and encouraging. Another way of their taking control was setting boundaries. For example, when a health professional started providing information or teaching when they were not ready to listen and learn, they would set limits and asked the professionals to come back later. These findings corroborate those of the studies done by Wong et al. (2003) and of Lundqvist et al. (2002).

This study had limitations because demographics such as religion and education were not collected as the purpose was not to identify any direct link or association between these variables and women's experiences, but to explore such experiences. The authors suggested that these variables be included in future studies. Also the sample collected was from the thrombophilia clinic of one hospital, the findings may not be transferable to other populations. This study's findings have offered implications for nurses and other health professionals caring for the population in the study. A significant nursing implication is the importance of providing specific resources to meet the needs of women with thrombophilia. They should be able to help women make decisions about the treatment for their diagnosis and be supportive of the decisions women make based on their knowledge of the condition.

Nurses should encourage peer networking for these women to provide opportunities to ventilate their feelings to women with similar experiences and to share knowledge. Moreover nurses are in a much better position to provide emotional support than other professionals and, given the stressful nature of the experience, the need for emotional support is great (Martens & Emed, 2007).

### The Pilot Study

The feasibility of the proposed dissertation research was pilot tested with two women, who had perinatal losses, and had a diagnosis of APS. These participants were recruited from an online general perinatal loss support group in which they had been members since their losses. The data for this preliminary study were analyzed by Colaizzi's (1978) method. Six themes emerged as the essence of the experience was discovered: (a) Getting diagnosed with APS and obtaining the best treatment available is challenging (b) Health care practitioners' knowledge of APS is a major determinant of maternal and fetal outcome, (c) Limited information from physicians on APS leading to desperate quest for knowledge, (d) Acknowledging the reality that live births are not always guaranteed despite treatment, (e) Cherishing the memories of the lost babies, and (f) Coping with the loss and moving on with hope and optimism.

One woman had her first baby stillborn at 41 weeks gestation after an uneventful pregnancy until the 39th week during which she showed signs of pregnancy-induced hypertension such as high blood pressure and moderate edema around face, hands, and ankles. The doctor did not give any treatment for this condition as he thought the delivery was 'around the corner.' There was no other indication that the baby would not be alive.

However, the woman came to know that the baby was not alive when she went to the hospital for the scheduled induction and found that her unborn daughter had died about 24 hours before. To this woman, the loss of her most wished-for, first-born daughter at 41 weeks of gestation meant the loss of a full person and the loss of her identity as a parent. This couple even selected a name for their daughter as soon as they knew that the baby would be a girl and made sure they did everything to assure the safe arrival of the baby. This respondent commented that the very first thing her husband told her after his initial shock was that he would want “a houseful of children.” This was contrary to his previous belief that only two kids would be all that they needed. The preciousness of having a family is reflected in these comments.

The cause for the stillbirth of her first born was documented as cord accident right after delivery. However, the doctor suspiciously tested this woman’s blood for APS using standardized laboratory markers, and found it to be positive for Lupus Anticoagulant. No referral was made by the obstetrician to an APS specialist for further follow-up and the couple wanted to get pregnant again soon as they came to know the preciousness of having a family more than ever. When the patient asked the obstetrician why a test was not done prenatally, he simply told her that “we don’t test for everything.” There is medical evidence in regards to the increased rate of still births between 38 to 41 weeks of gestation especially in the presence of any medical condition (Smulian et al., 2002), and the obstetrician in this woman’s case did not seem to be aware of the findings of current research. There is evidence in the social science literature on women’s experiences of receiving limited professional help (Thomas, 2004), that supports the experiences of women in this pilot study.

In her subsequent pregnancy, the signs of PIH started again. In addition to high blood pressure and edema, she had proteinuria in this pregnancy. This time, the baby delivered via emergency Caesarian Section at 38 weeks, survived. This participant had another problem in her second and third pregnancies: the formation of sub-chorionic hematoma in the late first trimester or early second trimester, which gave rise to bleeding. For this reason, bed rest was ordered along with temporary discontinuation of baby aspirin which the doctor had prescribed to treat APS at the first prenatal visit of both pregnancies.

This woman also shared her experience of taking clomid, estrogen, and progesterone in a certain combination to conceive her first baby as it took the couple a year for conception. In the subsequent pregnancy after the loss, again she took the same hormonal preparation to conceive. Once the second baby was born alive, this woman was advised to take birth control pills as she wanted contraception, despite the fact that she was diagnosed with APS. Fortunately, she could not tolerate its side effects and had to stop taking them. There is evidence in the APS literature that any hormonal preparation including birth control pills and medications that aid fertility should be prohibited as these would cause increased risk for thrombosis as mentioned earlier in the literature review. It is reasonable to suspect that this respondent's sub-chorionic hematoma could have been caused by her use of hormonal preparations.

Another finding from the above participant's data is that neither the obstetrician nor the nurses in the prenatal clinic asked her for the known risk factors for APS. This respondent reported that her maternal grandmother had a serious deep vein thrombosis and was diagnosed with APS a few years back. According to this respondent, had it been known

to her that APS tends to run in families, and if the health professionals had asked about such risk factors as a history of thrombosis in an immediate family member, she would have been able to prompt the professionals to screen her for APS. In this woman's words, "it would have been worthwhile getting a simple and inexpensive blood test done when looking back at the great price my husband and me had to pay for not being given the opportunity to do so." These responses supported the fact that it was really a challenge to get a diagnosis of APS and to get the treatment started.

The second respondent for the pilot study had a different loss experience as far as the gestational age in which her losses took place. This lady had three miscarriages consecutively at 9, 7, and 6 weeks of pregnancy. Her pregnancies were 3 months apart as her doctor told her that it was alright to conceive 3 months after the previous pregnancy was over, and all three miscarriages occurred within the same year. After the first miscarriage, this respondent noted that she had to console herself as no one in the prenatal clinic, or in the hospital talked about her lost baby, or showed any concern for her loss. This lady stated that she felt, "it was just my one miscarriage; after all, how many miscarriages happen everyday in the world."

However, when she lost her second one, she asked the physician who confirmed the absence of a fetal heart beat on the ultrasound scanning what was wrong with her. At this time she really 'questioned her future as a parent'. This time a blood test for APS was done, but was found to be negative. After the third loss, a reproductive endocrinologist suggested she take APS treatment if she was willing to try once more. This doctor felt that she indeed had APS, even if her blood tests indicated otherwise. In this woman's response, anecdotal evidence was suggestive of APS from her third pregnancy because placental tissue blood

vessels showed infarcts. This lady was willing to try once more, using the APS treatment regime. She conceived to give birth to three full-term healthy babies consecutively. Between the second and the third pregnancies, she learned a lot about common causes of perinatal losses and also about APS. According to her, the information she received from her doctor was minimal, and most of the information was gained from the Internet and an infertility clinic. The women in this pilot study felt that they needed to seek information elsewhere about APS because health care providers did not seem to have sufficient knowledge on this disorder to educate them. Once these women learned enough about APS, they felt they were armed with the existing medical information to fight for the best treatment. At the same time, these women constantly reminded themselves of the uncertainty of a successful pregnancy outcome despite the treatment and close monitoring.

Both of the participants had one aspect in common even though their experiences were quite different. The commonality was that both of them were religious and spiritual, and could acknowledge their losses as God's will. The second participant was "bewildered and angry" when miscarriages happened repeatedly as both her husband and she were serving in kids' ministry at their church. Initially, she thought that because of their service to God, 'a family should be guaranteed to them.' Both of the participants' experiences with their health care professionals were quite different. This might have been due to the different gestational ages of their babies, the first a stillbirth of a fully formed baby and the second, early miscarriages.

The woman who had the stillbirth had positive health care experiences with her obstetrician and nurses, though she gained most of the information about APS from her own

research on the Internet. In contrast, the woman who had miscarriages commented negatively about the care she received from the physician and the nurses. According to her, she received neither emotional support nor proper information regarding the cause of her miscarriages from these professionals. Unlike the experiences of the women in the thrombophilia study of Martens and Emed (2007), both the pilot study participants commented that they were taught by the nurses how to give themselves heparin injections, and that their blood monitoring was done regularly. Like the women in the thrombophilia study, and other perinatal loss studies mentioned earlier, the pilot study participants also expressed their fear, anxiety, and uncertainty about a successful perinatal outcome in subsequent pregnancies even if they were diagnosed and were on APS treatment.

The experiences with these women's social network were also different as the first lady told about her family and friends who were supportive not only emotionally but by providing food, flowers and taking care of other needs. The second participant said that people even asked her why she was crying and grieving several days after her loss. Some church members even told her that, "it might be God's will that you do not become a mother." Some others totally avoided her. As far as their partners are concerned, both the women's husbands grieved but there was a difference as well. The father of the stillborn baby had difficulty tolerating the loss and extremely missed the baby after her burial. He was very supportive of his wife and commented that this was a life-changing event for them and that they both had grown so much in faith in God and the belief that the loss was God's plan and for His purpose. In the case of the second respondent, her husband grieved and cried, but expressed emotions differently. This lady felt more comfortable talking about her

miscarriages with a friend who had a similar diagnosis and had experienced losses, as this friend ‘never got tired of listening’ to her.

The strategies of coping with their losses were different because of the difference in their life situations. The first woman started a charity in her stillborn daughter’s name and talked to pregnant teens about the preciousness of the life growing in their wombs, while the second woman initiated a new chapter of her support group that would serve women suffering from recurrent perinatal losses. Cherishing the memories of the lost babies by serving other women gave them the peace of mind to move on optimistically.

In summary, the pilot study indicated the feasibility of conducting a large study using online perinatal loss support groups to recruit potential participants and collecting data through semi-structured e-mail interviews. The unique experiences of women with APS-related perinatal loss included the challenges and difficulties of getting the diagnosis and the issues surrounding the medical treatments. In addition to these, the burden of self-educating on APS fell on the shoulders of APS-positive women, because physicians were not quite sure what it was like for women to have such a serious diagnosis and to lose babies one after the other.

