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Life After Menopause: Quality of Life in Women Diagnosed With PolyCystic Ovarian Syndrome After The Childbearing Years

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Life After Menopause: Quality of Life in Women Diagnosed with PolyCystic Ovarian Syndrome after the Childbearing Years

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CERTIFICATE OF APPROVAL

Clinical Research Project

This is to certify that the Clinical Research Project of

Katelyn Baker

has been approved by the CRP
Committee on

September 3, 2020

as satisfactory for the CRP requirement
for the Doctorate of Psychology degree
with a major in Clinical Psychology

Examining Committee:

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Date: 2021.02.02 19:52:16 -06'00'

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Reader

Reader

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Review of Literature

Polycystic Ovarian Syndrome (PCOS) is a complex, multi-symptom endocrine chronic illness that affects 1 out of every 15 women (Trivax & Azziz, 2007). According to an official website for PCOS, pcosaa.org (2017), symptoms of PCOS include irregular or missed periods, cysts on the ovaries, weight gain, fatigue, unwanted hair growth (hirsutism), thinning hair on the head, infertility, acne, mood changes, pelvic pain, headaches, sleep problems, insulin resistance, slow metabolism, and hypoandrogenism. Women diagnosed with PCOS have a higher risk for obesity, diabetes, eating disorders, and cardiovascular disease (Ferrell-Turner, 2015). It is important to note that PCOS looks different in every woman. Some women may have all of these symptoms while some may only have a few.

In addition to the multitude of the physical symptoms that accompany PCOS, there are also many mental health problems. However, the psychological effects of the disease often go undiscussed; "[O]f more than 2100 PubMed citations on PCOS appearing since 2000, only 3% addressed psychological concerns" (Himelein & Thatcher, 2006, p. 723). PCOS can also be associated with depression, anxiety, body dissatisfaction, difficulties with sexual and relational functioning, lower quality of life, eating disorders, anger, and aggression (Himelein & Thatchar, 2006).

PCOS is normally only recognized and diagnosed in women who are in their childbearing years (Trivax & Azziz, 2007). While there has been a multitude of research conducted around the area of perceived quality of life in pre-menopausal women that have been diagnosed with

PCOS, there is very little that has been conducted about the perceived quality of life in post-menopausal women diagnosed with PCOS. This lack of research may be due to a scientific and societal disinterest in women with PCOS once they are no longer able to bear children. However, while the perceived quality of life in pre-menopausal women diagnosed with PCOS may be interesting and important, women eventually age and experience menopause. Knowing what life post-menopause might look like for women diagnosed with PCOS is an area of research that needs to be explored.

To understand what PCOS looks like from a post-menopausal mental health perspective, it is first important to comprehend what PCOS is from a pre-menopausal mental health perspective. Per Ferrell-Turner (2015), "PCOS is the most common cause of female infertility, which in and of itself is associated with adverse psychosocial functioning" (p. 49). A study conducted in 2009 analyzed 60 women with a confirmed diagnosis of PCOS using The Primary Care Evaluation of Mental Disorders Patient Health Questionnaire. Among the women who participated in the study, the prevalence of depression was 40% and the prevalence of mood disorders was 56.6% (Kerchner, Lester, Stuart, & Dokras, 2009).

In addition to depression and mood disorders, anxiety is also higher among women with a PCOS diagnosis. It was discovered that anxiety is higher than depression in women with PCOS (although underdiagnosed) and that higher levels of depression were found in women who were deemed infertile (Deeks, Gibson-Helm, & Teede, 2010). Also, Jedel, Waern, Gustafson, Landen, Eriksson, Holm, Nilsson, Lind, Janson, and Stener-Victorin (2009), conducted a study that consisted of 52 women (25 with PCOS, 27 in the control group without PCOS). Participants were given the Brief Scale for Anxiety (BSA-S) with controls matched for Body Mass Index (BMI). This study found was that 63% of women with PCOS received elevated scores on the BSA-S (≥11) while only 13% of the control group indicated elevated scores (≥11). The study concluded that half of the women with PCOS reported worry which is more than double compared to the control group (Jedel et al., 2009).

A study conducted in 2008 further supports the claim that PCOS negatively affects mental health, and more specifically, anxiety. The study was comprised of 49 women with PCOS and 49 women without (control group). They discovered a lifetime diagnosis of Generalized Anxiety Disorder in 17% of the women (Jedel et al., 2009 per Mansson, Holte, Landin-Wilhelmsen, Dahlgren, Johansson, & Landen, 2008). In addition, this study also concluded that women with PCOS had higher correlations with depressive episodes, social phobia, and eating disorders when compared to the controls. Also, they discovered that suicide attempts were seven times more common in the PCOS group than in the controls as well as a higher lifetime use of antidepressants and anxiolytic drugs (Mansson et al., 2008).

Mental health is often correlated to overall quality of life (QOL). Women diagnosed with PCOS often have a lower QOL compared to women without PCOS (Barnard, Ferriday, Guenther, Strauss, Balen, & Dye, 2007). A study was conducted by Barnard et al. to examine the QOL in women with PCOS by using the PCOSQ, a QOL measure directed solely at measuring the QOL of women with PCOS. This measure consists of 26 items on a 7-point scale. Five factors within the assessment include emotional disturbances, hirsutism, weight difficulties, infertility, and menstrual difficulties. The authors of the study created an additional factor, acne, in an attempt to increase the validity due to shortcomings of the assessment in previous research (Barnard et al., 2007). The total number of participants for the study was 409 women. They were placed into 4 randomized groups: women with PCOS not taking anti-androgen (AA) medication, women with PCOS taking AA medication, healthy women not taking AA medication, and healthy women taking AA medication. “Women were excluded if they were pregnant, peri- or post-menopausal, had no ovaries, were unsure whether they had ovaries, or were taking hormone replacement therapy” (Bernard et al., 2007, p. 2280). The study concluded that “The two PCOS groups had significantly worse QOL than control groups on all seven factors of the modified PCOSQ” (Barnard et al., 2007, p. 2283).

