

“IF YOU NEVER CAME IN AND SAW ME, YOU WOULD PROBABLY BE DEAD”: EXPLORING INTERCULTURAL COMMUNICATION AND HEALTH COMMUNICATION ISSUES SURROUNDING PCOS

by

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DEDICATION

To women coping with PCOS. You are more than enough. You are beautiful, valuable, and fruitful. Keep speaking your truth!

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LIST OF ABBREVIATIONS

Communication Privacy Management Theory	CPM
Culture Care Theory	CCT
Polycystic Ovarian Syndrome.....	PCOS
Health Related Quality of Life Questions.....	HRQLQ

ABSTRACT

**“IF YOU NEVER CAME IN AND SAW ME, YOU WOULD PROBABLY BE DEAD”:
EXPLORING INTERCULTURAL COMMUNICATION AND HEALTH
COMMUNICATION ISSUES SURROUNDING PCOS**

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George Mason University, 2020

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Polycystic ovarian syndrome is a multifactorial, heterogeneous, complex genetic, endocrine and metabolic disorder which is characterized by chronic anovulation, and biochemical and clinical manifestations of hyperandrogenism (Allahbadia & Merchant, 2010). Symptoms of PCOS include infertility, obesity, hirsutism and alopecia. Moreover, women with PCOS endure discrimination due to the inability to conceive and deliver healthy children, maintain healthy weight, or obtain beauty as defined by dominant societal standards. This dissertation calls attention to the quality of care and support for nondominant individuals and groups in dominant healthcare settings. The dissertation also works to highlight communication issues surrounding PCOS, and address knowledge gaps in causes and cure.

Women living with PCOS experience subtle insults and invalidations by dominant group members who may be unaware of the condition, resulting in unintended emotional harm. This phenomenological study explored the communicative experiences of sixteen women diagnosed with PCOS, and five health care practitioners. The semi-structured interviews foreground general and nonmonolithic interactions associated with the invisible disease. Results yield four major themes: 1) the road to diagnosis; 2) the lived experiences of patients; 3) microinvalidations; and 4) physicians' communication. Additionally, the study revealed communicative tensions and strategies to achieve desired health outcomes. These respective voices contribute to knowledge about patients' interactions with doctors, family and friends.

Prior studies have explored invisible disease, but few studies include international populations. This research draws from the perspectives of African and African American women, European American women, and Hispanic women. Their educational backgrounds ranged from High School Diplomas to Ph.D. holders. Salaries ranged from 20k – 100k annually. Consequently, the value of this research includes contextualized experiences with PCOS across ethnicity, social economic status, education and age. Readers will also gain a better understanding of the precarious connection between communication and invisible disease.

CHAPTER ONE

The first chapter presents the recurring unsatisfactory health related communication challenges experienced by women with Polycystic Ovarian Syndrome (PCOS). Women with PCOS in the chapter are positioned as differently abled individuals due to the myriad of hoops they have to jump through to perform fundamental reproductive functions. Throughout this study, PCOS will be here on out referred to as a culture in accordance with Dawn Braithwaite's theorizing of people with disabilities as cultural group members different from able bodied cultures (Braithwaite & Mont, 2009). Although the health care industry in the U.S continues to grow in innovation and technological advancement there are still communicative issues in the quality delivery of care in socially disadvantaged populations (CDC, 2019).

This project expands intercultural communication and health communication theories, including co-cultural theory, culture care theory, communication privacy management, and issues of power, privilege and discrimination to explore the communicative practices of women with PCOS as they navigate care and support options with health care practitioners, family members, friends and acquaintances. The next sections introduce intercultural communication and health communication to describe the

inexplicable relationship between both in the delivery of care for women with PCOS. To better understand this relationship, PCOS will be explicated as a cultural health condition.

Section One: Conceptualizing Polycystic Ovarian Syndrome (PCOS) as a Culture

Polycystic ovarian syndrome is an invisible condition affecting more than 15% of women around the world (Sanchez, 2014; Weiss, 2009). It is a multifactorial, heterogeneous, complex genetic, endocrine and metabolic disorder, diagnostically characterized by chronic anovulation, polycystic ovaries, biochemical and clinical manifestations of hyperandrogenism (Allahbadia & Merchant, 2010). Peer reviewed medical literature has generated a comprehensive definition for PCOS as “the presence of hyperandrogenism (clinical and/ or biochemical), ovarian dysfunction (oligo-anovulation and/or polycystic ovaries) (Azziz, Carmina, Dewailly, Diamanti- Kandarakis, Escobar-Morreale, Futterweit, Janssen, Legro, Norman, Taylor, & Witchel, 2009. p. 480). PCOS is a complex psychological and physiological condition characterized by obesity, acne, insulin resistance, and alopecia or hair loss, among other symptoms.

Women may experience PCOS in different ways. From the perspective of intercultural communication, women with PCOS experience prejudice, and discrimination due to their inability to fulfil gendered societal expectations. For instance, most cultures across the world emphasizes the role of women as procreators especially in a marriage union without considering women who do not want children or women with health conditions preventing them from conception. Women experience prejudice and to an extent discrimination when they are unable perform this function. The communication surrounding pregnancy is one-sided in many cultures, even though the process requires both parties. The concept of a ticking biological clock is rooted in shaming women into

pregnancy since they may be running out of time. The simple outwardly harmless phrase is prejudicial since there is no equivalent saying to describe men's need to reproduce. Instead there is the celebratory idiom that men should sow wild oats. Gendered societal expectation becomes more problematic when there is an underlying health condition that prevents women from fulfilling these roles. In terms of health communication, stigmatized symptoms include infertility, obesity, hirsutism and alopecia. Diagnosis may occur through clinical tests such as an ultrasound, or blood tests by a primary care doctor, endocrinologist, gynecologist or a fertility specialist. A diagnosis may include at least two of the following symptoms: trouble conceiving or infertility, mood changes, acne, fatigue, insulin resistance, high testosterone levels, and thinning hair. Also, PCOS is known to include irregular or missed periods, low sex drive, dark pigmentation on skin, ovarian cysts, weight changes and/or trouble losing weight, and excessive body hair growth. The communication between patient and doctor will vary from person to person depending on their social location and value system. An individual's social location is based on positionality in terms of their race, gender, nationality, and socio-economic status. An individual with privileged social location has agency to communicate effectively with their health care practitioners to achieve desired goal. Other individuals may not possess the communicative skills to achieve their desired goals.

Section Two: Intercultural Communicative Perspective on PCOS

The U.S. is comprised of unique diversity in ethnicity, age, race, socio-economic status, and education (Census.gov, 2019; CDC.gov, 2019, Ting Toomey & Chung, 2015). Communication reflects our respective cultural values, social and personal identities (Allen, 2012). Intercultural communication occurs when individuals exchange messages within and between different cultures to create shared meaning (Samovar, Porter, McDaniel & Roy, 2015). Intercultural communication may serve to reflect the values of dominant group members and deny the value of non-dominant group members within employment, relationships and health care settings (Hopson, 2011). Therefore, intercultural communication is vital in the discourse of PCOS care for patients and doctors to develop better understanding of the condition and to adapt more effective care management plans.

It is important to address how the values of dominant group members in health care settings influence the quality of care for socially disadvantaged populations. Exploring the intercultural communication issues of PCOS may address the lingering knowledge gap in the causes of and treatments for PCOS.

Privilege, ability, discrimination and prejudice inform experiences of individuals living with invisible diseases. An intercultural communication approach in this research seeks to understand the lived experiences of women with PCOS with a critical lens on how their social positions as women influence their care options. Previous research suggests women with PCOS experience subtle insults, invalidations by dominant group

members who are sometimes unaware of the condition, and sometimes exhibit unconscious incompetence in communication with those with PCOS to perpetuate unintentional emotional harm (Dapherede Otusanya, 2018). Intercultural communication studies should endeavor to examine microaggressions associated with invisible diseases, including subtle insults that influence the psychological and mental health of women with PCOS. Microaggression is defined as subtle and everyday verbal, behavioral and environmental expressions of oppression based on one's race and gender (Sue, Capodilupo, Torino, Bucceri, Holder, Nadal & Esquilin 2008, p. 274). As such, this study intends to examine power differences in diverse health and intercultural communication contexts, such as doctor-patient interactions, patient-caregiver interactions, and other forms of discrimination women experience based on symptoms of PCOS.

Women with PCOS are positioned as non-dominant group members, due to the invisible nature of the condition. Non-dominant group in this context refers to a social group member who does not hold power to influence the value system in an environment, simply put anyone who is not European-American heterosexual middle-or upper-class males (Orbe, 1998). These individuals face the unique challenge of communicating effectively with health care practitioners and others to achieve quality health outcomes. Dominant group members play an important role in contributing to the health needs and solutions of women with PCOS. Many research studies on PCOS shared the overwhelming theme of late diagnosis for those experiencing PCOS related symptoms. One wonders why there is still report of late diagnosis in the 21st century with state-of-

the-art medical equipment and technological advancement in the U.S. There may be aspects of dominant medical practices or communicative behavior of health care practitioners that is contributing to the persistent issues of late diagnosis. As such, it is imperative to study the deep structures accountable for late diagnosis, knowledge gaps and lack of coordinated health management for patients (Weiss, 2009; Morgante, Massaro, Sabatino, Cappelli & Leo, 2017).

Braithwaite (1991) explicated intercultural communication and health communication issues to examine the communication challenges of persons with physical disabilities and how much information they are willing to disclose about themselves. The scholar suggests that persons with physical disabilities are faced with challenges of disclosing private health and body information to able bodied persons. The communication of persons with physical disabilities is a cultural issue as they experience marginalization of space, privacy and individuality different from able bodied individuals (Allen, 2012). The experiences of persons with disabilities are culturally derived as it affects their norms, values, beliefs and practices. Braithwaite indicated that the social location of persons with disabilities is not only different from able bodied persons but that there needs to be conscious awareness of how they are disadvantaged in the value systems that have been created without consideration for their needs.

Likewise, other women experience several privileges and advantages not afforded to women with PCOS in health and social contexts. These privileges are based on social identity, cultural identity and positionality. For example, non-PCOS women may not

have to deal with fertility issues when trying to start a family, they may find it easier to lose weight, and they may not experience psychosocial challenges due to hormonal imbalances. PCOS women find themselves at a disadvantage since it is harder to get pregnant without assisted reproductive technology, higher likelihood of weight gain, increased inability to lose weight due to insulin resistance, and increased struggle with body image issues due to hirsutism. In this regard, women with PCOS are nondominant, or co-cultural, group members who experience marginalization based on societal positionality (Orbe, 1998).

Furthermore, health care practitioners, family members and friends assert their dominance and privilege by communicating unsolicited opinions of women with PCOS. Examples of unsolicited advice include the following: “You need to lose some weight.” “You have gained a lot of weight.” “When do you want to start a family?” “You should start a family soon.” Women with PCOS use co-cultural strategies to manage unsolicited communication, because the advice often feels like microaggression, which is defined as subtle and everyday verbal, behavioral and environmental expressions of oppression based on one’s race and gender (Sue et al, 2008, p. 274). These have lasting psychological influences on the victims. This stigmatizing aspect of microaggressions contributes to the marginalization of co-cultural groups, including women with PCOS.

Moreover, women with PCOS symptoms can often fall short of the ideals of beauty upheld by societal norms. Acne, hirsutism, male pattern baldness, depression are significant stigmatizing conditions which influence all groups, especially marginalized

groups. Infertility is also a major stigmatizing issue. Co-cultural group members utilize communicative strategies to manage discussions surrounding infertility and miscarriage.

Section Three: The Intersection of Intercultural Communication and Health Communication in Disease Management

Intercultural communication and health communication explorations are necessary to better understand the complexities of PCOS and other invisible diseases. Intercultural communication occurs across various areas of social identity. Communication issues surrounding health communication include, but are not limited to, access to quality service; diagnosis, competent communication, adherence to medication and self-care management (Kreps, 2009). In addition, health communication includes a focus on doctor-patient interactions, availability of care, access, and the health literacy of patients.

Intercultural communication and health communication may unearth how power, privilege, ability, ethnicity, social-economic factors influence the communication surrounding PCOS and other invisible conditions (Braithwaite, 2009).

Intercultural communication and health communication work together to view the areas of differences as sites of struggle, attempt to understand the phenomenon, and provide the ability to describe the behaviors (Hopson, 2011). The goal of this paper was to explore the experiences of women with PCOS during the delivery of care. The

following section will offer background information about the definition, symptoms, and research on PCOS.

Stigma and Discrimination

PCOS symptoms are such that they are complex, confusing and intimate in nature. This makes it difficult for women to communicate some of the symptoms they are experiencing with family, friends, significant others and health care practitioners. Due to these embarrassing symptoms mentioned above, it is important to understand how women self-disclose, to whom they disclose, and in what circumstances these disclosures occur. Also, it is important to understand the motive behind disclosure. For example, some women disclose their condition to minimize the stigma or to prevent discrimination. For these women, in short, self-disclosure is an act of sharing private information that should be conceptualized within the larger framework of privacy management (Petronio, 2002; Petronio, 2013).

The current study will extend intercultural-health communication, by exploring the communicative concerns, discrimination, privacy regulations, and communicative challenges of those with PCOS. The following sections will define intercultural communication, and health communication, as it applies to this study.

Significance of the Study

There is tremendous potential value to exploring intercultural health communication for women with PCOS. First, while there are several organizations and

recommended treatments for PCOS, very few studies emphasize the voices of women struggling with PCOS. Their lived experiences are often minimized and reserved for their closed community. To remedy this gap in the literature, this study will examine and unearth how women with PCOS navigate dominant spaces while managing the challenging symptoms of PCOS. The study will reveal body shaming, and insults by family members, stereotypes held by medical practitioners and significant others and other embarrassing symptoms associated with the condition. Symptoms of PCOS have a tremendous impact on their daily lived experiences. There is a need to understand intercultural communication to facilitate better multicultural health care communication (Ting-Toomey & Chung, 2015, p. 10-11). The current study will explore the intercultural health communication challenges faced by women with PCOS. By extension, the study may contribute additional knowledge about other invisible conditions and diseases. The overall goal of the study is to reveal new perspectives on the roles, cultures, identity, power, privilege and biases that influence the health and well-being of people living with invisible conditions. More specifically, the study highlights intercultural communicative practices and strategies used by physicians and patients in health care settings.

Empirical Value of the Study

The intercultural health communication perspective associated with PCOS, will inform new ways to view and address invisible diseases. First, the research offers as a platform to create awareness to dominant group membership's discriminatory behavior towards women with PCOS. This study explored the importance of applying intercultural

communication theories, especially co-cultural theory and the concept of microaggression, to health communication contexts to increase interpretivist and critical research related to examining invisible diseases like PCOS. Second, the research findings should provide specific strategies for health care practitioners to communicate more effectively with women with PCOS and other invisible conditions.

Finally, the dissertation recommends specific communicative strategies to help women living with PCOS. The research heightens what we know about self-identity, social identity and cultural identity, and give voice to the lived experiences of marginalization.

In the following sections, I will offer my own interpretive observation as a woman living with PCOS. Next, I foreground examination of a body of literature on applicable theories and explanations including co-culture theory, culture care theory (CCT), communication privacy management (CPM), microaggressions and phenomenology.

Personal Story

As a teenager, and throughout my adult life, I have struggled with dysmenorrhea and anovulation. Dysmenorrhea is a condition characterized by pain during menstruation that lasts from the beginning of a period up to three to four days (NCBI, 2019).

Anovulation is when the ovaries do not release an oocyte during the menstrual cycle (Healthline.com). Although, the main effect of anovulation is mainly difficulty with conception or infertility, research has not found any threat to the health or well-being of women who do not ovulate or ovulate infrequently. From experiencing extreme fatigue

that renders one unproductive for days, to the mental fog that can last weeks, continued by the constant uncomfortable bloating, and finally, the knife jabbing pain that last for 2-3 days, dysmenorrhea and PCOS are the worst thing to happen to anyone. You are not only physically sick; you are too mentally exhausted to process thoughts and appear coherent at times.

Moreover, I have always been passionate about women's health and reproductive health because I have witnessed several women around me who have struggled with infertility. My closest aunt struggled with infertility, and multiple miscarriages for over twelve years, before she successfully carried a child to full term. I witnessed the microaggressions, depression, hostility and relationship challenge she endured during these trying periods of infertility, including having to give away baby items she had bought to use for her own baby. Her struggles, my current health challenges, and other women's struggles with reproductive related issues are the driving force for this research.

Furthermore, the health care industry in my country of origin, Nigeria, did little to help provide adequate health information and support to the plight of countless women dealing with several reproductive and endocrine conditions. After moving to the U.S, I was diagnosed with PCOS after experiencing delay to start a family of my own. My long years of pain, fear and uncertainty were confirmed when I was diagnosed with PCOS. I have always felt different from other women who did not have to struggle monthly when experiencing their period, whose period did not impact their daily lives, and work lives as an adult. I cannot count the number of times I have felt helpless and have had to call out

from work and other social engagements due to excruciating pains during my periods. While the diagnosis came as a relief, a new burden to understand, cope and fight for my health began immediately, in the doctor's room.

Prior to my diagnosis, I had never heard of PCOS. When I was seated in the well-lit room after a physical exam, in a vulnerable state, my doctor spewed out the following words: "you have PCOS, I know it's not only when you have body or facial hair for one to have it." As she uttered the words, I was taken aback and at the same time relieved that there is a name to my condition. What came next, was shocking to me. She went straight to, "I will put you on clomid and metformin to help with ovulation." I was expecting a better explanation of the condition that was new to me, how it impacts my health, then ways to manage and cope. I left the hospital that day, dejected and at the same time determined to learn all I need to know to fight PCOS. This dissertation is a continuation of my strong passion for, knowledge and better understanding of this phenomenon, for myself and millions of women around the world dealing with PCOS.

In the following sections, I dived in-depth into the process and findings unearthed during this exploratory study. In chapter two, I foreground the research literature on co-cultural theory, communication privacy management (CPM), microaggression and the phenomenological approach to studying the communication challenges of those with PCOS.

CHAPTER TWO

LITERATURE REVIEW

This chapter presents theoretical frameworks and models that were utilized in the conceptualization of the communicative challenges, experiences and strategies of women with PCOS. First, I will explicate some important intercultural communication concepts including power, prejudice privilege, discrimination in intercultural communication, discuss major theories and approaches that guided this study, and finally present a comprehensive review of past research on PCOS including studies on the communicative behavior of women living with the condition.

Role of power

Power in intercultural communication cannot be explicated without first understanding the concept of hegemony. Hegemony was first coined by the Italian philosopher-theorist, Antonio Gramsci when he opined that “that man is not ruled by force alone, but also by ideas” (Bates, 1975 p. 351). Gramsci suggested that the ideas that rule societies are often shaped by the ruling class without input or suggestions from the ruled. Values and ideas shape the world and the underlying factors of what drives particular values or ideas are inherently dictated by those in the hierarchy of power. In the article *Gramsci and the theory of Hegemony*, Bates (1975) defines the concept as “political leadership based on the consent of the led, a consent which is secured by the

diffusion and popularization of the world view of the ruling class” (p.352). In addition, hegemony is “the spontaneous consent given by the great masses of the population to the general direction imposed on social life by the dominant fundamental group” (Allen, 2011, p. 30). It describes the unconscious acceptance of ideology, values, and conformity to specific behaviors established by the dominant group.

A hegemonic force works at an unconscious level among the masses who subscribe to the rules and values the dominant group have structurally identified as truth and acceptable. Gramsci further described the structure of the dominant group as “the historical bloc” to signal that the group is only as powerful as it is united based on economic interests and that power can be disrupted through organic crisis (Gramsci, 1975, p. 364). Hegemony addresses how complex social practices, relationships, and structures are negotiated among diverse social forces (Allen, 2011).

Hegemony refers to how power is yielded to a few dominant groups and calls into question the origination of ideas to disrupt. Resistance is a crucial component to disrupt hegemony and its operationalization in a society. Resistance is the attempt to overthrow and undermine the dominant order (Allen, 2011). Hegemony is important to this study to expand how knowledge, ideas, and values operate in the health care industry to marginalize voices of certain patients due to the nature of their symptoms (Allen, 2011, p. 31). The idea that physicians are more knowledgeable than patients, and the imbalance in power during communication with patients are examples of how hegemony is perpetuated in health care settings. Furthermore, the expectation that women should look, speak, act and procreate influence how women with PCOS are perceived as not

normal or not fully women due to their inability to perform gendered expectations reinforced by hegemony.

A brief example of resistance/transformation against hegemonic academia features the rise of Afrocentricity by Molefi Kete Asante, who advocates for the centrality of Africa and African values in research and theory. Afrocentricity challenges Eurocentric framework used to largely study issues pertaining to Black/African America. U.S. Scholars like Molefi Asante, Cheikh Diop, Théophile Obenga, Yosef A. A. ben-Jochannan, John Henrike Clark Kwame Nkrumah, and Mark Hopson, research and teach utilizing Afrocentric theoretical frameworks to better understand the cultural struggles of African descendants. The premise of Afrocentricity is a deliberate response to hegemony by consciously investigating the history of the world focusing on the history of the people of African descent. Afrocentric scholars, rejecting the consent to be ruled by the dominant group, establish their research around issues surrounding the African continent. Similarly, the current study aims at using culturally derived theories to better understand the intersection of illness, health, and culture. The role of power in intercultural communication is further explicated below.