The nursing implications of this study were that nurses needed to be knowledgeable about APS so that they could educate these women and give them the support they needed. The pilot study suggested the following questions be raised: (a) What are the barriers for health care providers in diagnosing and treating APS women? (b) What is the likelihood that the first-born babies of women with APS can be saved? (c) What is the relationship of knowing the family risk factors and women’s personal medical history and diagnosing APS

in the pre-conception period? (d) What are the barriers in including routine screening of APS at the first prenatal visit for women who are high-risk for APS?

#### Directions for Future Research

Research on APS is contained within the diagnostic criteria and treatment modality areas. A little of the medical research conducted so far is on non-obstetrical complications of APS and the rare disorder of catastrophic APS. However, no one has investigated the effects of maternal APS on their offspring, though a few studies have investigated the effect of mothers' SLE on their children. Familial tendency in the development of APS is lacking as well in empirical literature. In addition, nurses may be able to investigate whether any one culture/ethnicity has more affinity to APS, though it is known that women are its victims more often than men. Medical research has 'speculated' that stress in women might be a trigger factor for APS-related perinatal loss but it is not empirically tested, partly, may be due to the fact that stress is not an easily measurable concept.

#### Summary

APS related perinatal loss is a devastating experience in women's lives. Once perinatal loss due to APS remained undiagnosed and was documented as unexplained. As a result of rigorous medical research, APS has come to be known as one of the treatable causes of recurrent perinatal loss, though such treatments are not without complications. Nursing research on APS-related perinatal loss and women's experiences of diagnosis and the medical treatment, the number of pregnancy losses they had before they were tested, and their familial risk factors for APS should be a priority. This research will add to the body of nursing knowledge as women's varied experiences of APS on their own health and the health

of their babies will close the gap in the nursing literature on APS-related perinatal losses. Evidence based medical and nursing education about APS is necessary to improve clinical practice and thereby the perinatal outcome and the ill effects of this condition for women during and after the childbearing period.

Perinatal loss literature revealed the various kinds of bio-psycho-socio-cultural and spiritual experiences of women. These women included women with APS, but they were unidentified as having such a devastating medical diagnosis. The nurses took care of them without adequate knowledge of the disorder, and the cause for their repeated losses. Had it been known that APS was the cause of their losses, many women who have suffered anxiety and depression, lack of prenatal attachment and its complications in mothers' and infants' lives, conflicts in marital relationships, and social networks could have been prevented. Such knowledge would have given answers to infertile couples' problems, and low-income families' distress to a great extent. Even the older primiparous women would have had their live first-born child in their much younger childbearing years. In fact, billions of dollars spent unnecessarily to treat the complications related to high risk pregnancies, and high risk babies should have been saved (Diehl-Svrcek & Richardson, 2005; Hawkins, 2005). This research on women's experiences of APS- related perinatal loss will shed light on this topic and fill that gap in the existing scientific knowledge in the nursing discipline.

## CHAPTER III

### EVALUATION OF ONLINE RECRUITMENT AND E-MAIL INTERVIEWS AS A QUALITATIVE METHODOLOGY IN AN APS-RELATED PERINATAL LOSS RESEARCH

#### Abstract

Researchers have had varied experiences on the use of online participant recruitment and the Internet surveys and interviews in qualitative nursing research. In a recent study of women's experiences of perinatal losses associated with antiphospholipid syndrome (APS), participants were recruited from online perinatal loss support groups. After receiving permission from the moderators of these groups, and the approval of the Institutional Review Board (IRB) of Texas Woman's University, the researcher gained access to these online communities. The proposed research, including eligibility criteria for participation, and the researcher's e-mail address were posted on their online message boards. Women who felt they met the eligibility criteria were invited to contact the researcher stating intent to participate and giving a postal address where the consent form and demographic data collection sheet could be mailed. Forty-nine women responded and 39 consented. One woman refused to participate after consenting, and the remaining 38 women actually participated by successfully completing the e-mail interviews, yielding a participation rate of 77.6% (38/49). A few women expressed their frustration and displeasure with the researcher's request to send their mailing address. Overall, the

participation rate was above average, compared to some of the other online studies. This research experience will add to the existing knowledge about online recruitment and e-mail interview as an emerging qualitative methodology that has the potential to be beneficial in the conduct of health care research.

### Introduction

Participant recruitment using online resources has been increasingly documented in the literature across disciplines within and outside health care. With the advent of the Internet, and its wide-spread accessibility, researchers found such resources beneficial and convenient for recruiting potential participants. Based on their experience using online data collection and computer-mediated interviewing, researchers have discussed its benefits and limitations, as well as strategies for future research (Granello & Wheaton, 2004; Curasi, 2001). Since the early 1990s, the Internet has attracted researchers from academia and business organizations because it has the potential to revolutionize the way primary and secondary data are collected (Curasi). Health care research began its expedition to online participant recruitment for data collection in the mid- late 1990s (Fawcett & Buhle, 1995; Lakeman, 1997; Murray, 1995). Many of these health care researchers experienced methodological and ethical issues while conducting quantitative or qualitative medical or nursing research (Eysenbach & Wyatt, 2002; Im & Chee, 2006; Koo & Skinner, 2005; Robinson, 2001).

Qualitative nursing researchers have extended their data collection techniques to include online recruitment and electronic web-based surveys. However, online recruitment and use of personal e-mail interviewing alone to collect narrative data in

nursing research is relatively a new method. In this review, the use of this data collection method for a descriptive phenomenological research with a group of women who have had perinatal losses associated with antiphospholipid syndrome (APS) is described.

The only previous qualitative nursing research that used similar methodology was a study of women's experiences of birth trauma in which the participants from around the globe signed consent forms electronically, and participated in e-mail interviews (Beck, 2005). Another nursing study that used an online listserv was an ethnography on perinatal grief in which women from four continents participated (Capitulo, 2004). In this study, the researcher communicated with the participants on a website she created for the purpose of that research, and analyzed the e-mails participants sent to each other in that online community (Capitulo). Likewise, Read (2004) used an e-mail listserv to recruit participants to administer a survey. In her study, the majority of responses to the call were received within the first 24 hours and 83 surveys were returned via e-mail within five days. Read (2004) concluded that the use of e-mail allowed more opportunities for researcher-participant interaction than web-based surveys, but the return rate of 51% reflected concerns about privacy when e-mail addresses were required.

In addition to these studies, Hamilton and Bowers (2006) examined the theoretical and methodological aspects of Internet recruitment and e-mail interviewing in qualitative research. These authors addressed methodological issues involving the appropriateness and adequacy of this method, sample representation and bias, data fraud, flexibility and consistency in interviewing, timing, elimination of the need for transcription, oral versus written communication, and ethics (Hamilton & Bowers). They offered an argument for

the scientific integrity of e-mail interviewing along with practical suggestions on a research design for a qualitative study employing both Internet recruitment and e-mail interviewing (Hamilton & Bowers).

Some authors have suggested specific mechanisms to ensure security, privacy, and confidentiality while conducting research using the Internet such as ‘digital signature’ (Kelly & McKenzie, 2002). They stated that the best protection against viruses is not opening e-mails from unknown sources, or those containing unusual message headers (Kelly & McKenzie). In this article, the author describes the security and confidentiality issues and other challenges she faced while conducting online recruitment of potential participants from perinatal loss support groups.

This review is organized into five distinct sub headings to enhance the ease of reading. First, the investigator briefly described her study, followed by the description of the online support groups. Then the practical issues she faced, and the possible measures that could have prevented those issues from happening, from the investigator’s perspective, are discussed. Finally, she has reflected on the advantages of e-mail interviewing for this study.

#### The APS- Related Perinatal Loss Study

For this research, the primary investigator (PI) first tested the feasibility of online recruitment of participants and semi-structured email interviewing in a pilot study, with two women who met the eligibility criteria for participation. Perinatal loss in general is a well researched area and the use of support groups to recruit their participants by these researchers (Cote-Arsenault, Bidlack, & Humm, 2001) gave this investigator the impetus

to seek online support groups as possible sources for the recruitment of potential participants. Also, the feasibility of getting sufficient number of participants from real-time support groups with this particular disorder and related perinatal loss seemed to be difficult. In addition, this investigator desired online recruitment to cross geographical boundaries to study this phenomenon from women across the globe.

For the pilot study, the PI contacted the webmaster of an online general perinatal loss support group and gained permission to access its message board. Upon approval of the Institutional Review Board of Texas Woman's University Institute of Health Sciences, Houston, the PI registered herself using the password the webmaster provided, to introduce her as the primary investigator to the women in this online community. The proposed research, including the eligibility criteria were posted on the message board. Women who felt they met the eligibility criteria were invited to email the PI stating intent to participate, and giving a postal address to which the consent form and a demographic data collection sheet could be mailed. Four women contacted the PI to state their willingness to participate, with the needed information. However, only the first two women were selected to take part in the pilot study, and the other two were requested to wait until the major study began, which they agreed.

The researcher then sent via post mail, two copies of the IRB approved consent form (one for them to keep and the other to return signed, to the investigator) along with a demographic data sheet with no personal identifiers, to these two women. A self-addressed, stamped envelope was enclosed for them to return the signed consent form. No incentives were offered to these respondents. They were assured that their personal

information and responses would be kept confidential, and their identity would not be revealed. Upon receipt of the consent form and the demographic sheet, the PI sent the two initial interview questions, embedded within the email.

The respondents were given two weeks to complete the answers and email them to the investigator. Both the women sent to her their description of the experiences written on 10-15 pages as attachments to e-mails. Based on the answers given for these two questions, the PI emailed mini-tour questions and probes to get an in-depth understanding of the phenomenon. This semi-structured interview took place 4-5 times for each participant, and ended with member checks via telephone to clarify the investigator's interpretation of the meaning of their experiences of the phenomenon under study.

Upon successful completion of the pilot study and the new IRB approval from the university, the investigator started online recruitment again, from the same general perinatal loss online support group from which she recruited the two women for the pilot study. She posted the research details one more time to remind the existing members and to inform the newly registered members. However, other than the two women who initially contacted and agreed to wait until the major study started, no one else contacted her from this online group. To the investigator's surprise, these women provided her with information of the existence of an APS-specific perinatal loss online support group, from which, they assured her to come to know more women with this disorder. This eventually led to the recruitment of sufficient number of respondents.