So, what happens when women with PCOS are no longer able to bear children? Since the focal point of the disease is infertility, what happens when a woman reaches menopause or undergoes a hysterectomy? Per Welt and Carmina (2013) there is very little research available in reference to what PCOS looks like post-menopause. What they did discover, however, is that many of the physical symptoms stay the same or even worsen; typically, the onset of menopause is later in women with PCOS than in women without, there is a greater risk of hypertension, a greater risk for developing Type II Diabetes, higher insulin levels, cardiovascular issues, higher BMI’s, higher cholesterol, higher triglyceride levels, and worsened metabolic properties (Welt and Carmina, 2013, Felton & Panay, 2008). Also, ovarian cysts are common in 37% of post-menopausal women according to a study conducted by Birdsall and Farquhar (1996). A longitudinal study that was published in 1992 by Dahlgren, Johansson, Lindstedt, Knuttson, Oden, Janson, and Lundberg had similar findings to the 2013 study conducted by Welt and

Carmina (2013). They discovered that women with PCOS undergo more hysterectomies compared to women without PCOS and there is also a higher prevalence of obesity, basal serum insulin concentration, diabeted millitus, hypertension, anovulation, hirsutism, and infertility. The older date and the number of years between the studies helps to further support the idea that PCOS in post-menopausal women is grossly understudied.

As stated above, infertility is one of the major reasons that women with PCOS develop mental health issues (Ferrell-Turner, 2015). Once a woman goes through menopause or has a hysterectomy, child-bearing is no longer an option. Post-menopause mental health can be affected by this in one of two ways: women with PCOS may no longer feel an intense pressure to try to conceive and their mental health may improve, or, women with PCOS may experience worsened mental health due to the hopelessness of never being able to conceive a child. A study was conducted that evaluated women 11-17 years after they received fertilization treatment (Gameiro, van den Belt-Dusebout, Bleiker, Braat, Leeuwen, & Verhaak, 2014). What the study found is that women who still had a child-wish were "1.5 to 2.8 times more likely to develop clinically significant mental health problems than women without a child-wish" regardless of infertility diagnosis, treatment history, and outcome (Gameiro et al., 2014, p. 2243). However, the study also concluded that the majority of women are able to come to terms with their infertility and only a few develop mental health problems due to their child-wish (Gameiro et al., 2014). This would suggest that women with PCOS who are post-menopause are able to adapt to their childlessness status and are therefore more likely to have a greater quality of life.

Summary, Specific Aims, and Hypotheses

The current literature appears to clearly indicate that PCOS negatively affects the Quality of Life in those diagnosed with the disease. However, the exclusion criteria of these studies include peri-menopausal, post-menopausal, and women without ovaries or those who have received hysterectomy's. Welt and Carmina (2013) describe the medical aspect of what happens to women who have been diagnosed with PCOS after they are no longer considered "fertile." Unfortunately, there is little to no research conducted on the QOL in women with PCOS past the age of 35.

This study aims to examine the quality of life in pre-menopausal women compared to post-menopausal women that have been diagnosed with PCOS. It is hypothesized that post-menopausal women diagnosed with PCOS will have a higher perceived quality of life than pre-menopausal women diagnosed with PCOS. The independent variable of this study is pre-versus-post-menopause and the dependent variable is the self-reported QOL.

Methods

Study Design

A Cross-Sectional Design was utilized in this study. The rationale for using this study design is that it helped to examine variables (pre-and-post menopause in women diagnosed with PCOS) that are associated with the factor of interest (quality of life). This type of study design is best suited for this study and helped to provide the most concise results possible.

Measures

The Polycystic Ovary Syndrome Quality of Life Questionnaire (PCOSQ-50) was the assessment tool utilized in this study. The PCOSQ-50 consists of 26 items related to 5 domains, each one related to a symptom of PCOS: body hair, emotions, infertility, weight difficulties, and menstrual difficulties. The measure is based on a 5-point scale with 1 being optimal functioning and 5 being poorest functioning (Cronin, Goyatt, Griffith, Wang, Azziz, Futterweit, Cook, & Dunaif, 1998).

This questionnaire demonstrates high construct validity, internal reliability (.73-.97), and high face validity. Intra-class correlation coefficients to evaluate the test-retest reliability were high for all domains (range .89 - .95, $P < 0.001$). However, validity could be increased with the addition of an "acne" domain. Overall, this was the most appropriate assessment tool to utilize in this study because it is the only QOL measurement tool normed for women diagnosed with PCOS and it has been proven to be effective in other studies that have used it (Jones, Benes, Clark, Denham, Holder, Haynes, Mulgrew, Shepherd, Wilkinson, Singh, Balen, Lashen, & Ledger, 2004).

Procedures

A survey was created (see Appendix B) that included demographic information (age, ethnicity/race), a confirmation of the participants' PCOS diagnosis (have you ever been diagnosed with PCOS by a licensed professional?) and a question concerning the age at which they were first diagnosed (if yes, at what age?), relevant questions related to menopause (when was your last period?), and questions to rule out participants who are pregnant or have had a hysterectomy. Then, participants were asked to complete the PCOSQ-50. The beginning of the survey included an informed consent and possible harm notice. Once all the questions were answered, a debriefing appeared at the very end of the survey that informed the participants about the intent of the study.

