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Polycystic Ovary Syndrome

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Polycystic Ovary Syndrome

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This thesis for honors recognition has been approved for the Department of Nursing.

Director

Date

Reader

Date

Reader

Date
Abstract

Polycystic ovary syndrome (PCOS) is an endocrine disorder that affects between 3.5 and 5 million women of reproductive age in the United States (Barron, 2004). It is characterized by hyperandrogenism and menstrual irregularities, and it causes several troublesome symptoms including, but not limited to, weight gain, excessive hair growth, infertility, and polycystic ovaries. The purpose of this thesis is to explore the lived experience of PCOS by interviewing three participants. The interviews were analyzed using Giorgi’s Method, and they revealed several common themes including Anticipatory Grieving, Fear of Infertility, Feeling Misunderstood, and Uncertainty about the future relating to PCOS. Participants experienced the Challenges of Physical Symptoms, such as pain, weight gain, and irregular menstrual cycles. The results of this research can help nurses increase their understanding and empathy towards women with PCOS, and further research needs to be done to explore how nurses can best prepare their clients for the challenges of living PCOS.
Acknowledgments

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To Mom and Dad
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Chapter 1

Polycystic Ovary Syndrome

Polycystic ovary syndrome (PCOS) affects between 3.5 and 5 million women in the United States (Barron, 2004), and this troublesome condition is known to have major negative effects on the “reproductive, metabolic, and cardiovascular health of affected women” (Ehrmann, 2005, p. 1223). Early diagnosis and treatment of this condition can improve health outcomes of women and adolescents with PCOS, and a greater public awareness of this disorder may aid in getting women effective treatment quicker (Ehrmann).

Polycystic ovary syndrome is defined as the presence of hyperandrogenism, chronic annovulation, and the “absence of a specific adrenal and/or pituitary disease” (Sheehan, 2004, p. 14). Hyperandrogenism usually presents as “hirsutism, acne, frontal and temporal balding, deepening voice, increased muscle mass, [and] decreased breast size” (Snyder, 2005, p. 416). Annovulation is generally clinically manifested as irregular or absent menstrual cycles (Sheehan). The ovaries of women with PCOS usually appear polycystic on an ultrasound, and they “are larger than average and have numerous surface follicles that never mature, develop or ovulate” (William, 2005, ¶ 1). PCOS is difficult to diagnose because symptoms can vary, even for the same woman depending on her age, but there are many clinical indicators of the syndrome (William). Sheehan remarked that hyperandrogenism and chronic annovulation are the “hallmarks of the disease,” but other indicators include oligomenorrhea or amenorrhea, infertility or first trimester miscarriage, and acanthosis nigricans (p. 14). Acanthosis nigricans is a “skin disease characterized by dark wartlike patches in the body folds” (dictionary.com, 2007, ¶ 1).
Risk Factors

Many risk factors for developing PCOS are closely related to obesity and the endocrine system. According to Ehrmann (2005), obesity seems to be a risk factor for developing PCOS because “obesity is present in at least 30 percent of cases” (p. 1227). However, obesity alone cannot predict the development of the syndrome, and other conditions such as insulin resistance, glucose intolerance, and dyslipidemia can also predispose a woman to develop PCOS (Ehrmann). According to Sheehan (2004), women with epilepsy may be at an increased risk for PCOS because it has been noted that there are a higher number of reproductive endocrine disorders among women with epilepsy. Sheehan also suggested that premature pubarche, which is pubic hair growth before the age of eight, could potentially be an “early expression” of PCOS (p. 19). It is not known whether premature pubarche is a risk factor for developing PCOS or if it is the clinical manifestation of an already present syndrome. Jahanfar, Maleki, Mosavi, and Jahanfar (2004) conducted a twin study and found a high incidence of PCOS among twins, and William (2005) also suggested genetics as a risk factor of PCOS. Dagre (2006) referenced research in Greece by stating that “prenatal exposure to androgen excess may result in the development of polycystic ovary syndrome during adult life” (p. 8). Coffey and Mason (2003) reported one study that found Asian women to have a higher incidence of PCOS than the general population.

In addition to the risk factors associated with the development PCOS, there are several conditions that PCOS predisposes a woman to acquire. Women with PCOS are more likely to develop infertility, type 2 diabetes, macrovascular disease, sleep apnea, hypertension, thrombosis, endometrial hyperplasia and carcinoma, and other
cardiovascular abnormalities (Ehrmann, 2005). In addition to the above physiological conditions, women with PCOS are at an increased risk for low self-esteem and depression related to infertility issues and the physical manifestations of the syndrome such as male-pattern hair growth and loss (Barron, 2004). Many women with PCOS have “reported feeling freakish, abnormal, and not feminine,” and a key nursing role is to help women address these negative feelings and cope with the permanent condition of PCOS (Barron, p. 86).

*Nursing Diagnosis*

Coffey and Mason (2003) found there to be “higher levels of depression, psychological, and psychosexual morbidity in women with PCOS” as well as “low self-esteem, decreased social activity and less romantic contentment” (p. 379). The combined symptoms of PCOS, especially weight and hirsutism (Coffey and Mason, 2003), can have a negative impact on a woman’s self-esteem, and a key nursing role in working with PCOS clients is identifying possible coping deficits and characteristics of low self-esteem. As stated previously, many women with the disorder feel inadequate, abnormal, and less than feminine (Barron, 2004), and women are often very concerned with how much the syndrome will impact their life. The nurse can initiate interventions to address these concerns. One possible nursing diagnosis to focus on is disturbed self-esteem related to infertility secondary to annovulation and appearance secondary to hirsutism and obesity (Carpentio-Moyet, 2006). The goal of this diagnosis would be that the woman with PCOS would “identify positive aspects of self and report freedom from symptoms of depression,” and this would be indicated by the woman verbalizing
acceptance of her condition and modifying unrealistic expectations (Carpentio-Moyet, p. 670).

The purpose of this research is to explore the psychosocial ramifications PCOS has on women and to address the nursing role in helping women with PCOS cope with their disorder. This disorder could potentially affect as high as 26% of women of reproductive age, and PCOS is the “most common endocrine disorder affecting women” (Coffey & Mason, 2003, p. 380). Nurses need to be aware of the clinical signs of PCOS so they can assist physicians with the early diagnosis of the disorder and the education of women.
Chapter II
Pathology and Etiology of PCOS

Researchers are working to untangle the causes of PCOS from its pathology, but it is difficult to distinguish what comes first in the progression of the disorder and what exactly triggers the syndrome. The overall current understanding of PCOS is that it is caused by an endocrine system imbalance, it involves abnormal amounts of several hormones, and it presents clinically with a variety of symptoms.