Once the PI got the URL for the website of the APS perinatal loss online support group the two women suggested, she contacted its moderator and gained permission to access this community of women with APS, by registering herself to introduce her as the primary investigator and then post the proposed research details. Furthermore, the moderator of this APS loss group gave the email address of the moderator of another similar group in a different country. This way, the PI could gain access to three different APS perinatal loss online support groups to recruit participants for her research. One of the group moderators endorsed this investigator by reposting her research details on the forum, asking the members who were interested to contact the PI directly at her e-mail address.

This convenience and snow ball sampling yielded 49 potential participants who contacted the investigator within a month stating intent to participate and giving postal addresses where the consent form and the demographic data sheets were sent. Of the 49 potential participants, 39 women consented during the first month of contact. The remaining ten women emailed the investigator their intention to not participate due to “time constraints” and other “personal problems.” One of the 39 women who consented declined to participate as well, as the interview questions were “too emotional” for her to answer, because of her recent loss. The 38 respondents comprised the final sample in this study. The demographic data of the respondents showed that the majority were Caucasian women in the age group of 30- 39 years, and either an undergraduate or graduate with high income. Seventy percent of the participants were American, 16 % British, 8 % Canadian, and included one participant each from South Africa and the Philippines.

As the consent forms were received, the PI emailed the two initial interview questions used in the pilot study. The respondents were given the flexibility of taking as much time as they needed to complete the answers in whichever format they liked, but in as much great detail as possible. When the respondents answered and sent to the investigator, the initial email interview questions, she analyzed them using Colaizzi's phenomenological method. Based on the depth of information given, the PI asked further questions to clarify what was written, and to elicit more information about their experiences, in at least 4-5 subsequent emails, as needed. Nine women from the U S were contacted by phone for member checks and they verified the investigator's interpretation of their experiences. The entire data collection lasted 4 months and data saturation determined completion of the data analysis.

#### The APS Perinatal Loss Online Support Groups

The APS perinatal loss online support groups were founded and moderated by women, who take the ultimate responsibility for maintaining the integrity of its registered members and the stories they share to each other. One of the three groups maintained a list of email addresses of women with APS for other members to relate to them and share their experiences. These online groups have established rules, which they expect everyone using the sites to follow. In the other two groups that did not publish the email lists of its members, the emails and the replies sent by the members reach the moderators first, and they post them on the message boards.

## Practical and Ethical Issues

The APS specific online support group in which the email addresses of its members were open to the public caused a bit of a confusion and ‘trouble’ to this researcher. Due to the lack of specific instructions for the registered members on the use of these email addresses, and as it was not mentioned in the ‘rules’ of the group to not contact other members directly using the email list, this investigator emailed some women to inquire about their interest in the proposed research. A few women from this group emailed the PI their frustration and displeasure in approaching them for recruitment in this way and decided to not take part in the study. The moderator, learning about the PI’s personal contact of them closed her ‘gate’, and no further recruitment took place from her group.

One woman from this group wrote to the investigator that she did not feel comfortable sending her postal address to a stranger and that she needed to see the research protocol posted on the message board. She questioned the legitimacy of the research as she did not find a way to prove that this investigator was not a hacker. Among the participants who agreed to enter the study was 1 woman who asked the PI to fax to her the consent form before she could decide on her participation. Once the consent form that was prepared for IRB approval was faxed, she signed it and sent back to the investigator’s mailing address. Several other women among the participants asked for the consent form in order for them to decide whether to participate or not. The PI sent these women the consent form prepared for the IRB approval, as an attachment, because the approved consent form was a hard copy. The PI was instructed by the IRB to make

copies of the consent form to send to the participants, to obtain their original signatures. Once these women read the consent form, they were assured of the legitimacy of the research, and agreed to participate.

#### Possible Measures to Prevent the Issues

This online recruiting experience gave this investigator insight into making future recruitment procedures more appealing to potential participants. It would have been better if the investigator had the permission from the IRB to scan the hard copy of the approved consent form and to upload it on the message board of these online support groups after receiving permission from the moderators. This approach would have avoided confusion and mistrust of the investigator among the women, and the legitimacy of the research could have been assured for them, to decide whether to participate in the study or not. Another possibility was that the researcher should have asked the moderator via email what she thought would be a legitimate way of contacting these women.

Furthermore, the provision of getting the consent signed electronically using the new computer technology called EchoSign would have been another safe solution for getting the consent signed without getting personal contact information of the participants. This new technology makes getting documents signed electronically and with a great deal of security and anonymity. Its use would have saved this investigator a lot of time, money, paperwork, and unnecessary frustration from not knowing the proper ways of contacting potential participants while recruiting from online resources. More information on this technology is available at [info@echosign.co](mailto:info@echosign.co).

However, 36 out of the 39 women who sent their consent form to the investigator did so without questioning the legitimacy of the research. Surprisingly, in their initial email stating intent to participate, several of them wrote a great deal about their experiences of perinatal losses and APS diagnosis. This illustrated their increased interest in participating in this study. They found it as a great opportunity to reveal their pent up feelings of losses due to an undiagnosed medical disorder, to a nurse investigator.

#### Advantages of E-mail Interviews

In spite of the methodological issues the PI encountered in this study, partly due to the lack of comparative studies on different interviewing formats in online research, and to the newness of this method, she felt that this method was the most appropriate for her topic of interest. This investigator believes that this study would not have been successful considering the geographical diversity and number of respondents who actually took part in the study, if she were to recruit them from elsewhere. The advantages were not only reckoned in terms of its reduced cost, time, and easy accessibility of this hidden population, but also in terms of the scientific rigor of this method. Unlike in the interviews in face-to-face focus groups, the email interviewing did not have problems with equipment failures and transcription errors, and the need for multiple researchers or research assistants.

The researcher was successful in establishing a rapport with the respondents early on through emails and gaining their confidence. This was evident in their willingness in providing her with their multiple contact numbers for member checking towards the end of the interviews. The anonymity of the respondents and their responses were maintained

throughout the research process. Though the visual cues or gestures could not be appreciated during the interview process, this investigator believes that each respondent provided their true emotional feelings in words and symbols for her to get an in-depth understanding of the meaning of their experiences. In face-to-face focus groups, respondents who do not express their true emotions considering social desirability and shame may not help researchers to get the data they seek.

### Discussion

This qualitative nursing research using online recruitment and email interviews was one of the first studies that used this unique data collection technique. The investigator, in spite of the challenges faced in her efforts, successfully completed the study. The investigator-participant interaction was maintained throughout the research process by getting to know each other and developing mutual trust through multiple e-mails, and the investigator's caring, non-judgmental approach in asking the interview questions. Online recruitment and e-mail interviews proved to be a useful and legitimate technique for data collection. The lessons learned from this research experience should improve understanding of the use of this methodology, and should assist future qualitative researchers in utilizing online support group resources efficiently.

## CHAPTER IV

### EXPLAINING ‘UNEXPLAINED’ PERINATAL LOSS: EXPERIENCES OF WOMEN WITH ANTIPHOSPHOLIPID SYNDROME

#### Abstract

In this study, women’s experiences of one or more perinatal losses associated with antiphospholipid syndrome (APS) were explored, and their thoughts, perceptions, and feelings about losses related to this disorder and its effects on their outlook on subsequent childbearing described. The respondents were recruited from various online perinatal loss support groups using convenience and snowball sampling. The participants included 38 women, above 18 years old, from different countries, who were members of general and APS online perinatal support groups, and who had one or more perinatal losses associated with APS. Semi-structured, email interviews were conducted.

Two major themes emerged from the data are Existence in Bewilderment, and Persistence in the Quest for Knowledge and Information. The first theme has two sub themes, Delayed Diagnosis and Living in Uncertainty. Women with APS and related perinatal losses perceive the need to persist in seeking scientific knowledge because the information they receive from health care providers is limited and unclear. Evidence-based medical and nursing education about antiphospholipid antibody syndrome is necessary to improve clinical practice and thereby the perinatal outcome and the ill effects of this condition for women during and after the childbearing period.

## Introduction

Perinatal loss or pregnancy loss can be a devastating experience in the life of a woman and her family. When such losses occur one or more times and remain unexplained, the result may be life-changing for many parents (Adolfsson, Larsson, Wijma, & Bertero, 2004). Unexplained perinatal loss refers to the loss of a fetus or a baby for which no explanation or cause could be identified. Approximately, 10% to 15% of all clinically recognized pregnancies end in miscarriage, majority of which occurs early, before the 8<sup>th</sup> week of gestation (Lowdermilk, Perry, & Bobak, 2000). Sixty percent of recurrent spontaneous abortions are unexplained, and 7% to 25% of unexplained recurrent spontaneous abortions have antiphospholipid syndrome (APS) as the main contributing factor (Vinatier, Dufour, Cosson, & Houpeau, 2001).

APS, first described in 1983, is an autoimmune, prothrombotic disease characterized by recurrent arterial and or venous thrombosis and pregnancy morbidity manifested by early or late fetal losses associated with antiphospholipid antibodies (APLA)(Bertolaccini & Khamashta, 2006; Hughes, 1983; Tincani, Bompane, Danieli & Doria, 2006; Lim, Crowther, & Kikelboom, 2006; Vinatier et al.). APLA are a heterogeneous group of autoantibodies directed against phospholipid-binding proteins (Lim et al). This syndrome is referred to as primary APS when it occurs alone and secondary APS when it occurs in association with other conditions, such as systemic lupus erythematosus (SLE).

