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Study of Intuitive Eating Ratings and Self-Efficacy Differences in Women with

Polycystic Ovarian Syndrome (PCOS).

by

Meaghan Ormsby Schillinger, RD

Thesis

Submitted to the School of Health Sciences

Eastern Michigan University

In partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

In

Human Nutrition

Thesis Committee:

Chair: Rubina Haque, PhD, RD

Alice Jo Rainville, PhD, RD, CHE, SNS

Rachel Liger, MS, RD

July 13, 2014

Ypsilanti, Michigan



Dedication

I would like to dedicate this work to my mom, Mary Jo Ormsby.



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Acknowledgements

I would like to thank my advisor, Dr. Rubina Haque, for the immense amount of time she spent guiding me during this process. Her knowledge and expertise was essential in successfully completing this thesis. I will always be grateful for her mentorship. I would also like to acknowledge with gratitude my other committee members, Dr. Alice Jo Rainville and Rachel Liger, MS, RD. Thank you for sharing your dietetic and editing feedback. I highly respect the dietitians on my committee and their academic backgrounds and skills.

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Lastly, I would like to thank the women who took the time to respond to my survey. Your contribution to the field of PCOS and nutrition is valued and I thank you.



Abstract

Background: Polycystic Ovarian Syndrome (PCOS) is an endocrine disorder, which if left untreated can lead to infertility and diabetes.

Objective: To determine whether women with PCOS who practice intuitive eating skills are more confident in sustaining healthy lifestyle changes.

Methods: A web-based survey was completed by 120 women with PCOS. Bivariate associations between the self-efficacy and intuitive eating scales was investigated using scatterplots, Pearson's correlation coefficient, and a simple linear regression model. Ratings on the intuitive eating scale were dichotomized as high or low and self-efficacy ratings were compared.

Results: Of the 120 responses, 89% of women (n=107) had previously dieted. A positive relationship existed between intuitive eating ratings and self-efficacy (p<0.001).

Conclusion: Women who engaged in fewer dieting behaviors and thinking were more likely to anticipate implementing and sustaining health behavior and lifestyle changes. Dietary approaches to PCOS which include intuitive eating skills will be more effective and lasting.



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Chapter 1: Introduction

Background

Polycystic Ovarian Syndrome (PCOS) is an endocrine disorder, affecting 6-17.8% of reproductive-age women ¹⁻⁵ with up to 69% of women being undiagnosed.² The study by Azziz et al.¹ (n=400) found 6.6% of women ages 18 to 45 participating in preemployment physicals had PCOS. In a retrospective birth cohort study, March et al.² interviewed and examined 728 women born 1973-1975 and found prevalence as high as $17.8\pm2.8\%$. Moran et al.³ performed a cross-sectional study with 150 female volunteers age 20 to 45 years. They found that 6% of the Mexican volunteers met criteria for PCOS. Nidhi et al.⁴ studied prevalence in Indian adolescents ages 15 to 18. 460 girls were evaluated and 9.13% had PCOS. In 2009, Ferdous et al.⁵ performed a cross-sectional study with Iranian women who were evaluated in a mandatory pre-marriage screening clinic (n=820) and found prevalence as high as 15.2%.

Originally called Stein-Leventhal Syndrome, PCOS was first recognized in 1935 as a syndrome involving ovarian cysts and reproductive challenges.⁶ Originally seen as a primarily reproductive issue, due to the broader understanding of the effect of androgens and insulin, PCOS is now mainly viewed as an endocrine disorder.⁶ PCOS features can be categorized into three groups: clinical, endocrine, and metabolic.⁶ The clinical features include menstrual abnormalities, hirsutism (excessive hair growth), acne, alopecia (hair loss from the scalp), elevated body weight, anovulatory infertility and recurrent miscarriages. The endocrine features include elevated androgens, luteinizing hormone, estrogen and prolactin levels.⁶ The metabolic aspects of this syndrome include



insulin resistance, elevated weight, lipid abnormalities and an increased risk for impaired glucose tolerance and type 2 diabetes mellitus.⁶

"Traditional" interventions for elevated weight or health concerns, including PCOS, have focused on helping individuals achieve and maintain a weight that is determined based on height, age, and sex. This traditional model focuses on creating a negative caloric balance, with a focus on portions, calories, and/or foods to avoid, with the target outcome being weight loss.⁷ Alternatively, the nondiet approach focuses on reconnecting with physiological hunger and using hunger and fullness rather than calories or food lists to guide amounts of food eaten. The nondiet approach differs from the traditional model in that knowledge about food and nutrition is used to inform food choice rather than drive food choice.

Purpose of the Study

The purpose of this study is to investigate if there is a difference in self-efficacy ratings among women with PCOS who rate themselves high on the Intuitive Eating (nondiet) scale compared to women with PCOS who rate themselves low on the Intuitive Eating Scale. This was achieved using a 23-question survey, which was completed by 120 women with PCOS.



Chapter 2: Review of the Literature

The literature to date describes dietary treatment of PCOS as a first-line treatment modality.^{6, 8-14} In their paper on pathophysiology, Tsilchorozidou et al.⁶ describe the associations between insulin resistance and PCOS and conclude that lifestyle modifications, especially diet and exercise, are critical in treatment. Badawy and Elnashar⁸ describe the importance of treating obesity associated with PCOS with diet, exercise, medical, and surgical treatment. Egan et al.⁹ describe the importance of dietary modifications, exercise, and Metformin in treating PCOS and preventing long term health risks. Ladson et al.¹⁰ describe lifestyle modification as the "cornerstone of therapy for PCOS". Moran at al.¹¹ call for more research on diet and exercise in the treatment of PCOS so that medication and surgery can be avoided. Ornstein et al.¹² describes the importance of lifestyle modification opposed to medications in the treatment of adolescents with PCOS. Jeanes et al.¹³ studied the varied nutrition advice given to women with PCOS and describe the lack of definitive dietary guidelines in PCOS treatment and the importance of lifestyle modification in managing PCOS. Sharma et al.¹⁴ surveyed the type of advice practitioners in the UK give to women with PCOS (n=107) and found diet and exercise to be the first-line treatments and recommendations.

Although there seems to be consensus among researchers and clinicians about the effectiveness and importance in recommending dietary changes to patients with PCOS as an effective first-line treatment, there are no definitive dietary guidelines. Generally, dietary treatments are either based on data extrapolated from diabetic studies/diets or on the results of research articles addressing PCOS and specific nutrition interventions ^{9, 10, 12, 15 - 17}; however, many of these studies showed high drop-out rates. In a six-month



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study, Egan et al.⁹ evaluated compliance to a low glycemic index (GI) diet and whether or not a low GI diet decreases the risk of endometrial cancer in women with PCOS (n=9). While the women were successful in eating an overall lower GI diet, longer-term studies are needed to draw conclusions about low GI and endometrial cancer. Ladson et al.¹⁰ compared lifestyle (exercise and calorie restriction) with Metformin to lifestyle changes and placebo and the effect on ovulation and testosterone levels; 114 women with PCOS were randomized in the study but only 38 women completed the six-month study (66.7% attrition).

Ornstein et al.¹² compared a low-fat (<40g fat/day) hypocaloric diet to a very low carbohydrate diet/high protein diet (20 - 40g carbohydrate/day) in females with PCOS age 12 – 22 years (n=16). 24 females were randomized in the study but only 16 completed the study (33.3% attrition). Kasim-Karakus et al.¹⁵ compared protein and simple sugar intake on the effect of metabolic and hormonal markers. Each group was instructed on a 450-calorie diet. Thirty-three women with PCOS were randomized to the study but only 24 women completed the two-month study (27.3% attrition).

Marsh et al.¹⁷ compared the effect of a low glycemic index (GI) diet to a macronutrient matched healthy diet in 96 women with PCOS. There was some improvement in menstruation regularity in the low-GI group, but the study had a 49% attrition rate. Questions remain about the most effective dietary changes for this population, as well as how to create sustainable change in women with PCOS implementing dietary changes. This study seeks to examine the latter.

Interestingly, in the literature to date, vocabulary and definitions that have seemed to become interchangeable are the term "lifestyle modification" and a hypocaloric diet.



