Assessment of perinatal nurses' knowledge of antiphospholipid syndrome and nursing management of pregnant women with antiphospholipid syndrome

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ASSESSMENT OF PERINATAL NURSES’ KNOWLEDGE OF ANTIPHOSPHOLIPID SYNDROME AND NURSING MANAGEMENT OF PREGNANT WOMEN WITH ANTIPHOSPHOLIPID SYNDROME

by

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A thesis submitted in partial fulfillment of the requirements for the Honors in the Major Program in Nursing in the College of Nursing and in The Burnett Honors College at the University of Central Florida Orlando, Florida

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Thesis Chair: Dr. Julee Waldrop
ABSTRACT

Background: Antiphospholipid syndrome (APS), a complex autoimmune disorder, is associated with thromboembolic events and 7%-25% of unexplained fetal losses. No research exists on perinatal nurses’ knowledge of APS or its nursing management.

Purpose: To assess perinatal nurses’ knowledge and nursing management of pregnant women with APS. This pilot study also may justify a study with a larger sample size and more recruitment sites, as well as determine the need for an educational program on APS for perinatal nurses.

Methodology: This is a descriptive cross-sectional pilot study. Ninety-two registered nurses working in perinatal areas from a metropolitan medical center in the Southeastern United States completed a 20-item survey on demographics and knowledge about APS and nursing management of patients with APS.

Analyses: Descriptive statistics were conducted to characterize the sample. ANOVA, t tests, Pearson’s correlation, and logistic regression were used to determine factors associated with knowledge of APS and its nursing management.

Conclusion: The average score of participants on the 8 knowledge items of the survey was 1.4. Only current work area was associated with knowledge scores, however, previous familiarity with APS was associated with higher scores.
DEDICATION

To my parents, brothers, and sisters, who made home a place where learning was loved and encouragement abounded.

To my professors and mentors, for their words of wisdom, guidance, and inspiration to excellence.
ACKNOWLEDGMENTS

I would like to express my deepest thanks to the individuals who have made this research study a reality. To Dr. Patricia Weinstein and Dr. Julee Waldrop for their countless hours meeting with me, helping to develop this project, collect the data, and synthesize it into this final document. I would also like to thank all of the nurse managers who graciously allowed me to survey their nurses. I am so grateful for the nurses who participated, for their willingness to participate and their evident love of learning.
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INTRODUCTION

Antiphospholipid Syndrome (APS), also known as Hughes Syndrome, is the most common cause of acquired thrombophilia. The syndrome is characterized by recurrent thromboembolic events and/or pregnancy loss in the presence of persistent laboratory evidence for antiphospholipid antibodies (aPLs)—lupus anticoagulant, anticardiolipin antibodies, and anti-β₂-glycoprotein I antibodies (Oretel, 2012). It is estimated that APS may be responsible for nearly one-third of cerebrovascular accidents in people under age 50 years, one-fifth of all cases of deep vein thrombosis, and one-fourth of recurrent miscarriages. In its most life-threatening form, catastrophic APS carries a mortality of 30-50%, even with treatment (Erkan & Pierangeli, 2012).

Although considered primarily a coagulopathy, APS may manifest as a complex systemic autoimmune disease with diverse organ and tissue manifestations. It can occur alone or secondary to other autoimmune disorders and has a particularly strong association with systemic lupus erythematosus (Pullen, Vincent, & Siess, 2011). Despite its clinical implications and prevalence, APS remains relatively unknown among healthcare professionals (Bulikova, 2012).

Background

Human cell membranes are composed primarily of fats called phospholipids (Marieb & Katja, 2010). These phospholipids are essential to the fluid structure and function of each cell and play a major role in the clotting cascade (Bertolaccini, Ateka-Barrutia, & Khamashta, 2010). Occasionally, due to medications, infections, malignancies, or underlying autoimmune disorders, the body’s immune system forms antibodies, called antiphospholipid antibodies (aPLs), directed
against epitopes on plasma proteins that are uncovered or created by the binding of these proteins to phospholipids. These antibodies not only inhibit proteins critical to hemostasis and prevention of thrombi formation, but also alter the complement pathways, thus creating a thrombogenic state (Iwasawa, 2011).

