E2.3: Explaining 'Unexplained' Loss: Women's Experiences of one or more Perinatal Losses Associated with Antiphospholipid Syndrome

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Abstract:

Introduction: Purpose: To explore women’s experiences of one or more perinatal losses associated with antiphospholipid syndrome (APS), and to describe their thoughts, perceptions, and feelings about losses related to this disorder and its effects on their outlook on subsequent childbearing. 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 APS? Rationale: APS related perinatal loss is rarely studied in nursing and represents a wide gap in perinatal nursing considering the morbidity and mortality this phenomenon causes on both mother and baby during and beyond pregnancy. To provide optimum quality care to women diagnosed with APS, nurses need to understand what it is like for women to live with this disorder and related losses. Such learning can take place by listening to the first-hand experiences of women who lived them.

Method(s): The respondents were recruited using convenience and snowball sampling and 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. Qualitative rigor was established using Lincoln & Guba’s criteria. Data were analyzed using Colaizzi’s phenomenological criteria. Limitations: Participants who were not members of online support groups were not included in the study and their experiences could not be explored.
Results: Two major themes emerged from the data. They 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.

Discussion & Conclusions: Evidence-based medical and nursing education about antiphospholipid antibody syndrome is necessary to improve clinical practice and thereby the perinatal outcome and to decrease the ill effects of this condition for women during and after the childbearing period.

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