To recruit participants, the survey was posted onto the PCOS support group forum "PCOS Diva" through Facebook. The survey stated that it is for a study about PCOS. No other information other than that was provided so as to not bias the results. Once the survey was posted to the forum, participants were given access to begin taking the survey.

Participants

This study required 128 participants (n=128): 64 pre-menopausal women diagnosed with PCOS and 64 post-menopausal women diagnosed with PCOS according to a statistical power analysis (Faul, Erdfelder, Long, & Buchner, 2007). Criteria for the post-menopausal group included women diagnosed with PCOS that have not had a menstruation cycle in 2 years. The optimal waiting period between a woman's last menstruation cycle and the participation in this study is two years due to the conclusions drawn by Cohen, Soares, Vitonis, Otto, and Harlow (2006) that state the menopause transitional period has a high correlation with depression. Therefore, the two year delay criteria is an appropriate amount of time to for participants to pass the peri-menopausal state.

Exclusion criteria included women who have had a hysterectomy, women who were pregnant, and women who have never experienced a menstrual cycle. Participants were at least 18 years old due to restrictions from the assessment tool (the PCOSQ-50).

Participants were recruited through PCOS support group advertisements. Women that met all the inclusion criteria were selected to participate in the study. The datum from those who complete the questionnaire but do not meet the inclusion criteria were discarded. According to a study completed in 2013, support groups for PCOS are growing rapidly so this method was effective in recruiting the necessary number of participants (Niemi).

The two groups consisted of 480 pre-menopausal women with PCOS and 22 post-menopausal women with PCOS. In total, 582 women responded to the survey. However, due to attrition and unmet inclusion criteria, the total number of participants in the study was 502.

Demographics for the participants included 15 African American women, 16 Asian/Asian American women, 414 Caucasian women, 26 Hispanic/Latina women, 18 Mixed Racial/Biracial women, 1 woman that chose not to specify, and 12 women that chose "Other". A chi-square test was completed to test the hypothesis that there would be no difference in the race distribution of the 2 groups. The result was (5 d.f.) = 1.88, p=0.865. The conclusion is that there is no difference in the race distributions.

In reference to relationship status demographics, 14 of the participants were divorced, 354 were married, 66 were romantically involved with a partner, 67 were single, and one was widowed. A chi-square test was completed to test the hypothesis that there would be no difference in the marriage distribution of the 2 groups. The result was (4 d.f.) = 1.15, p=0.886. The conclusion is that there is no difference in the relationship distributions.

Ages of the participants ranged from 20 to 65. In the pre-menopausal group, the mean age was 34.6 and in the post-menopausal group, the mean age was 42.45. There was a significant difference in mean age between the two groups (T=5.038, p <0.0001).

Results

The data collected from the surveys was entered into the Statistical Package for the Social Sciences (SPSS) program. Each question on the survey had 5 possible answers which were Never, Rarely, Sometimes, Often, and Always. Responses are more negative as regards quality of life as they go from Never to Always. These responses were recoded to the numbers 1, 2, 3, 4, and 5, respectively, so that a higher number indicates a more negative quality of life. For each participant the average of those numbers for the 50 questions was calculated to give an overall assessment of their quality of life. Some participants did not answer all questions so the average was calculated using scores for those answered.

The age of the participants at the time of the survey was significantly different between the 2 groups ($p<0.0001$) with the age of the post-menopausal group being almost 8 years older. A preliminary regression analysis showed that as age increased the scores decreased ($p<0.0001$). This indicates that an analysis of covariance (ANCOVA) with age as the covariate needed to be completed to compare scores in the 2 groups.

The ANCOVA results showed that the post-menopausal group had a slightly lower mean score before adjusting for age (3.18 vs. 3.28) indicating a better quality of life than the pre-menopausal group. However, the difference in mean scores was not significantly different ($p=0.428$). After adjusting for age, the mean scores (3.33 vs. 3.27) of the 2 groups are still not significantly different ($p=0.610$). The effect of adjusting for age was mainly to increase the mean score for the post-menopausal group to be about the same as the pre-menopausal group. The conclusion is that there is no significant difference between the mean scores of the 2 groups meaning no difference in the quality of life of the 2 groups.

Discussion

This study has both strengths and limitations. A major strength of this study is its simplicity; the inclusion criteria are specific, only one assessment is being used, and the results should be generalizable to the PCOS community. Another strength is the use of a PCOS based assessment instead of a general QOL questionnaire. The use of the PCOSQ-50 is beneficial because it has been normed on the population in question, therefore providing more concise results.

Among the limitations is a diversity component; because the survey was only available using a computer or smartphone, individuals of a lower socioeconomic status may not have had the opportunity to participate in the study due to a lack of accessibility to the necessary devices. Also, diversity proved to be another limitation in terms of race/ethnicity in this study. There was a large number of white women (n=414) compared to women of color (n=75). This could be due in part to the larger systemic issue involving women of color not having access to the same level of healthcare that Caucasian women do (Prather, Fuller, Jeffries, Marshall, Howell, Belyue-Umole, & King, 2018) and therefore has resulted in less PCOS diagnoses among women of color. This is an area of research that needs further evaluation in future studies.