At present, the criteria used to diagnose patients as having APS are derived from a consensus reached by medical professionals in the Sapporo International Workshop on

APS (Miyakis, Lockshin, Atsumi, Branch, Brey, Cervera, et al., 2006). According to these criteria, to be diagnosed the patients should have had at least one clinical condition and have met one laboratory criterion. The clinical criteria include (a) Objectively confirmed arterial, venous, or small vessel thrombosis, (b) Pregnancy morbidity consisting of recurrent fetal loss before the 10<sup>th</sup> week of gestation, one or more unexplained fetal deaths at, or beyond, the 10<sup>th</sup> week of gestation, or (c) Premature birth due to placental insufficiency, eclampsia, or preeclampsia (Lim et al.). Laboratory criteria include medium or high titer IgG or IgM anticardiolipin (ACL), or the presence of Lupus Anticoagulant (LAC) on two or more occasions at least six weeks apart (Tincani, Allegri, & Sanmarco, 2001).

For diagnostic or therapeutic purposes, recurrent perinatal loss is defined as three or more losses at any time in pregnancy (Vinatier et al.). “Association not being synonymous with cause,” the proportion of abortions related to APS is difficult to estimate for several reasons: the definition of recurrent abortions is variable, the laboratory assays for antiphospholipid antibodies (APLA) are not well standardized, and inclusion of patients in the study group according to the antibody titer is investigator-dependent (Vinatier et al.). Therefore it is quite a challenge for these women to be diagnosed with APS as a causative factor for their recurrent perinatal losses.

Many epidemiological studies now focus on APS as a cause of recurrent spontaneous abortion (Bertolaccini & Khamashta). Autoimmune diseases such as APS have a high prevalence in women, especially during their childbearing years (Tincani et al., 2006). For many years, the general advice to these women was to avoid pregnancy,

as there was an increased risk of maternal and fetal morbidity and mortality. However, recurrent pregnancy loss associated with the presence of circulating APLA is now considered a treatable clinical condition (Tincani et al.).

Despite this evidence, nursing research regarding APS-related perinatal loss and its impact on women's lives is lacking. Many nurse researchers have explored women's varied experiences of perinatal losses, in general (Armstrong, 2004; Cote-Arsenault, Bidlack, & Humm, 2001; Hitti, 2005; Swanson, Karmali, Powell, & Pulvermakher, 2003). However, APS-specific perinatal loss and its related experiences of women are not well understood from a nursing perspective. Prior to this study, only one qualitative study on APS was found in the nursing literature and it described the challenges of pregnant women coping with several different thrombophilias. This research was conducted in Canada with nine women participants from a local hospital's thrombosis clinic (Martens & Emed, 2007).

An in-depth understanding of the phenomenon of APS-related perinatal loss from a global perspective of a larger, more diverse, sample of women was needed. Such a study has the potential to enhance nurses' and other health care providers' knowledge and skills necessary to better care for these women and their families, and thus reduce the devastating effects of such losses. Therefore, the purpose of this study was to explore women's experiences of one or more perinatal losses associated with antiphospholipid syndrome, and to describe their thoughts, perceptions, and feelings about losses related to APS and its effects on their outlook on subsequent childbearing.

## Methods

### *Research Design*

This descriptive phenomenological study explored the APS perinatal loss experience. Because the linkages between APS and pregnancy loss have recently been identified, an in-depth qualitative investigation of the women's experiences and the implications of this new diagnosis warranted. The chosen design is appropriate to extract the essence of this poorly understood phenomenon and to discover the meanings of women's lived experiences through in-depth, semi-structured email interviews.

### *Participants*

Participants were recruited from online perinatal loss support groups, both general and APS specific. The online interview took place in the home or work setting where the participant had computer and Internet access. The convenience sample of 38 women met the following eligibility criteria: one or more perinatal losses and a medical diagnosis of either primary or secondary APS during the past 15 years; could read, write, and understand English; were 18 years or older; and may or may not have had any living children. Women who were expecting at the time of data collection or who had just given birth were included in the study. The time elapsed between the latest loss and data collection varied from three months to ten years among participants. See Table 1 for the demographic information of participants.

### *Data Collection*

Approval for the study was granted by the Institutional Review Board (IRB) of Texas Woman's University Institute of Health Sciences in Houston. The proposed

research, including eligibility criteria for participation, was posted on online message boards after receiving permission from APS and pregnancy loss support group coordinators or ListServ owners. Women who felt they met the eligibility criteria were invited to email the researcher stating their intent to participate and giving a postal address to which the consent form and demographic data collection sheet were mailed. Potential participants provided an original signature on a paper consent form and completed a paper copy of the demographic data collection form prior to their online interview. These “hard copy” materials were returned to the researcher via the self-addressed, stamped envelope if they were in the United States. International participants received an International Reply Coupon to cover postage costs and decrease attrition.

Upon receipt of the documents, the researcher emailed the consented women the following initial interview questions: (a) Please tell me what was it like for you to lose your pregnancy/pregnancies and (b) How would you describe your feelings, thoughts, and perceptions of your pregnancy loss/losses before and after receiving the diagnosis of APS as a causative factor for such losses? The participants were then asked to tell their stories of loss/losses and receiving a definitive diagnosis of APS. After the answers to the initial questions were received, the researcher emailed some women to clarify, validate, and expand responses.

#### *Data Analysis*

Colaizzi’s phenomenological method was used to analyze the data (Colaizzi, 1978). As the initial responses were received, they were read and analyzed for patterns and emerging themes. Descriptive, significant statements of study participants clustered

in two overarching themes. Additionally, two sub themes, interconnected in meaning and essence, were identified for the first major theme. These themes and sub themes were synthesized to describe the essential nature and structure of the phenomenon of APS-related perinatal loss experiences of the women in the study. The sample size was determined by data saturation, as the investigator could not find the emergence of new themes after rigorous analysis of the data and identification of the two major themes.

The trustworthiness of this qualitative research was maintained during data collection, analysis, and interpretation using Lincoln and Guba's (1985) four criteria. Credibility was established by consistently coding the data, consulting with members of the research team, and verification of interpretation with study participants. The validity of the findings was established by using the supporting and illustrating quotes from the participants verbatim to accurately reflect their experiences with authenticity.

## Results

The analysis of the data yielded two overarching themes. They are Existence in Bewilderment and Persistence in the Quest for Knowledge and Information. The first major theme has two sub themes. They are, Delayed Diagnosis and Living in Uncertainty.

### *Existence in Bewilderment*

Women in this study described the entire experience of perinatal losses, before and after diagnosis of APS, as having to exist in a somewhat confused state of mind, mixed with a perplexity of psychosocial emotions. These women had the unique experience of grieving not only the loss of their pregnancy but also the loss of total personal well-being once they were diagnosed with APS. From their description, it was

evident that their losses and the diagnosis had great physical, emotional, social, spiritual, and economic impact on their personal well being.

The physical impact included impaired personal health due to the effect of APS on different body systems, undergoing painful procedures to evacuate the dead fetus, induction of labor, and or emergency Cesarean Sections following each loss. These women suffered the loss of their self-esteem and self-image and their concept of being a woman, when they perceived their inability to become mothers and this negatively influenced their emotional health. This feeling increased when their usual acquaintances, including friends and relatives avoided them and thus their social network was disrupted. Women who were religious and spiritual prior to the experience lost their faith and were puzzled by not having an answer to their repeated losses and to having a disease which is not very well-known, even in the medical community.

Some women were advised to undergo unnecessary procedures, tests and bed rest that later proved to be futile and led to loss of their job and source of income. In some countries, women had to wait for months or years to get an appointment to see APS specialists. Due to the eagerness to learn the exact nature of their disease, and their desperate need to fulfill the unmet desire of becoming a mother expeditiously, some women chose to see specialists in private practice at increased health care cost thus directly affecting their economic well being.

A few women had some prior knowledge about APS and its debilitating and potentially life threatening nature from others' experiences. Such women were shocked to have the diagnosis themselves and feared its impending complications both for

themselves and for their offspring. The emotions of losing their babies and learning that those losses were caused by their own blood disorder were inseparable. In general, they used the terms “despair,” “confused,” “heart wrenching,” “panic,” “devastated,” “frustrated,” “numb,” “frightened,” and “saddened” to describe their reactions to their losses and the unexpected diagnosis. Some women felt hopeless and frustrated about their health care experiences. They suffered several perinatal losses in spite of having many clinical manifestations suggestive of APS outside of pregnancy, having obstetrical complications in previous pregnancies, and having known risk factors of APS affecting multiple body systems among their family members.

Despite the evidence for APS, the perinatal losses of these women were documented as “unexplained losses,” “unexplained infertility,” or as losses from “natural” causes because of the lack of awareness of this syndrome among obstetricians or perinatologists. Most respondents in this study attributed the delay in diagnosis with APS and the repeated pregnancy losses to medical ignorance about this disorder and its consequences. Women reported that knowing the cause of their perinatal losses gave them great relief from worrying about the unknown, self blaming, and feeling guilty. Such relief persisted for women who were diagnosed and responded to treatment that led to successful pregnancy outcome. For women who did not respond to the medications and continued to lose babies, though they were relieved from worrying about the unknown, blaming self and feeling guilty remained. Before knowing the cause, if they blamed themselves for their losses and felt guilty thinking that they did something wrong, after the diagnosis of APS they blamed themselves thinking that it was *their* body that

was betraying and “killing” their babies. They blamed themselves for having “bad blood.” However, a few women believed that having a blood disorder was not their fault.

Almost all women responded that knowing the cause of their losses did not ease their pain or other emotions about losing their pregnancies, because, regardless of the cause the babies they lost would never come back and fill the void in their hearts. What was even more confusing to some was the fact that knowing the cause was not curing their problem. Several women continued to have pregnancy losses and clotting episodes after the diagnosis and treatment although many women experienced motherhood after successful treatment. As a result they feared pregnancies after a loss but the unmet desire to become a mother motivated them to try to conceive again. They had a lot of anxiety and uncertainty in subsequent pregnancies as the outcome was unpredictable. This caused them to be extra cautious in pregnancy after loss, and to be extremely alert to any signs of impending loss. Several women reported being cautiously attached to their developing babies as a protective mechanism against another potential loss and grief. The uncertainty they felt was not only in regards to the unpredictable pregnancy outcome but also the unpredictable future for themselves and their offspring in relation to APS and its damaging effects on their lives.