Whereas the literal definition of lifestyle includes the habits and/or attitudes of an individual or group, and nothing about a restrictive eating pattern, lifestyle modification studies that examine dietary changes use hypocaloric diets or a focus on weight loss as the solution rather than a potential result of symptom improvement. The "lifestyle therapy" in a study by Ladson et al.¹⁰ included a hypocaloric diet (500 calories below calculated maintenance calories) and \geq 2 exercise sessions/week. Although the title of Ornstein et al.¹²'s study is "Effect of Weight Loss on Menstrual Function in Adolescents with Polycystic Ovarian Syndrome," the actual intervention is either a low fat or low carbohydrate diet.

In their study on insulin resistance and women with PCOS, Toscani et al.¹⁸ compared the macronutrient intake in women with PCOS (n=43) to controls (n=37). Although examining macronutrient intake, the authors begin by stating a positive effect of weight loss in women with PCOS. This may need reconsideration given that diets usually fail as long term solutions for health and weight management, with the majority of weight being regained within five years.¹⁹ High drop out rates and low self-efficacy may compound the anxiety and depression, which is already high in populations with PCOS.²⁰⁻²³

Kerchner et al.²⁰ surveyed 60 women with PCOS using an instrument designed to detect depressive symptoms, anxiety symptoms and binge eating. Forty percent of the women had depression, 11.6% had anxiety syndromes, 56.6% had mood disorders, and 23.3% had binge eating disorder. Additionally, cortisol has been shown to have a positive relationship with insulin, ^{23, 24} and dieting has been shown to increase cortisol levels, ²⁵ which are already higher in the PCOS population.²⁴



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The difficulty that women with PCOS have losing weight compared to the non-PCOS population has been reported.²⁶ The mechanism underlying this difficulty is insulin resistance, which 40-64% ²⁶⁻²⁸ of women with PCOS have. In their prospective, case controlled study, DuGarte et al.²⁷ found 64% of women with PCOS (n=271) had insulin resistance. With the weight dysregulation in PCOS women most likely being a product and a symptom of PCOS rather than the cause, the recommendation for weight loss is dim, given that it is not addressing the underlying cause of the weight dysregulation.

Conclusions that weight loss improved PCOS symptoms in studies with methods and results relevant to the dietary modifications themselves and not the outcome of weight loss are also questionable.¹⁰ For example, when the intervention is a severely low carbohydrate intake (20g/day x 3 weeks, progressing to 40g/day x 9 weeks), the body is not given the building blocks to raise glucose or insulin levels, but menstrual improvements were attributed to (starvation induced) weight loss rather than a likely decrease in insulin levels. While information about the physiological changes occurring with increased weight and adipokines may be relevant, ^{29, 30} improvement in insulin and glucose regulation may be a more worthwhile focus for dietary treatment of PCOS than weight-focused treatments, especially when it has been well established that programs focused on weight reduction and restriction have a high failure rate. In addition, insulin resistance occurs with and without obesity in women with PCOS, making weight-focused dietary interventions even less appropriate for this population. Lifestyle modification interventions aimed at improving insulin sensitivity rather than weight are truly most



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relevant because both lean and obese women with PCOS are more insulin resistant than their non-PCOS counterparts.³¹

The focus on weight loss improving symptoms of PCOS is also questionable because a review of lifestyle interventions shows mixed results with regard to differing weight outcomes, including weight loss without glycemic improvement and glycemic improvement without weight loss.^{11, 32} Weight-bias has been studied in non-PCOS population studies ^{33, 34} and can also be found in PCOS literature, where high drop out rates are attributed to low compliance associated with higher weight individuals.¹¹

The failure rate of dieting in populations without PCOS is high, with little long term success and only 30% of dieters maintaining weight losses of >10% for >5 years.^{35 -³⁷ Dieting and weight cycling is positively associated with depression and eating pathology, which are already more prevalent in the PCOS population compared to the non-PCOS population.^{21, 38 - 40} The dropout rates from dietary interventions with PCOS range from 27% - 67%.^{10, 12, 15, 17} There is a need for dietary intervention strategies that are sustainable. The nondiet approach for health management and improved outcomes has been demonstrated in populations without PCOS.^{41 - 44} There is a need for PCOS nutrition interventions which result in sustainable change. If the nondiet/intuitive model were used with PCOS nutrition recommendations, there may be a higher likelihood of successful, sustainable outcomes.}

Insulin resistance in women with PCOS exacerbates symptoms (including menstrual abnormalities, hirsutism, acne, alopecia, and weight disruptions), impairs fertility, impairs glucose tolerance, and increases risk for developing diabetes in both normal-weight and higher-weight women.⁴⁵ PCOS is also associated with a higher rate



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of cardiovascular risk factors.⁴⁶ The impact of dietary changes as a first-line treatment of PCOS will be greater if behavior changes are long-term versus short-term.



Chapter 3: Research Design and Methodology

The objective of this study was to investigate the nondiet approach compared to traditional dietetic approaches in treating women with PCOS by presenting differences in self-efficacy ratings between women with PCOS who are more intuitive and women with PCOS who are less intuitive. The study was approved by the College of Health and Human Services, Human Subjects Review Committee, Eastern Michigan University, Ypsilanti, MI (Appendix A).

Questionnaire

The principal investigator developed the questionnaire (Appendix B). The survey consisted of 23 questions, which assessed intuitive eating practices and beliefs as well as self-efficacy. The demographic questions, questions two and three, collected information on age and race. The biometric questions, questions four to six, collected information on height, weight and weight history. Questions seven to twelve collected data on the subjects' experience at the time of diagnosis. Questions about current PCOS treatment practices, questions 13 to 15, collected data about symptoms, exercise, medication use and supplement use. Questions sixteen to twenty-one collected data about past and current dieting practices. Questions twenty-two and twenty-three were adapted using questions that had been validated in previous studies and collected data about intuitive eating beliefs and practices as well as self-efficacy data.^{47, 48} The questions assessing intuitive eating were based on Tylka's intuitive eating scale which has subsections for unconditional permission to eat, eating for physical rather than emotional reasons, and reliance on internal hunger/satiety cues.⁴⁸



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Informed consent was obtained from each participant by her selection of "agree" at the start of the survey in response to question number one which asked participants to confirm that they reviewed and agree with the informed consent for participation in research summary seen on page one of the survey (Appendix B). The survey was available for 50 days and participants accessed it using the following link https://www.surveymonkey.com/s/pcos2012.

The cross-sectional questionnaire was delivered using the SurveyMonkey[™] software program which allowed the link to be posted on websites, including PCOS Seattle Meetup (http://www.meetup.com/PCOS-Seattle-Meetup/about/) and on the Principal Investigator's blog which is related to PCOS (<u>www.pcosseattle.blogspot.com</u>). The PI requested that the survey link be posted on Facebook pages related to PCOS (PCOS Seattle, PCOS Dietitian, Sound Nutrition Counseling, and Washington PCOS Support), which allowed more participants to be included in the study. It was not possible to view the identity of those who chose to participate in the survey via this blog. The link was introduced using text found in Appendix C. An incentive of a \$5.00 Starbucks gift card was offered to the first 40 women who participated in the study. Gift cards were delivered electronically to the email addresses provided.

The survey used in this study assessed the current status of intuitive eating skills used by study participants (women with PCOS, age 18 - 40). The results can inform nutrition treatment protocols in the future. The field of dietetics as well as other health fields may need to reconsider using the traditional model, which is weight-focused rather than health-focused. Women with PCOS may benefit greatly by being taught to use



nutrition information to make informed decisions about food, without the rigidity and deprivation associated with dieting.

Data Analysis

Bivariate associations between the self-efficacy and intuitive eating scales was investigated using scatterplots, Pearson's correlation coefficient, and a simple linear regression model was used. Responses to questions about intuitive eating were scaled and participants were categorized as low or high, using Tylka's scaling method.⁴⁸ Ratings on the intuitive eating scale were then dichotomized as high or low and self-efficacy ratings were compared. A two-sample t-test was used and a P-value of < 0.05 was considered statistically significant.^{49, 50} Intuitive eating responses (questions 22a - 22v) were also recoded in a way that a Cronbach's alpha statistic, which examines reliability by determining the internal consistency of a test or the average correlation of variables within the test, would suggest they should be coded. Data analysis was conducted using Stata/IC 12.1 (College Station, Texas).