Pathology

As stated previously, polycystic ovary syndrome is defined as the presence of hyperandrogenism and chronic anovulation without the presence of a specific endocrine disease (Sheehan, 2004). Hyperandrogenism presents as hirsutism, which is physically apparent as acne and male-pattern hair growth or loss (Sheehan). Anovulation is usually clinically manifested as irregular or absent menstrual cycles (Sheehan). The ovaries of women with PCOS consistently show up polycystic and larger than average on an ultrasound, and the numerous cysts on the surface of the ovaries are immature eggs that fail to develop (William, 2005).

The current theory concerning the pathology of PCOS suggests the involvement of abnormal ovarian theca cells (Erhrmann, 2005). Ovarian theca cells synthesize androgens, and studies “consistently suggest that the ovarian theca cells in affected women are more efficient at converting androgenic precursors to testosterone than are normal theca cells” (Erhrmann, p. 1224). Luteinizing hormone (LH), a gonadotropin, stimulates the ovarian theca cells to synthesize androgen, and follicle-stimulating hormone (FSH), another gonadotropin, stimulates granulose cells to synthesize estrogen.
The ovaries are inclined to synthesize androgen when there is more LH than FSH, and women with PCOS have increased levels of LH and subsequently increased levels of androgens (Erhrmann). The increased level of androgens is the cause of hirsutism, acne, male pattern baldness, and central obesity; the central obesity increases insulin resistance further and makes PCOS symptoms worse (Snyder, 2005).

Gonadotropin-releasing hormone (GnRH) is released by the hypothalamus, and it stimulates the pituitary gland to release LH and FSH (Erhrmann, 2005). The pulse frequency is the intermittent rate at which hormones are released from the hypothalamus, and the pulse frequency of GnRH release impacts the ratio of LH production to FSH production; an increased frequency “favors transcription” of LH over FSH (Erhrmann, p. 1225). Women with PCOS most likely have an increased pulse frequency of GnRH because they have increased levels of LH compared to women without PCOS (Erhrmann, 2005). The abnormally fast pulse rate of GnRH may be caused by “an intrinsic abnormality in the GnRH pulse generator,” or it may be caused by low progesterone levels due to “infrequent ovulatory events” (Erhrmann, p. 1225). Progestin is any hormone involved in preparing or maintaining the uterus for pregnancy, like progesterone (dictionary.com, 2007). Progestin slows the GnRH pulse frequency, so low levels may speed up GnRH release which in turn increases LH production (Erhrmann).

Insulin is also involved in the pathogenesis of hyperandrogenemia and PCOS, and most women with PCOS have hyperinsulinemia (Erhrmann, 2005). Insulin cooperates and interacts with LH to increase androgen production from the theca cells, and since androgen is the precursor to testosterone, this also leads to an increase in testosterone (Erhrmann). In addition, insulin inhibits production of a testosterone binding protein.
which further increases testosterone level (Erhrmann). The liver synthesizes sex hormone-binding globulin, and this protein binds to testosterone; unbound testosterone levels increase when insulin inhibits this production (Erhrmann).

**Etiology**

According to Ehrmann (2005), “no single etiologic factor fully accounts for the spectrum of abnormalities” in PCOS (p. 1224). Barron (2004) suggested that obesity and insulin resistance could be the causes, but other researchers have pointed to alternative causes for PCOS, such as genetic influences and irregular menstruation.

The symptoms of PCOS are caused by a variety of factors. Hirsutism is caused by abnormally high levels of testosterone, and menstrual disturbances are caused by decreased amounts of estrogen (Ehrmann, 2005). The polycystic ovaries are caused by the repeated failure of the eggs to ovulate, which become cysts.

Diagnostic tests help confirm the presence of PCOS by ruling out other etiologies of the symptoms. Tests rule out hypothyroidism, hyperprolactinemia, pregnancy, congenital adrenal hyperplasia, and adrenal and ovarian tumors; these conditions may mimic some of the symptoms seen in PCOS (Snyder, 2005). Health care providers also test for insulin resistance and measure different hormone levels, like testosterone.

*Leptin’s association with PCOS.* Many studies support the theory that PCOS has a genetic component, but it is still unclear what specific area of genetics influences the development of PCOS. A quantitative correlational study of 48 pairs of twins revealed no apparent link between leptin levels and PCOS, but the data did find that there is an increased incidence of PCOS among twins (Jahanfar, Maleki, Mosavi, & Jahanfar, 2004). The purpose of this study was to determine the incidence of PCOS, to find the how much
leptin level is related to genetics, and to evaluate the correlation leptin concentration and PCOS.

The study included a description of what leptin is and how it functions within the body, and it explained how leptin’s role as a metabolic hormone that influences “insulin secretion and glucose utilization” may be connected to PCOS (Jahanfar, Maleki, Mosavi, & Jahanfar, 2004, p. 327). “Leptin is a product of the obesity (ob) gene” and “PCOS endocrinopathy is also associated with obesity” (Jahanfar, Maleki, Mosavi, & Jahanfar, p. 328). The researchers pointed out that other research has been done on the correlation between serum leptin level and PCOS, and most of the studies suggested there is no significant relationship between the two.

One major limitation with this research is that the subjects selected themselves because they were recruited through the mass media. All of the twins in the study location did not have an equal chance of being selected, and those with no access to the media were automatically excluded from the study.

The study utilized a variety of instruments to gather data. Subjects had a fasting blood glucose test and blood test after drinking a glucose solution to measure serum glucose levels. The study measured serum hormone levels by using “well-established radioimmunoassay (RIA)”, and “leptin was measured by a direct RIA kit (DRG Instruments GmbH, Germany)”; “all assays intra-assay and interassay coefficients of variation did not exceed 7% and 15%” (Jahanfar, Maleki, Mosavi, & Jahanfar, 2004, p. 329). Hirsutism in the women was measured “using the Ferriman and Gallwey scoring system,” and the study did not describe this instrument beyond its name (Jahanfar, Maleki, Mosavi & Jahanfar, p. 329). The researchers included the vague statement that
“the scoring system of Marynick and co-workers was adopted for acne severity,” but the readers are left to wonder exactly what this scoring system involves (Jahanfar, Maleki, Mosavi & Jahanfar, p. 329). The instruments used were all vaguely described.

Although this study has a few flaws, it provided some information on the genetic component of PCOS. The incidence of PCOS was much higher for monozygotic twins than dyzygotic twins, and both types of twins had a higher incidence than non-twins. While the study results did suggest a genetic link in the development of PCOS, it pointed out that environmental factors may account for some of the differences (Jahanfar, Maleki, Mosavi & Jahanfar, 2004). This study provided interesting information, but nothing in this study would be particularly helpful in the clinical setting; the best this study can do is give nurses one more piece of information to impart to PCOS patients: that PCOS may be caused by genetics.