#### *Delayed Diagnosis*

The women in this study reported the challenging experiences of getting diagnosed with APS and having the mystery of their unexplained losses revealed. Many women had to consult a number of physicians from various medical specialties in order to receive a conclusive diagnosis. The reasons found to have influenced the diagnostic delay

included physicians' lack of consensus in determining the diagnostic criteria, differences in opinion about standardizing the laboratory markers for APS, and the variations in interpreting the blood test results. To further complicate matters, the Antiphospholipid antibodies (APLA) do not appear in the circulating blood at detectable levels at all times, and this might explain why several women could have babies without complications before their diagnosis and treatment, and in between losses.

One woman who lost her babies in the 2<sup>nd</sup> and 3<sup>rd</sup> trimesters described her experiences of getting a delayed diagnosis of APS as follows:

A simple blood test could have saved my babies. Hospitals usually don't test for it until a mother had gone through the agony of losing three or more babies. To lose one baby after 12 weeks was horrendous; to lose 2 seemed more than a coincidence. The doctors put my 2<sup>nd</sup> miscarriage down as just another "unlucky incident," but I wasn't so sure. I was happy to be referred to the APS specialist and understand APS better, but was so angry-why hadn't anyone picked up on it before. According to this specialist, APS is the commonest cause of recurrent miscarriages- so why isn't widely known about or tested for?

This statement was representative of many women's response to perinatal losses due to delayed diagnosis and treatment, which they attributed to lack of awareness among some physicians about this syndrome.

A woman who had her second daughter stillborn at 36 weeks of gestation, after her first child was born premature at 33 weeks gestation described her tragic experience of delayed diagnosis like this:

During my second pregnancy, I had premature contractions at 33 weeks of gestation but with medications, those contractions could be controlled and I was discharged home. After a few days, I felt that something was not right as I felt less fetal movements. The midwife told me to wait until the week end. My instincts told me that my baby was in danger and I called the hospital again. This time the midwife told me to get an ultrasound scan done. On this scan they could not get a fetal heart beat and I was admitted for induction. I never knew I had APS till 2 months after my daughter was born dead. Looking back now, I think a full blood screening should have been done when my first child was born so prematurely. Discovering my APS then would have saved my baby's life.

This quote also illustrates women's challenges of getting APS diagnosed. Many physicians who lacked knowledge of APS solely depended on the positive test results to diagnose women, while others took into consideration their clinical manifestations, and reproductive history including maternal-fetal complications. Relying on laboratory results kept many women from getting the diagnosis in spite of their perinatal losses for which other causes were ruled out. These women were denied medical management based on their negative APA results thereby causing them to experience further losses.

Most women reported that they and their family members had several risk factors that were suggestive of APS. For the most part, the family medical history included neurological, hematological, or immunological disorders among parents or siblings. In addition, several women reported reproductive losses and obstetric complications among

their mothers and or sisters, suggesting possible links to APS. In most cases, the physicians had difficulty understanding and interpreting the varied clinical manifestations women had before and after pregnancy and the maternal-fetal complications during pregnancy and child birth. The reproductive losses and obstetric complications the respondents reported are listed in Tables 2 and 3 respectively. Comparing to the incidence among general population of pregnant women, the increased frequency of obstetric complications the study population experienced further illustrates the links between APS and such complications.

For the most part, women reported that the obstetricians and general practitioners failed to listen to the women's complaints and ignored their reproductive history regardless of the number of times they had suffered pregnancy losses and the gestational age in which the losses occurred. The following quote from a woman who had seven miscarriages described her experiences of getting diagnosed with APS this way:

After having 7 miscarriages, I was not diagnosed with APS but with several other symptoms of clot formation, finally got diagnosed. I had a very hard time dealing with the "it is the nature's way" answers I got from the medical and personal contacts about my losses. I am angry that I didn't have to go through so many losses had the proper tests been done.

### *Living in Uncertainty*

Women in this study reported the feeling of living in uncertainty in regards to perinatal outcome and other APS complications, even after the diagnosis. From their reports, several physicians seemed not to be knowledgeable about the extent of damage

APS could cause in women's lives beyond childbearing. Women in this study reported that they had multiple symptoms that affected different body systems causing difficulties in daily living activities of varying magnitude. Some women reported they had pregnancy losses because they were not treated with anticoagulant agents when their APA levels were found to be border-line. These women said they switched their physicians or specialists to get medical treatment to bring a pregnancy to term and live birth. Those women who had losses while on treatment stated they believed that they were not prescribed the right dose or combination of medication, or the treatment was not initiated early enough in pregnancy. They also wanted the doctors to check their blood more frequently to see if their medications were working properly and were at therapeutic levels. These women wanted to know why some medication worked very well for some women and not for every woman, or in every pregnancy.

The following quotes illustrate the experience of living in uncertainty in regards to future perinatal outcome. One woman who had a pregnancy loss even when she was on medications, wrote,

I am not sure if the dose of the medications was effectively thinning my blood. I think doctors should monitor you more closely during pregnancy especially when you are high risk, providing scans when needed. They did not test my blood while I was on heparin and aspirin.

Another woman wrote, "I think, I should have pushed the doctor for more aggressive treatment. I should have forced him to test my blood more frequently to see I was getting enough medications."

A woman who had 7 losses at different gestation, wrote,

It was good to know that I had a physical condition causing the losses and that I wasn't cursed, but the losses were just as painful as when I didn't know the cause.

Maybe even more painful because after I was diagnosed, I started treatment with each pregnancy and was still not able to stay pregnant. I hope that since I am still young, there will be a breakthrough research and more knowledge before I am too old to conceive. The treatment offered today has done me no good.

Women who responded to the anticoagulant agents, and had no living children, felt fortunate to experience motherhood for the first time following several losses. However, they worried about their own health and the health of their offspring as they later learned more about APS complications, in spite of being treated.

Another woman's experience of the death of her fetus and the development of a DVT before her discharge from the hospital is illustrated in her description.

My impressions of sadness have faded but the reality of APS diagnosis remains. It is like living a nightmare. The APS has thrown a curve ball in my life and the future scares me. I am haunted by the outcome of my pregnancy and feel very ambivalent towards trying to conceive again. Mourning the death of my baby was replaced with fear for my life and later gratitude that I am alive to tell my story.

Would I necessarily believe that my next pregnancy will end differently?

#### *Persistence in the Quest for Knowledge and Information*

The participants in this study had the curiosity to learn about APS using different sources of information to get a better understanding of this condition. They persisted in

their quest for research based information and new knowledge about their disorder as they came to know that they need to live with the complications of APS for the rest of their lives. Seeking information became a necessity rather than a desire as the information received from health care personnel during pregnancies and losses was very limited. At times, women reported they got insufficient information from their obstetricians that proved to be wrong once they were seen by knowledgeable APS specialists. Women did their own research on their medical condition and often visited the Internet resources for updated information on APS. A majority of women shopped for new health care providers or changed their primary care physicians, obstetricians, or even specialists, who they thought to be knowledgeable of APS at some point. In these women's experiences, not all Rheumatologists were aware of APS and they misdiagnosed their condition as Lupus. One woman noted, "My doctor could not tell me why I was having lots of Lupus symptoms without having Lupus."

In their quest for updated knowledge on their condition, these women came to know of the existence of APS specific perinatal loss online support groups that were established by women who were diagnosed with this condition and suffered perinatal losses. When their losses remained unexplained, the women joined general perinatal loss support groups and then later switched to the APS groups or maintained dual membership. A few women got the information about support groups from the hospital staff but most women found out about such groups on their own. They read the newsletters such groups' coordinators sent to them and they shared their fears and concerns with other members who were knowledgeable about the syndrome. They found that the online

support groups were good sources of information and much needed support. The members of the support groups were knowledgeable about their disease and the medical evidence that emerged. Moreover, others' experiences made them feel that they were not alone. Sharing the knowledge among members on the online support groups helped them to ask questions and clarify information from their specialists. For these women, finding an online support group was similar to having their own personal haven of solace as no one other than the members of such groups could support and console them.

Women who reported being referred to APS specialists acquired knowledge from these doctors as well as from the Internet. A few women bought books on APS in addition to reading medical journal articles. The following quote illustrates a woman's description of her persistence in seeking information on APS:

I was referred to an APS specialist and he carried out blood tests and looked for underlying conditions which might have caused a miscarriage. In fact after hearing my history he said he was convinced that I had the condition even though he didn't have the results of my various blood tests. My APS doctor said that the low birth weight combined with my lack of amniotic fluid is classic APS and that if I hadn't been on the medication in pregnancy, my baby definitely wouldn't have survived.

### Discussion

The findings from this study have the potential to enrich the existing scientific body of knowledge in nursing. Many participants expressed their appreciation for this study in their emails and stated that they were not aware of any other nursing research in

which this particular disorder and the related pregnancy complications were studied from the women's perspectives. The majority of the women were diagnosed with APS after several losses in spite of having more than one clinical manifestation before and after each pregnancy. A few fortunate women were diagnosed prior to their first pregnancy because of the systemic effects of this condition in childhood. These women knew the complications they might face in pregnancy but the strong desire for motherhood outweighed the risk of the disease from their perspectives.

The findings of this study suggest that the women with APS have daily challenges and related complications consistent with that of the broader thrombophilia study (Martens & Emed, 2007). However, in this study, none of the women voiced their concerns about not receiving information about heparin injection. Most women noted that they had received adequate information from the nursing staff on the injection techniques and felt that the pain and difficulties surrounding daily heparin injections were worth enduring in the face of a positive perinatal outcome.

The participants' description of their pregnancy losses, challenges of getting the APS diagnosis, the related confusion and uncertainty, and their perceived need for persistently seeking information and knowledge about their condition are interrelated, and gives a comprehensive picture of what it is like living with this disorder during and beyond pregnancy. Almost all the participants voiced similar concerns while describing their experience with the medical professionals who had difficulties in diagnosing the syndrome earlier and initiating the treatment. The report that women had to take initiative in preventing their losses and that they often had to request their physicians to test them

for a possible explanation of their losses and for the treatment initiation and monitoring is consistent with that of the thrombophilia study.