Chapter 4: Research Results

A total of 130 women began the survey and 120 women completed the survey

(n=120). Inclusion criteria were as follows:

- 1. Females age 18 40 years old, with a diagnosis of PCOS
- 2. All ethnic groups

Demographics

The sample population consisted of females ages 18 to 40 years old. Most of the sample population was white (n=105, 87.5%) and 65.8% were between the ages of 24 and 35. Demographic characteristics of the sample population (n=120) are presented in Table 1.

Table 1. Demographics of participants in a study toassess self-efficacy in women ($n=120$) with varyingdegrees of intuitive eating skills in women with PCOSages 18 to 40.					
Demographic	Total (n)	% of Total			
Age					
18 to 23	6	5.0			
24 to 29	34	28.3			
30 to 35	45	37.5			
36 to 40	35	29.2			
Race (could choose >1)					
White	105	87.5			
African American	10	8.3			
Hispanic or Latino	10	8.3			
American Indian or Alaskan Native65.0					
Asian 4 3.3					
Native Hawaiian or Other0Pacific Islander0					



Weight History

Data on the weight history of the participants are presented in Table 2. The mean height was 5'5". The mean current reported weight was 228.4 pounds. Only one subject did not report lowest weight range. Nearly half (49.6%) of the participants reported lowest weights were between 151 and 200 pounds. Thirty two (26.7%) of the women reported a highest weight of 226 to 250 pounds. Survey question number 19 asked about the degree of weight fluctuation in the last 10 years. Over half (n=78, 65%) of women reported weight fluctuation(s) of 21 - 75 pounds within the last 10 years.



Table 2. Weight data of participants in a study to					
assess self-efficacy in women	with PCO	OS ages 18 to			
40 with varying degrees of intuitive eating skills					
(n=119, n=120).					
Weight history					
Responses (pounds) T	otal (n)	% of Total			
Lowest weight (n=119)					
100 – 150 lb	26	21.8			
151 – 175 lb	31	26.0			
176 – 200 lb	28	23.5			
201 – 225 lb	15	12.6			
226 – 250 lb	11	9.1			
251 – 275 lb	1	1.0			
276 – 300 lb	6	5.0			
301 – 325 lb	1	1.0			
326 – 350 lb	0	0.0			
351 – 375 lb	0	0.0			
376 – 400 lb	0	0.0			
401 – 450 lb	0	0.0			
451 – 500 lb 0 0.0					
Highest Weight (n=120)					
100 – 150 lb	5	4.2			
151 – 175 lb	5	4.2			
176 – 200 lb	11	9.2			
201 – 225 lb	15	12.5			
226 – 250 lb	32	26.7			
251 – 275 lb	19	15.8			
276 – 300 lb	16	13.3			
301 – 325 lb	6	5.0			
326 – 350 lb	5	4.2			
351 – 375 lb	3	2.5			
376 – 400 lb	1	0.8			
401 – 450 lb	1	0.8			
451 – 500 lb	1	0.8			
Weight fluctuation x 10 years (n=120)					
No fluctuation	3	2.5			
1-9 pound fluctuation	2	1.6			
10-20 pound fluctuation	15	12.5			
21-50 pound fluctuation	21-50 pound fluctuation 44 36.7				
51 – 75 pound fluctuation	34	28.3			
76 – 100 pound fluctuation	14	11.7			
> 100 pound fluctuation	8	6.7			



Diagnosis Data

Table 3 summarizes participants' responses to questions about age at the time of diagnosis, diagnosing practitioner, and symptoms used in the diagnosis. The mean reported age of diagnosis was 24.2 years. Over half (n=75, 62.5%) of women reported being diagnosed between the ages of 18 and 29. Fifty-eight percent (n=70) of the women were diagnosed by obstetrics and gynecology physicians. Women reported multiple symptoms with the most common being irregular menses (n=105, 86.8%) and visual symptoms (n=84, 69.4%), which included acne, balding, and hirsutism.

Table 3. Diagnosis data in a study to assess self-				
efficacy in women (n=120) with varying degrees of				
intuitive eating skills in women with PCOS ages 18 to				
40.		C		
Diagnosis data	Total (n)	% of Total		
Age of diagnosis				
≤17	15	12.5		
18 to 23	44	36.7		
24 to 29	31	25.8		
30 to 35	27	22.5		
36 to 40	3	2.5		
Diagnosing provider (could	l choose >1)		
OBGYN*	70	58.3		
Family practice physician	30	25.0		
Endocrinologist	23	19.2		
Other	12	10.0		
Self-diagnosed	9	7.5		
Internist	4	3.3		
Pediatrician	2	1.7		
Dermatologist	0	0.0		
Diagnosis symptom(s) (cou	ld choose >	1)		
Irregular menses	105	86.8		
Visual symptoms (acne,				
balding, excessive hair	84	69.4		
growth)				
Cysts on ovaries	78	64.5		
Elevated testosterone	67	55.4		
* OBGYN is Obstetrician/Gynecologist				



Referral and Resource Information

Table 4 summarizes referral and resource information. The majority of women (n=88, 73.3%) were not referred to another practitioner for support and further PCOS treatment. Of the 32 women who were referred to another provider, the most common (n=23, 72.9%) referral was to an endocrinologist. 17% (n=6) of the 32 women were referred to a Registered Dietitian. Weight loss (n=90, 75%), medication (n=82, 68.3%),

Table 4. Referral and resource information in a study			
to assess self-efficacy in women (n=120) with varying			
degrees of intuitive eating skills in women with PCOS			
ages 18 to 40.			
Referral/resource			
Information	Total (n)	% of Total	
Rate of referral to anothe	r provider		
Yes	32	26.7	
No	88	73.3	
Referral type			
Endocrinologist	23	19.2	
Other	8	6.7	
Registered dietitian	6	5.0	
Dermatologist	5	4.2	
Internist	2	1.7	
Advice received			
Weight loss	90	75.0	
Medication	82	68.3	
Exercise	76	63.3	
Diet/nutrition advice	44	367	
unrelated to weight loss	44	50.7	
No advice	18	15.0	
Dietary supplements	11	9.2	
Acupuncture	4	3.3	
Self-education			
Websites	102	84.3	
Doctor	54	44.6	
Blogs	47	38.8	
Books	45	37.2	
Family/friends with	26	01 5	
PCOS	26	21.5	



and exercise (n=76, 63.3%) were the most common types of advice given by the diagnosing practitioner. The most common resource utilized for PCOS information was websites (n=102, 84.3%).

Symptoms

Table 5 summarizes the symptoms reported by participants. In the survey, hirsutism was defined to the participants as "hair on the face, chest, back, stomach, thumbs, or toes". Weight disturbance was defined as "weight gain that felt mysterious, as though it did not make sense". None of the participants reported experiencing "no symptoms". The most common reported symptom was weight concentrated around the waist (n=106, 87.6%), followed by hirsutism (n=105, 86.8%), and mood swings (n=91, 75.2%).



to 40.		
Symptom	Total (n)	% of Total
Weight concentrated around the waist	106	88.3
Hirsutism	105	87.5
Mood swings	91	75.8
Depression	89	74.2
Anxiety	86	71.7
Insulin resistance	76	63.3
Weight disturbance	76	63.3
Irregular menstruation more than 35 days between menses	74	61.7
Infertility	72	60.0
Acne	66	55.0
Elevated testosterone on lab report	65	54.2
Irregular menstruation No menstruation	53	44.2
Sleep apnea	45	37.5
Alopecia	31	25.8
Menstruation without ovulation	29	24.2
Irregular menstruation More frequently than every 28 days	25	20.8
"I experience no symptoms"	0	0.0

Table 5. Symptoms of participants in a study to assess self-efficacy in women (n=120) with varying degrees of intuitive eating skills in women with PCOS ages 18 to 40.