Although many health professionals are not familiar with antiphospholipid syndrome (APS), it is not rare. APS is the most commonly acquired thrombophilia and the most common treatable cause of recurrent pregnancy loss. APS has a prevalence of 2-5% in the general population, occurring more commonly in women than men with a 5:1 ratio (Biggioggero & Meroni, 2010).

Perinatal loss, estimated to occur in 15-20% of all pregnancies, is a distressing event (Mathew, Cesario, & Symes, 2008). While 40% of pregnancy losses can be attributed to specific causes, 60% of miscarriages are unexplained. Research has shown between 7%-25% of unexplained fetal losses can be attributed to aPL antibodies (Vinatier, Dufour, Cosson, & Houpeau, 2001). This makes APS the leading cause of unexplained fetal loss. In addition, antiphospholipid antibodies are associated with 16% to 38% of fetal or embryonic deaths, 15% to 30% of fetal growth restriction, and 18% of preeclampsia in all pregnancies (Buyon, 2009).

Despite APS’ clinical significance, research on nurses’ knowledge of APS and its nursing management is limited. An extensive search of the literature using the electronic databases Medline, CINAHL and PsychInfo discovered only one qualitative study on fetal loss related to APS (Mathew, Cesario, & Symes, 2008), one qualitative study on patients’ experiences of heparin therapy during pregnancy (Martins & Emed, 2007), two case studies (Kais-Wyllie, 2002; Hilton, Reeves & Madavag, 1992), and two literature reviews (Vials, 2001; Ament 1994). To date, no research has assessed nurses’ knowledge of APS or its nursing management. This is
concerning since the qualitative study by Mathew, Cesario, & Symes (2008) showed that many of the participants felt their diagnosis was delayed due to their healthcare providers’ lack of knowledge regarding APS. In fact, many of the women blamed their providers for their subsequent fetal loss due to a delay in diagnosis and treatment (Mathew, Cesario and Symes, 2008).

Perinatal nurses often care for pregnant women with APS who require treatment, education, and support. Because of the prevalence of aPL antibodies and their associated adverse pregnancy outcomes, it is imperative that nurses are aware of APS, its risks, associated complications, medical treatment, and nursing management. Without this knowledge, nurses may fail to anticipate or overlook subtle changes indicating pregnancy complications. Likewise, nurses may not adequately educate their clients and their clients’ families regarding prevention and management of APS complications.

The primary purpose of this study was to assess perinatal nurses’ knowledge of APS. Additional goals of this study were to justify a larger study conducted at more than one site and develop an educational intervention to inform nurses about APS and nursing care of patients with APS.
METHODS

This study was a cross sectional survey design. It was reviewed by the institutional review board of the medical center where the study was conducted.

The researchers constructed a 20-item paper-and-pencil survey to assess demographic information regarding age, education, work experience and knowledge of APS and its nursing management of patients with APS. Eight questions covered demographics; twelve were knowledge questions. Knowledge questions were constructed by a nurse practitioner with experience in caring for patients with APS and who is the author of the Rheumatology Nurses Society Core Curriculum chapter on APS (Weinstein, 2013). In addition, the questions were reviewed by other content experts (obstetrician, rheumatologist and a nurse working in obstetrics), thereby increasing its content validity. Knowledge items covered information on the pathophysiology and diagnosis of APS, its medical treatment, and nursing management of pregnant patients with APS.

Sample size was calculated to be 83, using a 15% margin of error, 95% confidence level and 50% response distribution, and drawing from a target population of 600 RNs. Eligibility criteria for participation were age 18 years or older and employed as a registered nurse (RN) in Labor & Delivery, NICU, Mother & Baby, Antepartum, or Obstetrical Triage.