An additional limitation was the widely varying group sizes (580 pre-menopausal, 22 post-menopausal). Because the group sizes were so different in size, the results were deemed “not clinically significant”. As mentioned in the literature review, there is a large disparity of information about women who are post-menopausal that are diagnosed with PCOS. This idea leads to the conclusion that women who are post-menopausal are not being diagnosed with the same frequency as those who are pre-menopausal. In addition, information about PCOS in general is ever-evolving and research is mostly recent. This is indicative of a lack of PCOS diagnoses in those participants that were older (and part of the post-menopausal group) due to less information being available about PCOS during those women’s pre-menopausal years when they were the most symptomatic. It is highly likely that a large majority of women that are post-menopausal who experience the symptoms associated with PCOS are undiagnosed due to the recent relevance of the diagnosis (Wolf, Wattick, Kinkade, & Olfert, 2018). Also, due to issues in healthcare such as ageism, post-menopausal women may not be receiving the same level of care compared to women in the pre-menopausal group (Chrisler, Barney, & Palatino, 2016).

This study contained threats to internal validity that need to be taken into consideration. Attrition, or the loss of participants over the course of a study, affected the study. There were 80 individuals who began the study but did not complete it, making the data for those individuals invalid. History was also a threat to internal validity; if a participant was having a worse-than-normal day when completing the study due to symptom flare-ups or personal life issues, they might have responded in a more negative way than they normally would.

There was also a possible threat of construct validity to this study. Demand characteristics, or cues that influence how participants behave, are a potential threat. Because the participants were told that they are participating in a study about PCOS, it may have caused them to over-report or under-report their symptoms.

Lastly, there were also threats to external validity. Sample characteristics was an external validity threat because the results concluded from this study will only be generalizable to women within the PCOS community. Outside of the PCOS community, the results are not applicable. There was also a possible threat of reactivity of assessment and reactivity of experimental arrangements; the participants were aware that they are a part of a study in general and, more specifically, that they are in a study about PCOS. Because of this awareness, participants may have changed their answers based on what they believed was being assessed.

The methods within this study were altered to reduce threats to validity as well as limitations by using an assessment that has already been created and normed for the population in question. However, the lower validity of the actual QOL assessment (the PCOSQ-50) due to the lack of an acne domain cannot be controlled for until changes to the assessment itself are made. It is vital to use the PCOSQ-50 despite its lower validity because it is the only QOL scale made for women with PCOS.

In terms of future research for this topic, more studies need to be completed on women with PCOS that are post-menopausal. One way to do so would be to replicate this study with a sufficient sample size in both cells in order to achieve statistical power which would eliminate the confound of non-significance. However, this has proved to be difficult due to the reasons listed above such as post-menopausal women not being diagnosed as frequently as pre-menopausal women due to scientific disinterest past the child-bearing age.

It would also be helpful if future research could include more diverse populations. Due to the lack of healthcare for women of color as listed above, the results of this study were biased towards the results of the white respondents. It may also be helpful to include those women who have undergone hysterectomies because, technically, they would then be considered post-menopausal. However, for the purposes of this study, including women who have experienced hysterectomies would have presented more variables than necessary for the simplicity of the study design.

Future research conducted in the areas of child-wish would also contribute to the understanding of women in the PCOS community, especially those who are post-menopausal. If the quality of life in these women is affected by child-wish or lack-there-of, it could prove to be indicative of lower or higher quality of life scores in post-menopausal women. This is a fairly new area of research that should be explored in order to better understanding the daily functioning and mental health of women with PCOS who are both pre-and-post-menopausal.

In addition, research focusing solely on the mental health of post-meonpausal women diagnosed with PCOS would also be helpful. In general, there is very little information available about what life is like post-menopause for women diagnosed with PCOS. The only solution to this problem is to continue to conduct research about this important topic due to its prevalence rate in current society. In order for providers to better help and understand their patients, more information on post-menopausal women diagnosed with PCOS is a necessity.

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Appendix A

Informed Consent

I have been asked by Katelyn Baker, a doctoral student from the Illinois School of Professional Psychology at Argosy University, Chicago, to participate in her Clinical Research Project (CRP) about my experiences of living with Polycystic Ovarian Syndrome (PCOS). I was asked to be a possible participant because I have been diagnosed with PCOS. It is estimated that 124 people will participate in this study. The purpose of this study is to understand the quality of life in women who have been diagnosed with PCOS.

If I agree to be in this study, I will be asked to complete questionnaires including questions about demographic information and symptoms associated with PCOS. This study will take approximately 15 minutes to complete.

There is minimal risk in this study. However, potential risks that may occur with this study are feelings of mild discomfort or distress resulting from being asked to answer questions of a more private nature. There are no personal benefits to my participation in this study. Results from this study will provide valuable information regarding the effects of PCOS of women of all ages and provide possible areas for clinical growth and exploration.

All responses are treated as anonymous, and in no case will responses from individual participants be identified. Rather, all data will be pooled and published in aggregate form only. I understand this study is anonymous, and is done by completing an online survey utilizing Survey Money. I am aware, however, that the study is not being run from a “secure” https server of the kind typically used to handle credit card transactions, so there is a small possibility that my responses could be viewed by unauthorized third parties (e.g., computer hackers). My name will not be identified or associated with my responses to the questionnaires. The data will be sent to the researcher anonymously when completed and given a code. My IP address will not be recorded as the IP address tracking will be disabled in order to preserve participant anonymity. The records of this study will be kept private. No words linking me to the study will be included in any sort of report that might be published. The data will be stored securely at the researcher's home and only Katelyn Baker and her supervisor, Dr. Christopher Rector, will have access to the records. After three years, all collected data will be destroyed. I have a right to get a summary of the results of this research if I would like to have them.