*Clinical Manifestations*

Women with PCOS present with a wide range of symptoms such as oligomenorrhea, amenorrhea, infertility, first trimester miscarriage, obesity, hirsutism, deepening voice, acne, male pattern hair growth or loss, and acanthosis nigricans (Sheehan, 2004). Acanthosis nigricans and obesity, especially central obesity, are clinical markers for insulin resistance (Snyder, 2005). Women with PCOS will most likely not have all of the listed symptoms, and any given woman may experience different symptoms as she ages (William, 2005).
Connections between PCOS and Other Problems

PCOS and insufficient milk supply in lactating mothers. Insufficient milk production is a problem that frequently baffles both new mothers and their physicians, but three case studies revealed that there may be a connection between lactation difficulties and PCOS. The cases showed common threads among the women, all of whom had been diagnosed with PCOS and had serious difficulties producing sufficient milk to meet their babies’ needs. Nurses can play a role in helping to make connections among the different elements of a woman’s health history; an inability to produce milk would most likely be frustrating for a woman and knowing why she cannot lactate normally may help to determine what treatments to use. This research points to PCOS as a significant contributor in lactation difficulties and nurses need to be aware of this possible connection (Marasco, Marmet, & Shell, 2000).

This qualitative research provided interesting insight regarding another possible symptom of PCOS (insufficient milk supply), but it did not discuss the methods used in interviewing the women and how they were selected.

Diagnosis of PCOS

Before a woman can be treated for PCOS, she must first be diagnosed with the disorder, and there are several tests done to reach a diagnosis. However, there is no universal standard for diagnosing this syndrome, but a diagnosis is usually based on the presence of the cardinal PCOS symptoms, polycystic ovaries, and abnormal lab tests. It has been suggested that if menstrual disturbance, hirsutism, acne, or anovulatory infertility is present, an ultrasound should be done to assess for the presence of polycystic ovaries. If the ovaries are polycystic, then a diagnosis can be made without laboratory
tests, but if the ovaries are not polycystic, laboratory tests are done. Abnormal lab results are then sufficient for making a diagnosis of PCOS (Sheehan, 2004). The above formula is only a proposal, however, and there is currently no universal standard for diagnosing PCOS. However, according to Ehrmann (2005), an international consensus group suggested that PCOS “can be diagnosed after the exclusion of other medical conditions that cause irregular menstrual cycles and androgen excess” (p. 1223), and two of the following symptoms must be present: infrequent or absent ovulation, hyperandrogenemia or hyperandrogenism, and polycystic ovaries.

Diagnosis involves taking a complete health history, observing signs of hirsutism caused by hyperandrogenemia, observing for signs of insulin resistance (central obesity, acanthosis nigricans, and hypertension), testing hormone levels, and using an ultrasound to observe polycystic ovaries. There is not a specific test used to diagnose PCOS, but there are several red flags in the medical history of a woman with undiagnosed PCOS that should prompt health care providers to examine findings more closely (Sheehan, 2004). There are eight screening tests that should be done on all women suspected of having PCOS; these tests are not entirely conclusive, but they do provide supporting information for a PCOS diagnosis (Sheehan). The tests include the following: pregnancy test, TSH, prolactin, 17-hydroxyprogesterone, total testosterone, DHEA-S, a 24-hour urine free cortisol, and fasting glucose test. The fasting glucose test is done to test for insulin resistance, and it involves a 75 g oral glucose tolerance test.

It would be helpful to health care providers to have a standard guideline for the diagnosis of PCOS, but there are several diagnosis models available to aid in diagnosing PCOS. Most of the models involve eliminating other diseases and conditions that cause
similar symptoms, evaluating the health history, and assessing the presence of polycystic ovaries. Some institutions use laboratory tests as well to diagnose PCOS, but this may not be readily available to all facilities, and lab tests are not necessarily required to make the diagnosis of PCOS.

**Polycystic Ovaries and Syndrome X and Implications for Diagnosis**

Previous research has found a link between PCOS and vascular disease, but further research did not find a significant difference in the occurrence rate of Metabolic Syndrome (MetS) in women with polycystic ovaries (PCO) compared to women without PCO (Atiomo, Shaw, Mikhailidis, Wilkin, & Hardiman, 2004). MetS and PCOS have both been linked to vascular disease, so Atiomo, Shaw, Mikhailidis, Wilkin, and Hardiman hypothesized that MetS and PCOS might have a connection. However, the researchers cross-sectional pilot study on 66 women determined that “ultrasound features of polycystic ovaries” were not associated with MetS (Atiomo, Shaw, Mikhailidis, Wilkin, & Hardiman, p. 263).

The results of this study suggested that less emphasis should be placed on the presence of polycystic ovaries in the diagnosis of PCOS because polycystic ovaries alone are of no metabolic significance and may actually be a harmless normal variant (Atiomo, Shaw, Mikhailidis, Wilkin, & Hardiman, 2004). The researchers indicated that resources should be channeled to improve measurements of “endocrine and metabolic components of PCOS” because ultrasounds alone may not be accurate PCOS diagnosis tools (Atiomo, Shaw, Mikhailidis, Wilkin, & Hardiman, p. 266). Nurses should be aware of the limitations of ultrasounds in diagnosing PCOS so they can provide accurate education to women with PCOS. This study implied the possibility that PCO may be normal and
harmless in some cases, and this research could be used to help ease anxiety over newly discovered polycystic ovaries.

Once a diagnosis is made, the most common course of treatment involves lifestyle modifications, such as weight loss, and metformin therapy. Although metformin is frequently used alone, studies have shown that it may be more effective when used in combination with other drugs such as clophiphene. Despite metformin being the most common drug used, some women may not be responsive to it, and they will need to explore other medication options.

PCOS Treatment

PCOS can have a wide reaching impact on a woman's overall physical and emotional health, and treatment of the syndrome includes many different elements. There are four main issues that come up in the treatment of PCOS: regulation of menses, infertility, control of hirsutism, and management of insulin resistance and its "associated risks of type 2 diabetes mellitus, dyslipidemia, and cardiovascular disease" (Sheehan, 2004, p. 14). Traditional treatment of PCOS includes a combination of medication therapy and lifestyle changes.

Treatment for Regulating Menses

Regulating menses is important because as Sheehan (2004) reported "irregular menses can be embarrassing because of unpredictability and painful because the infrequent occurrence often leads to increased cramping with a heavier flow" (p. 17). Four possible treatment options for regulating menses include the use of oral contraceptives, periodic progesterone withdrawal, lifestyle modifications, such as weight loss, and metformin therapy (Sheehan). How the therapy will affect insulin resistance
should be considered when a treatment is being selected, because certain therapies, such as oral contraceptives, may do more harm than good if a woman is especially sensitive to insulin changes (Sheehan).