The survey was administered in one of the nation’s busiest women and children’s hospital in a metropolitan city in the Southeastern United States (Orlando Health, 2013). Ninety-three registered nurses completed the survey within a 6-day period to limit discussion of the survey’s content among staff. RNs who completed the survey received a $5 gift card in appreciation of their time. After the surveys were completed, all data were entered into an Excel worksheet.
RESULTS

All analyses were conducted using IBM® SPSS® Statistics (2012). Descriptive statistics were used to characterize the sample (Table 1). Ninety-two RNs completed the survey. Participants represented staff from all units. All participants except one were female. Their mean age was 41.5 years (±12.4). The entry level nursing education program for the majority of the RNs (51.6%) was baccalaureate. On average, they had worked as an RN for 14 years (±12) and in maternal health for 11.4 years (±10).

Table 1: Sample Characteristics

<table>
<thead>
<tr>
<th>Age (year)</th>
<th>41.5 ± 12.4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic Nursing Education*</td>
<td></td>
</tr>
<tr>
<td>• ASN</td>
<td>41 (44.1%)</td>
</tr>
<tr>
<td>• 3-year/Diploma degree</td>
<td>3 (3.2%)</td>
</tr>
<tr>
<td>• BSN</td>
<td>48 (51.6%)</td>
</tr>
<tr>
<td>Highest Degree Attained</td>
<td></td>
</tr>
<tr>
<td>• BSN</td>
<td>52 (55.9%)</td>
</tr>
<tr>
<td>• MSN</td>
<td>5 (5.4%)</td>
</tr>
<tr>
<td>Employed as an RN (years)</td>
<td>14 ± 12</td>
</tr>
<tr>
<td>Years working in maternal health</td>
<td>11.4 ± 10</td>
</tr>
</tbody>
</table>

*N = 92
Table 2: Current areas of work among participants

<table>
<thead>
<tr>
<th>Unit</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antepartum</td>
<td>10</td>
</tr>
<tr>
<td>Postpartum</td>
<td>42</td>
</tr>
<tr>
<td>Prenatal Clinic</td>
<td>10</td>
</tr>
<tr>
<td>Triage</td>
<td>6</td>
</tr>
<tr>
<td>NICU</td>
<td>20</td>
</tr>
<tr>
<td>Labor &amp; Delivery</td>
<td>5</td>
</tr>
</tbody>
</table>

Only 23.7% (N=20) of participants stated they were familiar with APS. The majority of participants (75.4%, N=70) reported they were either unsure or unfamiliar with APS. Almost 13% reported having cared for a pregnant woman with APS, and 2.2% reported personally knowing someone with APS.

Table 3: Participants’ familiarity with APS

<table>
<thead>
<tr>
<th>Reported Familiarity</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reported Familiarity</td>
<td>23.7%</td>
<td>55.9%</td>
<td>19.4%</td>
</tr>
<tr>
<td>Cared for a Patient with APS</td>
<td>12.9%</td>
<td>66.7%</td>
<td>20.4%</td>
</tr>
<tr>
<td>Personally Knew Someone with APS</td>
<td>2.2%</td>
<td>93.5%</td>
<td>4.3%</td>
</tr>
</tbody>
</table>

The majority of those nurses who responded that they were familiar with APS had reported three primary sources for their information about APS: in-hospital education (7.5%), nursing school (9.7%), and other (11.8%). Participants who marked “other” were given the opportunity to write in where they had learned about the syndrome. Of the 10 participants who marked “other”, 6 listed having cared for a patient with APS. One participant stated she had performed an online search of APS because her patient was diagnosed with APS. Others reported their knowledge came from various sources, such as rounds or while working on their specific unit.
Table 4: Sources of information about APS