I understand that I will not be compensated for this study. I understand that my participation is strictly voluntary. My decision regarding my participation will not affect my current or future relations with the Illinois School of Professional Psychology at Argosy University, Chicago. If I decide to participate, I am free to refuse to answer any of the questions that may make me uncomfortable. I can withdraw at any time without any penalty.

I understand that this research study will be reviewed and certified by the Institutional Review Board, Argosy University, Chicago. For research-related questions or issues regarding participants' rights, I can contact the Institutional Review Board through the IRB chair, Leah Horvath, Ph.D at (312) 777-7681, lhorvath@argosy.edu, Illinois School of Professional Psychology at Argosy University, Chicago, 225 N. Michigan Ave., Suite 1300, Chicago, IL 60601.

I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study. By completing the online survey, I consent to participate in the study.

If you are 18 years of age or older, understand the statements above, and freely consent to participate in the study, click on the “I agree” button to begin the experiment.

Participants are encouraged to print a copy of this informed consent for their records.

Appendix B

Demographic Information Survey

Have you previously been diagnosed with Poly Cystic Ovarian Syndrome by a licensed medical doctor?

- Yes
- No

If you answered yes to the above question, at what age were you diagnosed?

- (Blank space for fill in answer)

Racial/Ethnic Identity

- Caucasian/White/European
- African American/Black
- Asian/Asian American
- Mixed Racial/Biracial
- Latino/Latina/Hispanic
- Jewish
- I prefer not to answer

Gender

- Male
- Female
- I Prefer not to answer

Age

- (blank space for a fill in answer)

Relationship Status

- Single
- Married
- Divorced
- Widowed
- Romantically involved with a partner

When did your last menstrual cycle occur?

- (blank space for a fill in answer)

Are you currently pregnant?

- Yes
- No

Have you undergone a hysterectomy?

- Yes
- No

Appendix C

PCOSQ-50

Polycystic Ovary Syndrome Questionnaire (PCOSQ-50)—Self-Administered Instructions:

The questions concern your health-related issues. Please respond to each question by checking the box with the rating that best reflects how you feel. Choose only one option for each question. There is no right or wrong answer. Just choose the option that is closest to how you feel. Options for every question are as follows: never, rarely, sometimes, often, and always.

Section A: Psychosocial and emotional

In the past 4 weeks how often have you

1. Suffered from bad mood due to PCOS?

2. Experienced impatience due to PCOS?

3. Blamed yourself for having PCOS?

4. Experienced trouble dealing with others?

5. Suffered from low self-esteem due to PCOS?

6. Experienced aggressiveness due to PCOS?

7. Felt pessimistic about the treatment?

8. Suffered from embarrassment due to your appearance?

9. Felt different to normal women?

10. Experienced lack of control of emotions?

11. Felt ugly or unattractive?

12. Felt easily tired?

Section B: Fertility

In the past 4 weeks how often have you

1. Felt sad seeing children?

2. Felt sad seeing pregnant women?

3.Experienced concern about infertility?

4. Felt you will accept all other PCOS manifestations if assured of pregnancy?

5. Felt fear of abortion?

6. Felt concerned about infertility in the future?

7. Experienced fear of divorce or separation?

8. Felt uselessness of sexual intercourse due to infertility?

9. Experienced concern about the long term effects of PCOS medication?

Section C: Sexual function

*fill for those with partner

In the past 4 weeks how often have you

1. Felt unsatisfied with sex?

2. Experienced lack of sexual stimulation?

3. Experienced lack of sexual desire?

4. Experienced lack of lubrication during sexual intercourse?

5. Experienced lack of orgasm?

6. Felt ashamed of sexual coldness/unresponsiveness?

7. Experienced loss of libido because of PCOS?

Section D: Obesity and menstrual disorders

In the past 4 weeks how often have you

1. Felt concerned about being overweight?

2. Felt the need to decrease your weight to control PCOS status?

3. Felt concerned about a fast return to your previous weight after any weight loss?

4. Felt concerned about the complete cessation of menstruation?

5. Felt concerned about menstruation at long intervals?

6. Felt willingness to reduce your weight to be more attractive for your partner?

7. Experienced fear of diseases such as diabetes, hypertension and heart disease?

8. Felt the urge to abandon treatments because of repetitive visits to doctors?

9. Experienced fear of cancer?

Section E: Hirsutism disorders

In the past 4 weeks how often have you

1. Felt embarrassed because of excess facial hair?

2. Felt concerned about the progression of excess body and facial hair?

3. Felt concerned about having excess facial hair?

4. Felt concerned about rapid regrowth of unwanted hair after its removal?

5. Felt embarrassed because of having excess body hair?

6. Experienced the need to cover your body and face because of excess hair?

Section G: Coping

In the past 4 weeks how often have you

1. Felt a lack of family support and acceptance of your disease?

2. Felt lack of satisfaction with being a woman?

3. Felt the desperate need for a cure?

4. Felt complain with others about PCOS?

5. Felt difficult communicating with others with PCOS?

6. Felt lack of satisfaction with your appearance (self image)?

7. Felt lack of satisfaction with your role/future role as a wife?

Appendix D

Debriefing Statement and Referrals

Thank you for your participation in this research on the quality of life in women diagnosed with Poly Cystic Ovarian Syndrome**.** Multiple-choice/scale questionnaires were used for participants in this study. The goal of the questionnaires was to gather information on the quality of life in women diagnosed with PCOS both before and after menopause. It was hypothesized that women diagnosed with PCOS that are post-menopausal will have an overall higher quality of life.