Limitations of this study included convenience sampling limited to women who were members of online perinatal loss support groups. Therefore, women who were not members of such groups were not included and their experiences could not be explored. The participants comprised mainly white women from higher socioeconomic classes. The reason for not obtaining ethnic minority women is unknown. The online recruitment and email interviewing meant that the women's visual cues that would have enriched the description of their emotional experiences could not be seen. Furthermore, unlike in a face-to-face interview, questions, misconceptions, and misunderstandings in the investigator's questionnaire could not be clarified immediately and had to be explained via several emails between the participants and the investigator.

### Clinical Implications

The results of this study enhance understanding of APS-related perinatal loss experiences of women during pregnancy and beyond childbirth among nurses and other health care professionals. This study has implications for nursing and medical education, research, and clinical practice. APS should be included in the autoimmune disorders in nursing and medical textbooks so that graduating nursing and medical students can equip themselves with a prior knowledge base to care for APS patients in practice situations. Practicing nurses and physicians should be provided with evidence-based continuing education opportunities to increase their knowledge of APS and related topics.

Risk factors for APS and family history should be included in the obstetrical assessment of women to expedite diagnosis so that unnecessary perinatal losses and APS related complications can be prevented. Physical assessment to rule out the presence of thrombocytopenic purpura or other skin manifestations should be incorporated into routine prenatal check up. Simple and inexpensive laboratory tests may be of benefit to women at their initial prenatal visit if they are high risk for APS based on the medical and obstetrical history and or physical assessment. All health care providers benefit from up-to-date information and sensitivity to the needs and lived experience of the patients they care for. Women rely on health care professionals for information and evidence-based treatment following diagnosis. Therapeutic, sensitive, and supportive care of women and their families validates psychosocial needs and improves outcomes. Further research is recommended with a more diverse population of women who do not have access to computers or the Internet and are not members of an online support group.

- APS is not a well known disorder in medical discipline due to lack of randomized controlled trials, diagnostic difficulties including lack of consensus among medical experts on the standardization of diagnostic criteria and treatment modalities.
- APS is not included in the current nursing curriculum and the graduating nursing students are unaware of its existence.
- Continuing education should be mandatory for practicing nurses to increase awareness of APS and related complications.
- Nurses and other health care professional should validate and acknowledge women's feelings about perinatal losses associated with APS and be supportive and sensitive to their unique experience of having the debilitating/fatal disorder.
- A thorough medical, family and obstetrical history and physical assessment should be done in the first prenatal visit for every woman presenting risk factors or signs and symptoms of APS to expedite diagnosis and treatment
- Health care professionals should equip themselves with evidence based knowledge to improve perinatal outcome.

*Figure 1.* Summary of the clinical implications.

Table 1

*Demographic Characteristics of Participants (n= 38)*

Characteristics (%)	Number of Participants
Nationality	
American	27 (71.1)
Canadian	3 (7.9)
British	6 (15.8)
South African	1 (2.6)
Philippino	1 (2.6)
Race/Ethnicity	
Caucasian	35 (92.1)
Hispanic	2 (5.3)
Asian	1 (2.6)
Age	
20 - 29 years	7 (18.4)
30 - 39 years	28 (73.7)
40 - 49 years	2 (5.3)
50 & above	1 (2.6)
Religion	
Christian (Non-Catholic)	25 (65.8)
Catholic	2 (5.3)
Jewish	1 (2.6)
Agnostic/ None	7 (18.4)
Other	3 (7.9)
Marital Status	
Married	36 (94.7)
Single	2 (5.3)
Highest Education	
High School	7 (18.4)
Some College	11 (28.9)
Undergraduate	12 (31.6)
Graduate	8 (21.1)

Table 1 (Continued)

*Demographic Characteristics of Participants (n= 38)*

Characteristics (%)	Number of Participants
Annual Household Income (in U S dollar)	
35,000 - 54,000	6 (15.8)
55,000 - 74,000	4 (10.5)
75,000 - 94,000	8 (21.1)
95,000 - 114,000	10 (26.3)
115,000 and above	6 (15.8)
Unreported	4 (10.5)

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Table 2

*Reproductive Losses*

Manifestations/ Complications	Number of Women (%) (n= 38)	# of Losses In each category (%)
Infertility (No live children after losses)	2 (5.3) 19 (52.4)	NA 51 (62.2)
Early Miscarriage      (1- 12 weeks)		
Late Miscarriage      (13- 20 weeks)	10 (26.3)	16 (19.5)
Intrauterine Fetal Death (21-36 weeks)	6 (15.8)	8 (9.8)
Full term stillbirth      (21- 36 weeks)	3 (7.9)	3 (3.7)
Neonatal Death (Born alive but died during the first 28 days of life)	4 (10.5)	4 (4.9)

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Table 3

*Obstetrical Complications Related to APS*

Manifestations/ Complications	Number of Women (n= 38)	Incidence in Study Participants n/100	Incidence in General Population n/100
Placental Infarction	22	57.9	0.9
Pre term Birth	18	47.4	8.0-15.0
Headaches, Migraines	16	42.1	3.0
Intrauterine Growth Restriction	13	34.2	5.0
Hypertension	11	28.9	6.0-8.0
Emergency C/Section	11	28.9	Varies
Early Induction	9	23.7	20.0
Preeclampsia	7	18.4	5.0-8.0
HELLP Syndrome	6	15.8	0.2-0.6
Gestational Diabetes	5	13.2	2.0-4.0
Placental abruption	4	10.5	0.5-1.0
Bruise-like Lesions, Vasculopathy	4	10.5	7.0-8.0
Oligohydramnios	4	10.5	2.0-4.0
Depression	3	7.9	10.0-20.0

Table 3 (Continued)

*Obstetrical Complications Related to APS*

Manifestations/ Complications	Number of Women (n= 38)	Incidence in Study Participants n/100	Incidence in General Population n/100
Deep Vein Thrombosis	3	7.9	0.1
Subchorionic Hematoma	2	5.3	1.3
Nasal Bleeding	1	2.6	—
Strange Rash, Unexplained Swelling on One Foot	1	2.6	—

## CHAPTER V

### SUMMARY, IMPLICATIONS, AND CONCLUSION

#### Summary

Antiphospholipid syndrome-related perinatal loss has been documented as ‘unexplained’ loss or ‘unexplained’ infertility. For varied reasons, it continues to get reported as unexplained pregnancy loss. Many researchers in and out of health care disciplines have studied perinatal loss and its impact on women’s lives around the world. Medical research on APS diagnosis and treatment has enlightened the medical community with knowledge of this syndrome and its complications for women, in pregnancy as well as outside of pregnancy. However, there continue to be controversies among medical experts on screening for APS, laboratory diagnostic blood tests, and medical management of this disorder.

Nurses, if knowledgeable about this syndrome will be able to make a difference in the lives of these women and their families. Nursing research on APS and related perinatal loss is lacking in the literature. Evidence based nursing and medical education about APS is necessary to improve clinical practice and thereby the perinatal outcome and the ill effects of this condition for women during and after the childbearing period. Furthermore, nurses and other health care providers need to know what it is like for these women to live with APS- related perinatal losses and thrombotic complications. Such knowledge comes from the first hand experiences of women. Therefore, the purpose of

this research was to explore the experiences of women with one or more perinatal losses associated with APS.

The two research questions that explored the phenomenon of interest were

1. What are the perceptions, thoughts, and feelings of women with one or more perinatal losses associated with antiphospholipid syndrome?
2. Do women who have experienced at least one perinatal loss have a different outlook on subsequent childbearing after receiving a diagnosis of antiphospholipid syndrome?

The research design used to study this topic was descriptive phenomenology. Polit and Beck (2004) stated that the phenomenological approach is especially useful when a phenomenon of interest is poorly understood. Indeed, APS-related perinatal loss is a poorly researched phenomenon in nursing and the design chosen was quite appropriate to develop an in-depth understanding of this phenomenon. Descriptive phenomenology emphasizes descriptions of the meaning of human experiences (Polit & Beck, 2004). The goal of phenomenology is to fully describe lived experiences and individuals' perceptions of such experiences.

The participants were recruited for this study from a general online perinatal loss support group, and three different APS-specific online perinatal loss support groups. The investigator secured permission from the group coordinators to post the research details on the groups' message boards. Using convenience and snow ball sampling, the investigator interviewed 38 women who met the eligibility criteria and consented to participate in the study. Women from different nationalities were respondents in this

study. The majority were educated, white, American women, in the age group of 30-39 years. These women have had 1–7 perinatal losses at different gestational ages, and were registered members of the online support groups where they shared their experiences to each other and sought support and information about APS. Semi-structured, individual e-mail interviews with each woman provided the investigator with rich data to answer the two research questions.

Data were analyzed using Colaizzi's phenomenological method, and the analysis was completed upon data saturation. Two major themes emerged from the analysis of the data. They are Existence in Bewilderment, and Persistence in the Quest for Knowledge and Information. The sub themes for the first theme are Delayed Diagnosis, and Living in Uncertainty. Delayed diagnosis and treatment failures, and challenges of living in uncertainty made these women feel that they existed in bewilderment, a state of confused mind.

Many women had several perinatal losses before being diagnosed with APS. Before the diagnosis these respondents blamed themselves for their pregnancy losses because each loss was documented as "unexplained." They felt frustrated and hopeless. Some of them gave up the thought of becoming mothers because the physicians who treated them were unable to find out the cause for their repeated perinatal losses. Women who tried to conceive after unsuccessful pregnancies, worried about the perinatal outcomes in subsequent pregnancies. Many women responded well to the APS treatment with aspirin or heparin and had live births, other women continued to suffer perinatal deaths. The former lived in uncertainty about their health and the health of their children,

and the latter lived in uncertainty about becoming a mother and about living without complications of APS. This experience of living in uncertainty was evident because several women suffered clotting episodes affecting different body systems outside of their pregnancies.