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing School</td>
<td>9.7%</td>
</tr>
<tr>
<td>Medical/Nursing conference/workshop</td>
<td>1.1%</td>
</tr>
<tr>
<td>In-hospital education</td>
<td>7.5%</td>
</tr>
<tr>
<td>Personal reading or research</td>
<td>2.2%</td>
</tr>
<tr>
<td>Professional colleague</td>
<td>1.1%</td>
</tr>
<tr>
<td>Other</td>
<td>11.8%</td>
</tr>
</tbody>
</table>

The mean score on the 8 knowledge items of the survey was 1.4 (±2) correct responses (Figure 1). Most participants (57%) answered no questions correctly. The next largest group (9.7%) answered two questions correctly.

![Figure 1: Scores on knowledge items](image)

Participants scored lowest on items about diagnostic criteria and pathophysiology of APS and highest on items about clinical manifestations and postpartum care (Table 5).
Table 5: Nurses’ Knowledge of Specific Areas

<table>
<thead>
<tr>
<th>Questions (N)</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Unfamiliar</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic Criteria (1)</td>
<td>8.6%</td>
<td>67.7%</td>
<td>22.6%</td>
</tr>
<tr>
<td>Antiphospholipid Antibodies (1)</td>
<td>6.5%</td>
<td>19.4%</td>
<td>73.1%</td>
</tr>
<tr>
<td>Historical/Physical Finding (2)</td>
<td>26.9%</td>
<td>1.1%</td>
<td>72%</td>
</tr>
<tr>
<td>Obstetric Complications</td>
<td>20.4%</td>
<td>4.3%</td>
<td>75.3%</td>
</tr>
<tr>
<td>Nursing Assessment of Complications</td>
<td>15.1%</td>
<td>14%</td>
<td>71%</td>
</tr>
<tr>
<td>Patient Education</td>
<td>22.6%</td>
<td>7.5%</td>
<td>69.9%</td>
</tr>
<tr>
<td>Postpartum Care</td>
<td>24.7%</td>
<td>8.6%</td>
<td>66.7%</td>
</tr>
</tbody>
</table>

A t test for independent samples showed significant (p <.000) differences in scores between nurses who reported being familiar with APS (M=3.6±2.3) and those who were unfamiliar or unsure about APS (.77±1.5). Nurses who considered themselves familiar with APS did score higher, although the average score was below 50%.

Logistic regression was used to evaluate the effect of basic nursing education, highest nursing degree attained, years of nursing experience, years working in maternal health, and current area of work had on familiarity with APS. No variables were significant predictors for familiarity with APS (χ²=4.273, df= 8, p > .832).

A one-way between groups analysis of variance (ANOVA) was conducted to explore the impact of highest educational degree attained (3-yr, associate, baccalaureate and graduate) on participants’ scores on the knowledge items. No statistical significance was found: F (3, 86) = .517, p = .673.

An ANOVA also was conducted to explore the impact of current area of work (prenatal clinic, triage, antepartum, labor and delivery, mother and baby/postpartum, and NICU) on
participants’ scores on the knowledge items. There was a statistically significant difference for the six work areas at the $p < .05$ level in scores: $F(5, 85) = 4.949, p = .001$. The effect size, calculated using eta squares, was large at .22 or 22%. Post hoc analysis using the Tukey HSD indicated that the mean score of nurses working in triage was significantly higher than those nurses working in postpartum and NICU. Since the group sizes were uneven, a risk of Type I error exists.