Medication and Supplement Use

Medication and supplement use are summarized in Table 6. Metformin was the most common medication; 52.9% of women reported use of it. Seventeen subjects reported other medication or supplement use which was not PCOS-specific. It is unclear whether supplement use was recommended by the diagnosing or by the treating



physician, but over a third of women reported taking a multivitamin (n=49, 40.5%) and

vitamin D (n=44, 36.4%).

Table 6. Medication and supplement use of				
participants in a study to assess self-efficacy in women				
(n=120) with varying degr	rees of intui	itive eating skills		
in women with PCOS age	s 18 to 40.			
Reported useTotal (n)% of Total				
No use of medications or	21	25.6		
supplements	51	23.0		
Medications				
Metformin	64	52.9		
Birth control	33	27.3		
Spironolactone 16 13.2				
Fertility medicines or	8	6.6		
injections 8 0.0				
Supplements				
Multivitamin 49 40.5				
Vitamin D 44 36.4				
Omega-3 19 15.7				
Other (non-PCOS)*	17	14.1		
Herbs	13	10.7		
Other (PCOS-specific)**	6	5.0		
* Vitamin B12 (n=3), Iron	* Vitamin B12 (n=3), Iron (n=2), Phentermine (n=1),			
flax oil (n-1), progesterone (n=1), Glumetza 500				
(n=1), fortamet (n=1), Provera (n=1), cinnamon,				
biotin, B-complex, fish oil, garlic				
** Defined to participants as "other supplements				
marketed/labeled as being PCOS-specific"				

Exercise Behaviors

Table 7 summarizes exercise practices and exercise beliefs. Nineteen of the women (15.8%) reported engaging in no physical activity and having no enjoyment in physical activity, while 27 women (22.3%) reported engaging in no physical activity but enjoying physical activity. Approximately one third of participants (n=44, 36.7%) reported enjoying physical activity and engaging in it 1 to 3 days per week.



Table 7. Exercise patterns and beliefs of participants				
in a study to assess self-efficacy in women (n=120)				
with varying degrees of intuitive eating skills in				
women with PCOS ages 18 to 40	•			
ResponsesTotal (n)% of Total				
Activity frequency				
0 frequency + no enjoyment	19	15.8		
0 frequency + enjoyment	27	22.5		
1-3 days/week + enjoyment	43	35.8		
1-3 days/week + no enjoyment	18	15.0		
4-7 days/week + enjoyment	11	9.2		
4-7 days/week + no enjoyment	2	1.7		
Dieting & exercise behaviors				
Dieting + exercise	62	517		
(question #17)*	02	51.7		
Dieting separate from exercise	58	48.3		
Exercise enjoyment				
1 ("I hate exercise")	10	8.3		
2	6	5.0		
3	9	7.5		
4	10	8.3		
5 ("I could take it or leave it")	30	25.0		
6	20	16.8		
7	12	10.0		
8	15	12.5		
9	4	3.3		
10 ("I truly enjoy exercise very				
much") 4 3.3				
* Survey question number 17 asked if "exercise and				
dieting feel connected in such a way that when you are				
not dieting, you are likely to stop exercising also".				

Dieting Habits

Table 8 summarizes the reported dieting history of participants. Question ten

asked participants about the frequency of dieting in the last 10 years. Forty-one percent

of the participants (n=49) reported dieting seven times or more. Most diets (n=95,

79.2%) were self-created.



degrees of intuitive eating skills in women with PCOS				
ages 18 to 40.				
Dieting behavior	Total (n)	% of Total		
History				
None in the last 10 years	13	10.8		
One time	4	3.3		
Two times	12	10.0		
Three times	14	11.8		
Four times	16	13.3		
Five times	7	5.8		
Six times	5	4.2		
Seven times or more	49	40.8		
Diet choice (could choose >1)				
Self-created	95	79.2		
Diet books	47	39.2		
Commercial programs	40	33.3		
Medically supervised	26	21.7		
Weight-loss surgery	6	5.0		

Table 8. Dieting behaviors of participants in a study to

Intuitive Eating Attitudes and Behaviors

Table 9 summarizes the eating attitudes and behaviors of participants. Some women did not respond to 100% of the questions (items b, c, d, g, h, j, k, l, m, o, q, r, s, and t). The questions in Table 9 are the questions, which were used to assess and categorize participants as low or high intuitive eaters (each participant's intuitive eating rating was later compared to their self-efficacy responses to answer the hypothesis).

The results highlight an avoidance of foods high in fat (32.5%), carbohydrates (37.0%), and calories (37.8%). Approximately two thirds (n=78, 65%) of the women reported eating when emotional. When asked if a craving will be met despite whether or not they consider the food item healthy, over two thirds (n=84, 70.0%) of the participants responded that a craving will be met despite whether or not they consider the food item healthy. When asked about whether or not eating rules or diet plans dictate what, when



and/or how much to eat, slightly over half (n=63, 52.5%) of the women responded "strongly disagree" or "disagree". Non-hunger eating cues boredom (question 22h), loneliness (question 22l), and stress (question 22s) were at 57.5% (n=69), 46.7% (n=56), and 51.7% (n=62) agreed or strongly agreed. Responses to questions about ability to sense hunger and fullness (questions 22i, 22j, and 22q) show that over two thirds of the participants report the ability to sense hunger and fullness, however responses to questions about trusting their body to tell themselves when, what and how much to eat (questions 22m, 22n, 22o, and 22u) show that less than half of women agree or strongly agree.

Table 9 Intuitive eating attitudes and behaviors of participants (n=120) in a study to assess self-efficacy in women with varying degrees of intuitive eating skills in females with PCOS ages 18 to 40. The highest reported rate in each category is shown in bold text.

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Total (n)
a. I try to avoid certain foods high in fat.	9.2% 11	21.7% 26	23.3% 28	32.5% 39	13.3% 16	120
b. I try to avoid certain foods high in carbohydrate.	5.0% 6	20.2% 24	22.7% 27	37.0% 44	15.1% 18	119
c. I try to avoid certain foods high in calories.	5.0% 6	18.5% 22	29.4% 35	37.8% 45	9.2% 11	119
d. I stop eating when I feel full (not overstuffed).	3.4% 4	15.4% 18	21.4% 25	38.5% 45	21.4% 25	117
e. I find myself eating when I'm feeling emotional (e.g., anxious, depressed, sad), even when I'm not physically hungry.	9.2% 11	14.2% 17	11.7% 14	32.5% 39	32.5% 39	120
f. If I am craving a certain food, I allow myself to have it, whether I consider it healthy or not.	3.3% 4	9.2% 11	17.5% 21	48.3% 58	21.7% 26	120
g. I follow eating rules or dieting plans that dictate what, when, and/or how much to eat.	16.8% 20	36.1% 43	29.4% 35	10.1% 12	7.6% 9	119
h. I find myself eating when I am bored, even when I'm not physically hungry.	10.9% 13	17.7% 21	13.5% 16	40.3% 48	17.7% 21	119



Table 9 Intuitive eating attitudes and behaviors of participants (n=120) in a study to assess self-efficacy in women with varying degrees of intuitive eating skills in females with PCOS ages 18 to 40. The highest reported rate in each category is shown in bold text.