Power is at constant struggle within all types of communication (Orbe, 1998; Kramarae, 1981). Intercultural communication cannot be studied without examining power, hegemony and the social privileges that influences such interactions (Castle Bell, Hopson, Weathers, & Ross, 2015; Hopson, 2014; Orbe, 1998; Prado, 2000). Furthermore, power oscillates according to the behaviors of the actors or interactants. In *Discipline and Punishment*, and *The History of Sexuality*, Foucault explicated the concept of power as it

relates to government, knowledge and behavior conditioning (Prado, 2000). Additionally, Prado (2000) defined power as the sum total of influences that actions have on other actions otherwise known as “comportments” which impact the suppressed, unfamiliar, shunned and obscured (Prado, 2000). Power is embedded “in the various social hegemonies” like socio-economic class, ethnicity etc. Power also establishes itself in social settings between people, and includes the social, historical, and political forces that impact communication across difference (Castle Bell, 2017; Hopson, 2011). This study examines the role of power between health care practitioners and patients. It investigates how power influences communication or lack thereof concerning women’s reproductive health issues.

Power is a constant dynamic in intercultural communication. Several theories of intercultural communication center their propositions on the role power plays in such encounters. Co-cultural theory is one that conceptualizes the role of power in intercultural encounters, and it explores the lived experiences of co-cultural group members in communication with dominant group members (Castle Bell et al. 2015; Dapherede & Castle Bell, 2018). Orbe (1998), defines co-cultural group members “as individuals who are members of traditionally marginalized groups. Co-cultural theory describes the inimitable communicative practices utilized by co-cultural or marginalized group members in numerous communicative settings (Orbe, 1998). In exploring individual issue of race, culture, ability and communication, Orbe (1995; 1998) linked the power dynamic phenomenon in creating co-cultural theory, which is rooted in standpoint theory and muted group theory respectively (Orbe & Harris, 2008). This study extends co-cultural

theory to examine the role of power dynamic in health care settings and how women with PCOS choose what strategies to utilize based on their preferred outcome.

The issue of power at play is also specific when we consider the U.S. social hierarchies. Social hierarchies are governed based on an individual's location in an environment. Standpoint is used as a concept to describe and illustrate how social hierarchies impact knowledge and resource distribution. Standpoint is "achieved through a critical, conscious reflection on the ways in which power structures and resulting social locations influence knowledge production" (Castle Bell et al. 2015; Intemann, 2010, p. 785). Standpoint theory posits that people perceive the world from where they stand (Castle Bell et al., 2015). For example, for women with PCOS, their standpoints often differ from their health care practitioners' and family's perceptions of how the condition hinders their quality of life (Sanchez, 2014, Dapherede Otusanya 2018). Health care practitioners most likely do not see the world the same way patients make sense of their illness and sense of wellbeing (Helman, 2000; Leininger & McFarland, 2002). Women with PCOS experience symptoms that are contradictory to socially constructed standards of physical appearance. To date, there is still no known cause of PCOS. For this reason, health care practitioners are not adequately equipped to communicate well about how women can alleviate the symptoms considering their experiences and agency (Allahbadia & Merchant, 2008).

Taken together, these women possess a collective standpoint that other women may not be able to comprehend. By extension, the multifactorial nature of the condition makes each woman's individual experience different from the other. Each woman

experiences unique challenges when they are perceived to be inadequate in fulfilling their feminine social identity. Even though each woman's experience is different there are still the disadvantages of not being able to perform normal reproductive functions. Symptoms such as hirsutism, obesity, acne, dark spots, infertility, depression and insulin resistance make these women easy targets for insults, isolation and emotional trauma. More specifically, infertility is a major symptom of PCOS and a sensitive issue for most women. Comments about these issues can have adverse effects on women who are socialized to procreate. In certain societies women are not considered women if they are unable to conceive and deliver healthy babies. In African cultures infertility is not just a health issue but a deeply construed cultural problem. In African traditional wedding ceremonies, the majority of the prayers and well wishes given to the couple (brides) centers around fertility and the ability to cater to the will of the husband. It is ingrained in young African girls that marriage is the ultimate life goal, and children are the reward of being a woman. It is unfathomable for an African woman to be told that she has PCOS which might potentially truncate her ability to fulfill her "God given" purpose of procreation. PCOS holds a life altering meaning for women in such cultures where profound importance is placed on having children. Infertility in nations such as Nigeria, Ghana, and Sierra Leone often put pressure on women to use whatever means available to conceive.

Women not affected by PCOS are in a privileged hierarchical group, and have benefits denied to women living with the condition. Women without PCOS may conceive without much preparation and assisted reproductive services. This is not true for women

living with PCOS, especially in certain cultures where women living with PCOS must scale several physical, emotional, and financial hurdles to conceive.

In addition to the standpoint theory, another theory that helps to shape the social location of women and others who are disadvantaged in the society is muted group theory. Muted group theory indicates “that societies have social hierarchies where some groups are privileged over others, with the groups at the top of the hierarchies establishing the communication system of that society” (Kramarae, 1981; Ardener, 1978; Castle Bell et al. 2015, p. 3). Conversely, muted groups are disenfranchised members in a society that must accommodate and subscribe to the dominant group’s culture as hegemonic forces prescribe. The idea of double consciousness defined by Hopson (2011) describes how the group atop the hierarchical order will generally determine the communication system of the society. Women living with PCOS are a muted group, at the lower end of the social hierarchy when compared to women without this condition. These women are muted in communication regarding reproductive health since their experiences are perceived as abnormal. Some features of dominant communication that marginalizes women with PCOS include, statements that minimize their symptoms such as, diet and exercise will help you lose weight, just don’t stress and you will be pregnant, or that menstrual pain is not that serious. These communication in dominant spaces silences the experiences of women with PCOS as these symptoms are not normal to the dominant group. They are aware of both positions, because they live with it, and they can see how women live without it. PCOS women find it difficult to lead normal lives. The condition prevents them from identifying as complete women (Dapherede Otusanya,

2018). The inability to perform natural feminine functions makes women critically conscious of their unique position. Not only are they aware of their double consciousness, women of African descent living in the United States, who are diagnosed with PCOS experience additional burden of the cultural implications of the condition on their lives, marriage and their experiences with family members. Many African cultures are collectivist in nature not only in their relations but also in health-related issues. Health conditions and diseases are hardly shared or spoken openly about due to stigma that may be attached to the type of condition. It is almost a taboo for women in Nigeria to openly disclose their health issues regarding infertility to family members and friends. The goal of this study is to better understand how different cultures communicate about PCOS to loved ones.

By comparison, PCOS and non-PCOS women can be conceptualized as nondominant and dominant group members. Non-PCOS women are often oblivious of the struggle's women with PCOS experience (Dapherede Otusanya, 2018). This research will shed light on the unheard, shunned and often unrecognized standpoints of women with PCOS. Their unique experiences are important. This research will reflect women at the margin of society, especially as it relates to health care settings and intercultural interactions.

Prejudice, Discrimination, and Privilege in Intercultural Health Communication

Privilege is an unearned advantage based on social identity (Allen, 2011). McIntosh (1998) described how men were aware of the unfair treatment of women but could not recognize their own role in perpetuating that discrimination. Privilege

highlights oblivious advantages based on dominant group members' religion, race, education, class etc. An example of privilege in PCOS related communication is when women without PCOS have the privilege to determine whether to get pregnant, do not have to cope with managing hirsutism by regular visits to hair removal salons or dermatologists, or experience weight issues. For women with PCOS, conception is an uncertain and time intensive undertaking. Many women with PCOS struggle with infertility due to anovulation which is a PCOS related symptom.

Prejudice is a preconceived judgment or opinion, usually based on limited information (Allen, 2011; Tatum 1997). It refers to the preference for one's group members. For women with PCOS the prejudice of others is expressed when family members or acquaintances recommend diets and remedies for acne and other PCOS related symptoms. In other instances, health care practitioners may have preconceived judgements about women's reproductive conditions and fail to pay full attention to the experiences of patients.

Discrimination occurs when individuals act upon their prejudices (Allen, 2011). While there is little research specifically regarding PCOS, it is imperative to investigate areas of differences where women with PCOS may experience discrimination. Women with PCOS may experience discrimination due to their symptoms such as obesity, acne, baldness, or hirsutism. These experiences may be microscopic. A woman with PCOS may be unclear as to why she is being discriminated against, but none the less she feels the psychological impact of such interactions. For instance, an overweight woman with PCOS may notice people tend to avoid her on public transportation but may be unable to

determine or label the behavior. However, this does not negate the fact that there is non-verbal communication going on open to different interpretations. Microaggression best describes these discriminatory acts in communicative spaces. Microaggressions “are derogatory slights or insults directed at a target person or persons who are members of an oppressed group and it communicates bias and can be delivered implicitly or explicitly” (Torino, Rivera, Capodilupo, Nadal & Sue, 2019, p.3). Women with PCOS are oppressed based on the unique experiences of confusing health related symptoms. Confusion occurs before and after diagnosis. Microinvalidation, a form of microaggression, contributes to the confusion experienced by women with PCOS. An example of microinvalidation includes physicians telling women that they should not worry about their symptom of anovulation, attributing it to stress instead of conducting additional testing. This action further extends the diagnosis period. There are several tests and medical visits involved before the eventual diagnosis. Health care practitioners may/may not exhibit microinvalidating oppressive tendencies, yet women may lack the trust to articulate their embarrassing symptoms to their doctors, or they may feel that their physician lacks the ability to understand the gravity of their pain and concerns.

The current study extends co-cultural theory, culture care theory, communication privacy management and health related microaggressions to derive PCOS as a culture with dominant and non-dominant group memberships, facing diverse communication challenges in various social contexts, and using specific communicative strategies to navigate, survive and thrive in dominant spaces while seeking quality health care and psychosocial support.

Co-cultural Theory

Co-Cultural Theory originated from standpoint and muted group theories. Co-cultural theory brings out important aspects of communicative practices used by diverse co-cultural or marginalized group members in numerous communicative settings (Orbe, 1998; Castle Bell et al., 2015; Dapherede & Castle Bell, 2018; Razzante & Orbe, 2018).

Marginalized groups across communication contexts operate in the world in certain ways to survive (Orbe, 1998). Women, people of color, and persons with disabilities all constitute co-cultural groups with group members' unique interactive environments. Co-cultural theory was established to understand the role of power and how it shapes communication in specific communication settings.

Inherently, there are several interdependent parts of co-cultural theory and each one provides a conceptual framework to the communicative behaviors of co-cultural or nondominant group members especially as it relates to women with PCOS, including: strategies, influential factors, and communication orientations. The interdependent elements of co-cultural theory co-exist when non--dominant group members communicate with dominant or other co-cultural members who hold specific power and privileges (Castle Bell et al, 2015; Dapherede & Castle Bell, 2018).

Co-Cultural Communication Strategies. Co-cultural theory includes diverse verbal and non-verbal communication practices, or strategies, that non-dominant individuals use when interacting with dominant group members (Allen, 2011). There are 26 such strategies, that non-dominant group members including women with PCOS employ to communicate in intercultural tense environments where they experience acts of

marginalization, prejudices and discrimination: “Emphasize commonalities; develop positive face; censoring self; averting controversy; extensive preparation; overcompensating; manipulating stereotypes; bargaining; dissociating; mirroring; strategic distancing; ridiculing self; increasing visibility; dispelling stereotypes; communicating self; intragroup networking; using liaisons; educating others; confronting; gaining advantage; avoiding; maintaining barriers; exemplifying strengths; embracing stereotypes; attacking; and sabotaging others” (Orbe, 1998. p 8-9).

In 2014, Castle Bell, Hopson, Weathers, and Ross added rationalization to Orbe’s original list of 26 strategies. The authors included the following additional 11 strategies that other researchers developed since Orbe’s 1998 article was published: Interrogating self; checking yourself; remaining silent; journaling; rationalization; showing appreciation; reporting incident; speaking out; leaving the situation; isolation and intimidation.

Influential Factors. Orbe (1998) specified certain factors that non dominant group members select when using these communicative practices. The influential factors are factors that may enable women with PCOS and other non-dominant groups determine which one of the 37 strategies they may choose during intercultural tense communication with dominant group members: “preferred outcome, communication approach, field of experience, abilities, situational context, and perceived costs and rewards” (Castle Bell et al., 2015, p. 6). Collectively, these factors represent the core elements of co-cultural communication.

Preferred Outcome. Preferred outcome is the process by which women with PCOS analyze the desired result they seek to achieve during interaction with dominant group members especially health care practitioners. Preferred outcomes can differ depending on the situations or context of interaction and it includes the following: assimilation, accommodation or separation (Orbe, 1998). First, assimilation as a preferred outcome indicates that someone with PCOS consciously or unconsciously hopes to adapt to the culture of the dominant group member. To do this, they sometimes leave their culture behind to fit in with dominant group members (Castle Bell et al., 2015; Orbe, 1998). Second, accommodation as a preferred outcome, occurs when women with PCOS attempt to understand the multi-cultural set up of the health society and to interact with the dominant culture, while maintaining elements of their own culture and health abilities (Castle Bell et al., 2015; Orbe, 1998). Finally, separation as a preferred outcome when women with PCOS desire to maintain their own culture and to be separate from the dominant culture (Castle Bell et al., 2015) by taking up the identity of someone with PCOS unapologetically.

Communication Approaches. Communication approach suggests “practices that fall along the continuum of nonassertive, assertive, or aggressive behavior” (Orbe, 1998, p. 104). Dependent on a co-cultural group member’s preferred outcome when interacting with others about PCOS related issues, one of three communication approaches is employed: (a) aggressive (put one’s wants and needs above health care practitioners, family members and friends); (b) assertive (balance your wants and needs and consider others’ wants as well); or (c) nonassertive (put other’s wants and needs above your own

health needs (Orbe, 1998, p. 104-117). It is relevant to mention that no one strategy is positive or negative, rather the choice to employ either is dependent on the desired health outcome of the patients.

Field of Experience. Field of experience describes the motive for co-cultural group members' use of strategy based on their lived experiences as no two individuals operate from the same standpoint (Castle Bell et al., 2015; Orbe 1998). Specifically, past experiences with dominant (health care practitioners) and other non-dominant co-cultural group members (family members, friends and acquaintances) will likely determine how individuals respond in the present setting. Previous experiences with the health care system may also determine which of the co-cultural strategies will be used to manage on-going challenging intercultural communication encounters in managing invisible conditions (Orbe, 1998).

Ability. Ability refers to co-cultural members' capability to engage in different communicative behavior with dominant and non-dominant group members (Castle Bell et al., 2015; Orbe 1998). A patient dealing with an invisible condition such as PCOS cannot use a strategy without the ability to employ it. For instance, Orbe and Roberts (2012) illustrated that certain individuals possess the wherewithal to change their behavior to manage specific intercultural communicative situations – and others simply do not, especially women who are unfamiliar with the health care system in the U.S. Personality traits, previous experience, behavioral orientations, and one's physical abilities influence the strategies co-cultural members may employ at any given time (Orbe, 1998). In this

current study, these influential factors may be uncovered as subconscious characteristics that may be unknown to the patients.

Situational Context. Situational context indicates that there are different co-cultural communicative practices that are used in different situations when interacting with dominant group members and non-dominant co-cultural group members. In this study, the situational context includes health care settings and informal settings. Orbe and Roberts (2012) further describe situational context as considerations to include where the interaction occurs, who is present, and other key environmental concerns before choosing one co-cultural communication strategy or another. Although no strategy is better than the other, the context may significantly influence which strategy is employed at the time. A physician interacting with a patient with PCOS might be dismissive or lackadaisical about her patient's desire to start her own family. This situational context might influence how assertive or assimilative the patient might choose to be.

Perceived Costs and Rewards. Perceived costs and rewards are evaluations of the personal benefits and detriments related with each communicative practice (Orbe & Roberts, 2012). Castle Bell et al, (2015) postulate that a co-cultural member weighs the specific benefits or negative outcomes that could be associated with using certain communicative strategies. The need to evaluate the costs and rewards for one's strategic communicative response plays a role in deciding which strategy to employ in each situation. For women with PCOS, their perceived rewards would be addressing the symptoms that mostly affect their ability to function in their gendered identity. An example of weighing costs and rewards in communication might be self-disclosure of

embarrassing symptoms to others or being assertive whenever they experience microaggression from physicians or others. Thus, the cost of using a certain communicative strategy will be dependent on who they are interacting with.

In summary, co-cultural theory provides an intercultural communication lens to study invisible conditions in health care settings. The interrelated parts of the theory include six influential factors; field of experience, abilities, situational context, preferred outcomes, perceived costs and rewards, and communication approach; 27 co-cultural strategies; and nine co-cultural communication orientations, non-assertive assimilation, assertive assimilation, aggressive assimilation, non-assertive accommodation, assertive accommodation, aggressive accommodation, non-assertive separation, assertive separation, and aggressive separation. It is important to note that not all co-cultural theoretical components explicated above are applicable to understanding the communication challenges of women with PCOS, however, the theory provides an intercultural communication framework to better understand the complexity of patient-practitioners communication.

Microaggressions

Solórzano, Ceja and Yosso (2000) defined racial microaggressions as “subtle insults directed towards people of color” (p. 60). Racial microaggressions are communicated in hidden ways through “subtle looks, snubs, dismissive looks, gestures, tones, or when people of color are overlooked or under respected” (Sue et al, 2007, p. 273). Derived from racial microaggressions, I will examine

health related microaggressions towards women with PCOS. In a health context, microaggressions are subtle insults or invalidations directed towards patients to minimize or undermine the legitimacy of their pain and suffering.

Variations of Microaggressions. In theory, racial microaggressions occur in three forms: microinsult, microassault, and microinvalidation (Sue et al, 2007).

Microinvalidation will be used in this research to better examine how health care practitioners communicate with people living with invisible conditions. First, a microinsult is defined as “comments that convey rudeness and insensitivity and demean a person’s racial heritage or identity” (Torino et al, 2019, p.4). Comparably, health related microinsults are messages that convey rudeness or insensitivity and demean a person’s health condition. Microinsults also include subtle snubs, frequently unknown to the perpetrator, but clearly convey a hidden insulting message to the recipient of color.” (p. 274). For instance, a woman with PCOS, may be subtly insulted about her size or may get rude comments about her fertility from those around her.

Second, a microassault is “most similar to old fashioned racism; it is conscious, deliberate, though experienced in private, not in public settings” (Sue et al, 2007, p. 274). While a microassault is “direct, consciously carried out, and targeted at any person of color – it provides the perpetrator a level of secrecy” (p. 274). For women with PCOS, a microassault will be direct, conscious deliberate discriminatory communicative action based on their PCOS symptoms. For instance, a person struggling with infertility due to PCOS can be directly called infertile, or barren to their face which cause psychological and emotional damage to such persons. Microassaults can also occur in form of directly

addressing a patient's weight or receding hairline with subtle connotations of malice, condescension, or pity.

Third, microinvalidation on the other hand "is characterized by communication that excludes, negates, or nullifies psychological thoughts or feelings, or the experiential reality of a person of color" (p. 274). They provide the following examples of microinvalidation: "you speak good English, I don't see race, and don't be so oversensitive" (p. 274). In health-related contexts, microinvalidation describes communication laden with rudeness or insensitivity that demeans or delegitimizes a patient's symptoms and health concerns. Examples of microinvalidation in health-related settings include: "you are a strong woman", "nothing is wrong with you" and "it's in your head."

Ultimately, women with PCOS utilize certain communicative strategies in specific contexts when seeking care for PCOS related symptoms. Due to the diverse symptoms that are culturally congruent, many women with PCOS may experience diverse forms of microaggressions from health care practitioners, family, and others. Women with PCOS will draw on one or more of the co-cultural strategies to respond to the microaggressions of health care practitioners, friends and family.

In the next section, I will discuss the field of health communication, the role of culture-centered care and provide a theoretical framework for this research using the culture care theory developed by Madelene Leininger.

Impact of Culture on Physician-Patient Communication

Research continues to grow in the patient-physician communication field (Geist-Martin, 2015). According to the 2018 American Community Survey (ACS) data, one in seven U.S residents is foreign born and immigrants are currently 13.7 percent of the country's total population (Batalova et al, 2020). With this growth in migrant communities over the decades, there is large gap in delivery of quality care where one must be considerate of the language, traditions, beliefs and values of patients. With that in mind, research in recent times have explored the role of physician's values and beliefs that they exude when interacting with patients. Culture, health and communication in the delivery of care cannot be overemphasized.

Technological advancements in cancer research and treatment have resulted in groundbreaking solutions and better health outcomes for patients (Kreps, 2011). These advancements include improved imaging technologies, targeted forms of radiotherapy, and minimally invasive laparoscopic surgery. Although the health care industry continues to grow and develop in cancer care and other common disease management, other health care conditions are neglected (Grassi, 2017; Alexander, Tangchitnob, & Lepor, 2009). Invisible conditions that may not be easily visible to observers, such as arthritis, diabetes, and mental health problems, not only threaten the daily lived experiences of patients, but are also more likely can be dismissed by health care practitioners who do not understand the conditions or their potential risks (Alexander et al., 2009). In the following section, I will provide a brief background to using health communication theories for intercultural communication research.