The relationship between years working in maternal health and score on the 8 knowledge items on the survey was investigated using Pearson product-moment correlation coefficient. Preliminary analysis was performed to ensure no violations of assumptions revealed threats to normality because of the uneven group sizes. Analyses were conducted nonetheless since the sample size was large and this was a pilot study. There was a small, positive correlation between the two variables, $r = .28, n = 92, p = .007$. 
DISCUSSION

The purpose of this study was to assess perinatal nurses’ knowledge regarding APS and its nursing management. The majority of the nurses in this study (70%) were unfamiliar with APS. Although those nurses familiar with APS had higher knowledge scores compared to those nurses unfamiliar with the syndrome, the percentage of their correct responses was still less than 50%. Educational background, years of nursing experience, years working in maternal health, or current area of work did not predict familiarity. The only factor that significantly correlated with higher scores was current area of work ($p < .000$), with nurses working in triage scoring the highest. One could speculate that these nurses are the ones who are most likely to encounter women who are at increased risk for, or are experiencing obstetrical complications related to, APS. However, nurses working in prenatal clinics, including high-risk obstetrics, did not score higher than nurses in other areas of maternal health. The fact that nurses who reported being familiar with APS did score higher than those who were unfamiliar suggests that an educational intervention could positively impact knowledge about APS.

It is not appropriate to blame nurses for lack of awareness about APS. Educational experience and years working in nursing and/or maternal health were not associated with familiarity with APS or knowledge scores. It appears that neither nursing academia nor the health system has provided information about APS to nurses. Nurses who are aware of APS have picked it up as part of their work experience. The majority of the nurses in this study who were familiar with APS reported that their information about APS came from caring for patients with APS. About 13% of the nurses in the study first encountered this syndrome while working.
Physicians and other health professionals as well as nurses often are unfamiliar with APS. There may be a tendency to blame lack of knowledge about APS in the healthcare community on the syndrome’s relative rarity. This is a common misconception in medicine in general (Bulikova, 2012). APS is the most commonly acquired coagulopathy and the leading cause of undiagnosed miscarriage and fetal loss (Erkan & Pierangeli, 2012). Dr. Graham Hughes, who first described antiphospholipid syndrome (APS) and after whom Hughes syndrome is named, believes that APS will become the most diagnosed autoimmune disorder of the 21st century (Holden, 2003).

This study was the first to assess RNs’ knowledge of APS, so there are no other research findings with which to compare results. However, the findings of this study are in line with the results of the qualitative study by Mathew, Cesario, & Symes (2008) which concluded that women with APS had an overwhelming feeling that their healthcare providers were not aware of or knowledgeable about APS.

Limitations

All data were collected cross-sectionally from one medical center. Thus, any generalizations related to the findings must be made with caution. However, this hospital delivers over 12,000 babies annually and is one of the busiest women’s hospitals in the country. Although recruitment was aimed at achieving a sample representative of all areas within the medical center where the study was conducted, some areas were more represented than others. As a consequence, homogeneity of variance was threatened and may have affected ANOVA results. The knowledge
items on the survey were created by health professionals familiar with APS and content validity is justified, but no attempt was made at determining reliability or additional measures of validity.
CONCLUSION

Nurses play an integral role in the assessment and care of all patients. Educational efforts to increase awareness of APS and its nursing management have the potential to improve pregnancy outcomes and minimize postpartum risk in women with APS. Maternal health nurses who understand the complications of APS and its manifestations may be better able to quickly identify historical/physical findings that could alert them to the possibility of an embolic event or obstetrical complication.

The findings from this study justify a larger study at multiple sites that would determine specific educational needs of nurses in regards to APS. Likewise, this study points out the need for a reliable and valid tool to assess knowledge of APS. The ultimate goal would be to develop and test an educational intervention on APS for nurses, not only in maternal health, but other areas as well since APS is not limited to pregnant women.