_Treatment for Infertility_

Fertility complications associated with PCOS may be especially problematic for women who wish to become pregnant, and unfortunately “75% of anovulatory infertility” is caused by PCOS (Sheehan, 2004, p. 19). Equally distressing is the statistic that as high as 30 to 50 percent of the pregnancies that do occur in women with PCOS result in a first trimester miscarriage (Sheehan). The treatment options for this aspect of PCOS include lifestyle modifications, weight loss, and the use of several different drugs (Sheehan, 2004). Weight loss has been shown to reduce hyperinsulinemia which leads to a reduction of hyperandrogenism and thus improved chances of ovulation (Sheehan). Weight loss should be attempted before the use of medications that act as insulin sensitizers, such as metformin (Sheehan). However, weight loss maintenance for some women may not be realistic, and other options may need to be considered (Sheehan).

_Treatment for Hirsutism_

Both mechanical and biochemical remedies may be used to control hirsutism (Sheehan, 2004). Plucking, shaving, electrolysis, and laser therapy are possible mechanical treatment options to help control the undesirable hair growth (Sheehan). However, plucking could cause “folliculitis and scarring,” electrolysis may not be permanent, and laser treatment could cause erythema, edema, blistering, or alterations in pigmentation (Sheehan, p. 19). Electrolysis of just the upper lip can cost between $450 and $1035, and laser therapy on the upper lip is $400 to $800 (Electrolysis Hair Removal,
2007); such treatments are not covered by insurance and may not be possible for women with limited financial resources. Biochemical treatments revolve around decreasing testosterone production or action, but it may take months for a drug to take noticeable effect (Sheehan). In addition to the uncertain effectiveness of drug treatment, there is limited understanding on the safety of certain drugs (Sheehan).

Treatment of Insulin Resistance

According to Sheehan (2004), “most PCOS patients are inherently IR [insulin resistant] with obesity seen in many,” so a treatment priority is controlling this endocrine imbalance with the hope of preventing or delaying the development of type 2 diabetes mellitus (p. 21). The use of insulin sensitizers, like metformin, have been shown to reduce the development of type 2 diabetes mellitus, but studies have found lifestyle modifications to have a greater success rate (Sheehan).

Medications Used to Treat PCOS

Metformin hydrochloride. Metformin hydrochloride is the most common drug used to treat PCOS, and it can be used by women who have amenorrhea, anovulation and insulin resistance. It is an antihyperglycemic indicated as treatment for type 2 diabetes mellitus. This drug is available as an oral solution or tablet, and it acts to lower glucose levels by improving tissue sensitivity to insulin and decreasing both hepatic glucose production and intestinal absorption (Thomson Micromedix (TM), Metformin hydrochloride, 2007). When this drug is used for women with PCOS, it “corrects hyperinsulinemia and reduces LH, sex hormone-binding globulin, and ovarian androgens” (Barron, 2004, p. 86). Common side effects of metformin include weight loss, cobalamin deficiency, diarrhea, flatulence, indigestion, nausea, vomiting, and
asthenia. Lactic acidosis is a rare but very serious side effect caused by metformin hydrochloride accumulation, and the risk is increased with alcohol consumption, hepatic disease, hypoxemia, dehydration, sepsis, or surgery (TM, Metformin hydrochloride).

Ehrmann (2005) reported that a recent meta-analysis of 13 studies on metformin found that patients taking metformin had higher rates of ovulation compared with those taking a placebo. Studies have also found that metformin improves fasting insulin levels, blood pressure, and levels of LDL cholesterol; metformin also apparently decreases the chance of a miscarriage for those who become pregnant while on the drug (Ehrmann). Another study reported by Sheehan (2004) found that metformin induced “resumption of normal, ovulatory menstrual cycles in 40% to 90% of patients studied” (p. 17).

Medroxyprogesterone acetate. Medroxyprogesterone acetate is a progestin endocrine-metabolic agent derived from progesterone “that has androgenic and anabolic effects” (TM, Medroxyprogesterone acetate, 2007, ¶ 10). It is used to treat abnormal uterine bleeding, hormone imbalance, endometrial hyperplasia, and secondary physiologic amenorrhea. It is available as an intramuscular suspension, oral tablet, or subcutaneous suspension, but it is usually taken orally when it is used to treat PCOS. This drug should not be used in pregnancy, and common side effects include weight change, abdominal pain, asthenia, dizziness, headache, nervousness, amenorrhea, break-through bleeding, and menstruation disorder. Serious side effects include DVT, thrombophlebitis, jaundice, anaphylaxis, osteoporosis, and pulmonary embolism (TM, Medroxyprogesterone acetate). Research on medroxyprogesterone acetate as it is used to treat PCOS is limited, especially since this drug is usually used as a contraceptive.
**Pioglitazone hydrochloride.** Pioglitazone hydrochloride is an antidiabetic and thiazolidinedione used to treat type 2 diabetes mellitus. It is available as an oral tablet, and it acts to lower glucose levels by increasing insulin-dependent glucose disposal and decreasing insulin resistance. Common adverse side effects include edema, weight gain, anemia, myalgia, and headache. Serious rare side effects include hepatotoxicity, bone fractures, and macular retinal edema; this drug is not recommended for use by pregnant women or women who wish to become pregnant (TM, Pioglitazone hydrochloride, 2007).

Pioglitazone has been shown to be a successful alternative therapy for women with PCOS who did not respond to the traditional metformin therapy. A research study compared 13 women with PCOS who were not responsive to metformin to 26 women with PCOS who were responsive to metformin in order to explore the effectiveness and safety of using pioglitazone in combination with metformin. The results found that when pioglitazone was combined with metformin, “insulin, glucose, IR, insulin secretion, and DHEAS fell, HDL cholesterol and sex hormone-binding globulin rose, and menstrual regularity improved, without adverse side-effects” (Glueck, Moreira, Goldenberg, Sieve, & Wang, 2003, p. 1618). However, more research is needed on pioglitazone to find out if it truly is a safe and effective treatment of PCOS. Nurses need to be aware of the latest research regarding treatments so they can be effective educators.

**Clomiphene citrate.** Clomiphene citrate is a female reproductive agent that induces a rise in FSH and LH to improve ovulation (Ehrmann, 2005). It is available only in a 50 mg tablet, and it is recommended for women with PCOS who are trying to become pregnant (Ehrmann). Clomiphene citrate is a nonsteroidal ovulatory stimulant that interacts "with estrogen-receptor-containing tissues by competing with estrogen for
estrogen-receptor-binding sites and delaying the replenishment of estrogen receptors in cells” (TM, Clomiphene citrate, 2007, ¶ 9). Common adverse effects include flushing, abdominal discomfort, insomnia, blurred vision, nervousness, ovarian cysts, and ovarian hypertrophy. Thromboembolic disorder is a rare but serious side effect of clomiphene citrate (TM, Clomiphene citrate).

Clomiphene citrate was found to be less effective in obese women, and higher doses were needed to induce ovulation in obese women. Higher doses of this drug may increase the likelihood of multiple gestations. It has also been found that clomiphene in combination with metformin increased the likelihood of ovulation in obese women to a greater degree than metformin or clomiphene alone (Sheehan, 2004).