	Strongly	Disagree	Neutral	Agree	Strongly	Total
	disagree				Agree	(n)
i Lean tell when I'm slightly full	4.2%	12.5%	18.3%	49.2%	15.8%	
1.1 can ten when I in slightly full.	5	15	22	59	19	120
j. I can tell when I'm slightly	2.5%	10.9%	16.0%	49.6%	21.0%	
hungry.	3	13	19	59	25	119
k. I get mad at myself for eating	10.2%	17.0%	18.6%	28 00/2	26.3%	
something that is considered	10.270	20	10.070	20.070	31	118
unhealthy.	12	20		55	51	110
l. I find myself eating when I am	10.9%	22.7%	19 3%	32.8%	14 3%	
lonely, even when I'm not	13	22.770	23	39	17.570	119
physically hungry.	15	_ /	23	57	17	117
m. I trust my body to tell me	10.1%	26.1%	22.7%	26.9%	14.3%	
when to eat.	12	31	27	32	17	119
n. I trust my body to tell me what	17.5%	34.2%	25.8%	15.8%	6.7%	
to eat.	21	41	31	19	8	120
o. I trust my body to tell me how	13.8%	27.6%	18.1%	28.5%	12.1%	
much to eat.	16	32	21	33	14	116
p. I have forbidden foods that I	22.5%	33.3%	14.2%	17.5%	12.5%	
don't allow myself to eat.	27	40	17	21	15	120
q. When I'm eating, I can tell	1.7%	10.9%	22.7%	44.5%	20.2%	
when I am getting full.	2	13	27	53	24	119
r. I use food to help me soothe	10.9%	24.4%	16.8%	31.9%	16.0%	
my negative emotions.	13	29	20	38	19	119
s. I find myself eating when I am	7 60/	20.20/	20.20	22 (0/	10 50/	
stressed out, even when I'm not	7.0%	20.2%	20.2%	33.0% 10	18.5%	110
physically hungry.	9	24	24	40	22	119
t. I think of a certain food as	6 70/	12 60/	10.20/	10 20/	21.00/	
"good" or "bad" depending on its	0.7% Q	12.0%	19.5%	40.5% 19	21.0%	110
nutritional content.	0	15	23	40	23	119
u. I don't trust myself around	15.0%	23.3%	21.7%	24.2%	15.8%	
"fattening" foods.	18	28	26	29	19	120
v. I don't keep certain foods in	14.20/	23.3% 28	12 20/	20.20/	20.00/	
my home because I think that I	14.2% 17		13.3% 16	27.2% 25	20.0% 24	120
may lose control and eat them.			10	55	24	120

Question number 23 addressed self-efficacy. It asked participants to indicate level

of confidence in maintaining new health-related habits. Participants were asked to



indicate which statement best describes their current eating and activity behaviors. The

results are displayed in Table 10.

Table 10 Self-efficacy r	atings of par	ticipants (n=1)	20) in a s	tudy to assess	self-effic	acy in	
women with varying deg	grees of intui	tive eating ski	lls in fem	ales with PC	OS ages 1	8 to	
40. The highest reported rate in each category is shown with an asterisk.							
	Very uncertain	Somewhat uncertain	Neutral	Somewhat certain	Very certain	Total (n)	
I can manage to modify							
my eating behavior							
even if I:							
need a long time to develop the necessary routines.	5.8% 7	14.2% 17	14.2% 17	40.8% 49	25.0% 30	120	
have to try several times until it works.	4.2% 5	15.8% 19	14.2% 17	41.7% 50	24.2% 29	120	
have to rethink my entire way of nutrition.	6.7% 8	16.7% 20	14.2% 17	37.5% 45	25.0% 30	120	
do not receive a great deal of support from others when making my first attempts.	15.0% 18	23.3% 28	15.0% 18	30.0% 36	16.7% 20	120	
have to make a detailed plan.	6.7% 8	13.3% 16	18.3% 22	35.8% 43	25.8% 31	120	

When all of the data were pooled and analyzed, the results indicated a very strong relationship between intuitive eating ratings and confidence in sustaining change (p=0.047). Using a model that examines the intuitive eating scale's impact on self efficacy, once the variables were recoded using Cronbach's alpha statistic would suggest they should be coded e.g. variables that measure similar constructs should move in the same direction, an even more positive relationship is seen (p=0.007). It is a very significant positive relationship (p=0.047, p=0.007), indicating a positive relationship between the intuitive eating ratings and confidence in sustaining change. The more



intuitive the eater, the higher the self-efficacy ratings. The scatterplots in figures 1 and 2 display the association between intuitive eating and self-efficacy.





Figure 1. The association between the self-efficacy and intuitive eating scales.







Chapter 5: Discussion

The difference in self-efficacy ratings among women with PCOS who rated themselves high on the Intuitive Eating (nondiet) scale compared to women with PCOS who rated themselves low on the Intuitive Eating Scale was significant (p=0.007). These results are very informative as to how relevant the nutrition philosophy used in the delivery of nutrition education is. Based on these results, more positive (sustainable) outcomes will likely be achieved when dietitians use the intuitive eating model. If women with PCOS are encouraged to use intuitive eating as the backdrop for food selection, there will likely be improved lifestyle changes because the changes will last. In Bacon and colleagues' ⁴¹ two-year study comparing the diet approach (BMI diet group = $36.7\pm4.2 \text{ kg/m}^2$) to the non-diet approach (BMI health at every size group = $35.9\pm4.6 \text{ kg/m}^2$), 92% of the non-diet group (n=36) completed the program while 41% of the diet group (n=16) dropped out by the end of the study. The current study predicts more compliance and sustainability with less attrition when the nondiet approach is used, which supports Bacon's completion and attrition rate with a p value of 0.007.

There was a high prevalence of weight cycling in this sample of women with PCOS. Eighty nine percent of the women reported dieting 1+ times in the last 10 years and 83.4% reported weight fluctuations ranging from 21 - 100+ pounds. This is higher than the rate of weight cycling seen in a 2011 study, ⁵¹ which showed 56.8% women without PCOS intentionally losing and then regaining at least 10 pounds one or more times in their life, compared to 89.2% of the women in the present study who reported dieting one or more times. The higher rate of weight cycling in women with PCOS is disturbing and possibly exacerbated by the weight-related frustrations these women have,



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which are largely insulin resistance based, but in the diet mentality are framed as something to simply be controlled with a calorie deficit. Seventy five percent (n=90) of this sample of women with PCOS were advised to lose weight as part of their PCOS treatment, which would just encourage more unsustainable diet attempts.

The higher frequency of weight cycling and dieting among women with PCOS is also of concern because of the potential worsening of anxiety and depression. Seventy one percent (n=86) of the women in this sample reported anxiety; 73.6% (n=89) reported depression; and 75.8% (n=91) reported mood swings. Other studies have shown depressive symptoms in 40-71% of women with PCOS.^{19, 21, 52} The difference in depressive symptoms between this study and other studies may be due to the fact that depression in the current study was self-reported. The prevalence of anxiety in the current study was higher than what Dokras et al.⁵³ found in their review of the research to date in 2012 on women with PCOS and anxiety compared to controls and found 20.4% of women with PCOS exhibited anxiety symptoms compared to 3.9% in controls.

Like depression, the prevalence of anxiety reported in this study (71.1%) compared Dokras et al.⁵³ (20.4%) was likely due to the fact that in the current study, women self-reported their anxiety. In any case, research to date shows higher rates of anxiety in women with PCOS. With 89.2% (n=107) of the women reporting a diet history and 103 (85.8%) of the women reporting dieting at least twice in the last ten years, it is unknown what percentage of the mental health disturbance reported in this study can be attributed to dieting and how much of the mental health disturbance was unrelated to the dieting. In either case, it is interesting to note the common (n=90, 75%) recommendation by providers to lose weight given the high rate of anxiety, depression,



and mood swings and that dieting will likely just aggravate these negative mood states. In a review by Barry et al., ⁵⁴ the researchers found higher rates of depression and anxiety in women with PCOS and that the women with PCOS and lower BMI had slightly lower rates of anxiety and depression compared to the women with PCOS and higher BMI. The researchers chose to interpret this as suggesting that lower BMI reduces anxiety and depression, which would bring focus to weight and weight loss as the remedy. An alternative conclusion is that more weight cycling in women with higher BMIs could affect or increase depression and anxiety. This would bring attention to the weight cycling as the culprit and would allow for weight stabilization and the nondiet approach to be the remedy.

Table 9 summarized the intuitive eating attitudes and behaviors of the participants. A few things in this table are noteworthy, including the fact that while over half of the women agreed or strongly agreed that they avoid foods high in fat (45.8%) and foods high in carbohydrate (52.1%), only 17.7% of them agreed or strongly agreed that they follow eating rules or dieting plans that dictate what, when, and/or how much to eat. The previous table, table 8, showed that 79.2% (n=95) of the women had engaged in "self-created" diets. It is possible that these self-created dieting practices resulted in some fat and carbohydrate avoidance but were not perceived as "eating rules" or "dieting plans," which would account for the interesting difference in response to the fat and carbohydrate avoidance questions compared to the diet rules/eating plan question. It is also possible that the way the eating rules/eating plan response was so low because the question was worded as "I follow eating rules or dieting plans that dictate what, when, and/or how much to eat," indicating that to "follow" rules or plans means one is adhering



to the diet. Participants may have believed in specific eating rules and diet plans but answered "strongly disagree", "disagree", or "neutral" if they did not feel they were currently adhering to those rules and diet plans.