Culture Care Theory

Madeline Leininger developed culture care theory in the early 1960s to enable nurses to provide better delivery of care for immigrants and refugees after World War II (Leininger & McFarland, 2015). Culture care theory created a framework for understanding the role of culture and communication in the delivery of care for patients, in this case women with PCOS. Leininger alluded that although “caring for people of many different cultures was a critical and essential need, health care practitioners are not adequately equipped to meet the challenges” (Leininger & McFarland, 2015 p. 304). The authors sought to improve the quality of care for patients especially immigrants and refugees, with the development of innovative nursing practice models. For Leininger, developing the theory of CCT was vital for the effective administering of care by nurses and prior to the development of the theory, the medical field did little to nothing to factor in the role of culture and its multifaceted contexts in care management for patients from diverse cultural backgrounds.

After decades and continuous research, Leininger (2015) advocated for the nursing field to include social structures, including religion, politics, economics, cultural history, life span values, kinship and philosophy of living, and geo-environmental factors as potential cultural influences on care (p.9). What this means for the nursing profession is that for every patient that is culturally diverse from the dominant culture nurses should strive to communicate with them in accordance with the patient’s values, beliefs,

traditions and practices to better provide and to increase the patient's comfort and acceptance of care.

Although the author predicted CCT as a sound foundation for nursing science knowledge in the 21st century, people with PCOS experience moments of chaos and confusion during and after diagnosis. The ability for other health care practitioners to adapt the CCT tenets in theory when interacting with patients with invisible conditions may greatly increase the patient's overall health related quality of life. The theory was explicated on the premise that more research should be conducted concerning people with diverse ethnic and racial backgrounds in order to provide competent ways to help these patients and this study extends CCT theory to include invisible conditions especially PCOS as a diverse culture that requires research studies to better understand this patient population.

In summary, Leininger predicted that culture and care were embedded in each other and needed to be teased out and understood within a cultural context. Most importantly, she predicted this knowledge would contribute to transcultural nursing as a discipline and practice field. The culture care theory and transcultural nursing are closely related as bases for being human, but also for health and wellbeing. (Mcfarland & Alamah 2019).

Theoretical Tenets of Culture Care Theory

Commonalities. The first tenet of the CCT stipulates that diversities and commonalities in culture care expressions, meanings, patterns, and practices would be

found within cultures. The tenet aimed at inspiring nurses or other practitioners to understand each culture represented in their service and use the data to provide better outcomes. The following are CCT care factors to be considered in practitioners-patient interactions: religion, politics, economics, cultural history, life span values, kinship and philosophy of living, and geo-environmental factors. Leininger (2015) described that understanding these factors should become a goal that the nurse practitioners should strive to understand so they could provide quality culture care to patients from diverse cultural and ethnic backgrounds. This theory captures the sensibilities attached to the holistic treatment of PCOS since it impacts the physical, social, reproductive, and cultural aspects of the patients' lives.

Below, specific culture care concepts will be defined to provide a deeper understanding about how the theory is applicable to PCOS culture. Culture care theory defines culture as “the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular group that guides their thinking, decisions, and actions in patterned ways and often intergenerationally” (Leininger, 2006a, p.13). In this nascent research, the definition of culture by Leininger shows how culture guides the thinking, decisions and actions of a group. Women living with the PCOS condition often reprogram their lives and experiences to take on new identities or reject their PCOS identity altogether. It is important that at the point of care for PCOS, health care practitioners and support system staff must realize the meanings patients attach to their health condition. Some patients might view the condition as something else to deal with, based on their world view of disease management and the manifested symptoms, while

other women with more severe symptoms may view the condition as their new identity and seek to navigate the world with a cultural lens.

Care in CCT embodies “assistive, supportive, and enabling experiences or ideas towards others with evident or anticipated needs to ameliorate or improve a human condition or lifeway (Leininger, 2006a, p.12). In other words, caring includes actions, attitudes and practices that assists or help women with PCOS towards achieving quality health. The concept of care can begin from the moment the patient interacts with the health care facility, to speaking with the front desk administrator and ultimately to the doctor’s meeting. It is important and valuable that at each point of care women with this condition are helped and supported. However, research suggests the opposite of supportive care for women. A major concern of women dealing with PCOS is a lack of support from health care practitioners. Although Leininger designed the culture care theory for nurses, it is also important that doctors and other specialists adapt the tenets of the theory for better and improved health outcomes for patients.

Culture care indicates “subjectively and objectively learned and transmitted values, beliefs, and patterned lifeways that assist, support, facilitate, or enable another individual or group to maintain well-being and health, to improve their human condition and lifeway, or to deal with illness, disabilities, or death (Leininger, 1991a, p. 47). Finally, the culture care theory posits that there are differences or variabilities among human beings with respect to the meanings, patterns, values lifeways, symbols related to providing quality care to patients within a specific culture. Therefore, the theory charges

health care practitioners to focus on care meanings, beliefs, values and practices related to women with PCOS so that the subtle and obvious differences from other conditions can be identified and collected as data to further improve care for the cultural group members. While Leininger (2015), provided detailed definitions for the tenets and concept of culture care theory, these concepts are still very abstract, and derivative based on the culture and values of patients. In this current study, participants will provide information about the care meanings, values and beliefs they hold that can help improve their overall health related quality of life. The culture care concept is used to understand how one's cultural framework shape the patients' understanding of their condition and their relationship with health care workers.

As stated previously, PCOS is an intimate and private condition that can be shrouded in secrecy due to stigma or awkwardness about the symptoms. Thus, it is important to explore how women with the condition disclose or not about their symptoms to seek adequate support from friends and family. The author examines the communication privacy management theory to better understand the communication of self-disclosure regarding the phenomenon.

Communication Privacy Management (CPM)

Communication privacy management theory (CPM) suggests that individuals negotiate secrets and private information (Petronio, 2002; Petronio, 2013). They may or may not decide to share the information with significant others, family members and health care practitioners. Boundary linkage is created when individuals share private

information with others thus making them co-owners of the information. CPM theory can be used to study how individuals living with invisible diseases share and co-own their health information. For example, previous research investigated the disclosure of genetic cancer risks (Neuhauser, 2017). The results suggested that people disclose health information based on the family orientation. This dissertation investigated how people living with invisible diseases communicate their needs and conditions to others.

This dissertation uses qualitative analysis to understand the communicative practices of women with PCOS. Participants were interviewed on how they disclose their health condition, with whom they share the information, reasons leading to the choice to share or not to disclose information about their health. PCOS is an invisible condition affecting between 10-20% women around the world (CDC, 2018). There is a need to increase and expand the framework to understand how women disclose or no not disclose about the condition. The results will contribute to health education on PCOS, health campaigns serve as a toll for health care practitioners.

Individuals adhere to privacy rules that derive from five criteria which influences decisions about the amount and content of information that is revealed to others” (Durham, 2008; Petronio, 2002; Petronio, 2013). The five criteria include *cultural* (e.g. each culture has privacy values for judging levels of disclosure or privacy), *gendered* (e.g. “gender differences contribute to alternative rule structures that regulate boundaries for women and men”), *motivational* (e.g. “when a person has need he or she gathers and disseminates private information to satisfy the needs”), *contextual* (rules that address the

situational needs of privacy regulation”) and *risk benefit ratio* (e.g. the risks and benefits of disclosing or remaining private, there is always some measure of risk and benefit) (Petronio, 2002, p. 39; Petronio, 2013).

Invisible diseases are difficult to communicate (Radaelli, Leonardi, & Pessina, 2004; Williams, Sheffield, & Knibb, 2014; Schmid, Kirchengast, Vytiska-Binstorfer, & Huber, 2004; Sewitch, Abrahamowicz, Bitton, Daly, Wild, Cohen, & Katz, 2002).

Women with PCOS are challenged to discuss symptoms such as hirsutism, acne and obesity which affect self-body image of women (Sanchez, 2014; Weiss, 2009, Nasiri Amiri et. al, 2016). In addition, women are challenged to disclose issues of infertility and depression (all symptoms of PCOS) in interpersonal contexts (Bute, 2009).

In the following section, I will review past literature on the PCOS phenomenon highlighting the gaps that intercultural communication that will be addressed in this current research.

Previous Research on PCOS

Previous research in PCOS focused primarily on health-related factors related to PCOS, but not as much on the lived experience of women with PCOS (Amiri, Simbar, Montazeri, & Thamtan, 2014; Schmid, et al, 2004; Setiawati, Adiwijaya & Tjokorda, 2015; Allahbadia, & Merchant, 2008; Bharathi, Swetha, Neerajaa, Madhavica, Janani, & Rekha, 2017; Tomlinson, Pinkney, Stenhouse, Bendall, Corrigan, & Letherby, 2017; Sanchez, 2014). This current study will help fill this gap in the literature.

PCOS is an endocrine condition with specific criteria for diagnosis, and various clinical studies have been conducted regarding how to manage the condition. In addition, there are a handful of communication-based studies on the trend, and the challenges of PCOS. The trend of PCOS involves the steps and activities that led to the standard diagnostic criteria for the condition. One of the major challenges of PCOS was resolved after the standard for diagnosis was agreed upon. The previous literature help contribute a historical overview of how the condition have evolved over the years. Drawing on this previous research, the current study will reveal past and current trends for understanding PCOS. While PCOS is relatively common condition, the public remains largely unaware of its existence (Wolf, Wattick, Kinkade, & Olfert 2018). Medical practitioners, researchers and women with PCOS have contributed through websites, social media groups and conferences to study, enlighten and discuss the phenomenon.

Earlier literature on PCOS grappled with a standard definition of what the condition is. Several medical and science conferences were held until a consensus was reached as to how medical practitioners should diagnose and define PCOS in health care settings. The multifactorial nature of the symptoms makes it complicated to diagnose which supports previous research that women experience late diagnosis for the condition (Dapherede Otusanya, 2018; Amiri et al, 2014; Schmid et al., 2004; Setiawati,et al., 2015; Allahbadia, & Merchant, 2008; Bharathi et al., 2017; Sanchez, 2014). The ordeal to arrive at a consensus diagnostic criterion is also indicative of the fact that the care and treatment of PCOS will be complex. However, evidence suggests that there is still a huge gap in the care and understanding of PCOS by health care practitioners (Tomlinson et al.,

2015; Sanchez, 2014). The following section will highlight major reports and progress in the research on PCOS.

A systematic review of PCOS research activities around the world was conducted by a collaborative research endeavor between researchers from Germany and the U.S from 1900-2015. Bruggmann, Berges, Klingelhofer, Bauer, Bendels, Louwen, Jaque and Groneberg (2017) carried out a global chronological research examining the PCOS literature using a quantitative research methodology, the New QIS protocol to determine PCOS related research in a vast database web of science. The findings offered insights into historical research endeavors carried out spanning decades in understanding the scientific underpinnings of PCOS. A total 6,261 articles were analyzed, with the first article published in 1938. The U.S was identified as the most active country in conducting research on PCOS. Findings suggest that most PCOS research occurs in high income countries. The implication conversely is that low-income countries may not be included in the discourse of PCOS and its effects on varied communities.

The *International Journal of Women's Health* published a systematic review article that measured the health-related quality of life of women in Iran who had PCOS (Behboodi Moghadam, Fereidooni, Saffari, and Montazeri 2018). Articles published between 1945 and 2017 reveal general and specific instruments that have been used to measure the health-related quality of life for women with PCOS and to understand the factors that affect the health -related quality of life (HRQoL) in PCOS women. To identify studies that have used the general and specific instruments to measure HRQoL,

the researchers conducted an electronic database search in MEDLINE, ISI web of knowledge, Scopus, and Google Scholar using the following key words combination: questionnaire or scale or inventory and “quality of life” or “health-related quality of life” or patient-reported outcome and “polycystic ovary syndrome or PCOS. The results suggested that 52 studies met all the criteria for the studies. Nine of the studies were qualitative while the remaining were quantitative studies. The U.S conducted the highest number of studies. Other countries including the U.K, Iran, and Germany contributed between 5-9 studies. No major studies were found from developing countries or countries with low income indexes. While the results of the studies conducted focused heavily on health related factors of PCOS, this study captures the lived experiences of the women and how they communicate about the condition.

Polycystic ovarian syndrome questionnaire PCOSQ (50) and short form health survey SF 36 were the major measurements found to be most used in the studies investigated. PCOSQ is specifically designed to include the following items related to PCOS: emotions (8 items), hirsutism (5 items), weight (5 items), infertility (4 items) and menstrual disorders (4 items). These instruments have been documented and validated in several studies as the lived experiences in women struggling with PCOS to varying degrees. The article indicates that functioning impairments caused by PCOS may vary based on religion, race, culture and social factors but does not provide additional recommendations on how to capture these factors using the PCOSQ measurement. The model does not account for important health-related components of PCOS such as the cultural implications of dealing with the condition which include but not limited to

privilege, social location, race, cultural identity and discrimination due to symptoms cannot be accounted for with the method. However, this current study used the PCOSQ 50 developed by Nasiri-Amiri et al (2018) as a foundation for building interview questions that were used in this study.

Researchers in England conducted study measuring the health-related quality of life among adolescents with PCOS (Jones, Hall, Lashen, Balen, and Ledger, 2011). The qualitative study interviewed 15 adolescent participants from two out-patient gynecology clinics in Yorkshire, England. This study provided additional insights into the health-related quality of life of PCOS women specifically adolescents between 17-21 years old. Based on a thematic analysis of data, the authors established the following themes: (a) poor or delayed experience of diagnosis (the delay was due to varied reasons including misdiagnosis or dismissiveness of health care practitioners), (b) poor knowledge of PCOS, report of hirsutism, weight management issues, acne, menstrual problems, prospect of infertility, emotions, personal relationship and support (many participants only heard about PCOS for the first time during diagnosis and reported experiencing various symptoms long before diagnosis). Like other studies, PCOS was found to negatively influence the HRQoL of adolescents especially in the areas pertaining to weight and body perception issues, adolescents reported feelings of low self-esteem, poor self-image and self-consciousness etc. Lack of knowledge about the condition also contributed significantly to the HRQoL of these young girls. A major limitation to the study was that sample size was too small and the demographic information was too

vague. The researchers included the age, and other clinical records of the participants without indicating their race or ethnicity.

Past literature indicates that there is a range of functioning impairment such as depression and anxiety in women with PCOS based on religion, race, socio economic status etc. This suggests that the cultural factors can make it more difficult to confront the condition and find treatments or accommodations that help reduce suffering and stigma. This knowledge gap created by years of research that does not account for race or ethnicity of participants continues to increase the health disparities in communities with people of color. This article thus creating a further gap in capturing the experiences of other races and ethnicities.

Researchers across several areas of discipline have documented the impact of PCOS on the gendered roles of women across countries. Nasiri Amiri, Tehrani, Simbar, Thamtan and Shiva (2014), captured the interference of PCOS in gender roles in Iran. The study used qualitative content analysis to understand the lived experiences of 23 participants recruited from a reproductive endocrinology research center. The findings present a new discourse on the cultural implications of the condition. Four themes that emerged from the data indicated that PCOS women perceived themselves as unattractive, they feared the loss of their womanhood due to inability of their bodies to perform female biological processes such as ovulation and menstruation, sex and the disruption of the potential for fertility.

Besides the physiological symptoms and impact of PCOS, the article examined how women perceived their feminine identity as lacking or lesser than other women. These results suggest that in countries such as Iran, a collectivist culture places value on the community thus driving and maintaining the status quo of performative gendered roles of women in the society such as conceiving and raising children to continue the family line. Taking into the account of the cultural background of the research, the study could have theorized about the cultural influences of perceptions communicated by the participants. This current study will build upon this research to situate the experiences of the patient using a cultural lens to understand the meanings attached to such experiences.

In 2014, Nasiri Amiri and colleagues investigated the experiences of women affected by PCOS using a qualitative constant comparative analysis to understand the quality of life of women with PCOS in Iran. The results showed that the most important factors affecting the quality of life in women were the role functioning items as well as physical, mental, emotional, cognitive and social dimensions. The physical dimensions of having PCOS reported by the women included obesity, hirsutism, hair loss, acne, menstrual disorder, infertility, ovaries full of cysts and impaired general health. The research is relevant to the current to establish and reinforce the symptom manifestations for sample population in the U.S

PCOS is a multifactorial condition that requires a multidisciplinary approach to understand the different aspects of how the condition can be treated in varying degrees from patient to patient. There is abundance of literature on the biomedical approach to

understanding PCOS and treatment options available based on the most impacting symptoms and desires of the patient. For example, researchers in Australia have investigated the role of alternative medicine in managing PCOS related symptoms. Ee, Smith, Costello, MacMillan, Moran, Baylock and Teede (2018) addressed the weight management goals in PCOS women using acupuncture. Studies indicate that acupuncture is a potential weight loss treatment for non PCOS population, which, for these researchers, begged the question if it can also help PCOS women with weight loss goals. The main goal of the researchers was to examine the feasibility and acceptability of acupuncture for weight management in overweight or obese women with PCOS.

Ee et al, (2018) recruited 10 women to participate in focus groups and telephone interviews. Half of participants received real acupuncture while the other half received sham services with both groups receiving lifestyle coaching over a period of twelve weeks. The results of the study suggested that women with PCOS were open to considering acupuncture as additional weight loss intervention. The data also indicated that women shared the advantages of using acupuncture while also expressing their concerns with the approach to healthy lifestyle. An important finding in the studies indicated that women with PCOS required a lifestyle coach with in-depth knowledge about the condition that may or may not be accessible to the women. In addition to requiring a lifestyle coach, the participants also indicated that an individualized approach to weight management in PCOS women is more effective since each patient has unique needs. This is particularly important to note since no two patients experience PCOS the same way. The study contributes significantly to the literature on PCOS from an

alternative medicine approach which is still a controversial topic in the health care industry. This approach to PCOS study takes on a community approach that seeks to investigate the perceptions of treatment options for obese women with PCOS. This study as well as others suggests that acupuncture help women with PCOS lose weight. The current study will investigate diverse ethnicities in the U.S to better understand if the lived experiences of women with PCOS varies based on ethnicity/race.

A community approach to treating and managing PCOS was found in a quantitative study conducted by Moran, Grieger, Mishra, and Teede (2015). Lifestyle changes have been suggested to help manage PCOS. The study examined the association of a Mediterranean-style diet pattern with PCOS status in a community cohort. Insulin resistance is a major symptom of PCOS and prevents weights loss in women. Insulin resistance is characterized by a low-grade inflammation which makes our cells become resistant to insulin (McCulloch, 2016). Cells in our bodies respond to message of insulin after eating by breaking them down but in cases of insulin resistance, the cells do not respond thereby leaving too much sugar in the blood. The abundance of sugar in the blood exacerbates the ovaries, causing them to “produce androgens like testosterone that manifests in such symptoms as difficulty in losing belly weight, formation of skin tags, and dark pigmentation on neck and underarms” (McCulloch, 2016, p. 39).

Although optimal dietary strategy to manage PCOS remains controversial, Moran et al, used the Mediterranean diet strategy because of its association with decreased prevalence of hypertension and metabolic syndrome in other population. Data for the

study was collected from the Australian longitudinal study on women's health. A cross sectional analysis of dietary patterns in women with and without PCOS suggested that even though women with PCOS had similar physical activities with women without, women with PCOS had an elevated energy and fiber intake and lower glycemic index and percent energy intake from saturated fat. This confirms the presence of insulin resistance in women with PCOS. With the same physical activity, women without PCOS will get better results for weight loss than those with PCOS. In this current study, those women PCOS who struggled with weight loss will likely report having to work extra hard to shed the same amount of weight that a woman without PCOS can easily shed. After using logistic regression, the study discovered for each 1 SD increase on the high meat, fish, poultry, and take-away pattern there was a 9% greater likelihood for women to have PCOS. The research suggests that diet influences some symptom manifestation. Therefore, questions about diet and lifestyle changes will be incorporated in the current study to understand patient's perceived health information regarding PCOS.

There is a knowledge gap in the nutritional and dietary lifestyle patterns that should be recommended for those with PCOS. A major issue regarding dietary patterns and PCOS is the multifactorial and individualized manifestation of the condition in each patient. Although the current study does not investigate the dietary patterns used by participants, the study will examine the barriers to lifestyle changes as it relates to cultural, socio-economic and educational background of the participants.

People with PCOS are predisposed to behavioral health related issues and research indicates a lack of support for these women. Sanchez (2014), examined socio-demographic, mental health and health education of patients for PCOS related hospital visits. Research analyzed data from the National Ambulatory Medical Care survey. Results reveal health related disparities in PCOS related health care access through diverse variables including age, race, insurance type, and poverty indicator. This work provides a snapshot of the national representation of health access of diverse demographics. Specifically,

While previous research reveals statistical representation of health access to PCOS related issues, the voices of the participants were not captured to show how these disparities affect the health-related quality of life. The phenomenological method is discussed below.

A Phenomenological Approach

The study utilized a phenomenological approach to investigate the intercultural and health communication experiences of women with PCOS. I will define phenomenology, provide a historical background, discuss some philosophical assumptions, describe the types of phenomenology and discuss strengths and weaknesses of the approach.

The research draws from in-depth interviews to gather thick, descriptive narratives of the lived experiences of women living with PCOS. Research is the process

of asking questions and finding answers through the application of systematic and scientific methods.

Phenomenology is the study of individuals and groups with a shared experience, to better understand and interpret these lived experiences (Moustakas, 1994; Orbe, 1998; Van Manen, 1990; Creswell, 2013 & Alvarez, 2017). Phenomenology is grounded in interpretive approach to studying social science. The interpretive approach aims to systematically observe individual behaviors as they occur organically in order to understand how people create and maintain their social worlds (Neuman, 1997).