Spironolactone. Spironolactone is a cardiovascular agent and potassium sparing diuretic used to treat acne and hirsutism. It is taken orally in 50 to 200 mg doses, and therapy may last up to one year. Spironolactone “inhibits the effect of aldosterone by competing for the aldosterone-dependent sodium-potassium exchange site in the distal tubule cells” which increases sodium and water loss (TM, Spironolactone, 2007, ¶ 9). Common adverse side effects of this drug include a rash, urticaria, gynecomastia, hyperkalemia, diarrhea, nausea, vomiting, stomach cramps, headache, lethargy, somnolence, confusion, and menstruation disorders. Serious side effects include a skin ulcer, metabolic acidosis, gastric hemorrhage, gastritis, agranulocytosis, systemic lupus, and breast cancer (TM, Spironolactone).

Sheehan (2004) reported a study done by Crosby in 1991 that found that spironolactone reduced hirsutism scores by 40% and is effective for 50% of the women who used it alone. Sheehan (2004) also noted that spironolactone reduced hirsutism
scores even more when it was combined with an oral contraceptive, like medroxyprogesterone acetate.

*Lifestyle Changes in Treatment*

As mentioned previously, medications in combination with lifestyle changes tend to produce more favorable results than when medications are used alone. Diet and exercise are important elements in the overall treatment plan for a woman with PCOS.

*Nutrition.* A large percentage of women with PCOS are obese, and nurses can assist clients to decrease excess calorie intake and provide nutritional education (McCook, Reame, & Thatcher, 2005). According to the National Guideline Clearinghouse, women with PCOS should decrease their fat intake, increase fiber intake, avoid smoking, and be screened regularly for glucose intolerance and dyslipidemia (Crawford, Miller, Munoz, & Perkins, 2006).

*Exercise.* Stankiewics and Norman (2006) pointed out that “any intervention directed at reducing central obesity will not only improve quality of life but also correct hyperinsulinism and improve fertility and lipid and androgen profiles” (p. 903). Helping clients establish a regular exercise routine or referring them to an appropriate weight loss program has been shown to have a positive impact on the symptoms of PCOS by reducing obesity and thus decreasing the impact of glucose intolerance (McCook, Reame, & Thatcher, 2005). Nurses can be instrumental in helping clients to set reasonable exercise goals and establish reasons as to why exercise is important. Hoeger (2007) conducted research that found that modest reductions in weight of 5 to 10 percent were effective in decreasing the effects of PCOS and increasing the likelihood of normalizing ovulation, and that modest reduction in weight was as effective as severe weight
reduction. This is important information for a nurse helping a client plan an exercise regime because weight reduction can be a difficult task for many women, and it may be helpful to know that drastic weight losses are not necessary (Hoeger).

Nursing Role in Treatment

*Psychosocial support.* PCOS can be an upsetting condition to live with, and nurses can implement crucial intervention for their clients by providing support, comfort, and empathy for their patients. PCOS is a complex disorder with a wide range of symptoms requiring nurses to evaluate each individual patient and decide what interventions are best suited to that patient. The key nursing interventions for PCOS are focused around lifestyle modifications, patient teaching, and psychosocial interventions.

Lee (2003) conducted research on the effectiveness of a nursing crisis intervention program on the psychosocial responses and coping strategies of women struggling with infertility. Infertility is a common symptom of women with PCOS, and it was found that women who received relaxation training and cognitive-behavioral counseling had improved psychosocial responses.

*Patient teaching.* Snyder (2006) reported that many women with PCOS were frustrated by the lack of information regarding PCOS, and they did not feel as if they received sufficient education regarding their diagnosis. Nurses need to provide thorough education concerning the symptoms, treatment, and causes of PCOS, and this has been shown to decrease the anxiety of women with PCOS (Snyder).

Psychosocial Impact of PCOS

There is a wide range of research regarding PCOS and its symptoms, but there is limited research concerning the psychosocial impact PCOS has on women. Critiquing
research involves analyzing the study by looking at its method and results, and then discussing the relevance of the study in relation to PCOS. Valuable research provides practical implications for how to use the acquired knowledge in practice.

There is a growing volume of research on the pathology and treatment of PCOS and figuring out how genetics plays a role. However, there is still a limited amount of qualitative research that explores the psychosocial impact that PCOS has on women. There is research on the psychosocial impact of various symptoms often associated with PCOS, such as obesity and infertility, but there is a lack of research specifically concerning the whole scope of PCOS.

_Lived Experience of Women Diagnosed With PCOS_

_Leafed experience._ Patient teaching is the most important nursing role in working with women with PCOS according to a qualitative research study on the lived experience of 12 women diagnosed with polycystic ovary syndrome (PCOS) (Snyder, 2006). The design used was phenomenology, which is a “research method that explores and describes everyday experiences as is appears to human consciousness in order to generate and enhance the understanding of what it means to be human” (Russell, 1999, p. 220). Snyder addressed the question of how PCOS affects women’s lived experience, and semi-structured interviews were used to gather the data.

Snyder (2006) found that the results of analyzing the interviews revealed recurrent themes in the women’s lives. First, the women identified differences between themselves and other women. Second, the women acknowledged how the physical signs of PCOS made them feel less feminine. Third, the women wanted to know and understand why they had PCOS, and being diagnosed was a very frustrating process for
many of the women. Fourth, the women had a strong desire to be normal, and most of them felt somewhat abnormal. Fifth, the women wanted to feel more in control of their healthcare. Sixth, the women struggled with guilt, especially about being overweight, and the diagnosis of PCOS helped them to let go of guilt and realize that having PCOS was not their fault. And finally, the women had to learn to deal with PCOS in some way or another (Snyder).

An especially prominent theme in the interviews was that the women wanted more information regarding their disease. Having PCOS is stressful, and thorough education about the disorder pathology and treatments would help reduce the uncertainty and sense of lack of control that women experience. Thorough patient teaching is a major evidence-based nursing implication that this study supported. Women in this study expressed having feelings of “isolation, guilt, and devastation,” and nurses need to work to create a supportive therapeutic relationship with these clients (Snyder, 2006, p. 391). Nurses can direct women with PCOS to support groups because as this research found, these women deal with intense psychological issues (Snyder).

Health related quality of life in women with PCOS. Research has found there to be a significant correlation between the severity of PCOS and the health-related quality of life (McCook, Reame, & Thatcher, 2005). The researchers conducted a cross-sectional, correlational study of the health related quality of life of 128 women with PCOS, and they used the questionnaire PCOSQ to measure the quality of life of the women. The purpose was “to evaluate the influence of obesity, fertility status, and androgenism scores on health-related quality of life” (McCook, Reame, & Thatcher, p. 12). The PCOSQ was developed by clinicians in three phases. The first phase involved reviewing the literature,
interviewing 10 PCOS patients, and obtaining feedback from health professionals, and this phase came up with 182 items concerning emotional, physical, and social issues of women with PCOS. The second phase involved interviewing 100 women with PCOS and having them rank the importance of the previously identified items to reduce the number of relevant items, and the third phase was the final version of the questionnaire which contained 26 items. The reliability coefficient of the PCOSQ was $\alpha = 0.89$, and this signifies a reasonable degree of reliability. In addition to administering the questionnaire, participants were also evaluated using laboratory tests and clinical measures of the disorder; hirsutism was scored using specific criteria from 0 to 36, BMI was determined, and hormone levels were measured (McCook, Reame, & Thatcher).