If you feel that you need assistance with issues that are caused by feelings or experiences as a result of this study, please utilize the list of referrals that has been provided below.

Current research has very little information about what PCOS looks like from a post-menopausal light. Your participation was important in helping researchers understand the differences in symptomology and overall quality of life of women with PCOS who are both pre- and post-menopausal.

Final results will be available from the investigator, Katelyn Baker. You may contact me at (219) 765-8584 to receive a copy of the final report. All results will be grouped together; therefore individual results are not available. Your participation, including your name and answers, will remain absolutely confidential, even if the report is published.

If you have any additional questions regarding this research, please contact me using the information provided above.

Referrals

National Suicide Prevention Lifeline: 1 (800) 273-8255

National Alliance on Mental Illness: 1 (800) 950-6264

Appendix E

Permissions

4/18/2018 Mail - Kebaker94@stu.argosy.edu

Re: Request for research participation

Hi Katelyn,

Sure would be happy to share if it gets approved.

Kindly,

Amy Medling

Health Coach, PCOS Diva

amy@pcosdiva.com

www.pcosdiva.com

New Book! Preorder my book Healing PCOS, on sale May 1st! Click to preorder and claim your bonus items.

The views and recommendations shared by PCOS Diva LLC and pcosdiva.com, as well as the information contained in this email, if any, are for general health information only and do not constitute, and are not intended to be a substitute for professional medical advice regarding an individual' s specific health condition. The information is intended to provide accurate and helpful health information. The information is not intended as medical advice for individual problems or for making a diagnosis of a medical condition or an evaluation as to the risks and benefits of taking a particular drug or product.

On Mar 20, 2018, at 1:57 PM, Katelyn Baker <Kebaker94@stu.argosy .edu> wrote:

Hello!

My name is Katelyn Baker and I am a third year clinical psychology doctoral student at the Illinois School of Professional Psychology at Argosy University, Chicago. I am in the midst of working on my Clinical Research Project (more commonly known as a dissertation) and my topic is on PCOS. I'm writing in the hopes that, once my study gets approved, you would be willing to share a brief survey on the PCOS Diva Facebook page so that women with PCOS may be able to participate in my study?

Please let me know your thoughts as well as any questions you might have. My contact information is listed below.