Of the 1257 women without PCOS in a 2013 study ⁵⁵ examining intuitive eating practices, 64.8% indicated trusting their bodies to tell them how much to eat, compared to only 40.6% in this study. However, 65% of women in the current study reported being able to "tell when I'm slightly full" and 59.9% reported that they stop eating when full and not overstuffed (Table 9). This difference between being able to identify fullness (59.9% and 65.0%) and trusting their bodies to tell them how much to eat (40.6%) is interesting and curious as is the difference in body trust between women without PCOS (64.8%) and women with PCOS (40.6%). It is possible that women without PCOS have more body trust because they have less underlying insulin resistance which would mean experiencing less seemingly-mysterious weight gain, despite responding to fullness, than women with PCOS.

All of the women in this study reported having PCOS-related symptoms. Acne was reported in 55% of the women which is similar to what Sivayoganathan et al.⁵⁶ found in their study (53% experienced acne), however this study showed higher frequencies of alopecia (25.8% versus 16%) and hirsutism (87.5% versus 56%). Both hirsutism and acne prevalence were similar to what Jeanes et al.¹³ found in (80% hirsutism, 58% acne). The most common experience of the majority of women with PCOS, ages 18 - 40 years, is a diagnosis after age 24 (n=114, 95%), with irregular menses as the most common symptom used in diagnosis (n=105, 86.8%). Most often the diagnosis is by the woman's obstetrician gynecologist (n=70, 58%) or family practice physician (n=30, 25%),



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compared to only 26.7% of women (n=32) who were referred on to another practitioner despite the fact that PCOS is also considered an endocrine issue and despite the wealth of evidence supporting the value of nutrition, exercise, medication, and stress management in treating PCOS. However, although the rate of referral was low, the most common referral was to an endocrinologist (n=23). Seventy two percent of the women who had a referral were referred to an endocrinologist, which was also only 19.2% of the total respondents.

Only six of the women who received referrals were referred to a registered dietitian, but only 5% of the entire sample were referred to a registered dietitian, despite the fact that over a third of the participants (n=44, 36.7%) were given nutrition advice and 75% (n=90) of the women were told to lose weight. Note that the most common advice given is weight loss despite the high rate of diet failure and despite the high frequency of dieting in this sample (n=107, 89.2%). Also notable is the fact that over a third of the women reported dieting seven or more times (n=49, 40.8%), indicating repeated diet failure. A 2010 study, ¹⁴ which surveyed 196 women with PCOS, showed that only 15% of the women had seen a registered dietitian, but only 3% had more than two appointments.

In this study over two thirds of the sample (n=82, 68.3%) of the women were instructed to take medication and the most common medication prescribed was Metformin (n=64, 52.9%) followed by birth control (n=33, 27.3%). Medication and supplement use are summarized in Table 6. Seventeen of subjects reported other medication or supplement use, which was not PCOS-specific. It is unclear whether supplement use was recommended by the diagnosing or by the treating physician, but



over a third of women reported taking a multivitamin (n=49, 40.5%) and vitamin D (n=44, 36.4%).

While almost two thirds (n=76, 63.3%) of the women received the recommendation to exercise as part of treating their PCOS, 32.5% (n=39) of the women reported no enjoyment of exercise and over half (n=62, 51.7%) responded "yes" to the question number 17 which asked "Do exercise and dieting feel connected in such a way that when you are not dieting, you are likely going to stop exercising also?" A 2011 study ³² showed improvement in triglycerides, visceral fat, and insulin resistance in women with PCOS (n=13) who engaged in a 3 hour/week exercise program for 12 weeks. Hutchison and colleagues ³² concluded that weight-loss should not be the sole focus of exercise programs. Sixty three percent of the respondents in the present study were instructed to exercise to treat PCOS, but slightly over half of the subjects described a low likelihood of exercise could be sustained for women who engage in the non-diet approach because without a diet, there could be less of an all-or-nothing feeling with exercise, thus lower attrition.



Chapter 6: Conclusion

Conclusions

The results of this study showed that women with PCOS who eat more intuitively feel more confident about sustaining healthy habits than women with PCOS who eat less intuitively. This is an important advancement in the treatment of PCOS because a sustainable intervention has not been found. "Sustainability" was predicted based on participants' ratings of self-efficacy. The self-efficacy questions used here measured participants' belief in their ability and competence in incorporating changes in an ongoing manner.

Application to Practice

The significant relationship (p=0.007) between intuitive eating practices and selfefficacy should be acknowledged by the dietetic community and incorporated into dietetic practice. As registered dietitians, it is our responsibility to at the very least do no harm (e.g. recommend restrictive diets, perpetuating the diet/weight cycle and possibly worsening symptoms including anxiety and depression) and to recommend nutrition changes we know will benefit our patients. So much focus in dietetic learning is on *what* to recommend, with little about *how* to recommend it. This study is a reminder to us about how important the context of the nutrition recommendations is. That is, that the PCOS nutrition recommendations be laid in the context of intuitive eating/nondiet rather than the diet approach/mentality.

Weight and mood issues were among the most common symptoms reported by the women in this sample. However the rate of referral to other practitioners by the diagnosing physician was only 26.7% (n=32). Physicians, particularly



obstetrician/gynecologists, family practice physicians, and endocrinologists, would have a much higher likelihood of improving outcomes of women with PCOS if they would refer these women to mental health specialists and to registered dietitians who use the nondiet approach.

Limitations

The cross-sectional nature of this study is limiting. Without being able to follow women over a period of time, it is impossible to be conclusive about how effective the nondiet context for PCOS nutrition recommendations is in improving self-efficacy. This study asked women to predict future behavior change, however without a long-term study, the responses are only predictions.

The self-reporting nature of data gathering is also limiting. Participants were asked to report mood and physical symptoms. "Total testosterone based on lab report" is the only question about symptoms that inquired about a medical evaluation and result. Symptom data was gathered based on respondents' perception of symptoms.

Another limitation is the methods used to recruit participants. The survey link was posted on social media in places online where women who were seeking information about PCOS are looking. Therefore, the results of this study do not represent women with PCOS who do not seek out PCOS information online. This is also limiting because of the possibility that women who do not seek out PCOS information or resources may have different characteristics and/or also be in a stage of change that is less motivated to make behavior changes.

The survey inquired about omega-3 supplement use but did not inquire about omega-3 intake via food so it is unclear whether or not the women in the study who



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reported no omega-3 supplement use (n=101, 84.2%) are consuming inadequate omega-3.

Seventy one percent (n=86) of the women in this sample reported anxiety and 73.6% (n=89) reported depression; and 75.8% (n=91) reported mood swings. However, referral to a mental health practitioner was not an option in question number 11 on the survey. One participant (n=1, 0.83%) who responded "other, please specify" described being referred to a therapist. It is unknown how much of the reported mental health issues were related to dieting.

Future Research

The significant relationship (p=0.007) seen here between intuitive eating practices and self-efficacy could be examined in more depth with clinical studies that compare the traditional dietetic approach to the nondiet approach. Assessments using many of the questions in this survey could be done and compared before, during, and after interventions that used the diet approach and the nondiet approach. Longer term studies following women with PCOS who completed each program (traditional/diet, nondiet) would allow the dietetic community to draw more concrete conclusions about the proper way to deliver nutrition recommendations to women with PCOS.

The results of this study also lead to these new questions: Do obstetrician/gynecologists ask about diet history and take into consideration diet failures and likelihood of future weight loss via dieting? Are obstetrician/gynecologists familiar with the nondiet approach and the intuitive eating model? And can referral rates from physicians to registered dietitians increase?