According to the PCOSQ, the areas of concern ranked from greatest concern to least concern were the following: weight, menstrual problems, infertility, emotions, and body hair. The study found that the severity of hyperandrogenism and clinical features correlated with poorer emotional health and lower health-related quality of life (McCook, Reame, & Thatcher, 2005).

This research established the importance of assessing quality of life in patients with PCOS. It recommended the use of PCOSQ as a screening tool for nurses because it can help health care providers prioritize patient concerns; nurses need to be aware of the psychological impact of the disorder in addition to the physiological impact. This research also suggested that nurses can use this information to justify the use of support groups for women with PCOS, and nurses can be instrumental in connecting women with appropriate support groups (McCook, Reame, & Thatcher, 2005).
Coffey and Mason (2003) also conducted research on the impact of PCOS and “some of the manifestations of PCOS” on the health related quality of life (Coffey & Mason, p. 379). The results of this study supported the research of McCook, Reame, and Thatcher (2005) by reporting that women with PCOS have lower self-esteem, decreased social activity, and less romantic satisfaction (Coffey & Mason). Coffey and Mason found that weight and hirsutism were the most problematic aspects for women with PCOS over menstrual problems and infertility. This is a slightly different result than McCook, Reame, and Thatcher found, who ranked hirsutism as a lesser concern than menstrual problems and infertility; both studies found weight to be of the greatest concern, and overall they agreed that PCOS has a negative impact on the quality of life.

*Infertility and Psychosocial Responses*

Women suffering from infertility responded favorably to a nursing crisis intervention program that included watching a video on the therapeutic process of infertility treatment, self-relaxation training, and cognitive-behavioral counseling (Lee, 2003). Lee used an experimental research design with a control group and experimental group to measure the impact of the nursing crisis intervention program on helping women with infertility cope with their condition. The research used a questionnaire and found that the women in the experimental group showed less anxiety, fewer confrontational problems, and better mind and body relaxation following the crisis intervention program. This quantitative research clearly explained the study design, the methods, and the results. The questionnaire used was derived from several questionnaires. The Infertility Questionnaire to measure psychosocial responses regarding “self-image/self-esteem, guilt/blame, sexuality problems, and interpersonal relationships” (Lee, p. 200), and the
internal consistency Cronbach’s α ranged from 0.61 to 0.87. Depression was measured by using the Zung’s self-administered depression scale, and this scale has a Cronbach’s α of 0.6. Anxiety was measured using the State-Trait Anxiety Inventory, which has Cronbach’s α scores between 0.88 and 0.93. Finally, coping strategies were measured using the Jalowiec’s coping scale, which has Cronbach’s α scores between 0.64 and 0.92. All scales used were clearly explained and verified as credible measurement tools.

The major nursing implication of this research is that the nursing crisis intervention program used could be a helpful tool in assisting women to cope with infertility (Lee, 2003). Since many women with PCOS also struggle with infertility, this research carries over beneficial information for nurses working with these women. PCOS often includes a variety of troublesome symptoms, and understanding the impact of an isolated symptom, like infertility, on the woman’s psychosocial health is an important aspect of effectively treating the different PCOS symptoms.

This study focused on a specific action nurses can take in working with infertile women, and Allan (2005) added another piece to the treatment puzzle by presenting research that indicated women seeking fertility treatment prefer and benefit from having a female nurse. Allen used observation and semi structured interviews to explore why female nurses are preferred “during intimate sexual examinations” (p. 181). It was acknowledged that this research may not be readily accepted in a profession that is trying to move away from gender expectations and balance out the number of female nurses versus male nurse (Allen).
Perceptions and Impact of Being Overweight

According to McCook, Reame, and Thatcher (2005) “weight was the greatest concern reported” by women with PCOS (p. 16), and Ehrmann (2005) reported that obesity is present in as high as 75 percent of women with PCOS. The study done by Chang, Liou, Sheu, and Chen (2004) highlights the negative effect that obesity may have on a women’s self-image, and this is significant information for women with PCOS because obesity rate is so high in these women. The researchers were not surprised to find that women who consider themselves overweight have a significantly more negative body image than women who are satisfied with their weight. Semi-structured and in-depth interviews were used to conduct this qualitative study and explore the lived experience of five women who consider themselves overweight. All of the interviews were transcribed immediately and “analyzed using content analysis and constant comparative method” (Chang, Liou, Sheu, & Chen, p. 155).

One of the criteria for selection in this research was that the women be “self-designated as overweight,” and this criterion is already biased towards selecting women with a negative self body image (Chang, Liou, Sheu, & Chen, 2004, p. 154). It automatically excluded women who are clinically overweight but do not perceive themselves as being overweight; such women would be more likely to have a more positive body image, but their voice would not be heard in this study which only selected individuals that would be more likely to confirm the expectation that there is a positive correlation BMI and body dissatisfaction.

These researchers pointed out that nurses can play an active role in helping to reshape attitudes toward being overweight; nurses need to be involved in teaching their
patients about weight control and helping their patients set realistic goals that are not based on society’s standards of the ideal weight (Chang, Liou, Sheu, & Chen, 2004). Nurses need to also pay attention to women who perceive themselves as being overweight but are actually within normal limits.
Chapter III
Methodology

Design

The goal of this research is to gain an understanding of the lived experience of women with PCOS. To gain this understanding, the research method used was phenomenology, which Russell (1999) describes as “both a philosophy and a research method that [explores] and describes everyday experiences in order to generate and enhance the understanding of what it means to be human” (p. 220). It is a condition that impacts a whole person, and understanding this impact can help guide nurses in caring for PCOS clients.

Avoiding Bias

An important aspect in any data collection is avoiding bias, which may alter the results of the study. Avoiding bias is of a particular importance in phenomenology because researchers have their own lived experiences that they bring into the research, but personal views and opinions must not confound the research. Personal biases should be explored before data collection takes place to help minimize their effect, and all preexisting knowledge the researcher has will be bracketed. This means that the researcher will conduct each interview naively to make sure the researcher’s preconceived opinions and values do not interfere with the interview process (Russell, 1999, p. 228). The researcher has bracketed personal opinions and ideas in Appendix A.