Phenomenology embodies textual and structural description (Husserl, 2008). It is a human science, a study of the lifeworld, the world as we immediately experience it pre-reflectively rather than as we conceptualize or theorize about it (Orbe, 1998). It seeks to disclose and elucidate the phenomena of behavior as manifested in perceived immediacy (Moustakas, 1994).

PCOS is an invisible condition wherein members are a marginalized group. Phenomenology will be used to focus on the conscious experience of those with PCOS. This approach is suitable to capture the standpoints of group members operating from the margins of society, and the experiences of members belonging to diverse co-cultures made invisible by the persuasiveness of the dominant culture (Samovar & Porter, 1994)

Phenomenology is especially relevant here. Boylon (2008) and Potts (2014) both describe participants in phenomenological studies as co-researchers invited into the study at every level of development and analysis. In addition, interviewees become joint

contributors and investigators in the study. As such, participants shift away from being objects who are “researched” to active contributors in the creation and sense making process (Creswell, 2013). The phenomenological process includes description, reduction, interpretation. Below I briefly discuss the key assumptions of the approach.

First, it rejects the notion of an objective research and positivist claims of a single truth about a phenomenon that can be unearthed through quantitative research. Second, it seeks to gain a deeper understanding of the nature and meaning of everyday experiences. The researcher’s intention is to set aside preconceived notions of the phenomenon, to be receptive to the interpretations and meanings as derived from the participants themselves. Third, it seeks to understand the phenomenon without predicting behaviors or examining causes.

Philosophical Assumptions

Phenomenological ideology is based on empirical observations. The phenomenon to be studied must be situated in human sciences where empirical observations can be observed and understood.

Prior knowledge of the phenomenon or participants should be suspended and if at all, clearly stated in a transparent form by the researcher. Researchers should be “without judgement” (Moustakas, 1994, p.77). Through reflexivity, researchers should account for interpretations, biases, and preconceived knowledge about the phenomenon. It can be difficult to remove the voice of the researcher from the research, which is why the

researcher uses intentionality of consciousness to reflect, capture, identify and bracket herself out of the interpretations derived (Van Manen, 1990).

Again, phenomenology is especially useful to study the communicative experiences of marginalized group members who are involved as “joint contributors and investigators” in the study. Below I will discuss some strengths and challenges of phenomenology as a qualitative approach.

Strengths of phenomenology. Phenomenology can be used to provide a deeper understanding to the of lived experiences of research participants. My research seeks the universal nature of PCOS in women and to further explain their descriptions and meaning. This allows in the review of emerging themes and meanings. Phenomenology allows the researcher to notice trends and observe big picture. Phenomenology may contribute to the development of new theories, changes in policies or changes in responses. More specifically, my results may help expose misconceptions about PCOS, and challenge pre-conceived notions and complacency.

Weaknesses of Phenomenology. Co-research participants articulate their thoughts and feelings about the experience being studied. Thus, it may be challenging to collect data if the co-researchers are unable to articulate their feelings or encounter communication challenges in the process of data collection. For example, it may be difficult for women with PCOS to express themselves due to language barriers, age, cognition, embarrassment and other factors. PCOS is a condition that is stigmatizing and also embarrassing which may be difficult to express. Phenomenology requires

researchers to describe, reduce, and interpret the lived experience of others. The ideological biases of researchers are difficult to determine or detect yet almost certainly play a role in shaping interpretations. Finally, sometimes it is difficult to gain access to participants due to the sensitive nature of communicating about invisible health conditions.

Using a phenomenological approach to understand the culture care components, co-cultural strategies, communication privacy management strategies, and the role of power, privilege, and discrimination, the following research questions are proposed:

Research Questions

RQ 1: How do women with PCOS describe their communication with health care practitioners when seeking care?

RQ 2: How do women with PCOS employ communication accommodation strategies and privacy management skills with family members and others, if they utilize them at all?

RQ 3: How do women with PCOS describe their communicative experiences with discrimination, power and privilege if they experience such at all?

RQ 4: How do health care practitioners describe their communication when delivering care to PCOS patients?

CHAPTER THREE

METHOD AND METHODOLOGY

Chapter three illustrates the methods used in this dissertation. This study focused on interviews with 16 women who have been diagnosed with PCOS, including 9 women who self-identified as Black or African American, 5 White European American women, and 2 Latinx women. These interviews were coded and analyzed to understand the meanings of the phenomenon as described in data collection and to highlight the voices of participants who have experienced the phenomenon (Moustakas, 1994; Van Manen, 2014).

Participant Demographic Information

Primary participants of the study consisted of those with PCOS and health care practitioners. Data collection occurred via semi structured interviews participant entry criteria include a diagnosis of PCOS, and/or two or more symptoms of PCOS such as hirsutism, acne, insulin resistance, obesity, and infertility. In addition, data were collected via interviews with endocrinologists, nutritionists, nurse practitioners, and obstetricians to gain insights into health practitioners' perspectives on what they perceive to be the challenges for women with PCOS.

Sample Size

Sixteen participants with PCOS were interviewed about their daily lived experiences with the condition. Participants ranged between 18-60 years in age; they earned an average income of \$60,000, and they varied in education from PhD degree holders to high school certificate holders . There is a wide range in geographic and socio-demographic information collected from these respondents. The study included similarities and differences based on socio-economic status and ethnicity. In addition, five medical practitioners, including nursing practitioners, a therapist, an OBGYN, and an endocrinologist were interviewed for their knowledge of PCOS as a phenomenon and best practices for treating patients.

Data Collection Procedures

Procedures employed to execute this study included: participant recruitment, establishing rapport, maintaining confidentiality, qualitative interview process, transcription and data analysis processes. This study was approved by the George Mason Human Subjects Review Board. These will be discussed in the following sections.

Participant Recruitment. Recruitment began with social media network sites dedicated to providing support for women with PCOS. Participants were recruited through purposive sampling. Purposive sampling method non-randomly select potential participants on the basis of a particular characteristic (Frey, Botan, & Kreps, 2000). Participants were located through Facebook, Twitter and Instagram. More specifically, the invitation circulated among a large community of PCOS Facebook closed-group and PCOS-Instagram accounts. The researcher is an active member of the online support

groups and familiar with the way that persons with PCOS are willing to share their stories.

Moreover, a convenience purposive convenient sampling method was utilized to recruit medical practitioners (Tongco, 2007). A purposive convenient sample affords the researcher to select non-randomly respondents on the basis of availability (Frey et al, 2000). As a researcher living with the condition, I recruited health care practitioners as participants for the study and used a snowball recruitment strategy where I asked for recommendations from these respondents to identify other health care practitioners who might be willing to discuss issues surrounding PCOS with me (Tongco, 2007).

Rapport. The first goal was to establish rapport based on the sensitive and vulnerable nature of the topic. I informed the participants about what they should expect during the interview. Next, I discussed with the participants, the vulnerable nature of the questions. I further assured them that they could choose to discontinue the interview process at any time.

Confidentiality. To invite and encourage truthful narratives, I placed special emphasis on confidentiality. At the first step of recruitment, it was important for the participants to know that their personal information would be kept private and secure. Participants chose a pseudonym which were used throughout the process of the research. Also, an informed consent form was explained, signed, collected, and stored prior to the interview process.

Qualitative Interviews. Twenty semi-structured qualitative interviews were conducted to collect data for this proposed study. Interviews lasted between 40 to 70 minutes.

Audio-Recording. A hand-held audio-recorder was used during interviews. The device also helped the researcher to accurately capture participants' responses and focus on their responses. Later I was able to ask follow-up questions that generated deeper insights into respective lived experiences.

Member Check and Respondent Validation. One goal of a member check is to clarify interpretation of data; in this case, it did provide an opportunity to confirm participants interpretation of their daily lived experiences. Initial themes and categories were revised based on the feedback and included in the final manuscript. Also, the member check was used to co-create themes and categories to reflect the feedback of participants. These additional insights and new understandings which were incorporated to the final manuscript. While the participants' understanding of the researcher's interpretation is one of the goals of member checks, their objections were not taken at face values. Etic and emic observations provided respondent validations. These observations originate from ethnography of communication methodology where etic is the perspectives of themes and data drawn from researcher's theories and concepts, and emic is derived from terms and language used by participants to understand their world.

Seale (1999) explained the value of member checks to determine members' descriptions, to show the researcher's account as successful, ask members to judge the adequacy of researcher's account in the final report, and regard successful action research

as form of member validation. All these steps were utilized in the study to provide member checks.

Method of Data Analysis

Moustakas (1994) recommended that researchers must transcribe, read and reread transcripts, study their field notes and listen to the recordings to familiarize themselves with the data. Then, researchers should identify key experiences shared by the participants. After rigorous reading and rereading of data. The researcher coded and recoded certain experiences shared by the participants. These experiences were labelled using key words from the data. The researcher used the qualitative software NVivo to study each transcript, listened in for key phrases, also conducted search of key words or phrases from the data. The researcher used analytic memo process to generate codes, categories, and eventual themes. According to Saldana, (2009) analytic memos are sites to “ dump your brain” about the participants, phenomenon, or process under investigation by thinking and thus writing and thus thinking more about them” (p. 32). The analytic memos included notes the researcher wrote on the margin of the printed interview questions. The researcher then compared notes on each interview including additional notes written during the data collection stage of the research. Other notes were written at odd times when the researcher thought about the responses provided by the respondents. Next, the researcher categorized similar codes into themes and sub themes (Moustakas, 1994). The researcher used etic and emic to incorporate theoretical concepts and terms to make sense of the participants language and experience. Finally, to provide thick descriptions of data, several quotations were highlighted to reflect the themes found in

the data. The researcher recognized her positionality and was conscious about her bias or knowledge of the phenomenon during the interview and data analysis process. Prior knowledge of the phenomenon or participants were clearly stated in a transparent form by the researcher (Moustakas, 1994, p.77). Through reflexivity, the researcher accounted for interpretations, biases, and preconceived knowledge about the phenomenon. It was difficult to remove the voice of the researcher from the research, however the researcher relied on intentionality of consciousness to reflect, capture, identify and bracket herself out of the interpretations derived (Van Manen, 1990). The researcher shared initial themes with her advisor for this study to ensure accuracy, interpretation, and precision.

Member Checks was also conducted to clarify interpretation of data. The researcher contacted some of the participants again and discussed the initial themes and sub themes. This member check was used to co-create and reinforce themes and categories to reflect the feedback of participants.

In the above section, the author describes the approach and methodology used to explore the communicative behavior of women with PCOS when seeking health care services and support from health care practitioners, family members, spouses and others.

CHAPTER FOUR, RESULTS

Chapter four discusses the themes I discovered in the data and analysis process. The examples provided below illustrate the communicative challenges patients encountered during the different stages of the prognosis for PCOS including diagnosis, treatment and care for several invisible conditions. For women with PCOS to develop agency for care and treatment of the condition, it is vital to identify the communicative challenges they surmounted or navigated in the health care system. Participants divulged varied communication challenges when interacting with health care practitioners, significant others, family members and others.

Table 1 Participant Demographics

Participants	Race/Ethnicity	State	Age Range	Occupation	Income	Status	Year of Diagnosis	Education
Kell	A/A	AL	Over 30	Admin	60-80	Married	2012	PhD
Felicia	A/A	VA	Over 30	Military	60-80	Single	2017	M.A
Ann	A/A	VA	Over 18	Blogger/SHM	50-60	Married	2016	High school
Maggie	Wh	AR	Over 30	SHM	80-100	Married	Decade	M.A
Darlina	AA	VA	Over 30	Project Manager	80-100	Divorced/ single	9 y old	B.A
Yvonne	Wh	Maryland	Over 55	Professor	Over 100	Married	At 30	PhD
Maria	Wh	PA	Over 18	Lib Assist	32k	Single	2011	M.A

Chloe	<i>Wh</i>	VA	Over 30	Professor	100	Married	Age 30	PhD
Kathy	<i>Wh</i>	PA	Over 40	Lib Admin	60-80k	Married	Puberty	M.A
Trisha	<i>AA</i>	VA	Over 18 Over 30	Student	20k	Relationship	2016	B.A
Victoria	<i>AA</i>	PA	Over 18	Medical Coder	60-80	Single	2009	B.A
Allison	<i>Hisp</i>	VA	Over 18 Over 18	Consulting Librarian	20-30k	Relationship	2015	B.A
Frances	<i>Hisp</i>	Puerto Rico			Under 20k	Single	2016	M.A
Cathy	<i>AA</i>	VA		Student	20-30k	Single	16 years	M.A

Helen	AA	Georgia	Over 30	Therapist	Married	2005-2006	PhD
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Total	15
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Practitioners	Nationality	State	Occupation	Education
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Leticia	AA	CA		PhD
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Clinical				
Researcher				
Monica	AA	MA		PhD
RN				
Winifred	A/A	MA		PhD
Clinical				
Specialist				
Tink	A/A	VA	Nurse Admin	PhD
Alison	AA	NY	OBGYN	M.D
Helen	AA	GA	Therapist	PhD

Total 6

Data analysis revealed four major themes and subthemes that illustrated how those with PCOS communicated with health care practitioners, family members and acquaintances.

1. RQ1 asked: How do women with PCOS describe their communication with health care practitioners when seeking care? The following are the results. *The tough road to diagnosis*. With the following subthemes: a) How I got diagnosed b) PCOS, now what? Relief, grief and hope c) Infertility the new normal?
2. RQ 2 probed: How do women with PCOS employ communication accommodation strategies and privacy management skills with family members and others, if they utilize them at all? The following include the themes *PCOS and the lived experiences of patients* had 3 subthemes: a) The effects of PCOS on physical health; b) Emotional impact of dealing with PCOS; (c) lifestyle changes; and (d) Need for better care and fear of dying.
3. RQ 3 inquired: How do women with PCOS describe their communicative experiences with discrimination, power and privilege if they experience such at all? The response to the inquiry generated the following theme and sub themes: *communication challenges of PCOS*: (a) PCOS, a disadvantage; and (b) microaggressions due to PCOS.
4. RQ 4 queried: How do health care practitioners describe their communication when delivering care to PCOS patients? The result

generated this theme: Communicative challenges with relatives and health care practitioners and recommendations for health care practitioners. For this theme, exemplars of communicative challenges from health care practitioners' perspectives are provided.

As Table 2 shows, each major theme had several distinct sub-categories. In the following section, examples from the data illustrating the major themes and subthemes are provided below. The presentation of data concludes with a brief theoretical analysis, which is reviewed in depth in the discussion section.

Table 2 Major Themes and Subthemes

<u>MAJOR THEME 1:</u> <i>The road to diagnosis</i>	<u>MAJOR THEME 2:</u> <i>PCOS and the lived experiences of patients</i>	<u>MAJOR THEME 3:</u> <i>Communication Challenges</i>	<u>MAJOR THEME 4:</u> <i>Physicians' Communication on PCOS</i>
How I got diagnosed PCOS, now what? Relief, grief and hope	The effects of PCOS on physical health	PCOS, a disadvantage	Building trust and rapport with patients
Infertility, the new normal	The emotional impact of dealing with PCOS	Experience of microaggressions due to PCOS	SMART care plan for treating invisible conditions

	Lifestyle Changes	Communication challenges with relatives and health care practitioners	
	Better care and fear of death		

Tough road to diagnosis

The theme *tough road to diagnosis* corresponds with the RQ1 “How do women with PCOS describe their communication with health care practitioners when seeking care?” I set out to understand participants’ communication with their health care practitioners prior to, during, and after diagnosis. The responses I received were in form of narratives without the participants’ direct admittance of experiencing difficulty with the U.S health care system. Diagnosis stories provided detailed information of the participants’ experiences before and after their prognosis. Many participants struggled with some physical symptoms for years that affected their self-esteem and confidence. Overall, in a data set of 15 interviews there were 32 paragraphs which described experiences of the women with PCOS, there were a variety of expressions shared by women in the process of diagnosis which changed their lives tremendously. For clarity, this theme will be organized based on problems with practitioners and problems with patients.

Problems with practitioners

Most participants have never heard of the condition prior to their doctor’s visit and heard the term for the first time at their appointment. The experiences of women included having bleeding ovaries, failed attempts at pregnancy, abnormal menstrual cycles and appearance of other symptoms. Trisha, a university student narrated her diagnosis story below:

Yeah, so I actually wasn't called by a doctor originally. It wasn't tested for, but I had noticed like I was having abnormal menstrual cycles and I was

starting to get a lot of acne, all of a sudden. And I was having a lot of trouble with my weight and I shouldn't have because I'm a very active, eating very well. So, all these things. And so when I went to the doctor, the first time they tested my thyroid and they said everything was fine and so, they sent me away but I knew something was wrong so I started doing research about it. And one of the things that came up was PCOS and so I went back to the doctor and I asked them if they could test me for PCOS. And so basically, they did blood work and they said, yeah, you know, you probably could have it, you have your hormones are definitely imbalanced. And then I had to go get a scan and found where they confirmed that I had PCOS.

It is vital to note that majority of participants in this study shared same sentiments as Trisha about visiting the doctors after experiencing sudden and persistent symptoms that were initially misdiagnosed. To be fair, each participant visited doctors with different specialty including primary care doctors, OB/GYN, and nutritionists. However, regardless of the practice visited, the initial encounter did not result in accurate diagnosis. Some of the interviewees had to suggest the idea of getting tested for PCOS to their health care practitioners when other results were cleared. In Trisha's case, her doctor listened to her and conducted an additional test before the official diagnosis was made. Other patients were not as lucky as Trisha and their symptoms were dismissed.

Even though the interviewees mentioned the symptoms they experienced, the type of tests conducted could not ascertain the condition at the initial stage. Trisha on her own had to conduct additional research before she was able to nudge her practitioners to take a different route. In short, the women interviewed in this study often had to initiate PCOS talk with their doctors. The experiences of these women mirror those found in previous research. As Singla et al. (2015) found, many women did continue to encounter roadblocks on their way correct diagnosis and will endure

avoidable pain and emotional stress until physicians and other stakeholders include PCOS testing for patients especially when the symptoms mirror other conditions like hypothyroidism, diabetes or obesity. Trisha's experience suggests that although physicians listen to their patients and test for common diseases, PCOS is still not as equally recognized in the most practices.

One of the reasons for this gap in diagnosis, could be the inability of doctors to elevate PCOS as an important disease that requires immediate attention than merely women's hormonal issues that can be regulated by exercise like most physicians suggest. In my own case, my physician, after running a series of tests, announced almost nonchalantly that I had PCOS and proceeded to recommend prescriptions. There is nothing wrong with a physician accurately diagnosing a patient and recommending care plans immediately. The problem arises when the patient is not included in the discussion or properly educated on the symptoms and implication of the condition. My experience is far from unique. In fact, many of my participants said that they did not feel well supported or cared for by their health care practitioners at the point of diagnosis.

Women go through blood tests, ultrasound and other diagnostic tools and before being diagnosed with PCOS. Overall, these participants were largely unfamiliar with PCOS prior to diagnosis and generally did not understand nor have information about the condition. This resulted in asking for advice from friends and doing helpful (or harmful) research to find answers they were unable to get at the clinic.

For example, Felicia during the interview stated that she had to call her best friend who has PCOS to get better understanding of her new health condition:

And I asked my best friend because she was going through the same and she's the one that actually put a name to it. I didn't know what PCOS was. I just thought I had really bad acne and my friend is the one that said it like actually it sounds like PCOS.

A similar experience shared by many participants indicate that given either an incorrect initial diagnosis or insufficient doctor-patient communication even when the diagnosis is correct, family, friends, and the internet served as valuable resources to managing and understanding PCOS as a whole.

Kell also described how she encountered the term PCOS:

At the beginning, I didn't have any change in feeling because I hadn't heard of it before, so I didn't know what it (PCOS) was. So, my feeling was obviously to research to figure out what exactly did this mean.

At the time of diagnosis, it also appeared that some women were unwilling and unable to accept the condition due to various reasons. Particularly, Felicia who works in the military refused to be formally diagnosed with the condition and she explains why below:

So...when I actually got the results from a gynecologist and she was like, yeah, she's like, you know, we could diagnose you with PCOS. I told her no because I don't want that on my records. As a military member if you have something on your records, that's questionable, it could be grounds for... dismissal or anything like that...

Studies have shown that between 30-50 percent of women with PCOS report being depressed compared to 19 percent of women without PCOS (healthline.com). The high rate of depression associated with women with PCOS calls for more attention to be paid to women with PCOS who may be manifesting depressive symptoms.

It is interesting that although the U.S boosts itself as one of the most forward thinking and advanced nation, similar issues faced in African countries also abound. The difference however is in how much awareness programs and headlines mental health issues occupy in both areas.

Problems with patients

Among the majority of participants interviewed (64%), many did not have children at the time of the interview. There were only few cases in which women had children before the diseases appeared or after treatment. Yvonne who was diagnosed over two decades ago while she was trying to start a family recalled below how she was diagnosed. Her experience echoed previous research that suggests women get diagnosed when trying to start a family of their own (Dapherede Otusanya, 2018).

By then, by the time I was 29, I was married, and we wanted to have children. So, I went off it again [, (birth control pills)] and then I didn't get any periods. I went to a fertility specialist who did the ultrasound and showed me inside my ovaries, the ring of pearls around the ovaries, and said, "This is polycystic ovarian" – at the time they called it "disease." But that's not the label it has now. It's "syndrome" now, I think, isn't it.