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APPENDIX A: PERMISSION LETTER

Date: Sat Dec 8 2012 Subject: MS #1100 - College of Health and Human Services Human Subjects From: Gretchen Dahl Reeves Decision: Accept Submission

Meaghan Ormsby Schillinger E00687815

837 Main St Edmonds, WA 98020

Dear Meaghan,

Congratulations! After careful review, your modified proposal "Intuitive Eating Ratings and Self-Efficacy Differences in Women with Polycystic Ovarian Syndrome (PCOS)." has been accepted by the College of Health and Human Services Human Subjects Review committee.

Please insert in the consent form the approval dates "from December 8, 2012 to December 7, 2013",

The current version of your paper is available here: <u>http://commons.emich.edu/cgi/preview.cgi?article=1100&context=chhs_hs</u>

If any revisions are needed in the future, please upload those documents to your file MS #1100.

We stress that you do not stray from your proposed plan. Good luck with your research effort.

Sincerely,

Gretchen Dahl Reeves, PhD Chair, CHHS-HSRC



APPENDIX B: CONSENT FORM AND QUESTIONNAIRE

I. INFORMED CONSENT

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH

Project Title:

Intuitive Eating Ratings and Self-Efficacy Differences in Women with Polycystic Ovarian Syndrome (PCOS).

Principal Investigator (PI): Meaghan Ormsby-Schillinger, R.D. **Co-investigator:** Rubina S. Haque, Ph.D.,R.D.

Purpose of the Study:

The purpose of this research study is to evaluate if there is a difference in self-efficacy ratings among women with PCOS who rate themselves high on the Intuitive Eating scale compared to women with PCOS who rate themselves low and the Intuitive Eating Scale.

Procedure:

Participation in the study will involve completion of 27 scale rating questions. The survey will be administered by SurveyMonkey[™] software. This survey will be accessible online using the link provided. The questions should take a total of approximately 20 minutes or less to complete.

Confidentiality:

Responses to the survey questions will remain anonymous. Your questionnaire responses will be identified by a unique computer-generated number without being associated with your name or your email address. The principal investigator will not know who you are. There is an incentive offered to the first 40 women who complete the study (\$3.00 Starbucks gift card). These women will be asked to provide an email address so the PI can request a mailing address to mail the gift card.

No reference will be made in oral or written reports that could link you to the study.

Expected Risks:

Minimal risk. This study has little or no risk.

Expected Benefits:

Your participation will help to advance scientific knowledge about PCOS interventions using nutrition.

Voluntary Participation:

Participation in this project is strictly voluntary, and if you choose not to participate, this will in no way affect any interactions with Meaghan Ormsby Schillinger or Eastern Michigan University. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled.



If you withdraw from the study before data collection is completed, your data will be destroyed.

Use of Research Results:

Results will be presented in aggregate or coded (using coded subject numbers and no names or other identifying information) form only. No identifying information will be revealed. Results may be presented at research meetings, in written articles, at conferences, in scientific publications, and as part of the thesis project being conducted by the Principal Investigator.

Future Questions:

If you have questions at any time about the study or the procedures, or if you are experiencing any adverse effects because of participating in this study, you may contact the principal investigator, Meaghan Ormsby-Schillinger at 206-706-2696 or soundnutritioncounseling@gmail.com.

This research protocol and informed consent document has been reviewed and approved by the Eastern Michigan University Human Subjects Review Committee for use from December 8, 212 to December 7, 2013. If you have questions about the approval process, please contact Dr. Gretchen Dahl Reeves, Chair, College of Health and Human Services Human Subjects Review Comittee, 734.487.0077, <u>greeves@emich.edu</u>.

Please proceed to participate in the survey if you are a female with Polycystic Ovarian Syndrome, age 18-40.



II. CONSENT PAGE

Consent to Participate:

I have read or have had read to me all of the above information about this research study, including the study procedures, possible risks, possible side effects, and the likelihood of any benefit to me. I understand that information that I give will be held in the strictest confidence and that my responses are not linked to any identifying information. I have read the above information and agree to participate in this study. By clicking on the "agree" button below, entering the survey and answering the questions, I hereby consent and do voluntarily offer to follow the study requirements and take part in the study. I can withdraw from the survey at any time. I can click on the "disagree" button below to decline participation in the study.

O Agree

O Disagree



III. SURVEY

Please note that this is not a test. There are no right or wrong answers to this questionnaire. We only ask that you answer each question as honestly and accurately as possible about your experiences. Thank you!

- What is your age?
 O 18 to 23
 O 24 to 29
 O 30 to 35
 O 36 to 40
- 3. What is your ethnicity?
 O African American
 O Asian
 O Hispanic or Latino
 O White
 O American Indian or Alaskan Native
 O Native Hawaiian or Other Pacific Islander
- 4. What is your height in feet and inches? Feet_____ Inches_____

5. What is your current weight in pounds? _____

6. Please select a weight range that includes your lowest weight in the last 10 years and a weight range that includes your highest weight in the last 10 years. Lowest weight:

 $\begin{array}{l} \text{Dowest weight.} \\ \text{O } 100 - 150 \text{ lb} \\ \text{O } 151 - 175 \text{ lb} \\ \text{O } 176 - 200 \text{ lb} \\ \text{O } 201 - 225 \text{ lb} \\ \text{O } 226 - 250 \text{ lb} \\ \text{O } 251 - 275 \text{ lb} \\ \text{O } 276 - 300 \text{ lb} \\ \text{O } 301 - 325 \text{ lb} \\ \text{O } 326 - 350 \text{ lb} \\ \text{O } 351 - 375 \text{ lb} \\ \text{O } 376 - 400 \text{ lb} \\ \text{O } 401 - 450 \text{ lb} \\ \text{O } 451 - 500 \text{ lb} \end{array}$

Heighest weight: O 100 - 150 lb O 151 - 175 lb O 176 - 200 lb O 201 - 225 lb



- O 226 250 lb O 251 - 275 lb O 276 - 300 lb O 301 - 325 lb O 326 - 350 lb O 351 - 375 lb O 376 - 400 lb O 401 - 450 lb O 451 - 500 lb
- 7. What age were you when you were diagnosed with PCOS? $O \le 17$
 - O 18 to 23
 - O 24 to 29
 - O 30 to 35
 - O 36 to 40
- 8. How were you diagnosed with PCOS? Who diagnosed you? O Endocrinologist
 - O Pediatrician O Family Practice Physician O Internist O OBGYN O Dermatologist O Self-diagnosed O Other:
- What symptoms/information was used in your diagnosis?
 O Elevated testosterone
 O Irregular menses
 - O Cysts on ovaries
 - O Visual symptoms (acne, balding, excessive hair growth)
 - O Other:_____
- 10. Once you were diagnosed, were you referred to another provider for more help and support?
 - O Yes
 - O No
- 11. If so, what type of provider were your referred to?
 - O Endocrinologist
 - O Internist
 - O Dermatologist
 - O Registered Dietitian
 - O Other:



- 12. What advice were you given about treating your PCOS (indicate all that apply):
 - O Exercise
 - O Weight Loss
 - O No advice
 - O Diet/nutrition advice unrelated to weight loss
 - O Acupuncture
 - O Dietary supplements
 - O Other:

13. What sources do you use most for PCOS information?

- O Websites
- O Blogs
- O Friends/family with PCOS Books
- O My doctor
- O Books

14. What PCOS symptoms do you experience?

- O Hisutism (hair on the face, chest, back, stomach, thumbs, or toes)
- O Alopecia
- O Acne

O Weight disturbance: weight gain that felt mysterious, as though it didn't make sense

- O Weight concentrated around the waist
- O Irregular menstruation: more than monthly more often than every 28 days
- O Irregular menstruation: less than normal more than 35 days between periods
- O Irregular menstruation: no menstrual cycle
- O I menstruate but do not ovulate
- O Mood swings Sleep apnea Infertility
- O Anxiety Depression
- O Insulin resistance Elevated testosterone levels on lab report
- O I don't experience symptoms
- O Other symptoms:_____

15. Please indicate whether or not you take any of the following medications and/or supplements. Please select all that apply.