Thank you,

Katelyn Baker

Therapy Extern at TherapyWorks, Valparaiso/Michigan City

Third Year Clinical Psychology Doctorate Student

Illinois School of Professional Psychology

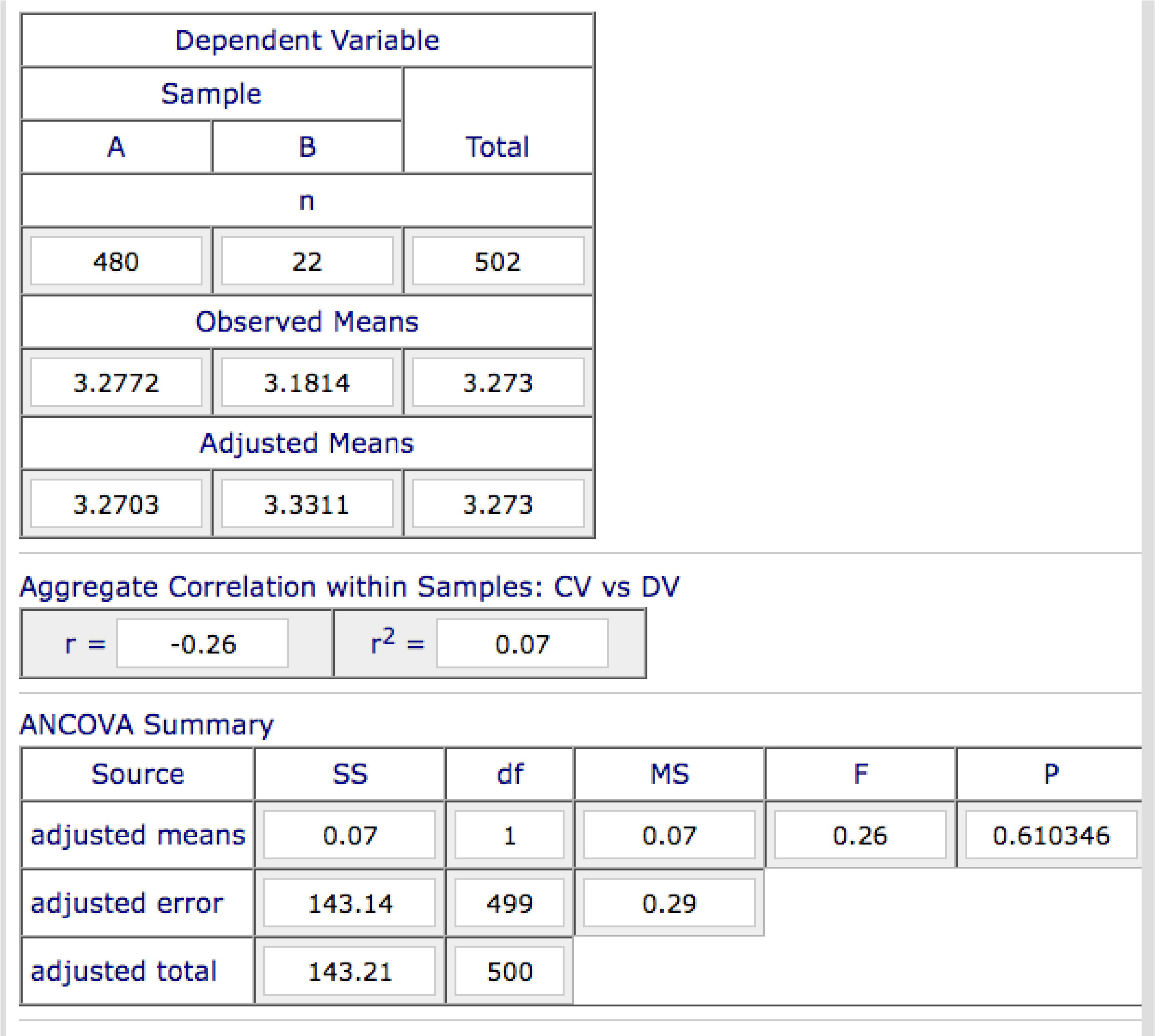
kebaker94@stu.argosy.edu

(219) 765-8584

Appendix F

Results Tables

Table 1



Dependent Variable		
Sample		Total
A	B	
n		
480	22	502
Observed Means		
3.2772	3.1814	3.273
Adjusted Means		
3.2703	3.3311	3.273

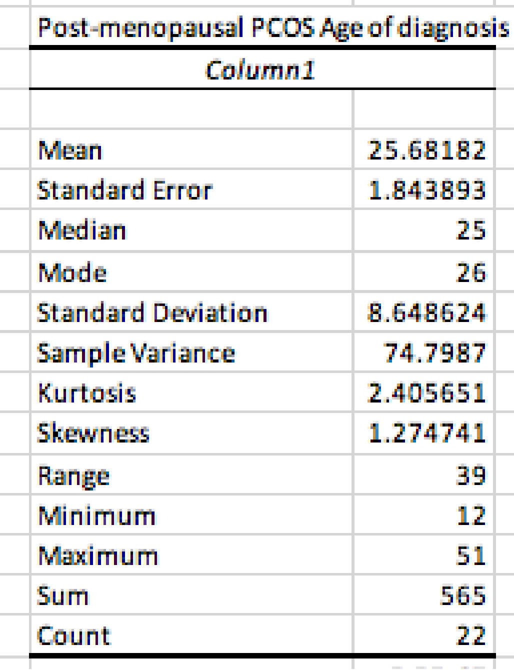
Aggregate Correlation within Samples: CV vs DV

r =	-0.26	r^2 =	0.07

ANCOVA Summary

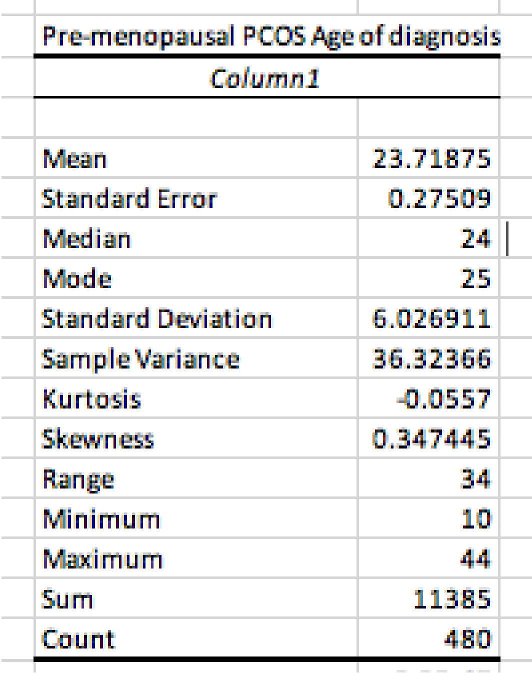
Source	SS	df	MS	F	P
adjusted means	0.07	1	0.07	0.26	0.610346
adjusted error	143.14	499	0.29		
adjusted total	143.21	500			

Table 2



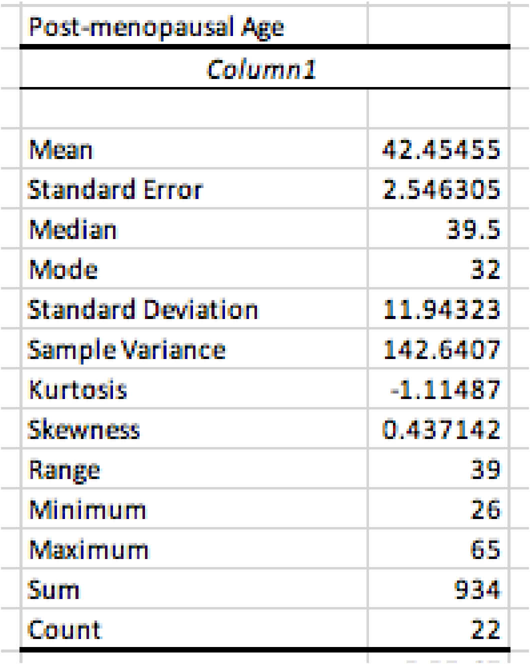
Post-menopausal PCOS Age of diagnosis	
Column1	
Mean	25.68182
Standard Error	1.843893
Median	25
Mode	26
Standard Deviation	8.648624
Sample Variance	74.7987
Kurtosis	2.405651
Skewness	1.274741
Range	39
Minimum	12
Maximum	51
Sum	565
Count	22