The interviewee had planned to go for birth control when she was diagnosed with the disease. She had irregular periods and became pregnant but when they consulted doctors and went through several tests PCOS was diagnosed. About 90% of women had irregular menstrual cycles before going for treatment to their hormonal balance. During this treatment, they were diagnosed with PCOS. Ann, who started a blog about PCOS to increase awareness about the condition, shared the following:

People don't realize that PCOS is like the snow and if you let it build up over time it creates this effect, this trickle effect. PCOS causes me to have an irregular cycle, so I'm bleeding two months straight and I guess my body couldn't keep up with my iron you know what I really need for my cycle.

Her analogy of PCOS as snow is very impactful to note for health care practitioners as well as women with PCOS. Although a common condition, PCOS is not easily diagnosed and failure to monitor and treat symptoms with immediacy will lead to certain co-morbidities both for women of reproductive age and women in menopause. These comorbidities include diabetes mellitus, dyslipidemia, obesity, hypertension metabolic syndrome, depression, anxiety, obstructive sleep apnea, nonalcoholic fatty liver disease, endometrial cancer, and cardiovascular disease(Cooney& Dokras 2018). Health care practitioners should become more involved in the multidimensional care for those with PCOS so they can effectively communicate and monitor these long-term health risks to provide proper screening, counselling and treatment plans for their patients.

In addition to monitoring PCOS and its impending comorbidities, many patients are often prescribed medications to help with the symptoms which sometimes make them even more sick, as described below.

A third participant recounted her diagnosis story surrounding infertility:

So, from after that, I thought that that tied together with the PCOS, but they told me that it wasn't just that, that my chances of getting pregnant was low, I stopped taking birth controls because I wanted to have a baby. So then because I had PCOS I had birth control, which I stopped because not only wanting to have the baby, but it was making me sick. So, I started taking the Metformin, which helped me regulate my periods, but it also makes me more fertile. I was doing that for about a year and then they kept telling me to the only way that I can reverse my

PCOS was to lose weight. And which I found out that is kind of true because every time I had dropped a significant amount of weight, I no longer take Metformin, my period became regular. So that's what I mean by the last six years I've been finding out about my body and what affects the PCOS, how can I help it and how can I not help it...

The above excerpt indicates the use of medication, its impact and how weight loss can help minimize symptoms of PCOS. According to the National Institute of Health (NIH), some lifestyle changes including change in diet and weight loss help improve some of the PCOS related symptoms as experienced by this interviewee (www.nichd.nih.gov/). Ultimately, lifestyle changes and weight loss help regulate some symptoms more than medication.

Some of the participants also shared that they were dismissive of some of the symptoms they initially noticed until they visited their doctors. The condition is often treated by patients as some sort of annoyance they have to deal with until they realize that those symptoms are just the tip of the iceberg and that they are predisposed to even more chronic conditions. Among the participants there were also a few women (two out of 15) who said that they are strong enough and able to manage their condition they do not put much thought on it to avoid bringing life to it. PCOS is a deceptive condition that catches its sufferers unaware. A critical health information that is seldom discussed by health care practitioners are the long-term impact of PCOS on the quality of health of patients. Women with PCOS have higher risks of cardiovascular diseases, type II diabetes, and suicidal rates (PCOSchallenge.org; PCOSAA.org). There is an urgent need for women to take their health seriously by monitoring sudden changes in their bodies that are unexplainable such as sudden weight gain, adult acne, hair-loss and infertility.

PCOS, now what? Relief, grief and hope

After diagnosis with PCOS, there are varied emotions that each participant experienced. Many were relieved that they can address the specific health issues without the confusion they have tolerated for years. Others were vindicated that the symptoms and emotions were not just in their heads while some expressed that it has become yet another hurdle they have to overcome. The most common emotions reported by 80% of the women interviewed included feeling stressed, sadness, disappointment of not being woman enough, fear of medication side effects and the risk of infertility for women who want children. The dominant responses were a mix of relief and stress. The participants were relieved that they were not overreacting about the symptoms, but they also stressed about the impending hurdle of dealing with some symptoms, especially infertility. About 20% women also reported anxiety and depression when they were diagnosed with PCOS. Darlina expressing a sigh of relief after diagnosis explained her feelings about the journey to diagnosis below.

At the time, you really don't think much of it because you're not sure what's happening with your body. But now that I think back, it's like, man, I shouldn't have been that way, I should have been more in tune with what was going on with me and the feelings behind it. Because I can tell you times that it hurt school or personal relationships and at that moment it was like, I guess this was my life, this is what I must deal with, so this is it. But again, now that you're asking that question and thinking back, it should not have been that way.

Darlina, like many other women dealing with the severe form of PCOS, experience more challenges in their health, relationships and work. She did not realize that some of the challenges she faced prior to the diagnosis were directly or indirectly linked to some her symptoms. For others, they attributed the stress in their lives to being

responsible for some of the symptoms of PCOS. It is interesting that in both cases as expressed above and below, PCOS impacts relationships and productivity and vice versa. Trisha, in recounting how PCOS had impacted her, recounted that the stress she was dealing with caused some of her symptoms to flare.

I'm like constantly stressed out and everything. I'm 100% like positive that stress is what causes all my symptoms to go up and crazy because it was over spring break and over winter break where all my symptoms despite my diet, disappeared really; two weeks or a month and I had a regular period. All my acne disappeared, and I was losing weight like really rapidly.

The feelings of stress and other related emotions contribute to the increase in symptom manifestation in many patients. In the interviews with health care practitioners, many did not speak on or attribute PCOS to stress induced thus their conversations were limited to patients need to lose weight. In our current fast paced society, it is almost impossible for people not to be under stress due to finance, work related or relationship issues. Effective communication on the influence of stress management by health care practitioners with actionable goals need to be incorporated in the treatment and care for PCOS.

Due to some of the symptoms of PCOS that mirror pregnancy, or thyroid issues, interviewees shared they were accused of being lazy or being pregnant when in actual fact they were not. Such accusations and attack on their behaviour caused such great harm and distrust of health care practitioners, parents and guidance. It is a common belief that it is hard to gain trust of health care practitioners, so imagine you going to a health care practitioners to help you with a health related issue but getting accused of something you clearly did not do.

From self-advocating for PCOS screening to having to defend themselves before health care practitioners and family members, those with PCOS are in constant communication tensions with dominant group members. Maggie, recounting her experience as a teenager, mentioned how not having a period for a significant amount of time got her in trouble during a doctor's appointment.

I was so upset after that appointment because they were accusing me of being pregnant and I must be sexually active and that's why I wasn't getting it (period).... I was still a virgin I was like no! I'm telling you something's not normal. That...stuck with me. I mean, I'm in my 30s now...that was when I was 18 and just that feeling of not being trusted.

Recalling this experience evoked fresh anger and sadness in Maggie's voice that she tried to mask the betrayal by stating her mom or doctors could not advocate for her because they were not knowledgeable about PCOS back then. She further explained how the experience affected her health later on.

I went back to my mom. My mom was aware of everything that was going on and I think for her she didn't have the knowledge either. She didn't know how to ask for further stuff.

Looking back on it. I don't really feel anyway, or did I feel sad because I feel like if I had information sooner I could have saved myself a lot of heartache as I got older especially when we were trying for a family. Like I would have been prepped. We could have saved time instead of trying for as long as we did on our own without an answer. But I also do think God had purposes and plan for everything and that there was a reason why I wasn't supposed to know when I was 18. I don't know the reason why I'm supposed to go through the experiences that I did maybe to make me a stronger person or maybe a combination of the two.

The above excerpt suggests that there may be the sense of rationalizing not getting the accurate diagnosis at a younger age for a higher purpose or lesson. This is a sad conclusion Maggie came to because not only is PCOS a malignant condition, it is

also one of the most time-consuming health conditions to manage. To detect and start treatment on time will yield immediate results as opposed to the long wait to start a family or lose weight.

The communication tactic utilized here describes rationalization, developed by Gina Castle Bell (2015) in her extension of co-cultural theory. Rationalization, an assertive assimilation communication approach describes how Maggie did not put the blame of her late diagnosis on the previous experience she had with the health care practitioners. Castle Bell et al (2015) defined rationalization as instances where individuals provide alternative explanations for communication rather than labelling them as forms of injustices (e.g., racially insensitive, prejudice, or discriminatory). Using rationalization to explain the harmful communicative experience allows the perpetrators to escape responsibility for their actions. Looking closely however, these actions are costly and leave patients with chronic conditions in the future.

In addition to rationalizing the failure of health care practitioners, social stigma also influences the communication surrounding PCOS. The communication challenge of stigma and distrust due to accusations of pregnancy or laziness was shocking but not surprising to me. I remember I was also accused of being pregnant as a teenager by an acquaintance because I seemingly looked bloated and had missed my period for some time. Bloating is associated when girls/women of reproductive age experience fluid retention in the body due to hormonal changes. At the time, I did not think to probe further why I was experiencing irregular periods, but I was upset that someone will suggest such to my mom about me being sexually active at that age. I do not recall my mother's reaction, but I know

we never addressed the issue again. It will be interesting to note that several years after, I am still asked if I am pregnant whenever I look bloated. It is important to note that this has only happened in an African setting or cultural context. Africans, especially Nigerians do not see anything wrong in commenting or speculating about your reproductive activities' due to a change in your size or shape.

It is so bad that comments about one's weight can be an equivalent of a greeting. For instance, I was at a Nigerian birthday party recently and was repeatedly told, that I was "fat" by not one, not two, but by several people who had not seen me in a while. Looking back, I remember thinking to myself, we are in the U.S, why am I still experiencing these rude comments? It is even more painful especially when you are trying to conceive, and your weight is seen as a positive result of your efforts. Then not only do you have to combat being called fat, now you must publicly acknowledge your difficulties with conceiving. Having PCOS as an African woman, especially a Nigerian woman, is not a stroll in the park.

Looking back, I should have probed further why I was seeing only my period every other month. At the time I felt I was blessed because I was being spared the excruciating pain for that month but in retrospect, not having regular period could pose serious health implications. According a fifty-year study of California women, and other research conducted recently, an irregular period is associated with a higher risk of developing and dying from ovarian cancer later in life (Harris, Titus, Cramer & Terry, 2017; Sciencemag.org, 2016). In short, the stigma of being shamed for PCOS symptoms can literally cost women their lives or affect the quality of health for women. PCOS although

a common condition requires sensitivity and thoughtfulness in communicating with patients especially regarding symptoms that may mirror other conditions.

Another participant Darlina, narrated how she was accused of “faking it” because she complained of pelvic pains which is quite invisible to the naked eyes. She recounted how they kept visiting the hospital but with no results in sight. It is interesting to note that physicians, families and friends participated in dismissing patient’s symptoms:

And then I just started getting like massive pelvic pain and there were times where my mom thought maybe I was faking it because it was almost like every week I'd be like, "Oh, I don't feel well and something's going on." So, again, back to the doctors. Actually, to be very honest with you, at that time, the doctors told my mother that it was in my head and that I was manifesting these symptoms, and something was not right and that I should probably see a psychiatrist.

Not only did her mother doubt her symptoms, her doctors suggested she needed to see a psychiatrist because she might be hypochondriac. Invisible conditions are usually difficult to manage due to stigma and discrimination attached to such symptoms that people cannot see or understand. PCOS, an invisible condition where expectations of reproductive functions are seen as common and easily manageable. Women are different in pain tolerance for bodily functions that others may not experience any pain or discomfort just like labor pains. Due to this generalization of experiences, women also perpetuate minimizing or discriminating against others who find it difficult to conceive etc. Because one woman finds it easy to conceive, lose weight, have no pain during their menstrual cycle, does not mean that is the experience of other women. Health care practitioners need to have this concept imprinted on their manual as a constant reminder not to dismiss women’s symptoms. One of the main purposes of this dissertation is to highlight the health struggles with PCOS that are not often communicated in dominant

spaces and will not be communicated in dominant spaces because that is not the common experience of women. Bringing the challenges to print indicates that there is more work to be done in the health care settings to give more attention to women's voices. The data suggest that women voiced their concerns, however the problem occurs when these voices are silenced through accusations or by gaslighting. The idea of sexism or misogyny is at play here although subtly. Both women and men perpetuated the dismissive and minimizing behavior towards the patients.

Theoretical Analysis. Women diagnosed with PCOS used co-cultural strategies including extensive preparation to advocate for themselves when interacting with health care practitioners. Orbe (1998) describes *extensive preparation* as “engaging in an extensive amount of detailed (mental or concrete) groundwork prior to interactions with dominant group members (p. 16). PCOS is seen in health care settings as a common condition which is not often screened for in women presenting reproductive health symptoms described above (Sanchez, 2014). It is imperative that health care practitioners bridge the knowledge and late diagnosis gap of the condition by including the screening for PCOS. In the above excerpt the participant extensively prepared by conducting her own research and she had to self-advocate by using the knowledge of the preparedness to advocate for testing for PCOS. Many women rely and trust their health care practitioners blindly often do not do additional research to better understand their symptoms. Trisha utilized *assertive assimilation* as a communication approach to achieve her desired health results. Assertive assimilation describes orientation that strive to “downplay co-

cultural differences and promote a convergence into existing structures using non passive voice (Orbe, 1998 p.112). Participants after conducting extensive research on PCOS suggested to their practitioners to run additional tests. The communication approach does promote a level of collaboration and partnership between doctor-patient interactions where patients suggestions are taken into consideration and acted upon.

Infertility, the new normal

I came across a tweet recently which tugged deep in my heart. The tweet felt like the words I and my participants were trying to conjure to describe the feelings and trauma of infertility. Her tweet reads “infertility breaks you down. It ages you. It weighs on every single aspect of your being. It is lasting trauma that reminds you every waking day that something isn’t working, it crushes your soul”. This captures what I aim to describe below with this theme.

Infertility is one of the main symptoms of PCOS and has great implications for these patients. In the next section, I will discuss how participants shared their fears, sadness, and hope about the likelihood of infertility due to PCOS. According to the Centers for Disease Control and Prevention (CDC), infertility is not being able to get pregnant after one year of trying or six months if a woman is 35 or older. Currently, about 10 percent of women in the U.S ages 15-44 have difficulty getting or staying pregnant. In African countries, the average infertility is 10.1% in couples and higher in other countries (Gerias & Rushwan, 1992). Infertility is not only a health issue but has great cultural

implications for those affected. In many African cultures, and other continents, being fertile signals wealth, productive, good fortune and generational blessings. For this reason, the communication surrounding infertility in African context, specifically Nigerian context is complicated and traumatic. Below, I will discuss how infertility due to PCOS impacts women's lives and how its cultural ramifications should be addressed.

About 60% women interviewed shared that they were upset, unable to talk to people and felt terribly lost when they realized PCOS can/will affect their ability to get pregnant. The young women in particular were traumatized to learn that PCOS affected fertility, although they do not want children at the time but wanted later in life.

Maria who is in her 20s recalled how upset she was at the news:

So, I was very upset. Because what teenager wants to worry about birth fertility and reproductive issues at that age. So, I was upset. I eventually...you know read more about it and coped. But at the time the moment that I was diagnosed I was very upset.

Several patients cried, felt weird, ashamed and thought about how life will be going forward after getting diagnosed with PCOS. The feeling of shame, sadness and disappointment was common for most women, and each participant coped with the news in their own way. For example, Chloe, who was diagnosed when trying to start a family of her own, recounted how she responded to the news about infertility and PCOS.

When I got the diagnosis, I had my best friend come over and we finished off a bottle of Tequila together and cried because I was really scared. I wanted kids and I didn't know if it would be possible. At the very least, it was going to be very difficult. So, yeah, it was horrible. But no, I had never heard of it, I knew nothing about it until I got diagnosed.

The news of infertility to some women might be like a death sentence and can be quite traumatizing. Even for women who were not actively looking to start a family, they were also traumatized by the news. Some of them, hearing such news felt like their dreams have been shattered or in the least, now have cracks and holes they have to fill and work through to achieve their goals of becoming parents. Chloe's reaction to her diagnosis indicates that PCOS is trauma and surviving it takes a lot of empathy, dedication, patience and good support system.

Helen, a therapist aptly describes getting diagnosed for infertility as traumatic and should be properly grieved so that women can accept their new normal identity of being different in that regard:

...grieve the loss of naturally conceiving what they thought conception was going to look like, you know, we're going to have sex, we're gonna get pregnant this month and then we're going to deliver the baby literally on their due date nine months later and be at work, you know, and so having to sometimes grieve what they thought conception was going to look like...

In addition, she mentioned that women need to process their new normal which may take a short or long time depending on the individual.

That's a huge grief and a huge loss you may not ever accept it. I may just get to a point where I can deal with and cope with it better...but getting to a point where they are saying. Okay. This is my new normal. And this is what it just has to look like for me and kind of reconciling what they thought it was going to be so that they can kind of move forward with how it actually is going to be so and sometimes that process is a little long sometimes it's super quick.

Her acknowledgement that PCOS and dealing with infertility is traumatic is very eye opening. Many women who struggled with infertility in this study did not attribute

their experience as traumatic. However, the therapist's knowledge and experience helped unravel some of the participants' narratives as traumatizing. Symptoms of trauma such as shock, denial, confusion, anxiety, guilt, shame, self-blame and withdrawing from others greatly impact women dealing with PCOS in varying degrees. Participants' inability to recognize their experiences as trauma, is indicative of the emotional burden and underlying issues that is contributing to their mental health. During the interviews, some of the women articulated symptoms of trauma but then either dismissed it or made jokes instead of viewing themselves as experiencing a life-changing traumatic event. There is a gap between their self-understanding of their experiences and the views of experts regarding the symptoms of trauma. Therefore, it is imperative that health care practitioners have better communication skills and plan when delivering news of such magnitude to patients. Reassurance and showing empathy to women during this process will improve the overall quality of health.

A few other women bravely accepted their diagnosis but also acknowledged the hurdle ahead of them. Ann describes her relief and also the battle ahead of her:

I feel like my ultrasound show it... and this is the reason why I'm not able to have a child. I feel better but I know my battle is not over.

Indeed, PCOS is a constant battle for each patient diagnosed since there are no known causes or cure for the condition. As such every normal female reproductive function for these women will require medical assistance in form of assistive reproductive technology or in some cases deliberate lifestyle changes. Due to the uncertainty attached to women with PCOS and the risk of infertility, a few participants discussed how to tackle infertility when they are ready to start their own family. Trisha narrated her fears for the future regarding infertility:

So, it's hard; more than anything, I'd want to be able to become a mom and both my mom and my grandmother probably had PCOS and experienced miscarriages. So, when I think of having children, I think I'm definitely going to have a miscarriage and trying to figure out already how to deal with that if I'm even able to. And it makes me definitely sad because my best friend is pregnant now with her second child and I'm the godmother of both children and I adore them and I want definitely what she has one day, like not now, but in the future.

The above heartbreaking fear disclosed by Trisha and other participants about the future causes emotional pain and trauma. PCOS is thief of joy in the past, present and future of women dealing with the condition. Even when a patient is sure of their current health status, the future is not guaranteed as the unpredictable nature of PCOS does not permit one to be certain about easy pregnancy. With the fear of infertility looming in the future of women with PCOS, only one participant Trisha shared how she is prepared for her future if she decides to start a family.

I'm 21 and have made plans to either have a very good mother (surrogate), like have someone carry a child if I'm able to produce eggs or have someone totally have a child for me with my partner, like them doing the sperm donation thing with them and I've looked at so many adoption options and I'm 21 and haven't even started trying for kids. I've looked at like at least three different backup options, like all of it.

It is commendable that some of the participants were proactive about finding alternative ways to achieve their desired goals of having children. It signals that there are many ways to start a family and other options are available to women with PCOS. For others who are more resilient about starting their own family by experiencing the process themselves the future might look a little different. In the U.S and other developed countries surrogacy and adoption are less stigmatized but in other cultures the fear of stigma might lead women to either not think of the alternative options.

The next theme discusses the lifestyle changes participants made due to PCOS and its symptoms.

PCOS and the lived experiences of women

The theme was uncovered when the participants were asked research question two: *How do women with PCOS employ communication strategies and disclose their condition to others?* The following subthemes are discussed below: (a) Impact on physical and psychosocial care of women; (b) Lifestyle changes, and; (c) Need for better care and fear of dying.

Impact of PCOS on physical and psychosocial care of women. PCOS greatly changed the lives of women in a variety of ways causing them to experience physical and emotional needs before they were diagnosed. These participants were mostly prompted to make certain changes in their routine by being placed on medication and advised to change diet and lose weight. The experiences shared by the participants in this research are serve as eye openers for others to learn and to get help dealing with such conditions. A few of the participants recounted being placed on certain medications to help them ovulate or help them trigger a normal menstrual cycle. Metformin a common medication prescribed for women with PCOS is used to help the women normalize their menstrual calendar. Although some of the participants mentioned metformin, they did not share any worries or side effects they experienced using the medication. This is interesting to note that metformin is an anti-diabetic medication that reduces the amount of sugar the liver releases to the body, thus it is originally for those diagnosed with diabetes. Those participants who were prescribed metformin saw some changes however, they did not adhere to the directions of the medication due to fear of overreliance on it. Victoria, who was diagnosed in 2009 describes how metformin was not the final solution she needed to help regulate her period.

No. I don't like medications, so that's why I stopped taking the Metformin because with the Metformin, they give it to you and I had to take 3 pills at night, and they are huge pills. I've been able to research on myself, but this is what I had to do to figure out my body because I don't want to have to rely on Metformin for the rest of my life to get a period. So, what I've been doing now it's just monitoring my period and if it gets to the point where, I haven't taken the Metformin, but if it gets to the point where I go, I can't go five months without a period, I feel disgusted...