O I do not take any medications or supplements for PCOS

O Metformin

- O Spirinolactone
- O Birth control
- O Fertility medicines or injections
- O Multivitamin
- O Omega-3 supplement
- O Vitamin D
- O Herbs
- O Other supplements marketed/labeled as being PCOS-specific
- O Other (please specify)_



16. Do you regularly engage in physical activity? (this includes walking, dancing, yard work and other life activities)

O No, I do not engage in physical activity. I do not enjoy physical activity.

O No, I do not engage in physical activity, although I do enjoy it.

O Yes, I do engage in physical activity. I do this on average 1-3 days per week. I enjoy physical activity.

O Yes, I do engage in physical activity. I do this on average 1-3 days per week, although I do not enjoy it.

O Yes, I do engage in physical activity. I do this on average 4-7 days per week. I enjoy physical activity.

O Yes, I do engage in physical activity. I do this on average 4-7 days per week, although I do not enjoy it.

17. Do exercise and dieting feel connected in such a way that when you are not dieting, you are likely going to stop exercising also?

O Yes O No

18. On a scale of 1 - 10, please rate the level of enjoyment you feel with exercise. 1 = "I hate exercise", 5 = "I could take it or leave it", 10 = "I truly enjoy exercise very much"

01 02

O 3

O 4

O 5 O 6

0.0

08

09

O 10

19. In the last ten years, how much has your weight fluctuated?

O My weight has been stable, without fluctuating any noticeable amount.

- O 1-20 pounds
- O 21-50 pounds

O 51-75 pounds

O 76-100 pounds

O More than 100 pounds

20. How many times have you dieted in the last 10 years? (If you have dieted in the last 10 years and have repeated the same diet more than one time, please count these as separate diet experiences)

O I have not engaged in any diet in the last 10 years. O One time



O Two times O Three times O Four times O Five times O Six times O Seven or more times

21. What type of diets/weight-management programs do you most often choose or have the most experience with (indicate all that apply):

O Self-created O Medically supervised O Commercial programs O Diet books O Weight-loss surgery O Other_____

For each item, please circle the answer that best characterizes your attitudes or behaviors.

- 22a. I try to avoid certain foods high in fat.
 O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree
- 22b. I try to avoid certain foods high in carbohydrate. O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree
- 22c. I try to avoid certain foods high in calories. O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree
- 22d. I stop eating when I feel full (not overstuffed). O Strongly Disagree
 - O Disagree
 - O Neutral
 - O Agree
 - O Strongly Agree



- 22e. I find myself eating when I'm feeling emotional (e.g., anxious, depressed, sad), even when I'm not physically hungry.
 - O Strongly Disagree
 - O Disagree
 - O Neutral
 - O Agree
 - O Strongly Agree
- 22f. If I am craving a certain food, I allow myself to have it, whether I consider it healthy or not.
 - O Strongly Disagree O Disagree
 - O Neutral
 - O Agree
 - O Strongly Agree
- 22g. I follow eating rules or dieting plans that dictate what, when, and/or how much to eat.
 - O Strongly Disagree O Disagree O Neutral O Agree
 - O Strongly Agree
- I find myself eating when I am bored, even when I'm not physically hungry.
 O Strongly Disagree
 O Disagree
 - O Neutral
 - O Agree
 - O Strongly Agree
- 22i. I can tell when I'm slightly full. O Strongly Disagree O Disagree
 - O Neutral
 - O Agree
 - O Strongly Agree
- 22j. I can tell when I'm slightly hungry. O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree
- 22k. I get mad at myself for eating something that is considered unhealthy.



- O Strongly Disagree O Disagree O Neutral O Agree
- O Strongly Agree
- I find myself eating when I am lonely, even when I'm not physically hungry.
 O Strongly Disagree
 O Disagree
 - O Neutral
 - O Agree
 - O Strongly Agree
- 22m. I trust my body to tell me when to eat. O Strongly Disagree O Disagree O Neutral O Agree O Strongly Agree
- 22n. I trust my body to tell me what to eat.
 O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree
- 220. I trust my body to tell me how much to eat. O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree
- 22p. I have forbidden foods that I don't allow myself to eat. O Strongly Disagree O Disagree O Neutral O Agree
 - O Strongly Agree
- 22q. When I'm eating, I can tell when I am getting full.O Strongly DisagreeO DisagreeO Neutral



- O Agree O Strongly Agree
- 22r. I use food to help me soothe my negative emotions.
 O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree
- 22s. I find myself eating when I am stressed out, even when I'm not physically hungry.O Strongly Disagree
 - O Disagree O Neutral
 - O Neutra
 - O Agree O Strongly Agree
- 22t. I think of a certain food as "good" or "bad" depending on its nutritional content.
 - O Strongly Disagree
 - O Disagree O Neutral
 - O Neutra O Agree
 - O Strongly Agree
- 22u. I don't trust myself around "fattening" foods.
 O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 - O Strongly Agree
- 22v. I don't keep certain foods in my house/apartment because I think that I may lose control and eat them.
 O Strongly Disagree
 O Disagree
 O Neutral
 O Agree
 O Strongly Agree

Questions adapted from: Tylka, T.L., (2006). Development and psychometric evaluation of a measure of intuitive eating. Journal of Counseling Psychology, 53(2), 226-240.



Using the following as a guide, indicate which statement best describes you at the present time for each of the eating and activity behaviors listed below in the space provided next to each statement.

- I can manage to modify my eating behavior even If I need a long time to develop the necessary routines.
 O very uncertain
 O somewhat uncertain
 O somewhat certain
 O very certain
- 23b. I can manage to modify my eating behavior even If I have to try several times until it works.
 O very uncertain
 O somewhat uncertain
 O somewhat certain
 O very certain
- 23c. I can manage to modify my eating behavior even If I have to rethink my entire way of nutrition.
 O very uncertain
 O somewhat uncertain
 O somewhat certain
 O very certain
- I can manage to modify my eating behavior even If I do not receive a great deal of support from others when making my first attempts.
 O very uncertain
 O somewhat uncertain
 O somewhat certain
 O very certain
- 23e. I can manage to modify my eating behavior even If I have to make a detailed plan.
 O very uncertain
 O somewhat uncertain
 O somewhat certain
 O very certain

Questions adapted from: Schwarzer, R., Renner, B. (n.d.). Health-Specific Self-Efficacy Scales. Retrieved from <u>http://userpage.fu-berlin.de/health/healself.pdf</u>



Thank you for completing this survey! Your contribution to this study and to PCOS research is appreciated. The first 40 women who complete and submit this survey have the opportunity to receive a \$5.00 Starbucks gift card. If you are interested in receiving this incentive, please include your email address here and the Principal Investigator will contact you. You will then be asked to provide your mailing address. If you are not within the first 40 respondents, you will not be contacted. All contact information will be destroyed upon completion of this study.



APPENDIX C: RECRUITMENT FLYER

Research Study:

Intuitive Eating Ratings and Self-Efficacy Differences in Women with Polycystic Ovarian Syndrome (PCOS).

Who Can Participate?

Females age 18 - 40 years old, with a diagnosis of PCOS All ethnic groups

Where?

The link to the research survey can be found at: www.surveymonkey.com/pcos2012

PROJECT SUMMARY

Polycystic Ovarian Syndrome (PCOS) affects between 5 and 17% of reproductive age women and is associated with reproductive, metabolic, and psychological dysfunction. PCOS diagnosis is based on presentation with any two of the three criteria of hyperandrogenism, irregular anovulatory periods, or polycystic ovaries on ultrasound, with exclusion of related reproductive disorders (European Society for Human Reproduction and Embryology/American Society for Reproductive Medicine consensus 2003, Rotterdam criteria). Research to date examines "lifestyle modification" and effect on PCOS symptoms, where "lifestyle modification" means dietary restriction, and improvement is often measured by weight loss. Other data provides evidence for lack of long-term sustainability and failure of diet interventions, which explains the high dropout rate of participants in "lifestyle modification" studies with women who have PCOS. This will be the first research study to compare the eating styles of women who predict sustaining dietary and lifestyle behaviors to those who feel less optimistic about sustaining positive dietary changes. The purpose is focused on empowering women with PCOS to make dietary changes that are sustainable.

