2013

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

Gabrielle Dennen
University of Central Florida

Showcase of Text, Archives, Research & Scholarship

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

by

GABRIELLE K. DENNEN

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

Spring Term 2013

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

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

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-β_2-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

2

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

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

*N = 92

Table 2: Current areas of work among participants

Unit	Number
Antepartum	10
Postpartum	42
Prenatal Clinic	10
Triage	6
NICU	20
Labor & Delivery	5

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

	Yes	No	Unsure
Reported Familiarity	23.7%	55.9%	19.4%
Cared for a Patient with APS	12.9%	66.7%	20.4%
Personally Knew Someone with APS	2.2%	93.5%	4.3%

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

Source	Percentage
Nursing School	9.7%
Medical/Nursing conference/workshop	1.1%
In-hospital education	7.5%
Personal reading or research	2.2%
Professional colleague	1.1%
Other	11.8%

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

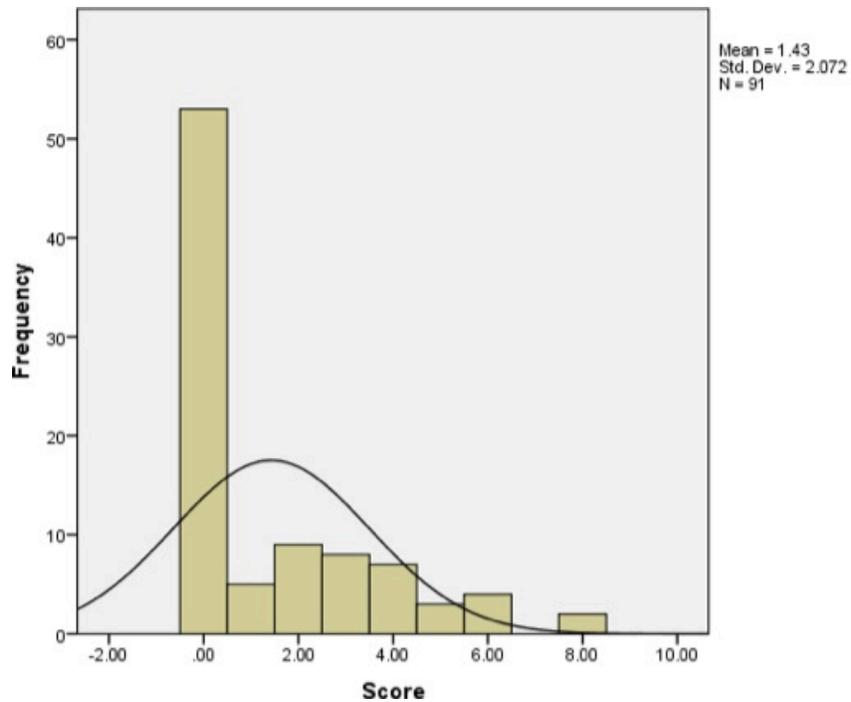(9.7%) answered two questions correctly.

Figure 1: Scores on knowledge items

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

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

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 (x^2=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.

10

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

11

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.

APPENDIX: SURVEY

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

15

◎ d. Pulmonary embolism
◎ d. I am unfamiliar with diagnostic criteria for antiphospholipid syndrome

14. Which of the following is considered an antiphospholipid antibody?
   ◎ a. Lupus anticoagulant
   ◎ b. Anti-platelet factor
   ◎ c. Anti-phospholipidase
   ◎ d. Anti-double stranded DNA
   ◎ e. I am unfamiliar with antiphospholipid antibodies

15. Which of the following historical or physical findings in a patient would alert you to the possibility of antiphospholipid antibody syndrome?
   ◎ a. Hyperemesis gravidarum
   ◎ b. Unexplained second or third trimester fetal death
   ◎ c Hydatidiform mole
   ◎ d. Incompetent cervical os
   ◎ e. I am unfamiliar with the historical or physical findings of antiphospholipid antibody syndrome

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/mm^3
   ◎ 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?
  ⊚ a. Diaphragm with spermicidal cream
  ⊚ b. Low-dose estrogen birth control pills
  ⊚ c. Condoms
  ⊚ d. Intrauterine device
  ⊚ 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?
  ⊚ a. Prednisone
  ⊚ b. Methotrexate
  ⊚ c. Low molecular weight heparin (LMWH)
  ⊚ d. Low-dose estrogen birth control pills
  ⊚ e. I am unfamiliar with postpartum medications for patients with lupus and antiphospholipid antibody syndrome

Thank you for completing this questionnaire.