Although metformin may work for some, it is a medication that you have to rely on for the rest of one's reproductive life. It is not sustainable and some of the participants realized it and had to seek alternatives to using metformin. Going through the data on how PCOS has impacted the lives of women, the fear of reliance on medication recurred. Darlina, who was diagnosed with PCOS at age nine, explained her frustration on the reliance on medications and symptoms she had experienced all her life. She took matters into her own hands and made lifestyle changes.

So, about four or five years ago, I said to myself, nope, I can't do this anymore. I can't go through this insane weight gain, for no reason. I can't go through the hair and the pain, pelvic pain and going back and forth. I think at the time because, well, because of my cervical cancer issue, I was seeing the doctor every two months so there were just things that I just was like, I can't do this anymore...And so what I did is I went to an all-natural path. I came off of Metformin, I came off of birth control pills and I'm not telling everybody to do this; don't do this unless you really are going to make a commitment to get healthy. So I came off of all medications. I really wasn't dieting; I was changing the things that I was eating.

The frustration and stress related to dealing with PCOS and other comorbidities drove Darlina to make certain changes of her own. Suffice to say that in the treatment of PCOS, the most valuable resource for health care practitioners are the patients themselves. These interviewees and other patients dealing with PCOS know their bodies best and are the most important resource to help guide the care management for PCOS. While it is important to make certain decisions about your body, it will be beneficial that the health care practitioners and doctors are informed about the decision to stop the medications. Many participants who decided against using metformin did not communicate if they informed their doctors about their decisions to discontinue the prescription. Although deciding to change what to eat like Darlina or monitor your body like Victoria, if the doctors are not informed about these decisions there may be

complications in the future for these women. There is an underlying tension here between celebrating women's control and autonomy and the need to rely on expertise and science. It is imperative that both parties are open and trusting to share information. Patients on the one hand, need to be assertive in ultimately choosing the best care plan for themselves but also they must communicate their choices with the health care practitioners before starting on a diet or exercise regimen. Likewise, physicians need to be receptive of patients' involvement in their own care by asking questions and also empowering them to make suggestions of their own. Building agency for one's health goal is one essential skill to have in the treatment and management of PCOS. An essential aspect in the prescription of medications for women with PCOS is that doctors need to be more understanding of their patient's needs. Ann aptly describes what PCOS patients mostly require from their doctors.

Well, what women with PCOS need the most is understanding, because I feel like doctors don't understand enough, or care enough of what they give to you or what they say to you. Understanding that you are not like the average woman so I can't treat you like that or understand that...something is not working for me. Understanding that you can't just force the same pills on everybody and say "hey, this is all we've got" So, in just understanding when we speak to you we are not seeking for attention, we are not seeking for... we are speaking for you to understand that there's something wrong and it's attacking our bodies and we need to come up with a better game plan.

Ann could be referring to alternatives to medications in this case as there have been better results for women who used natural alternatives like eating more vegetables and maintaining low carbohydrate diet (Krystock, 2014). Moving forward, doctors should

suggest healthier non-invasive and less medicated options to helping women navigate the care for PCOS.

Too often, patients are referred to take metformin without further explanations or information about some of its side effects or how it works in the body. For instance, the researcher interviewed a therapist, Helen whose patient population is largely African American, described how her patients are prescribed metformin without a clear understanding of the medication.

I've been told that PCOS is going to make it difficult for them to have children or they don't even know what it is a doctor just said, oh you have PCOS take this metformin...and they don't know what that really means.

There is a need for better communication of prescription instructions and alternatives to prescriptions should be known to the patients. Patients discontinue to use metformin for several reasons including the multiple pills per day dosage which is often uncomfortable to take or is easily forgotten.

In addition to adjusting to medications, some participants shared how PCOS had affected their emotions and mood. Frances shared how PCOS affected how she felt on some days:

I would get off a little more emotional. For example, when I'm close to ovulating, I would have a day where I'm just angry with the world. I don't want to deal with anything or with anyone and no one can tell me anything. The other thing, sometimes I would also cry for no reason and I know it's I'm about to ovulate because the next day, cramps. But it would be like extreme emotion and without any reason. Like I would be okay, everything is going okay with the world and then I start to cry and I'm like, what's going on with me? A lot of extreme emotions and they are negative”.

When I asked her how she coped with the extreme emotions she stated that her colleagues at work help and she reads a book to calm herself down but she said was also thinking about speaking to a professional about it but is yet to book an appointment. PCOS can be overwhelming and isolating due to the spectrum of emotions one can feel or go through in a short amount of time and without professional or positive coping mechanisms may escalate to depressive episodes or extreme mental health issues. For others like Ann, PCOS dominates and controls their life. She stated that:

PCOS has severely taken over my life, it is my life now and it shouldn't be like that but unfortunately PCOS doesn't have a warning when it will attack your mood. One day I'm chipper; I can get up and move mountains. And other days, I don't even want to get out of bed.

She is however very resilient to keep on living her life in spite of PCOS and she attributed that to being a mother:

And I'm a mother, that's one the hardest things about being a mother and having PCOS, you have to fight yourself to see why you're living, why you're breathing, why you're doing things. Because there is someone depending on you, you have a whole human. PCOS, it does take the joy out of it, so you have to keep reminding yourself that 'I've got this, I am this, I'm more than just my ovaries, more than this is PCOS'. You start to kind of move past it, but I'm not going to lie to you, days are hard. There are some days where I question, what am I doing? Who am I? Why am I doing this? Then I realized I'm doing this for everybody who has ever felt like they didn't have a chance.

Some of the women shared that they sought counselling to deal with emotional distress as a coping strategy when they could not cope by themselves. Maggie who struggled with infertility decided to go for counselling because of how she felt at the time:

...because I really wanted a family, I wasn't sure if that was going to happen at all and my sister had just gotten pregnant with her second child. I had to

go in for counselling for a while because I was just devastated like I was so happy for her, but it felt like my body was kind of failing me at this point.

Others sought alternatives to counselling such as religion, meditation and yoga to help fulfil some psychosocial needs they required. Kell and Felicia stated they coped with their emotions using these strategies especially prayer:

Kell: Prayer, meditation, Yoga, you got to find things to keep yourself busy and engaged. Because I mean, there's so much going on in your body and in the world, you have to have an outlet.

Felicia: ...if I'm struggling to write a paper ain't gonna talk about the struggle writing a paper. I'm going to sit down. I might first say to myself "this sucks". I say a prayer, give it to God and then I'm going to sit down and do it...

Several participants utilize diverse coping mechanisms to deal with PCOS including prayer for those who are religious and therapy for others. No one way is preferred to the other however each participant shared strategies that had worked well for them.

Changes in Lifestyle of the Women with PCOS

The third theme discovered in the data referred to how the participants made new lifestyle changes. Although it is difficult to create new lifestyle behaviour goals, some of the participants recognized the benefits of these goals to their health and they adapted to the changes. Currently, there is no cure for PCOS, however some lifestyle changes have been shown to improve the quality of life for women (Teede et al, 2019; Krystock A. 2014). These lifestyle changes such as exercise and PCOS diet were adapted mostly due to the self-efficacy of the participants to see changes in their health outcomes.

Exercise

Almost 90 % of those interviewed were involved in some type of exercise routine and they shared how regular exercises helped with some of the symptoms they experienced.

Frances attested to the benefits of exercise:

I'm exercising a whole lot more. That actually helped me a lot with my ovulation cramps. I decided to alter also a little bit of my diet regime. I tend to consume less sugar now. I'm mostly focusing on exercising.

Although exercise was beneficial to some of the participants, women who were trying to get pregnant were cautious about exercising. In a few cases infertility treatment did not allow others to continue an exercise routine. Chloe expressed her concern about exercises due to the infertility treatment she had to go through:

...because I was trying to get pregnant, I had already made a lot of those lifestyle changes, but I was cautious about, I tried to exercise a lot, although a lot of the infertility treatments ended up making it impossible to exercise. There were times of the month or places in your cycle or drug regimen where you just couldn't, it ended up being bad for my health in that sense. I tried to lose some weight, but that wasn't the issue.

The infertility treatment and in other cases other health concerns puts women in a conundrum of how to improve their health through exercise alone. Another beneficial lifestyle changes some participants used to improve their health is change in diet.

Change in diet

At the suggestion of their doctors, some participants changed their diet and saw results afterwards. Diet change is a vital aspect of managing PCOS and reducing symptoms for women. Change in diet can either be easy or difficult for patients due to several factors. Majority of women interviewed for this study conducted personal research and sought

additional information on the type of diet that will help with either weight loss or help to reduce insulin resistance. Trisha who tried several diet options before settling for what worked for her body described her diet journey:

Yeah, so my diet definitely changed. At first, I turned to Keto for three months, which was horrible. And then now it's low-glycemic, so I should be doing it better than I am, but I'm low-glycemic.

It can be a difficult task to figure out what diet best fits an individual based on their health needs. It is interesting to note that even though most of the participants changed their diet only a few consulted with a nutritionist before embarking on such a significant lifestyle change. The tension between individual empowerment and institutional expertise is evident in some of the data. The fear of fad diets or diet recommendations by non-experts was briefly mentioned by Maggie who was skeptical about the role of online support community for PCOS that provide non-expert diet advice:

We talked about like different medications that they tried which is great, but it doesn't work for everybody or fad diets. Like you should try this diet. You should try that diet. Well, I think that that's really dangerous to be suggesting any type of diet to somebody if you're not a nutritionist and you don't understand nutrition...

Diet and exercise significantly help with managing symptoms more than medications. However, it was shocking that only one participant recalled being referred to a nutritionist. Kell was the only participant who mentioned that she hired a nutritionist to help with her diet. She explained her decision to hire a nutritionist below:

I hired a nutritionist to kind of help me figure out what my body would respond to best, because I learned prior to my diagnosis that I couldn't eat dairy, milk and stuff like that, so I've not drunk cow's milk in like 15 years.

Many other women with PCOS will benefit more from working with a nutritionist than using medications that are unlikely to adhere to. PCOS is an expensive condition, and it will become even more expensive and dangerous for patients if they do not seek help on time. Health care practitioners need to collaborate with nutritionists in the care management of PCOS related cases.

The fourth subtheme that will be discussed below is the need for better care and they fear of dying. In general, doctors provided patients with basic information on what PCOS is and provided them with mostly prescriptions and advice to lose weight. This “band-aid” approach to communication surrounding PCOS care is insufficient for the growing population of persons with PCOS. Some of those interviewed had to seek additional information outside of their doctor to better understand how to effectively manage the condition. The lack of knowledge about PCOS and the inability to communicate opens the door for individuals to engage in “self-expertise” to the detriment of their health.

In the quest to get better care, some participants changed doctors, others used their voices to prompt their doctors to carry out additional tests, while most made additional changes to improve their health status through diet and exercise. Darlina, who was dissatisfied with her doctors articulated what can be done to improve care for women with PCOS:

There have been studies out there that prove that with the right care and the right plan of action, you could do deal with these symptoms. Of course, it's incurable, but we can treat the symptoms and be healthy and live positive lives that don't involve certain things we are going through. No, I was never

given a plan of action. I was literally told to lose weight and I was sent on my merry way and it was kind of like, okay, well, how are we supposed to do that? Because everything we had tried as I said, my mother is my biggest advocate, everything that my mother tried with me, Weight Watchers for literally two months, my mother lost like 10-15 pounds and I followed it to a tee. Like she would make my breakfast, lunch, and dinner and she made sure that we worked out together and what not and I lost point two pounds, point two! Like, not even two pounds, just point two. And that is so discouraging in itself.

The above excerpt captures the real struggle of women with PCOS who are told to lose weight without the right knowledge or adequate information of how to lose weight. Darlina represents the several thousands of women who will continue to fall for fad diets and spend money without seeing results. The conversation surrounding weight loss for women with PCOS needs to be readdressed and be inclusive of a knowledgeable nutritionist. It is surprising that the health system has made certain services inaccessible to patients by minimizing the resources available to patient by cutting costs and boosting profits.

Communication Challenges of Women with PCOS

The final major theme that will be discussed below communication challenges experienced by women with PCOS addressed research question three: *How do women describe their communicative experiences regarding discrimination, power and privilege?* The theme has the following subthemes: (a) PCOS, a disadvantage; and (b) experiences of microaggressions due to PCOS. In some cases, women shared the communication challenges they encountered to having PCOS. While some considered themselves lucky to experiencing only mild symptoms others were not so lucky. Some participants suggested that PCOS impacted their jobs, and careers. On certain days, the

pains from symptoms impacted the overall performance of the interviewees at their workplaces. For example, Frances recalls how she could not carry out her duty at work due to severe pains.

My job, yes, especially when I'm ovulating and my cramps are terrible, my supervisor knows that I have the syndrome so I would just tell them, I can't do it. I'm literally in pain or she see me collapse on the desk and she would say, take the day off, relax because I can't really focus. It can get really, painful.

PCOS does affect work performance of the women affected. In the long run, this will greatly impact career choices and limit the extent to which these women can dream about their goals and aspirations. PCOS places the lives of those diagnosed in such a disadvantaged point that all their lives have to be put on hold to recover from severe pains or at times elaborate plans have to be made and scheduled in order to start a family that other women do not have to worry about. Trisha realizing her disadvantage as her woman with PCOS, shared her fears for the future and on how PCOS will impact her career and ability to get pregnant and deliver safely.

It's scary. I don't like relying on other people generally to do everything for me, I don't like that. It's scary because I've worked so hard to be where I am in my major that it could basically go left. And I totally lose all job credibility because I must take time off in order to keep a child alive. So that's totally terrifying and it might mean it's also scary because it could mean that I put basically my life on hold, my career on hold. And it means that I'm going to try for children earlier rather than later like I originally wanted it because I'm already at risk from not being able to be fertile. So, the longer you wait, the harder it is anyways. So, it means I'm just fighting now to put a lot of my life on hold, then that's hard because this world is like constantly moving and changing. So, the idea that I must stop and hope I can jump back into it is horrible.

The above excerpt captures how women with PCOS rethink their entire lives, career choices and future of their unborn children due to the uncertainty and difficulty associated with managing PCOS in a day to day basis. Currently, there are no clear policies categorizing PCOS as a disability, however, due to the severity of some symptoms it should be considered as a disability that hinders human function. In addition, the excerpt further demonstrates the dominant notion of productivity and how capitalism productivity is conflated with personal or social worth. Many women need to constantly factor their health status into the choices they have to make in their careers and livelihood. It may not be the same for other women who do not experience challenges with PCOS or other invisible diseases. PCOS is disruptive in an unpredictable manner therefore most patients are in need of additional support and assistance to help ameliorate the symptoms and enable them better opportunities at leading normal lives.

Another disadvantage of dealing with PCOS is a limit to food choices without health consequences. Research suggests that diet in low carbohydrates and high vegetables are beneficial to reduce inflammation and other PCOS related symptoms. Although this information is not communicated by the doctors, it is common knowledge in the PCOS community that food habits inflame or reduce symptoms manifestation. However, there are certain challenges with sticking to a strict PCOS diet. Socializing in certain contexts can be difficult for these women due to the type of food available. Some participants are apprehensive to attend social functions due

to the inability to adhere to food choices that will help their symptoms. Trisha recounted how eating outside of the PCOS diet affects her social life.

I can't go out and eat sugar or flour or anything like that, which is like in so much of our food, without vomiting or without having to take medicine for it or without just feeling horribly sick... So I can't have most of the things my friends want to go out and have without feeling horrible. So I'd say it affects a good portion of my life.

The unpredictability of PCOS also causes anxiety and fear in some women. Yvonne described the unstable nature of her period and its effect on several other aspects of her life.

Because I wasn't getting regular periods, I was constantly worried about birth control. So, I think it made me overanxious about birth control because I never knew. And I never knew when to expect a period, so I'd get caught without supplies. What that means is that I have this habit of having menstruation supplies everywhere. Everywhere, in every coat pocket, in every bag, all over my house. [laughs] I bring my bag in and put my things down and then I unpack the bag because I need to use the bag for something else, so there's pads and tampons all over the place. Even though my periods were really irregular, I was constantly concerned about them because I would never know. You can't plan a trip. You can't plan a mammogram. You can't plan other things that you have to be aware of your cycle for planning. So, I think that the irregularity of my menstrual cycle is what impacted my life more than anything else. And then the PMS that comes with it, the moodiness.

Yvonne further stated that having PCOS even affects one after getting a hysterectomy. It was intriguing to note that even after a hysterectomy, PCOS is still incurable. This was corroborated by Darlina who also got a hysterectomy to help improve her quality of life. Darlina who is a PCOS advocate indicated that some women she spoke with about PCOS were dismissive of the condition because they have had hysterectomy surgeries not realizing that it is not a cure. PCOS is incurable and a hysterectomy will not cure the condition (Kuppermann et al, 2013).

There is an apparent misinformation by health care practitioners who encourage their patients to get hysterectomy to cure the condition. Ann who also got a hysterectomy cautions about this misinformation. She stated:

I think that the hardest thing about PCOS to explain to people what is it? They are like “oh, it's my ovaries”. I ain't got ovaries I had a hysterectomy, it's not that. So I feel like that's the greatest disconnect because some doctors go around saying if you get a hysterectomy you're cured.

Research over the years have suggested that doctors carry out unnecessary surgeries on patients without exploring alternatives to surgeries (Stahel, Vanderheiden, & Kim, 2017). These unnecessary surgeries expose patients to higher health risks and surgical malpractices. It is important that doctors educate women on the benefits and complications of hysterectomy. PCOS related hysterectomy should be elaborately discussed with patients. With that carefully communicated, women will be able to make informed decisions on their health.

Interactions with others and socialization is also mostly impacted due of some PCOS related symptoms. Ann shared that her menstrual cycles prevents her from going out:

I would say predominately, especially around my cycles. My cycles they do prevent me from going out because I had a bleed out at one point in my life that was bad and I bled through all my clothes and my husband's car, it was a mess.

These circumstances create painful and stressed conditions that are often isolating thus preventing women from building and maintain friendships. Trisha painfully recounted how she is often left out of events due to her symptoms.

I mean it affects my conversations with people who are like me agreeing to go out or not agreeing to go out because I'll feel sick. But other than that, not really. I'd say the biggest impact PCOS have is obviously it's made it hard to lose weight, which that does impact my life all the time.

Trisha was quick to state that she is more affected by the weight more than how the condition

had impacted her friendships. PCOS is a disadvantage to many women as it affects how they manage their weight or otherwise.

PCOS affects the physical looks, due to excess acne, weight gain facial and body hair, and baldness and tiredness in women. Those with PCOS battle against the ideal standard of beauty due to the symptoms that are against the societal expectation on the physical attributes of women. Some participants mentioned how they have coped with having these symptoms and how it affected their self-esteem or not. Frances recalled being bullied in school due to some PCOS related symptoms.

Usually, back in elementary and middle school, I was bullied because of my body hair issues and my weight. After I found out that I had PCOS and after I started getting hair treatment, everybody's like, oh my gosh, your hair is so great.

When asked how she felt about being bullied due to her looks Frances said the following:

Terrible. I would brush it off but I bottled a lot of emotions back then. I look like a bear, they would say stuff like that. I mean, mean stuff that they would be said in elementary or middle school, but I would take it in extreme levels.

Being bullied for one's look continue to be pervasive in our society especially for people of color and for those who look different from the "standard of beauty". Even those who have agency are not left out of being bullied due to their race or ethnicity. Not too long ago, a "legendary" BBC broadcaster was fired for tweeting a picture of chimpanzee as the royal baby when Megan, the duchess of Sussex delivered her baby.

Racism is still pervasive in the beauty culture and no one can escape it, not even someone who is associated with royalty. Many women with PCOS are not left out of the receiving end of insults about their looks. The impact of being compared to a bear or a chimpanzee leaves lasting emotional trauma on people's lives. Although the broadcaster was fired as a consequence for knowingly being racist, many discriminations against women with PCOS will go unknown but will leave a dent in the self-esteem of such women.

The idea of gendered beauty standards and pressure are especially experienced by marginalized groups including women with PCOS. In a broad context, these standards intersect with issues of race and racism. For instance, the communication dimension of bullying is often accomplished via social interactions including among friends and family.

One of the participants, Darlina shared her struggle with managing some of her symptoms.

But then, I think that my biggest qualm about myself is the hair growth on like my neck and my chin, which I see an electrologist and I think I go like once a month for that so it can get expensive but we do what we got to do”.

And she went further by providing a lasting solution to another symptom she struggled with

“Like I said I shaved my hair off bald in the summer of 2017 because I was having bald spots and I just got tired of it”.

Experiences of Microaggression

The second subtheme experiences of microaggression due to PCOS will be discussed below. As these women struggled to cope with their symptoms and live healthy lives, some of them recounted experiencing microaggressions in form of microinvalidations while seeking care and support from health care practitioners. The third subtheme in this section is microaggressions and strategies employed to seek proper care. Microaggressions are defined as “subtle insults directed towards people of color” (Solorzano, Ceja, & Yosso, 2000, p.60). There are three forms of microaggression: microinsult, microassault and microinvalidation. The data best captures the third form which is microinvalidation.