Participant Selection

Participants were self-selected, and were never directly recruited by the researcher. The researcher advertised through mass emails and verbal announcements on
a college campus, and individuals from the college passed the information on to women they knew who had PCOS; the information included the researcher's email address and phone number. A woman with PCOS was then able to contact the researcher if she was interested in being interviewed. All three participants were from different states, and only one attended the college where the advertising took place.

Confidentiality and Informed Consent

The confidentiality of each interview participant was strictly observed throughout the entire research project. The names of the participants were not attached to the interview. The transcripts and audiotapes were stored in a locked safe box. Each participant signed an informed consent agreement which explained the purpose for the interview, her right to withdraw from the study at any time, and contact information of the interviewer.

Data Collection

The data collection method used was semi-structured interviews, and all interviews took place between October and November of 2007 in a location of the participants choosing. A prepared list of open-ended interview questions guided the interviewer, and the interviewer used probing to limit the vagueness of participant responses. A list of interview questions can be found in Appendix B; based on individual interviews, not all of the questions may have been used. Interviews were audio taped if possible or written by participants, and audio tapes were transcribed verbatim following the interview. The interviews aimed to gather information about the lived experience of PCOS, such as what it has been like to live with PCOS and how it has impacted the lives of women.
Data Analysis

Data analysis of the interviews entailed thoroughly involving the researcher in rereading the interview transcripts. The method that this research will follow is Giorgi’s Method.

Giorgi’s Method (Russell, 1999, p. 230)

1. Read the entire disclosure of the lived experience straight through to obtain a sense of the whole.

2. Reread the disclosure to discover the essence of the lived experience under study. Look for each time a transition in meaning occurs. Abstract these meaning units or themes.

3. Examine meaning units for redundancies, clarification, or elaboration. Relate meaning units to each other and to a sense of the whole.

4. Reflect on the meaning units, and extrapolate the essence of the experience for each participant. Transform each meaning unit into the language of science when relevant.

5. Formulate a consistent description of the meaning structures of the lived experience for all participants.

Limitations of Study

This study was limited by the number of participants involved in the interviews. The data collected provides three snapshots of the lived experience of women with PCOS, but it does not provide conclusive evidence to generalize what the lived experience of PCOS is like. PCOS is such a varied syndrome that it would be difficult to make any generalizations, but this would be especially true with such a small sample.
Another limitation of the study is that the participants were self-selected and chose to participate in this research after learning about it by word of mouth, and this limited advertising could have impacted the results.
Chapter IV

Results

The lived experience of three women with PCOS was explored by phenomenology. Although each participant described a unique experience with PCOS, the analysis revealed several common themes including Grieving, Infertility, the Negative Impact of Symptoms, Feeling Misunderstood, and Uncertainty.

Themes

Grief: A common theme among the participants was grief over perceived or actual loss of health and coming to accept a diagnosis of PCOS through a grieving process. All of the participants had to redefine their concept of wellness. Finding out they had PCOS involved a sense of loss of both health status and fertility. The loss of fertility could be described as anticipatory grieving because it has not actually come to pass, although two of the participants are currently experiencing difficulty getting pregnant.

One participant described how when she was first diagnosed she was shocked, and she said, “At first I was really freaked out because…it causes infertility and all these things, and so I was so freaked out. I was just like, Oh my gosh” (personal communication, October 10, 2007). But later on in the interview she elaborated that “at first it was really scary because I didn’t know, you know, what it was, but now it’s almost more relieving because…at least I know it wasn’t something more serious…I know how to take care of it, and it barely effects my life.”

Another participant described how when she was first diagnosed with PCOS her doctor told her that she would not be able to have any children, and she said, “That made me really upset, and I was very, very sorry for myself. I would cry” (personal
communication, November 2007). She stated later in the interview that now she has “no problem talking about [PCOS]” and it has actually had a positive impact on her outlook towards parenting. She stated, “It has made me appreciate much more the privilege of being a parent and the privilege of having a child and watching that child grow up because there was a time when I didn’t think that I would be able to have one at all.”

Another participant described how she is “only now learning to accept [her] body for what it is, and trying to like it” (personal communication, October 7, 2007).

**Infertility.** All three participants stated that the most distressing aspect of PCOS is the infertility factor, including fear of a miscarriage.

One participant said:

Right now the biggest issue for me is trying to get pregnant. We have been trying for almost a year with no results, so now is the time to start with a specialist and start some treatment. I guess this is the part I have feared the most, as I have always wanted to have children and I have no idea how hard it will be to become pregnant… I am worried my body will let me down now as we are trying to have a baby. [I am] scared that I won’t be able to get pregnant, or sustain a pregnancy (personal communication, October 7, 2007).

Two of the participants described how learning that PCOS can cause infertility when they were first diagnosed was incredibly distressing, and one woman said, “It’s still in the back of my head… that this can cause infertility… that scares me so much, you know” (personal communication, October 10, 2007). Another woman stated:

When I was trying to get pregnant, that was very hard because I, well, every month I was going to get my blood tested to see if I was ovulating and if the drugs
were working, and I was having a really hard time getting pregnant, and the drugs weren’t working. I experienced about two and one-half years trying to get pregnant, and it got very frustrating. And that’s why I just stopped, and I wasn’t going to do it. I stopped for a few months, and I went to go see a fertility specialist and...I found out that I was pregnant...if I wouldn’t have gone to the specialist, I probably would have miscarried my son because of the syndrome my progesterone was really low (personal communication, November 2007).

The same woman stated later on in the interview that:

I haven’t been able to get pregnant since I had my son...so we’re going on five years now that I have been trying to get pregnant...so that’s been difficult...you know, every month, following all of the doctor’s orders, taking the medication, you know, all that stuff that they had recommended, and every month finding out that you’re not pregnant. I think that that’s probably the hardest thing for me...to be disappointed every month, after month, after month.

*Negative impact of symptoms.* Each participant described a different set of physical symptoms of PCOS, but all of the women agreed that the symptoms impact their lives to varying degrees. The symptoms described as having the biggest impact included weight gain and irregular and painful menstruation. Two of the women described weight gain as being a particularly difficult aspect of dealing with PCOS, including maintaining a normal weight. One participant said:

I felt different and weird during high school when I didn’t have a normal menstruation cycle like my friends, and of course being overweight did not help. I also had some extra hair growth and I was very self-conscious about it...I felt
very undesirable and did not have a serious boyfriend until after college (personal communication, October 7, 2007).

Another participant described how excruciatingly painful it was to have one of her ovarian cysts pop: “it used to, like, completely ruin, like, a day or two of my life because it would hurt so bad and I would be really, really sick. You literally feel like someone stabbed you in the lower stomach and leaves the knife there” (personal communication, October 10, 2007).

*Feeling misunderstood.* A desire to be understood was expressed by all three participants, and a common theme was feeling misunderstood and abnormal. One woman described how joining a PCOS group in college gave her support, and one of her aunts is also a support who has “always been very understanding.” But she still felt “different and weird during high school” (personal communication, October 7, 2007).