The respondents in this study had many questions for their physicians about APS. A majority of the women wrote that they did not get accurate information from their health care providers. They found it necessary to shop for new providers and specialists. The limited knowledge and inaccurate information they received from their physicians led them to seek information elsewhere. So, the women in this study persisted in the quest for knowledge and information. They searched for up-to-date scientific knowledge about APS on the Internet, read books and journal articles written by APS specialists, and joined APS-specific support groups to share knowledge with each other. Most women found that the online support groups were sources of great relief and comfort, while grieving their pregnancy losses and suffering the complications of APS. The knowledge that they were not alone after joining these groups gave them a feeling of belonging, and solace and strength to take initiative in their treatment plan.

The findings in this study corroborate the results of the thrombophilia study (Martens & Emed, 2007). Unlike in the thrombophilia study, the respondents in this study wrote that their nurses taught them how to give heparin self-injections. However, the perceptions, thoughts, and feelings about perinatal losses and having a chronic medical condition were similar among respondents in both the thrombophilia and the current APS-related perinatal loss studies. Furthermore, the mothers' outlook on subsequent

pregnancy after at least one perinatal loss and a diagnosis of APS was similar in both the studies. However, in the thrombophilia study, though majority of the participants were women diagnosed with APS, a few were suffering from other thrombophilic disorders. Women in the APS-related perinatal loss study responded that their perinatal losses and the subsequent diagnosis of APS strengthened their interpersonal relationships with their partners. On the contrary, Swanson et al. (2003) found that perinatal losses impaired women's relationships with their partners.

The psychosocial feelings such as self blame, guilt, emptiness, anger, bereavement, social isolation, and anxiety in subsequent pregnancies in regards to perinatal losses women expressed in this study, are similar to that of previous perinatal loss studies (Armstrong, 2002.; Capitulo, 2005.; Cote-Arsenault & Freije, 2004.; Cote-Arsenault & Mahlangu, 1999.; Cote-Arsenault, Bidlack, & Humm, 2001.; De Montigny, Beaudet, & Dumas, 1999). Regardless of the cause, women who experienced perinatal losses had intense emotions that were evident from these studies. The findings in this study have implications for nursing education, practice, and research.

#### Implications for Nursing Education

The findings from this study have implications for nursing education. From examining the contents of textbooks in Maternity nursing, and from personal communication with colleagues in educational institutions, this researcher gained the knowledge that currently, the nursing curricula does not include APS in the autoimmune disorders that are taught to students. The reason may be that APS was considered a rare disorder until recently because it remained undiagnosed. The literature suggests that not

only women, but also men and children suffer from this disorder and its debilitating complications. By incorporating APS into the curricula, nursing students will have the knowledge base that they need to care for this population upon graduation. Nurse educators should have current scientific knowledge of this disorder so that their students will feel comfortable and confident in caring for these mothers in practice situations.

### Implications for Nursing Practice

The findings of this study emphasize the need for practicing nurses including bedside nurses, clinical nurse specialists, and nurse practitioners, to become knowledgeable about APS to better care for women who experience perinatal losses associated with this disorder. The in-depth understanding gained from exploring APS-related perinatal losses, of what it was like for these women to experience pregnancy losses and not knowing the cause for such losses, the challenges of getting the diagnosis, and the treatment failures, and the uncertainty in life they face, will enhance nurses' knowledge and skills in providing holistic care for them. The knowledge of the family risk factors suggestive of APS will help nurses to take a comprehensive family medical history from pregnant women who have complaints of clotting episodes and a history of unexplained perinatal losses, in the initial prenatal visit.

Nurses are in the forefront of health care professions. Prior knowledge of APS and its symptoms will enhance their ability to complete a thorough physical assessment of women during prenatal visits so that any cutaneous manifestations of APS such as idiopathic thrombocytopenic purpura can be noticed and further screening for this particular disorder can be undertaken before it is too late. The bedside nurses are in the

front line of caring and therefore, should be able to assess these women's unique needs. Their assessment findings of patients' physical, emotional, social, and spiritual needs should be conveyed to the researchers to assist them in developing ideas for further research to improve care to meet those needs. Nurses while caring for women with APS and perinatal losses are in a better position to carefully listen to the concerns and fears these women have about their own and their children's future health. This information should direct future researchers to develop research topics to add evidence to existing knowledge about APS and related perinatal losses.

The finding that these women live in uncertainty and bewilderment from their repeated pregnancy losses, and the medical diagnosis calls for increased sensitivity to these women's psychosocial needs. Nurses should understand that these women are vulnerable and have varied emotions, not only related to losing pregnancies, but also of having a disorder that, if left undiagnosed and untreated, can be debilitating or even fatal to themselves. The findings in this study will improve nurses' knowledge of the importance of therapeutic communication and maintaining a caring relationship with these women. Nurses should be able to support women in a non-judgmental manner, and refrain from making insensitive comments when they are in need of emotional support.

The nurse practitioners should be proactive in screening these women based on their medical history and family risk factors, so that the diagnosis will not be delayed. Being nurses themselves, nurse practitioners are in a better position to treat these women's bodies, minds, and spirits. The clinical nurse specialists should conduct continuing education sessions about APS and its complications for practicing nurses so

that they will be armed with sufficient knowledge base to render better care for women with APS and for their families.

The women in this study commented that they expected changed behaviors and attitudes from health care providers and staff when grieving the loss of their babies and the loss of their total personal well-being upon knowing their medical diagnosis. Nurses should assure the patients that APS can be managed effectively with proper treatment and regular monitoring of blood. The findings of this study revealed that the women are in need of information and research-based knowledge about their diagnosis, medical treatment, and the side effects of the medications that they should take for the rest of their lives, appropriate technique for heparin self-injections, and the preventive measures of further perinatal losses. Nurses are great patient educators and effective listeners to patient complaints. A scientific knowledge of APS will enhance their abilities to teach women with APS and related pregnancy losses, and provide them with information that these women seek for. Such knowledge comes from the first-hand experiences of women who lived the multiple complications of this disorder. Practicing nurses should have the opportunities to attend professional seminars, and workshops on APS, and to gain increased understanding from continuing education on this topic to keep them updated with evidence-based knowledge.

#### Implications for Nursing Research

Evidence-based medical and nursing knowledge and practice are rooted in scientific investigations of phenomena. APS is well-researched in Medicine while it remains poorly understood in Nursing. The findings of the current research on APS-

related perinatal loss will direct nurse researchers to study this phenomenon both qualitatively and quantitatively. The demographic data collected for this research will open up topics related to APS for future research. For example, the respondents in this study constituted white women predominantly. The reason could be that they had access to computers and the Internet and were educated whereas women from other ethnicities might not have such privileges. Also, these women were registered members of online support groups while many women who are APS sufferers do not join such groups. They might not even be aware of the existence of such groups. Future research should include these women who are not members of online support groups, and women from ethnic minorities. Such research will answer questions on the prevalence of APS among different ethnic groups, and its impact on women's lives from diverse cultural perspectives.

To the knowledge of this researcher, nursing research on the occurrence of APS among children of women with APS is lacking. There are controversies within the medical community about the genetic predisposition of APS and its familial nature. Future nursing research will fill the gaps in these areas and add to the existing literature about APS.

### Conclusion

The focus of this qualitative research was women's experiences of perinatal losses associated with antiphospholipid syndrome. The philosophical perspective guided this study was descriptive phenomenology. The principles and assumptions of this philosophy directed the exploration of a poorly understood phenomenon of APS-related perinatal

loss. Colaizzi's phenomenological method was appropriate to analyze the data gathered from the respondents to better understand the meaning of women's experiences of one or more perinatal losses associated with APS. The findings of this study will fill the gaps in the existing nursing literature on maternal and neonatal nursing. APS-related perinatal loss continues to be of great concern for women, health care providers, and the society as it constitutes a global issue. The findings in this study will enable nursing students, practicing nurses, nurse educators, and researchers to better understand this phenomenon that was considered rare, and thus enhance their knowledge and skills in rendering sensitive care to these women and their families.

Exploring the first-hand experiences of women who lived this disorder and who continue to live its complications, has greatly contributed to explaining the 'unexplained' perinatal loss. It is this researcher's hope that future health care research on this topic will proliferate, leading to finding interventions and preventive measures to avoid perinatal losses, thereby saving the first-born babies of mothers with APS.

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APPENDIX A  
Additional Interview Questions

### Additional Interview Questions

1. Can you tell me what was it like for you to lose babies several times?
2. What are your feelings, emotions, and thoughts related to unsuccessful childbearing?
3. How were your feelings, emotions, and your ability to cope with the losses different before the cause of your repeated losses was identified, from what they are now, after your diagnosis of APS?
4. How will you describe your general health in terms of presence of any medical condition before being diagnosed with APS?
5. How will you describe the health of your family members in terms of presence of any medical condition?
6. How will you describe your pregnancy history?
7. How will you describe your social support system during pregnancy and after losses?
8. What were your experiences with hospitalizations and care providers?
9. Can you please tell me about your lost babies in terms of their gestational age, any tests performed to find the cause of their demise etc.?
10. What do you think a health care provider may have to do to prevent pregnancy losses, and how do you think that the impact of such losses can be kept at a minimum if at all possible?

APPENDIX B  
Research Summary for the Participants

## Summary of the Findings of APS-related Perinatal Loss Dissertation Research

This is the summary of the findings of the research I did with you as a respondent.

The topic of this dissertation research was Explaining Unexplained Loss: Women's Experiences of One or More Perinatal Losses Associated with Antiphospholipid Syndrome. The data that you contributed towards this study was analyzed systematically. I read each and everyone's responses multiple times very carefully, noting down significant statements. Each respondent's similar statements were put together under a category. Each category was reread and analyzed to come up with a theme. I did it several times to get a thorough understanding of the meaning of your experiences.

Many of you had similar experiences and some had dissimilar experiences. I took both kinds of experiences into my analysis to get a comprehensive understanding of what it was like for you to experience one or more perinatal losses and getting a diagnosis of antiphospholipid syndrome- the so-called 'sticky blood' syndrome. The data analysis resulted in two major themes. The first theme is named as, 'Existence in Bewilderment', and the second theme as, 'Persistence in the Quest for Knowledge and Information'. The first theme has two sub themes. They are 'Delayed Diagnosis' and 'Living in Uncertainty'.