In a health context, microaggressions are “subtle insults or invalidations directed towards patients to minimize or undermine their pains and suffering” (Torino et al, 2019, p. 6) . Furthermore, microinsult are “an explicit derogation characterized primarily by verbal and non-verbal attack meant to hurt the intended victim through name calling, avoidant behavior or purposeful discriminatory actions” (Torino et al, 2019, p.6). Microassault is defined as “conscious, deliberate...direct, consciously carried out, targeted at any person experienced in private not in public settings” (Torino et al, 2019, p.6). Finally, microinvalidation: is “communication laden with rudeness or insensitivity that demeans a patient’s symptoms and health concerns” (Sue et al., 2007, p. 274). The experiences of microinvalidations in the data occurred during doctor patient interactions where health care practitioners dismissed the complaints of the participants. Ann, who

experienced a near death incidence recounted how she was continuously dismissed by health care practitioners. This excerpt was used earlier for another theme as well:

I'm bleeding for two months straight, I guess my body couldn't keep up with the iron because of the blood I was losing from my cycle and they kept telling me to go home until I found myself in an emergency room and I was told there was nothing they could do for me. I had to tell them hey, there is something wrong, I do not feel 100%". Then I had to change doctors and went for an appointment when I was told that I was severely anemic, and I needed blood transfusion". Then the doctor said "If you never came in and saw me you would probably be dead ... if I had said no, I'm not going to see another doctor, I could have easily lost my life.

Ann recounting a near death experience shared how she was dismissed several times until had to be rushed to the emergency room. The excerpt above shows the level of negligence, perhaps lack of knowledge about PCOS that can lead to such a tragic ?. Ann who did not accommodate the health care practitioners dismissive behavior, utilized Orbe's (1998) *separation* communication strategy by changing to doctors who will listen to her without invalidating her concerns. Separation is defined as "the attempt to seclude themselves" (p. 93). The act of removing oneself from a health situation that is life threatening is very enlightening to note. Many health care practitioners may or may not be aware of their dismissive attitude towards patients especially patients of color or people suffering from invisible conditions such as PCOS. The communicative strategy of separation usually occurs after patients realize their health is in danger. Ann, in addition to using a separation communication strategy also rationalized the health care practitioners's behavior. Rationalization occurs when individuals provide alternative explanations for

behavior rather than labelling the form of injustice. In providing an alternative to the dismissive behavior she had experienced Ann explained further:

Like I said military doctors are completely different from civilian doctors. Military doctors see 10 times more patients, so they are “hi and bye”. In case you have something, you can't say “hi and bye” to, so they took it as “oh you are another stay at home mom, who has got 99 problems. Your husband is in the service, so you just need something to claim”. On top of that, some doctors did not know much about PCOS, they're like "oh, I kind of know a little bit about it", that's what one doctor said to me and I'm like "what do you mean, you are a doctor and just don't know this? This is not good? Like I said certain young doctors do not know, but they know the basic. So, when it comes to my case, they treat you like everybody else, you got PCOS? which is slightly different from a common cold.

Drawing from the notion of hegemony, some patients rationalize the behavior of physicians due to the socialization that physicians are the authority in the room and should be listened to. Physicians hold enormous power in the health industry that often jeopardizes people's lives due to the blind trust patients have in them. People tend to make excuses for health care practitioners and sometimes place too much power in their hands to decide our health outcome that we rationalize their behavior when it can be labeled accurately as malpractice or microinvalidations.

Lack of understanding of PCOS is one of the contributing factors to the dismissive attitudes of both military and civilian doctors. Some doctors do not have intensive knowledge about PCOS and treat it as they would a common cold. This is very detrimental to the health of the patients as some underlying conditions related to PCOS will not be addressed on time if appropriate care is not given to the patients. Chloe, also used the separation strategy when her communication with her doctor proved to be futile and her feelings were dismissed:

Yeah, so I went to try and get pregnant and I didn't have a period for three months and I went to my doctor and she's like, are you pregnant? I'm like, nope. And she's like, well, you're probably just stressing about it. And I was like, no, I'm not stressing about it. Like there's something wrong. I ended up leaving that doctor because she was just kept telling me like, stop stressing and it will come, and it never did. And so, I went to a second doctor and she's like, okay, you have PCOS and that will make getting pregnant really hard.

One of the most insensitive statements to say to someone trying to get pregnant is that they should not stress about it. It is an insensitive statement because getting pregnant and carrying a baby to full term is one of the most personal, intimate and sacred process any woman will experience, having PCOS not only threatens that opportunity but also is a risk to that process. Women with PCOS who get pregnant are also at a higher risk of miscarriage than other women, so telling someone to not stress is like pouring petrol on a campfire.

It cannot be overemphasized the wealth of knowledge health care practitioners have at their disposal if only they are be attentive listeners to their patients. Microinvalidations as such described above is also costly to these practices. A satisfied patient will not only be retained but will also serve as the word of mouth advert for others. The cost of losing patients due to microinvalidations should be studied on a large scale to help health care practitioners realize they are running at a loss if patients keep getting dismissed. It is baffling that the theme of dismissive behavior by doctors' cuts across race or ethnicity as these participants are of different races and ethnicity. The common denominator however is that they are women and they are all dealing with a reproductive invisible condition.

Other participants who experienced microinvalidations utilized different communication strategies to achieve their preferred outcome. Darlina, who had dealt with PCOS all her life recounted how she was also invalidated even though she was in severe pains:

Actually, to be very honest with you, at that time, the doctors told my mother that it was in my head and that I was manifesting these symptoms, and something was not right and that I should probably see a psychiatrist.

Experiences of microinvalidations not only affected the physical wellbeing of the patients but also affected their mental health. The rude comments stated above that the patient needed a psychiatric evaluation was not only insensitive but also culturally inappropriate. At the time of the incident, the participant was only 9 years old, a vulnerable age where many children do not have their own agency to advocate for themselves. Trisha who also experienced microinvalidation when interacting with a doctor, recounted it occurred via electronic health communication.

And I said, hey, I started my periods and she said, okay, keep going and report back to me in like a week. And I'm saying I'm still on my period, I'm just not receiving replies anymore. So, it's frustrating in that sense too because I'm like, I can't tell her everything. She's not with me, she doesn't understand what I'm doing every day. And then she's going to be like, well this is okay. This is okay. Report back in three months and we'll do another ultrasound. So that's like the most frustrating thing.

Although the use of e-health has been linked to improved care and innovations in health care settings, and its potential can greatly improve the lives of women with PCOS, there are still communication challenges to its uses. Patients

such as Trisha continue to experience frustration with their health care practitioners if their concerns are not addressed. Women with PCOS continue to experience dismissive behavior by health care practitioners. It is more problematic for those struggling with invisible conditions such as PCOS where the pains and experiences are not easily quantifiable.

Microaggressions caused additional stress to their victims, who have to decode the invalidations and insults and then choose what communication strategies to use to achieve desired health results. The effect of microaggressions against women dealing with PCOS is dangerous and life threatening. Continuous dismissive behavior by health care practitioners will exacerbate distrust in health care environment for those who are marginalized. Moving forward, the power dynamics between health care practitioners and women with PCOS need to shift from a dominant non-dominant perspective to more patient centered care.

For women with PCOS, experiencing microinvalidations created barriers to seeking better care and treatment for their symptoms, yet they persisted and utilized several communicative devices to achieve their desired goals. Those with PCOS also experienced other communication challenges with other individuals and some insightful excerpts are analyzed below.

Communication Challenges with relatives

In general, the participants did not experience extensive interpersonal communication challenges when interacting with others. However, when certain topics are

brought up in social settings, it affected some women. Allison, who is very much aware of her slim chances of starting her own family, recounted how she got apprehensive when topics surrounding pregnancies and children are involved:

I just let it go because you know, that's just how it is. You can't control, you know, if other people have regular cycles and get pregnant and all that. So, it was a little bit hard, you know, when talking to people and they would talk about their children or you know, people getting pregnant it was sad, but I didn't want to show it to anyone. I just kind of kept it to myself.

Listening to conversations about pregnancies and children is difficult for women with PCOS and even more difficult because you want to be happy for others about their own journey to motherhood but at the same time it is a rude reminder to you that you might never have such experiences or that your own journey will be longer and more painful. Keeping to one's self like Allison described can be both beneficial and detrimental to a person's mental health. It is imperative that women dealing with infertility find and build support system to help them navigate the obstacles they will encounter.

Helen who also experienced a period of infertility discussed how she was able to navigate difficult conversations with family members with the help of her partner:

So, once I educated my mother-in-law and sister-in-law on what was going on because you know, we would go to the family reunions every year and everyone's like when you're having babies, let me anoint your womb. Let me touch it I speak life into you and you know at some point it was good and encouraging but then at other points it became again, very traumatic and a lot of grief to say we're going oh God here comes the family reunions. Oh God, here comes another holiday. I don't want to go and so my husband kind of energetic and just say, you know,

when it's our time, the Lord will bless us or something or when we're ready or we just having fun practicing...

Communicative tactics such as educating, using jokes, and having a liaison in person of her husband helped Helen navigate difficult conversations during reunions and holidays. Family reunions and holidays are supposed to be joyful and celebratory. For women dealing with infertility, those holidays and family gatherings are traumatic and filled with a lot of grief. Having a supportive spouse who can help ease the pain by taking up some of the burdens of the questions and unsolicited advice are so valuable for these women. While these strategies may be helpful at the moment, it does not erase the sting of some words spoken by others who are not sensitive enough to know what to say to couples experiencing infertility. Helen further shared some insensitive comments she had heard from someone close to her:

...someone very close to me one day was just like "that's a lot of money to be spending on trying to have kid" and I'm thinking...you think I really want to do that you think I want to spend tens of thousands of dollars to reproduce so it's not a choice, you know, this infertility is not a choice for me...

People sometimes do not know what to say but there are some things that should not be voiced out especially when it comes to infertility. Infertility is not a choice and women should not be questioned about what lengths or how much they are willing to spend to have a child. Many participants shared that they desired to have children, however the desire may stem from personal convictions or social and tied to the gender ideologies and cultural ideas about femininity and womanhood. The above statement was distressing to hear and countless of women going through infertility continue to hear such statements. This example of a painful comment by someone

close to the participant made her realize that there are certain conversations that should not be told to some people. Using the communication privacy management theory, disclosing specific details of the financial commitments she had made to help in her journey to someone she considered close to her was her choice. Boundary turbulence occurs when a co-owner intentionally breaks the coordinated boundary to disclose the private information. What Helen described is like Petronio's (2013) boundary linkage which is created when individuals share private information with others thus making them co-owners of the information. Sharing such intimate information with a friend who then makes such insensitive statement created a boundary turbulence which in turn made Helen reassess her boundary linkage with the said friend. In reassessing her stance with the friend, she had to renegotiate her boundary linkage when she decided to limit how much she shared with others who did not provide enough empathy to a friend in need.

...so sometimes the best thing is to limit the information that you share with them.

Navigating communication surrounding infertility is complex and confusing in the sense that some people close to you might feel a sense of duty to know the details of the issue because they feel they can offer sound advice or feel that they need to know. But sometimes, people are not ready to self-disclose to family members, and friends.

Personally, it was grueling to open up to my Nigerian family about our struggles. At first, I thought I could escape sharing such intimate information with my mother in law, but soon enough I realized the earlier I bit the bullet and told her about PCOS the better for us all. Deciding to share the information with my family members was not negotiable. There is a popular adage in the Yoruba Tribe of Nigeria that a “woman marries not just the husband but the entire family”. This adage rang deep in my head when I decided to disclose our fertility issues with both my mother and mother in law. The advantages of disclosing such private information to those stakeholders is that I stopped getting asked “how far”? But now we are getting advice on prayers and fertility treatment options. PCOS with infertility is a private yet very public stigmatizing condition for women.

Something very funny just happened as I typed this section. I received a call from my aunt back home in Nigeria, asking me very intimate questions about what we are doing to help with our condition. It is always cringe worthy describing certain details to loved ones other than a doctor, but I am conscious that it is coming from a very good place and they all want the best for us. It does not remove the sting of shame, sadness and sometimes deep vulnerability that infertility really sucks for a Nigerian! I digress. The collectivist culture in many Nigerian families make infertility journey to be both a curse and a blessing. A curse because you are forced to have some type of conversations and receive unsolicited advice. It is a blessing because you are guaranteed that you are been prayed for by your loved ones and when you

own strength fails you, someone is always there to cover you in prayers and for that I am very grateful.

The notion to share or not to share PCOS related issues with others varied from participant to participant. Some found it easy to share PCOS related information with family, while others thought it to be private. Chloe indicated that she told her family and friends about her condition but also recognized that it was a personal thing to do.

I mean, I certainly told people, especially about the infertility bits, close friends knew. I told all my sisters, both my sisters... It's a very personal experience to be talking about shots and hormones and eggs.

I think people choose to share intimate information about their fertility journey when they are comfortable that they will receive the appropriate support necessary during that period.

Talking about PCOS is not always public or not worth sharing with everyone. Some women also keep it a private matter and do not talk about this. Further explaining why, she is more comfortable talking about PCOS with only close friends and family, Chloe stated:

I'm not ashamed of it. But my health issues are mine. That's just the way I was raised, that that's a backstage thing. That's not the face you present to the world. The face you present to the world keeps that stuff backstage because health issues are private issues. I think that's just cultural".

In the workplace and other settings, Chloe identified that talks about infertility should be

put backstage because you want to present your competent face to the world. This is very

important to recognize that many women hold the same stance as Chloe as they navigate the world pushing the struggles of infertility and other health related issues backstage. Another participant who shared her PCOS diagnosis only disclosed the information to her friend who also was experiencing the same condition. Felicia recounted why she decided to share her health information with her friend:

I shared those with my best friend. She was going through the same thing. So, we shared different articles and different resources that we had and then talked about how we can overcome it.

People decide to share private information with others who can help and support them with what they are going through. With a above excerpts people share private information about PCOS for various reasons including to seek support, to find resources and for cultural reasons.

In the above section, I discussed the three major themes and sub themes that were uncovered in the data: a) *The tough Road to diagnosis* b) *PCOS and the lived experiences of women* c) *Communication challenges with relatives and health care practitioners*. Overall, women with PCOS experienced several communication challenges and used various communicative tactics to navigate interactions with health care practitioners, family members, friends and acquaintances.

ANALYSIS

The current study explored the intercultural communication and health communication challenges faced by women with PCOS. By extension, this study contributes to the pool of knowledge about doctor patient interactions on invisible conditions and diseases. Overall the study revealed certain communication challenges women with PCOS encounter when seeking care and support from health care practitioners and others. The role of culture, power, privilege, and discrimination were examined to understand how to better communicate effectively with those living with invisible conditions to minimize microinvalidations and other forms of microaggressions.

From the themes discussed in previous chapter, women with PCOS experience communication challenges with health care practitioners, families, and friends. Some of the communication tension are derived from socially constructed hegemonic ideals of misogyny, sexism and structural racism in the health system and society at large. Most especially, this study contributes to the scholarship that situates PCOS as a condition that silences the patients who have to navigate dominant spaces by using diverse communication strategies to achieve their desired goals. PCOS symptoms are contradictory gendered expectations for women, women struggle to rationalize, minimize or confront discriminatory behavior. Women with PCOS who experience microaggressions in form of microinvalidation employ co-cultural strategies such as rationalization, separation, educating self, and communicating self to navigate communicative tensions.

Helman (2000), asserted in the book *Culture, Health and Illness* that, “physicians and patients even if they come from the same social and cultural background, view ill-health in very different ways (p. 79). The author in clarifying the statement, suggested that both health care practitioners and patients “differ in perspectives based on very different premises, employ different system of proof and assess the efficacy of treatment in different ways” (p. 101). Not only does the author confirm the study’s thesis, he further reinforces the premise that PCOS culture impacts patient outcomes just because of the difference in perception of the physician.

The evidence in data collected in the current study further reiterates that patients changed doctors due to the perception of the illness the doctors had towards PCOS that was not in agreement with the patient’s perception of severity of the condition. Many practitioners even though they are familiar with PCOS, often interact with patients with dismissive behavior. Perhaps, as Helman suggests, many patients may see their ill health as important and threatening to their values, beliefs, and practices while their doctors may not be disposed to such information. The interviews conducted with health care practitioners revealed that there is not much attention given to PCOS, because some of the health care participants only discussed basic knowledge about the condition. Only a few of the participants had deep interest in PCOS and thus their communication with their patient was significantly effective compared to others.

The excerpts above from participants who experienced dismissive behavior from their practitioners emphasizes Helman’s position especially with invisible conditions

such as PCOS. Without putting into consideration, the cultural aspect of treating PCOS, many practitioners will miss opportunities to collect cultural data on their patients that will help improve delivery of care.

CHAPTER FIVE

Physicians Communication on Delivery of Care for Women with PCOS

Within this study the researcher conducted telephone interviews with five health care practitioners. Their organizational experiences represented different perspectives on communication surrounding PCOS. In the section below, I discuss recurring themes that shed light on how health care practitioners perceive and communicate with women with PCOS and related invisible conditions. For example, interesting feedback resulted from the research question: *How do health care practitioners describe their communication when delivering care to PCOS patients?* Responses included the following subthemes: a) By building a cultural trust and rapport with patients; and b) By using a SMART care plan for treating invisible conditions. I applied a culture care theoretical lens to better understand similarities and differences among women's experiences with PCOS.

A focal point in this dissertation is the role of culture on patient-physician communication. Culture includes beliefs, practices, traditions, and values that shape and orient the lived experiences of groups (Ting-Toomey & Chung, 2012). Culture can be derived through shared nationality, ethnicity, gender, organizations, socio-economic status, education, religion and ability. The culture of PCOS includes a unique situation for women who feel they have limited voice due to despair, fear, and anxiety. In this

study PCOS is a unique culture of ability/disability and common experiences among women.

Women with PCOS may have different cultural schemas but they are a unique cultural group due to the shared experiences of invisible disease (Braithwaite et al, 2009) . The experiences of persons with disabilities are culturally derived as it affects their norms, values, beliefs, and practices. Braithwaite indicated that the social location of persons with disabilities is not only different from able bodied persons but that there is a call for conscious awareness of how they are disadvantaged in the value systems that have been created without consideration for their desires. Therefore, the public should be aware of the condition will make able bodied individuals to check their privilege when interacting with those with invisible conditions by being culturally sensitive to women's reproductive talk in general.

Yet, their experiences are minimized within the health care system. For example, research on cancer, diabetes and other chronic conditions dominate mainstream media. The positive result includes a decrease in illness. In a recent report, the NIH suggested that in all cancer sites combined, cancer death rates have declined in men, women, and children between 1999 – 2016 (NIH.gov, 2018). The continuous decline in cancer death rate across all U.S. populations is certainly good news and newsworthy. However, this feat was achieved largely through organizational collaboration and research funding made possible by the popularity of the issues. PCOS does not have the same status.

PCOS is complex in that it includes higher risks for other chronic diseases, yet it has not gained much attention. Within this study, participants suggest that health care practitioners take a nonchalant or dismissive attitude toward PCOS. Practitioners do not take the condition as seriously as they would cancer or diabetes. As a result, I interviewed five health care practitioners to understand their own perceptions on care.

Physicians' Communication on PCOS

Health care practitioners' attitudes and outlooks result largely from prior experiences treating other medical conditions. They may use dated standards to address new issues. In other words, many practitioners are challenged by medical ethnocentrism. Medical ethnocentrism describes biased perceptions at work in the health field. Geest and Reis (2005) defined medical ethnocentrism as "an attitude or outlook in which values derived from one's own cultural background are applied to other cultural context where different values are operative (p. 45). This definition best described practitioners and patient perspectives disclosed in this study. Medical ethnocentrism captures how PCOS patients are invalidated and dismissed as less of a health threat—unlike cancer, diabetes and heart diseases. However, women with PCOS have much higher risks for major chronic conditions, if symptoms are not discovered and managed in a timely manner.

Furthermore, Geest and Reis (2005) foreground a continued struggle between patients and physicians. There is a power struggle enforced by hegemony where physicians have great power to decide and control the direction of communication. In this study, women articulated how they were dismissed by health care practitioners, even after

several visits and complaints. Conversely, the practitioners' perspective on PCOS and other invisible conditions differed significantly. One major explanation for the dismissive behavior towards patients is the lack of knowledge about PCOS by many physicians.

Below Dr. Queen described health care practitioners' attitude toward women with PCOS:

I think it's a discomfort some times because even when I talked to other practitioners and they're like, yeah, okay, do you want them, I'll send them to you because I don't really know what to do for them. I don't know. And I'm like, okay, yeah, send them on my way.

The lack of familiarity and confidence when meeting with women with PCOS is due to several reasons. For example, in Dr. Queen's opinion, many physicians lack awareness and education necessary to communicate effectively with patients. The doctor went on to suggest how increased education will empower physicians to accept and treat patients with PCOS:

Because practitioners, we need information, we need education, we need to know what's going on with our patients, how they feel, what they need. So, I like this as a start to find out how can we communicate? Because it is difficult for these women who are constantly going to different visits and different practitioners and hearing different things. Because sometimes we're saying things as practitioners. We might not really have a whole lot of information on and we're just trying to guess something. So, if we were better educated, informed and we can hopefully provide more efficient and better service to these women and then to understand it's not just her; if she has a family, how do we incorporate them and inform them? Because that's one aspect that actually I hadn't thought about until a man came up, spoke to me and says, you know, I hear you doing research. Has anyone ever thought about doing research about the family and about the husbands and what we go through? And I was like, wow! No, I never thought about that. So, we just need more research and we need more information, more education, and awareness. Because I think the more you know, the more comfort you have with dealing with that thing.