Table 3



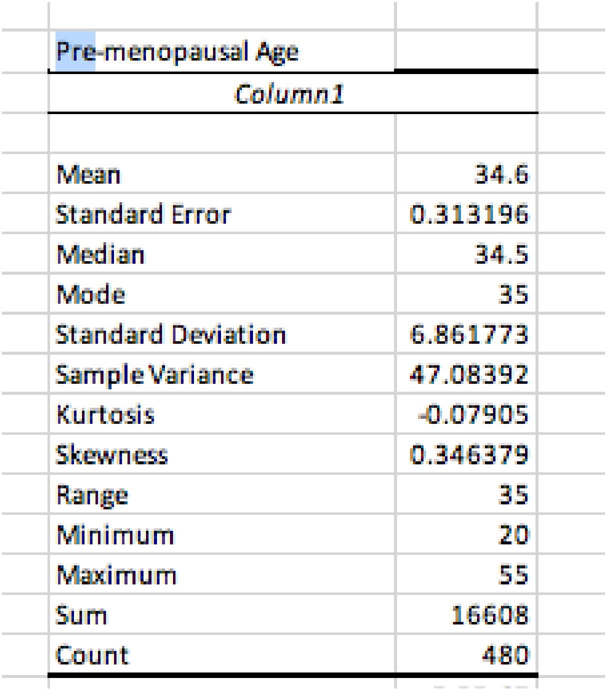
Pre-menopausal PCOS Age of diagnosis	
Column1	
Mean	23.71875
Standard Error	0.27509
Median	24
Mode	25
Standard Deviation	6.026911
Sample Variance	36.32366
Kurtosis	-0.0557
Skewness	0.347445
Range	34
Minimum	10
Maximum	44
Sum	11385
Count	480

Table 4



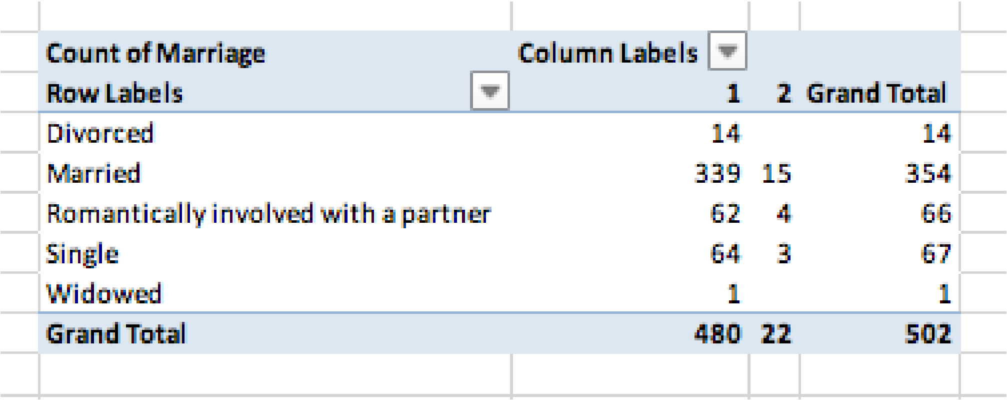
Post-menopausal Age	
Column1	
Mean	42.45455
Standard Error	2.546305
Median	39.5
Mode	32
Standard Deviation	11.94323
Sample Variance	142.6407
Kurtosis	-1.11487
Skewness	0.437142
Range	39
Minimum	26
Maximum	65
Sum	934
Count	22

Table 5

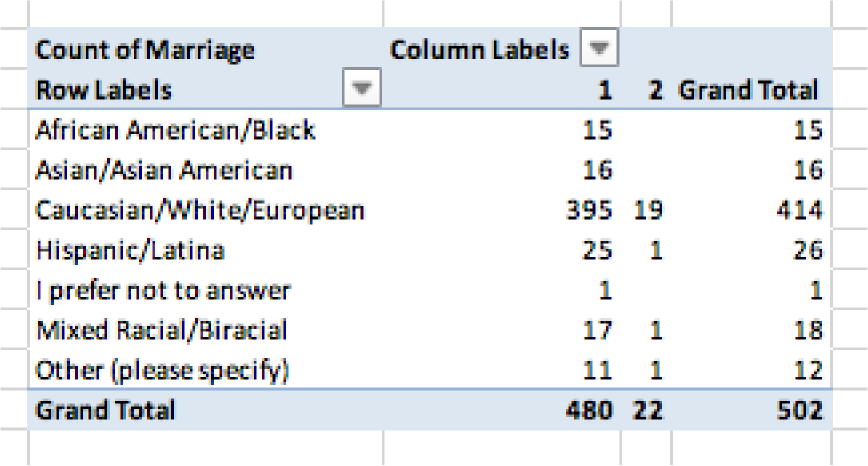


Pre-menopausal Age	
Column1	
Mean	34.6
Standard Error	0.313196
Median	34.5
Mode	35
Standard Deviation	6.861773
Sample Variance	47.08392
Kurtosis	-0.07905
Skewness	0.346379
Range	35
Minimum	20
Maximum	55
Sum	16608
Count	480

Table 6



Count of Marriage	Column Labels		
Row Labels	1	2	Grand Total
Divorced	14		14
Married	339	15	354
Romantically involved with a partner	62	4	66
Single	64	3	67
Widowed	1		1
Grand Total	**480**	**22**	**502**



Count of Marriage	Column Labels		
Row Labels	1	2	Grand Total
African American/Black	15		15
Asian/Asian American	16		16
Caucasian/White/European	395	19	414
Hispanic/Latina	25	1	26
I prefer not to answer	1		1
Mixed Racial/Biracial	17	1	18
Other (please specify)	11	1	12
Grand Total	**480**	**22**	**502**