With increased awareness of APS, nurses have the potential to swiftly identify manifestations of a thrombotic event or obstetric complication and decrease the time between symptom onset and treatment. Just as importantly, nurses’ role as patient advocates and educators allow them to empower patients with APS with the self-care tools that decrease their risk for embolic events and poor pregnancy outcomes. Given the consequences of untreated APS, educating nurses about APS is a more than worth the effort.
1. Birthdate: ___________  

2. Gender: ☐ Female  ☐ Male

   YEAR ONLY

3. Basic nursing education (entry into nursing profession)
   ☐ Associate degree  ☐ 3-year/diploma degree  ☐ Bachelor of nursing degree

4. Year of graduation from basic nursing program (above) ___________

5. Highest nursing degree attained
   ☐ Associate degree  ☐ 3-year/diploma degree  ☐ Bachelor of nursing degree
   ☐ Master of nursing degree  ☐ Bachelor of nursing degree  ☐ DNP/PhD

6. Number of years employed as a nurse ______

7. Number of years working in maternal (prenatal, labor & delivery, postpartum, neonatal intensive care) nursing _____

8. Current area where you work primarily:
   ☐ Prenatal clinic  ☐ Triage  ☐ Labor & Delivery  ☐ Mother & Baby/Postpartum  ☐ NICU

9. Are you familiar with antiphospholipid antibody syndrome/Hughes Syndrome?
   ☐ Yes  ☐ No  ☐ Unsure

10. Have you personally cared for a pregnant woman with antiphospholipid antibody syndrome?
    ☐ Yes  ☐ No  ☐ Unsure

11. Do you or anyone you personally know have antiphospholipid antibody syndrome?
    ☐ Yes  ☐ No  ☐ Unsure

12. Where did you first learn about antiphospholipid antibody syndrome?
    ☐ nursing school  ☐ medical/nursing conference/workshop  ☐ in-hospital education
    ☐ personal reading or research  ☐ professional colleague  ☐ other
    ☐ I am unfamiliar with antiphospholipid antibody syndrome

Please check ONE answer for each of the following questions:

13. Which one of the following manifestations would meet diagnostic criteria for antiphospholipid syndrome?
    ☐ a. Thrombocytopenia
    ☐ b. Anti-prothrombin antibody
    ☐ c. Livedo reticularis
16. Which of the following complications is associated with antiphospholipid syndrome in pregnant women?
   ☐ a. Fetal growth restriction
   ☐ b. Post-term/overdue pregnancy
   ☐ c. Prolonged labor
   ☐ d. Neonatal heart block
   ☐ e. I am unfamiliar with pregnancy complications associated with antiphospholipid antibody syndrome

17. Which one of the following medical treatments would you expect in a pregnant woman with antiphospholipid antibody syndrome?
   ☐ a. Low dose aspirin
   ☐ b. Coumadin (Warfarin)
   ☐ c. Dabigatrin (Pradaxa)
   ☐ d. Immunosuppressive therapy
   ☐ e. I am unfamiliar with treatment for antiphospholipid antibody syndrome

18. Which one of the following symptoms/manifestations by a patient with antiphospholipid syndrome should most concern the nurse?
   ☐ a. Severe headache of sudden onset
   ☐ b. Platelet count of 140,000/mm³
   ☐ c. Fever of 100°F
   ☐ d. Fatigue
   ☐ e. I am unfamiliar with symptoms/manifestations associated with antiphospholipid syndrome
19. A 26-year-old woman with antiphospholipid syndrome delivered her first child one day ago and you are preparing to discharge her. She asks you about birth control methods. Which one of the following would you NOT recommend?
① a. Diaphragm with spermicidal cream
② b. Low-dose estrogen birth control pills
③ c. Condoms
④ d. Intrauterine device
⑤ e. I am unfamiliar with recommended birth control methods for patients with antiphospholipid antibody syndrome

20. A 26-year-old woman with lupus and antiphospholipid syndrome delivered her first child one day ago and you are preparing to discharge her. Which one of the following discharge medications would you most likely anticipate her to be on for the next 6-8 weeks?
⑥ a. Prednisone
⑦ b. Methotrexate
⑧ c. Low molecular weight heparin (LMWH)
⑨ d. Low-dose estrogen birth control pills
⑩ e. I am unfamiliar with postpartum medications for patients with lupus and antiphospholipid antibody syndrome

Thank you for completing this questionnaire.
REFERENCES