Another woman described how comforting it was to find out that PCOS is not uncommon, but she also said:

I know something is wrong with me…I just wish I could be normal. Whenever it comes out, people will look at me differently…I’m really self-conscious…[PCOS] is a hard thing for me to talk about. Like, it’s fine with talking about it with girls I guess, because they can sometimes relate (personal communication, October 10, 2007).

She described how she feels girls are more understanding with regards to PCOS, but she said, “It’s harder for me to talk to guys about it…because they don’t understand what’s going on, and…I feel like they do look at you differently.”
The last woman asserted that PCOS is “something that people don’t really understand...unless you’re in that position, you don’t really understand” (personal communication, November 2007).

Uncertainty. All of the participants expressed uncertainty about how PCOS will continue to impact their lives, especially with regards to fertility. As one woman stated, “I want to have more children [but] I don’t know that I’ll ever have another child” (personal communication, November 2007).

Another participant who described PCOS as a “guessing game” echoed the concern about infertility, and she wondered: “Is [PCOS] going to affect my future?” She also said, “Hopefully it will just go away, but I don’t know if it will ever. I don’t know. It’s like in the back of the front of my mind, like, I don’t forget about it, but I don’t think about it every day, I guess” (personal communication, October 10, 2007).
Chapter V
Discussion

All of the women who shared their story provided tremendous insight about PCOS and how it has impacted their lives. The most common theme was infertility, and all of the participants stated that it was the most distressing aspect of PCOS. Participants felt like most people did not understand PCOS, and all of the women had a desire to be understood while at the same time feeling abnormal. Dealing with the daily issues of PCOS eventually became “normal” for the individuals, but there was always the fear of the unknown about how PCOS will impact the future. Living with PCOS did not necessarily become easy for the women, but they reached a level of acceptance and have found ways to cope with the challenges of PCOS.

Although infertility was stated as the greatest concern among participants, not all of the women expressed the same degree of concern. For example, one woman’s disclosure was almost all related to infertility and pregnancy, while another mentioned infertility only a few times. The degree of concern seemed to be correlated with whether or not the woman was currently trying to become pregnant. Cook (1987) supported this finding by pointing out that “individuals who are committed to not having children (e.g., members of a religious order) are not likely to experience a major crisis upon learning of their infertility,” and she hypothesizes that physical infertility only presents a crisis when it is linked with “powerful expectations they and others hold about being a parent” (p. 465).

Cook (1987) described a crisis of infertility as being the grief, anxiety, low self-esteem, and uncertainty about the future related to potential or actual infertility, and she
pointed out that the private nature of an infertility crisis increases the likelihood that the grief will go undetected and unaddressed. The grief associated with an inconclusive diagnosis of infertility may be especially difficult to work through “because there remains some chance of pregnancy” (Cook, p. 468). Successful resolution of grief involves the individual working through the “powerful reactions to their infertility” and proceeding on “with the rest of their life” (Cook, p. 468). According to Williams and Boyd (2005) grief usually follows three stages: shock, acute mourning, and resolution. The acute mourning phase is characterized by intense feelings, such as depression, crying, or irritability and social withdrawal, such as preoccupation with health. Women with PCOS may feel grief over a potential loss of infertility and the diagnosis of PCOS. They may have more than one issue to work though before they return to a sense of well-being.

Receiving a diagnosis of PCOS seemed to be a highly stressful experience for the women and nurses can utilize therapeutic communication to allow clients to express their feelings, which may include fear and a sense of grief. Therapeutic communication involves both verbal and nonverbal communication that promotes a therapeutic relationship between the nurse and the patient. It involves being caring and nonjudgmental, and making sure questions and responses are client centered (Forchuk & Boyd, 2005). The nurse should never bring her own feelings or opinions into the discussion, and it is rarely helpful to use the phrase “I understand.” As one of the participants in my research pointed out, unless you have PCOS, it is unlikely that you understand how the client is feeling. However, nurses can still be empathetic, even if they do not fully comprehend what the client is experiencing.
Therapeutic communication does not end after the first appointment: the issues a woman has to deal with related to PCOS may change over time. For example, one participant was not currently attempting to get pregnant, and the possibility of infertility is “still in the back of [her] head” (personal communication, October 10, 2007). Her current issue with PCOS is the inconvenience of irregular and painful menstruation, but this could change. Infertility may move to the front of her mind if she ever decides she would like to have children and she experiences difficulty. She may have a renewed sense of grief and need to talk about new feelings. One participant was similarly distressed when she first learned of the possibility of infertility, but she said, “It really was not much of an issue until after I got married and wanted to have children” (personal communication, November 2007).

Research has also supported the usefulness of crisis intervention programs in assisting individuals to cope with infertility (Lee, 2003), and one of the participants in this study described how helpful a PCOS support group was for her in college. Perhaps utilizing either a crisis intervention program or a support group could be an effective way to assist women in coping with PCOS and the associated infertility. In addition, all of the participants expressed a desire to be understood, and a support group could be an effective place to find both support and understanding from women struggling with the same syndrome. Nurses could be instrumental in directing clients with PCOS to a local support group or perhaps starting a group if there is not one already active in the community.

Another prevalent theme among the interviews was a negative body image. Weight gain was mentioned several times as being a very difficult aspect of PCOS, and
research done by Coffey and Mason (2003) and McCook, Reame, and Thatcher (2005) also found weight gain to be a prevalent theme in their research. Nurses can assist their clients with PCOS by helping them develop an appropriate diet and exercise program.

Conclusion

The original purpose of this research was to explore the lived experience of PCOS and find out how it impacts a woman’s life. Living with PCOS is a unique challenge that sometimes involves a renewed effort to cope with. Themes from this study were previously identified by research, including being full of grief over a loss of health and fertility, body image, feeling misunderstood, and uncertainty. Nurses can provide caring support for their clients with PCOS and refer them to additional support groups.
Appendix A

Personal Opinions and Ideas about PCOS

Prior to completing the interviews for this thesis, I conducted a thorough review of the literature, and through that I gained a broad understanding of the syndrome. I explored both quantitative and qualitative research on PCOS, and I went into the interviews with only a theoretical understanding of PCOS. I have no personal experience with PCOS, and I did not know anyone with PCOS prior to the interviews.
Appendix B

Interview Questions

1. When were you diagnosed with PCOS, and how did that make you feel?
2. How has PCOS impacted your life? What has your experience with PCOS been like?
3. What symptoms have you experienced related to PCOS, and how do they effect you?
4. How has PCOS impacted your relationships with others?
5. Who do you go to for support?
6. What influence has PCOS had on shaping your self-concept?
7. How do you feel about your body?
8. What do you like about yourself?
9. How do you cope with stress in your life?
10. What do you do to relieve stress?
11. What aspect of having PCOS do you find to be the most distressing?
12. How do you feel about PCOS in general?
13. Do you have any final thoughts about PCOS?
References