These themes are actually self-explanatory and are easy to understand especially when you had the experience of extreme confusion when you heard that sticky blood syndrome was to blame for your pregnancy losses, on the top of the terrible tragedy of such losses. Many of you wrote to me that you did not know what to do and where to turn for help and support. When the pregnancy losses were documented as 'unexplained' and

the doctors did not find an explanation or a cause for your losses, you kept worrying, what it could be that was causing unsuccessful pregnancies. Many women wrote to me that they were hopeless and frustrated all the more angry- angry with themselves, their doctors, and with almost everybody on their way.

Many of you got the diagnosis so late that they had to suffer pregnancy losses more than once, and at different gestational ages. Your family risk factors for APS, your previous medical history, and reproductive history, and warning signs during pregnancies, were not taken into consideration, or were misleading to physicians, to come up with a diagnosis. This caused delayed diagnosis. Many women who were diagnosed and treated were lucky to have successful births. Unfortunately, this was not the case with some of you. For some reason, these women did not respond well to the medical treatment. So the uncertainty they had before diagnosis continued even after the diagnosis and treatment, because they did not know, for sure, if their pregnancy would end up in full term live births. The women, who have had live births, were uncertain about their future health and the health of their children. So if it was the uncertainty about a successful pregnancy, or about a healthy and uncomplicated life with APS, women lived in “uncertainty”.

You expected to get answers from your providers for the many questions that you had when you were diagnosed, and for a long time after the diagnosis. However, you got frustrated, as many times the doctors did not know what exactly was going on with your body. You all repeatedly wrote that the information you got from your providers and nurses about this medical diagnosis was minimal and was often inaccurate, that some of you had to switch your doctors and even specialists. Most of you wrote about your

curiosity to learn more and more about APS and why it was causing harm to your precious pregnancies. You searched on the Internet, joined support groups, and tried to find doctors and specialists who were knowledgeable about APS. Some of you even went ahead and bought text books on APS, in addition to reading the newsletters that your support groups provided. This information led me to the second theme, persistence in the quest for information and knowledge. No matter what, for the most part, majority of you persisted in seeking up-to-date information and scientific knowledge about APS. You all were determined to learn as much as possible about this mystery disease, to fight for a successful pregnancy.

I am glad to learn that you all are members of APS online support groups so that you can support each other emotionally and with knowledge and power. No matter where you are on the globe, these online support groups are a great source of consolation and information. Yes, you are not alone.

## **APPENDIX C**

Evidence of Submission of the Methodology Manuscript to  
Journal of Qualitative Health Research

**Subject:** QHR - Confirmation of Receipt of Manuscript  
**Date:** 5/21/2008 1:24:24 P.M. Central America Standard T  
**From:**  
**To:**

*Sent from the Internet* ([Details](#))

21-May-2008

Dear Mrs. Mathew

This is to confirm receipt of your manuscript, entitled "Evaluation of Online Recruitment and E-Mail Interviews in a Perinatal Loss Research," at Qualitative Health Research (QHR). Our online system has assigned a document ID number to your manuscript, and we would appreciate your referring to this number whenever you contact us about your paper.

Your manuscript ID # is QHR-2008-xxxx.

If you have questions or need assistance, please contact us at [xxxxx@xxxxxx](mailto:xxxxx@xxxxxx).

Thank you for submitting your manuscript to Qualitative Health Research (QHR).

Sincerely,

Dori A. Fortune  
Technical Editor

## APPENDIX D

Evidence of Submission of the Findings Manuscript to Journal of Perinatal and Neonatal

Nursing

**JPNN Submission Confirmation for Explaining 'Unexplained' Perinatal Loss: Experiences of Women with Antiphospholipid Syndrome**  
**Date: 5/2/2008 9:45:19 P.M. Central America Standard Ti**

**From:**  
**To:**

*Sent from the Internet ([Details](#))*

**May 02, 2008**

**Dear Mathew,**

**Your submission entitled "Explaining 'Unexplained' Perinatal Loss: Experiences of Women with Antiphospholipid Syndrome" has been received by the journal editorial office.**

**You will be able to check on the progress of your paper by logging on to Editorial Manager as an author.**

**Your username is: xxxxxxxx**

**Your password is: xxxxxxxx**

**Your manuscript will be given a reference number once an Editor has been assigned.**

**Thank you for submitting your work to this journal.**

**Kind Regards,**

**Journal of Perinatal and Neonatal Nursing**

## APPENDIX E

Permission from the Owner of the Online Perinatal Loss Support Group

**Subject:** (no subject)  
**Date:** 10/15/2006 11:24:03 A.M. Central America Standard  
**From:**  
**To:**

*Sent from the Internet ([Details](#))*

Dear Susan,

Thank you for your note. I am glad to learn of your research efforts and would like to help. The Hygeia Community is a very caring and supportive community. It has a database of over 28000 families many of whom have experienced loss from the Antiphospholipid syndrome. You can register and then access the databases yourself. I would ask that any data that is gathered from Hygeia would be appropriately referenced in your work and Thesis. I hope this is helpful.

Best regards,  
Michael

Michael R. Berman, M.D.  
Clinical Professor of Obstetrics, Gynecology and Reproductive Sciences  
Yale University School of Medicine

Founder and President  
Hygeia Foundation and Institute for  
Perinatal Loss and Bereavement  
<http://hygeia.org>

Founder, The Ephemeris Project:  
Preserving humanism, values and ethics  
fundamental to the healthcare professional student  
<http://ephemerisproject.com>

**APPENDIX F**  
**Informed Consent Form**



DENTON DALLAS HOUSTON

**Pioneering Nursing's Future:  
An Adventure in Excellence**

**Nelda C. Stark College of Nursing**  
Houston Center  
6/00 Fannin Street, Houston, TX 77030-2343  
713-794-2100 Fax 713-794-2103

TEXAS WOMAN'S UNIVERSITY

**CONSENT TO PARTICIPATE IN RESEARCH**

Title: Explaining Unexplained Perinatal Loss: Women's Experiences of One or More Perinatal Losses Associated with Antiphospholipid Syndrome

Investigator: Susan Mathew, MSN..... (281) 499 8329

Advisor: Sandra Cesario, Ph.D..... (713) 794 2110

**Explanation and Purpose of the Research**

You are being asked to participate in a research study for Ms. Mathew's dissertation at Texas Woman's University. The purpose of this research is to understand women's experiences of one or more perinatal losses associated with antiphospholipid syndrome which is a blood clotting condition. In particular, the study will explore women's health care experiences in regards to perinatal losses when the cause for such losses was not identified, as well as to the diagnosis of antiphospholipid syndrome.

**Research Procedures**

For this study, the investigator will conduct email interviews via personal emails sent directly to each participant. A follow-up telephone call may be done to verify the researcher's interpretation of the information given in the e-mails. Your maximum total time commitment in the study is estimated to be approximately four hours.

**Potential Risks**

Potential risks related to your participation in the study include fatigue, loss of time and emotional discomfort during your email interview. To avoid fatigue, you may take breaks during the email interview as needed. If you experience emotional discomfort regarding the email interview questions, you may take a break and use Hygeia support group resources. To avoid loss of your time, please write a little at a time and come back to it later when you feel relaxed and at leisure. Another possible risk to you as a result of your participation in the study is release of confidential information. Confidentiality will be protected to the extent that is allowed by law. A code name, rather than your real name, will be used on the email response sheets. Only the investigator and her advisor will have access to these responses. The hard copies of the email responses and the computer diskettes containing the email response text files will be stored in a filing cabinet at the investigator's residence. The email response diskettes will be destroyed and the hard copies of these responses will be shredded within two years of completion of the data collection. It is anticipated that the results of this study will be published in the investigator's dissertation as well as in other research publications. However, no names or other identifying information will be included in any publication.

*The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and she will help you. However, TWU does not provide medical services or financial assistance for the physical or emotional trauma that might happen because you are taking part in this research*

Approved by the Texas Woman's University Institutional Review Board
Date: 8-8-03

Participate in Research  
**Think SUCCESS** **Think TWU**

Title: Explaining Unexplained Loss: Women's Experiences of One or More Perinatal Losses associated with Antiphospholipid Syndrome

**Participation and Benefits**

Your involvement in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty. There are no direct benefits of participating in this study. At the completion of the study, a summary of the results will be mailed to you upon request.

**Questions Regarding the Study**

If you have any questions about the research study you may ask the researchers; their phone numbers are at the top of this form. Their email addresses are [nlindley@twu.edu](mailto:nlindley@twu.edu) and [aschulman@twu.edu](mailto:aschulman@twu.edu) respectively. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2840 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu). You will be given a copy of this signed and dated consent form to keep.

Signature of Participant

Matthew

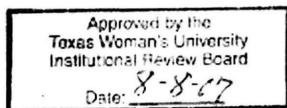
Date

8/16/07

Signature of Investigator

Date

\*If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent:



Page 2 of 2

## **APPENDIX G**

### **Institutional Review Board Approval**



**Office of Research**  
6700 Fannin Street  
Houston, TX 77030-2343  
713-794-2480 Fax 713-794-2488

August 8, 2007

Ms. Susan Mathew  
6700 Fannin Street  
Houston, TX 77030

Dear Ms. Mathew:

*Re: Explaining unexplained loss: Women's experiences of one or more perinatal losses associated with antiphospholipid syndrome*

Your application to the IRB has been reviewed and approved.

This approval lasts for one (1) year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

Remember to provide copies of the signed informed consent to the Office of Research, IHS 10110 when the study has been completed. Include a letter providing the name(s) of the researcher(s), the faculty advisor, and the title of the study. Graduation may be blocked unless consents are returned.

Sincerely,

A handwritten signature in black ink that reads "William P. Hanten".

Dr. William P. Hanten, Chair  
Institutional Review Board - Houston