REFERENCES

Atterbury, J.L., Munn, M.B., Groome, L.J., & Yarnell, J.A. (1996). The antiphospholipid
antibody syndrome: an overview. *Journal of Gynecologic, and Neonatal Nursing, 26*(5),
522-530.

Bertolaccini, M.L., Ateka-Barrutia, O., & Khamashta, M.A. (2010). *Antiphospholipid syndrome
handbook*. [Adobe Digital Editions version]. doi: 10.1007/978-1-84628-735-0

Biggioggero, M., & Meroni, P.L. (2010). The geoepidemiology of the antiphospholipid
syndrome. *Autoimmunity Reviews, 9(*5), A299-304.

Bulikova, A. (2012). Antiphospholipid Syndrome: Changing Knowledge During the Time- The
"Four P" Pattern. In A. Bulikova (Ed.), *Antiphospholipid Syndrome* (pp.3-10). Rijeka,
Croatia: InTech.

Buyon, J.P. (2009). Updates on lupus and pregnancy. *Bulletin of the NYU Hospital for Joint
Diseases,67*(3), 271-275.

Erkan, D. & Pierangeli, S.S. (Eds.) (2012). *Antiphospholipid syndrome: Insights and highlights
of the 13th International Congress on Antiphospholipid Antibodies.* New York: Springer
Publishing.

Holden, T. (2003). *Positive options for antiphospholipid syndrome (APS).* Berkley, CA: Hunter
House Publishers.

Iwasawa, Y., Kawana, K., Fujii, T., Schust, D., Nagamatsu, T., Kawana, Y., . . .Taketani, Y.
(2011). A possible coagulation-independent mechanism for pregnancy loss involving
β2glycoprotein 1-dependent antiphospholipid antibodies and cd1d. *American Journal of
Reproductive Immunology, 67,* 54-65. doi: 10.1111/j. 1600-0897.2011.01028.x

Marieb, E.N., & Hoehn, K. (2010). *Human anatomy & physiology*. San Francisco, CA: Pearson

    Benjamin Cummings.

Mathew, S., Cesario S., & Symes, L. (2008). Explaining "unexplained" perinatal loss:

    experiences of women with antiphospholipid syndrome. *Journal of Perinatal & Neonatal*

    Nursing, 22(4), 293-301.

Oretel, T.L. (2012). Antiphospholipid syndrome: laboratory testing and diagnostic strategies.

    Amer J Hematol, 87S, S75-81.

Orlando Health, (2013). About us. Retrieved from

    http://www.orlandohealth.com/winniepalmerhospital/AboutUs/AboutUs.aspx?pid=2576

Pullen, R.L., Jr., Vincent, R.D., Siess, J.M. (2011). The puzzle of antiphospholipid syndrome.

    Nursing Made Incredibly Easy. doi: 10.1097/01.NME.0000386794.73141.73

Simchen, M.J., Dulitzki, M., Rofe, G., Shani, H., Langevitz, P., Schiff, E., & Pauzner, R. (2011).

    High positive antibody titers and adverse pregnancy outcome in women with

    antiphospholipid syndrome. *Nordic Federation of Societies of Obstetrics and*

    *Gynecology,90,*1428-1433. doi: 10.1111/j.1600-0412.2011.01236.x

Vinatier, D., Dufour, P., Cosson, M., Houpeau, J.L. (2001). Antiphospholipid syndrome and

    recurrent miscarriages. *European Journal of Obstetrics and Gynecology, 96*(1), 37-50.

    doi: 10.1016/S0301-2115(00)00404-8