The doctor's disclosure speaks volumes about how communication becomes uncomfortable for health care practitioners. Patients often assume that doctors have all the answers. Yet doctors may have as many questions as their patients. This is a crucial aspect of intercultural and health communication. Women suffer because of a lack of understanding, and indifference to natural reproductive conditions.

Dr. Queen further described how the lack of awareness can impact a patient's quality of life:

Oh, unfortunately, it's not and I get that from a lot of women. When they come to see me, they're floored because no one has ever given them any information like this and so much in depth and they didn't know that it was such a significant diagnosis and conditions. So that has been my life's goal and passion now is to share out a way to help on the practitioners side. That's why I was so excited about this study because I'm finding that a lot of practitioners are not aware or if they are aware, it's kind of an uncomfortable condition because they're not really sure what to do. And so again, that's why I was so excited about the guidelines that came out because now you have this actual, okay, here you go and get something you can look at to help you with.

Dr. Queen was excited about the recently published evidence-based guidelines for the assessment and management of PCOS. The doctor is hopeful that more doctors will use these resources when treating patients. It is important to note that the international guideline was published in 2018. Future research should continue to take a critical approach when considering the communicative challenges of women with PCOS. The international evidence-based guidelines included 166 recommendations and practice points, prioritized questions to promote consistent evidence-based care, and sought to improve health outcomes of women with PCOS (Teede et al,2018).

In another interview Dr. Thelma recounted PCOS-related fears expressed by her patients. The clinical specialist recalled her reaction to diverse experience. Here she is referring to how doctors need to take the shock of diagnosis into account and take time to ease patients treatment and lifestyle changes.:

I think most of the time people are kinda shocked. They're kind of in the shocking state of, I have diabetes, (or PCOS) what does that mean? Or they're trying to figure out how did they get it. So, there might not be anybody in their family or they'll say, you know, I really eat well, and I exercise. I don't know how I got diabetes. And so, I think part of it is just kind of that initial shock. And some people will, depending on each practitioners, they might give them three to six months to make some lifestyle modification. But for the most part, I think people are just kinda like in, not so much a disarray, but kind of like disbelief or they don't want to say, or they're in denial.

Dr. Thelma described what many patients experience at the initial stage of diagnosis. The feeling of shock is not uncommon. Practitioners can minimize shock by using a care model based on Mary Leininger's (1996) culture care theory. Dr. Thelma draws from the model to help patients reconcile their new reality:

I think, for the most part, people are kind of like in awe and a little bit of denial that they have this condition. But when you try to really explain to them how they may have gotten it, that it could be genetic, that it could be due to diet, lack of exercise or lifestyle, then it kind of sinks in.

Leininger's (1996) culture care theory may increase a client's understanding of a life changing condition. Care is defined as "the abstract and manifest phenomena and expressions related to assisting, supporting, enabling, and facilitating ways to help others with evident or anticipated needs in order to improve health, a human condition, or a lifeway" (p. 73). Anticipating a patient's shock or denial, physicians should proactively utilize the care concept by communicating in detail and describe causes and symptoms of

the condition. Unfortunately, the current health system force physicians to spend limited time with each patient to boost profits. The structure of the health system is sadly for profit making instead of providing care. Additionally, physicians must reassure patients that potential care plans will improve their quality of life.

Dr. Thelma utilized the care orientation to describe how she interacts with her patients. However, women with PCOS reported few experiences of care orientation. In fact, they provided opposing narratives. When I was diagnosed, I did not experience careful explanation of the condition or possible causes for PCOS. As such, I write this dissertation with hopes that practitioners will take note of opportunities to utilize care orientation when breaking news of diagnosis. I want to help patients minimize these stages of grief.

Other practitioners claim to use the care concept as well. For example, OBGYN Dr. Camilla described similar strategies to build trust and rapport—not usually achieved on the first visit:

I mean, I think that needs to be established in the doctor-patient relationship. And so sometimes not all issues can be addressed the very first time you see someone because patients as well as need to develop trust in their health care practitioners so, you know it is not that uncommon for patients to address some issues with us one visit and then patients get to know us better feel more comfortable with their health care practitioners addressing other issues as that trust is established. So, in general establishing trust with your patient, you know, sort of being there for them feeling like their concerns are being heard and that sort of organic. I can't tell you exactly how that happens other than just trying to hear your patient as best as you can so that patients can feel like they can address their concerns. This sort of happens with time and experience and you know taking care of people over time.

Intimate and sometimes embarrassing symptoms like excessive bleeding, alopecia, and infertility can be difficult to manage. The presence of a new doctor makes one even more vulnerable. It is important that doctors recognize their ability (and duty) to build trust by actively listening to patients concerns. It is also important to address these concerns. The major key findings concern how patients and practitioners deal with uncertainty and a lack of knowledge. The health system is set up for uncertainties through quick diagnosis, and prescription of medication. But PCOS is all about uncertainties due to the multifactorial nature of the condition. Culture of care and open communication become the way to fill this gap and develop treatments that work for patients. However, there are numerous barriers to culture of care including sexism, racism and a health care system that is designed to deliver minimal care to cut costs.

Care orientation is based on truth and mutual respect. Often women who struggle with PCOS are mistrusted by health care practitioners. Mistrust leads to invalidations of symptoms and pains. Many patients communicate with their health care practitioners, but their symptoms are not validated. As a result, doctors may not provide adequate information, which results in increased anxiety or harmful health-seeking behavior on the internet. Conscious and deliberate actions are necessary to provide care-oriented services.

Common care plan for managing invisible conditions.

Dr. Queen, a nurse scientist and women's health nurse practitioner, is well versed in PCOS related care. She described how women narrate difficulties and plans associated with PCOS:

The big thing they talk about is the frustration of the different symptoms and not knowing from day to day how they're going to feel, physically and psychologically. So, it really weighs on them because, by the time they receive the diagnosis, they're so frustrated with the path that they've been on. So, then anything that seems to happen, any aches or pains or mood swings, it's like, okay, is this PCOS? Was it because of that? So, they're constantly consumed with their health and their status and their situation. So, I think it has a significant impact on quality of life. You know, it seems to rule their lives actually, you know, what can I do that won't worsen it? Or how can I make myself better?

Above are common frustrations and concerns described by health care practitioners. An elaborate understanding of the condition will help motivate other practitioners to utilize culture care sensibilities.

Culture care orientation refers to culturally derived, assistive, supportive, or facilitative acts toward or for another individual or group. These include evident and anticipated needs which guide nursing decisions and actions held to be beneficial to the health or well-being of people (Leininger, 1996, p. 73). Understanding PCOS as a culture with specific sensibilities and nuances should be at the forefront of care management for the condition.

The culture care approach to diagnosis and care management of PCOS is a five-step process gleaned from Dr. Queen's narrative of how she communicates with her patients:

If it is a new diagnosis, I talk to them about, okay, what exactly is PCOS. And a lot of times all they really hear is, you won't be able to have children or it's going to affect your fertility. But I really try to get it across them that there really is a metabolic condition as well and that there are psychological components. So I really like to take my time and just talk about the different aspects of okay, what is it that you're having increased, hormone levels, which are called androgens and what androgens are for and the imbalance with the estrogen and the progesterone and how that impacts the body.

And then we talk about, you know, a lot of women are insulin resistant, so it depends on what their labs look like. We'll go over their labs and talk about the risk factors for high blood pressure and you know, pre-diabetes and gestational diabetes. So, it's really involved. We talk about fertility if they're desiring to have any children. And then, I always like to give them some positive information and some hope that yes, all this is going on, but there are some things that you can do to assist yourself and to manage a condition. And so, we talk about treatment options, of course a lot of women are hesitant or don't really want to, you know, I don't want to take medication, or I don't want to do birth control. So, the first line is really lifestyle and you really should think about lifestyle modification anyway, just because. And we talk about fitness and nutrition.

Dr. Queen's care management is based on the culture care theory. If this plan was applied to each health interaction, we would have no reason to conduct this research. I strongly believe in the efficacy of a holistic and culture care centered process. This dissertation joins other scholarly literature to support a five-step approach to effective communication for women with PCOS.

The five-step care management plan is recommended for health care practitioners when communicating with women suffering from PCOS. Steps include a) Definition of condition; b) Risk factors associated with PCOS; c) Infertility and PCOS; d) Build agency; and e) Lifestyle changes. The five-step process is strikingly like the initial themes discussed in previous chapters. In general, I suggest that women with PCOS need information in the order of the five-step process.

Definition of the Condition

The first step to competent intercultural health communication regarding invisible diseases occurs at the site of diagnosis. For this experience to be considered satisfactory to patients, physicians must communicate what the condition is; how a patient might get

the condition; address significant symptoms (such as infertility). Also, physicians need to use relatable language and/or visual aids to communicate how the disease or condition is manifested in the body and mind of patients.

Discuss the Risk Factors

Second, physicians need to discuss the risk factors associated with the condition. This is an opportunity for physicians to ask family background questions for genetic risk factors, etc. It is also a chance for patients to ask questions. No matter how mild or severe, practitioners are charged to effectively inform patients of potential risk factors or comorbidities likely to hinder the quality of life.

Infertility and PCOS

Third, practitioners must address the most common symptom of the disease—infertility. PCOS is one of the major causes of infertility in women. This should be communicated to patients regardless of whether they are actively trying to start a biological family. The importance of this talk cannot be overemphasized. As was discussed in the previous chapter, questions around infertility may cause anxiety, fear and depression.

Build Agency

Fourth, communication should be conscious and deliberate, and encourage patients to take specific action with regard to their circumstances. Building agency

affords patients the sense of hopefulness and capability to fight the disease. Building agency may involve suggestions for educational materials and care options, instead of quick prescriptions and referrals to specialists.

Lifestyle Changes

Fifth, the final step to a culture care centered communication requires discussion of possible lifestyle changes. In the previous chapter, participants recounted how they were told to lose weight or make lifestyle changes without being equipped with the right information for how to achieve the goal. For example, Dr. Thelma administers care to women with PCOS and others. When doing so she suggests a SMART goals plan.

SMART stands for specific, measurable, achievable, realistic, and timed goals:

So a SMART goal, say for example and I'll break it down to what it actually is, but it's basically, instead of saying, I wanna lose weight, what I would say is, I want to lose five pounds and I want to be able to lose that five pounds within the next two months. So, it's specific, it's measurable, it's attainable, it's realistic and it's timed. So, a lot of times we will say we want to do something, but we don't have necessarily the strategy to really kind of do it. So, we try to kind of be a little bit more specific with them. So, you tell them, okay, yeah, you want to lose weight, but how much weight do you want to lose? When we say it's achievable, it's not achievable for me to say I want to lose five pounds in a week. That's not realistic and it's probably not going to happen. Versus if I give myself two months based upon one, am I going to make any changes to my diet and am I going to exercise? What are some of the things that could be hindering me from being able to lose weight? So, the SMART goal is, it's specific, it's measurable, it's achievable, it's realistic and it's time specific.

The SMART goals plan will help provide patients with the tools to achieve their goals.

Dr. Thelma further elucidated on why the SMART goal is efficient:

With the SMART goals, the good thing about them is that the patient themselves determine what they want to do. So if I have someone who comes in here, they

have high blood pressure and they said, listen, I'm going to eat what I want to eat but I'm willing to stop smoking, then the SMART goal would be concentrated around tobacco cessation. Not necessarily what they eat because they've already said they don't want to make any changes to their diet, so you have to also factor in that readiness to change.

The patient centered care plan gives the patient a sense of involvement and collaboration to help physicians provide the best possible care. The SMART goal plan has great potential to encourage sustainable health behavior changes.

This dissertation captured physicians' perspectives on the communication challenges of women with PCOS. The theme of physicians' communication on PCOS, included two subthemes: a) building trust and rapport with patients; and b) build a SMART care plan for treating invisible conditions. These subthemes were discussed using a culture care theoretical foundation, to understand how practitioners can communicate with patients. This dissertation contributes to the body of knowledge on evidence-based recommendations. Together with the international guideline's publication (Teede et al, 2018) , this dissertation can serve as a dyadic narrative on the communication challenges and best practices for both patients and physicians to better understand the multiplicities of invisible illnesses.

The following recommendations further support the findings in this dissertation. These recommendations cater to the communicative challenges of women living with invisible illness. The publication of the international guidelines (Teede et al, 2018) is a great stride towards the comprehensive care for women suffering from the condition. Future studies will do well to examine the effectiveness and usage of the

recommendations. Best practices for *the tough road to diagnosis* include the following recommendations:

- a) Information and education resources for health care professionals should promote diagnostic criteria, appropriate screening for comorbidities, and effective lifestyle and pharmacological management.
- b) PCOS, infertility due to anovulation, semen analysis, risks, benefits, costs and timing of tubal patency testing should be discussed on an individual basis.
- c) Information and education resources should be culturally appropriate, tailored and high-quality, use a respectful and empathetic approach, promote self-care, and highlight peer support groups.

These recommendations will help reduce the late diagnosis timeline, and also help reduce anxiety, grief and uncertainty associated with poorly delivered diagnosis narratives by health care practitioners in the recent past.

PCOS and lived experiences of women include the following recommendations:

- a) Health professionals and women should be aware of the adverse impact of PCOS on quality of life.
- b) Factors including obesity, infertility and hirsutism deserve special consideration as they may independently exacerbate depression, anxiety and other aspects of emotional wellbeing.

- c) Anxiety and depressive symptoms should be routinely screened in all adolescents and women with PCOS at diagnosis. If the screen for these symptoms and/or other aspects of emotional wellbeing is positive, further assessment and/or referral for assessment and treatment should be completed by suitably qualified health professionals and informed by regional guidelines.
- d) Lifestyle intervention (preferably multicomponent including diet, exercise and behavioral strategies should be recommended for anyone with PCOS, excess weight, reductions in weight, central obesity, and insulin resistance.
- e) Health care practices including diet and exercise, need to be respectful, patient-centered and value women's cultural, socioeconomic and ethnic differences. Health professionals also need to consider personal sensitivities, marginalization and potential weight-related stigma.
- f) Consideration of the individual's personal characteristics, preferences, and values are important when recommending pharmacological treatment.
- g) Healthy lifestyle and weight management is the joint responsibility of health professionals partnering with women with PCOS. Complex issues require referral to suitably trained allied health professionals.
- h) Prior to prescribing pharmacological therapy, practitioners must discuss benefits, adverse effects, and contraindications.

For *communication challenges* recommendations include the following:

- a) Women's needs, communication preferences, and beliefs should be considered and addressed through provision of culturally and linguistically appropriate co-designed resources and care.
- b) Ethnic groups with PCOS who are at high cardiometabolic risk as per 1.6.1, require greater consideration in terms of healthy lifestyle and lifestyle intervention.
- c) Care should be person-centered, address women's priorities, and be provided in partnership with those with PCOS and where appropriate, their families.

Finally, *physicians' views on PCOS*, include the following recommendation:

- a) Foreground collaborative communication between health care practitioners and women with PCOS.
- b) SMART (Specific Measurable, Achievable, Realistic and Timely) goal setting and self-monitoring can enable women to achieve realistic lifestyle goals.

This dissertation contributes to the evidence-based international guidelines, educative and informative purposes for health care practitioners, and stakeholders and women with PCOS. Most importantly, this dissertation supports a holistic approach and cultural care orientations necessary to inform communicative tools to manage care for women with PCOS.

This dissertation contributes to a body of knowledge. While various studies have explored invisible diseases within different ethnic groups, very few have compared across

groups including international populations with considerations to diets, lifestyle and occupation. Diversity could be a strength and a challenge considering the relatively small data set. This study included White women, African American women, and Hispanic women—with educational backgrounds ranging from High School Diploma to Ph.D. holders. Salaries that ranged from 20k—100K annually. Across the board, PCOS affects women in every ethnicity, social economic status, education and age. The impact and severity of the condition varies from person to person regardless of their demographics.

In this research, co-cultural theory established women with PCOS as marginalized health populations who navigate dominant spaces using different co-cultural strategies to achieve desired goals. Communication privacy management model recognized that women with PCOS self-disclose their symptoms for support and health seeking behavior from friends and families. It also established that after self-disclosure, these women found support in most cases by sharing with others who are going through the same condition or provided psychosocial support in general. Interestingly, some participants who self-disclosed on fertility issues were shamed. For instance, after Helen disclosed the financial burdens she had to bear for infertility treatments, a friend speaking from a place of privilege without considering the implications of her statement said to Helen:

Everyone doesn't know what to say, someone very close to me one day was just like “that's a lot of money to be spending on trying to have kids” and I'm thinking I said you think I really want to do that...you think I want to spend tens of thousands of dollars to reproduce. So, it is not a choice, you know, this infertility is not a choice.

The feelings of blame or shame permeated the interview session as she recounted how spending a lot of money for fertility treatment in Helene's voice and it reminds me of thousands more women who are in her shoes or who would kill to have the money to go through fertility treatments to have a child.

Infertility indeed is not a choice in many cases for women with PCOS who are not only at a disadvantage to start their own family but are burdened with financial costs for fertility treatment. Self-disclosure in communicative privacy management only deals with the contract of not sharing the information with others. However, in this research, boundary turbulence takes a different form. Boundary turbulence in definition can be extended to include unfavorable or negative feedback from co-owners of the information who responds with judgement, shaming or discrimination of the person's self-disclosure. The co-owner of that information shared by Helen failed to recognize the heavy responsibility attached to the disclosure. When women share their reproductive challenges with privileged others, it is of the outmost importance that they realize there is a heavy responsibility attached to it and their feedback or comment can either shame the owner of information or provide support.

Women suffering from PCOS also experience microaggression when disclosure of symptoms to health care practitioners and family members are dismissed or invalidated impacting not only their wellbeing but affect their emotions. While they are experiencing severe pains due to the invisible nature of the condition, they are deprived of quality care and are also subjected to emotional trauma.

Finally, as these women navigate dominant spaces, using co-cultural strategies and are being selective of who to self-disclose their condition to, and as they experience microaggressions, these hurdles are often ameliorated when those in the dominant space use culture care theoretical model to administer care and support to them. Like Rao affirmed in Samovar et al (2015), interaction between a physician and patient is inherently an intercultural encounter even when the two parties perceive they are from the same culture” (p. 330). This dissertation pushes the discourse even further to establish that interactions between physicians and patients dealing with invisible conditions are intercultural encounters thus, certain communicative practices and behavior of both parties should be done with intent and self-awareness of these cultural differences.

The definitions of disease and illness defers according to Rao (2015). Disease is defined as “the malfunctioning of biological and/or psychological processes whereas illness may be defined as the perception, evaluation, explanation, and labelling of symptoms by the patient and their family and social network (Rosen et al, p. 496 see SPMR for reference)

Extending Rao’s research focus on bringing culture and communication together, this dissertation significantly reinforces the notion that the role of culture, power, privilege and discrimination needs to be studied in patient-physician’s interactions. It should be clearly stated that the purpose of this dissertation is not to apportion blame to either physician or patient, rather, the purpose of this dissertation is to reinforce the importance of intercultural flexibility and sensitivity in patient-physician interactions.

Unlike Rao's literature review of 91 physicians, this dissertation approached the research using the patient-physician dyadic communication. To do better justice to the study, the family and friends' interactions was included to form a triangular communication to share ideas and present intercultural model for competent communication among these stakeholders.

CHAPTER SIX

LIMITATIONS AND FUTURE DIRECTIONS

The final chapter provides a summary of research, limitations to the study, and future research directions. The women in this study faced unique challenges navigating their health care. The study presented a conceptual framework of communication privacy management, culture care diversity, and discrimination and microaggressions associated with invisible diseases. Below I recap the significance of the research.

Scholars from diverse fields have investigated PCOS using various methodologies and theoretical frameworks. Literature used in this study includes clinical research for diagnosing, defining and identifying women with PCOS, diet and exercise, and lifestyle changes (Amiri et al, 2014; Schmid et al, 2004; Setiawati et al, 2015; Allahbadia, & Merchant, 2008; Bharathi et al, 2017; Tomlinson et al, 2017; Sanchez, 2014).

The past literature points to the problematic nature relating to research around invisible disease. This dissertation highlighted discourse on the painful lived experiences. Respondents articulated severe symptoms and struggles to resist social constructions of values for women of reproductive age.

In the end women with PCOS face a paradox to manage the condition by ignoring completely. Others will struggle with communicating to others why they haven't started a

family. Some may experience weight gain while simultaneously dieting. And they will avoid certain food items that trigger PCOS symptoms. Taken together, the accounts of participants interviewed, and social media posts indicated there is still need for more ground to cover in understanding what PCOS is and what it isn't. There is more work to be done to determine the best approach to care and management.

Limitations

Whereas the research contributes significantly to the discourse on women's reproductive health and communication, there were significant challenges involved in this study. Four limitations are emphasized to consider during future research study: a) sample size; b) gatekeeping of the community; c) and scope of study.

Sample size

First, there is limitation on the sample size of the participants. The sample size for this thesis included 15 women who identified as being diagnosed with PCOS and 5 healthcare practitioners. PCOS is a medical and private condition so recruitment was difficult to achieve. A higher number of participants and equal ratio of patient to physician would yield similar or new emerging themes other than the ones generated from this study. Although participants' demographic was representative in race/ethnicity, socio-economic class, age and education, a higher number would further reinforce the themes in the data or new themes may be uncovered. It would be beneficial for researchers recruit using established organizations such as women's health center, clinics, and women's organizations.

Gatekeeping of PCOS social media groups

The researcher experienced an iron-clad gatekeeping behavior from administrators of PCOS related social media support groups. Although the researcher belonged to some of the online groups, each invitation sent out was declined. One of the informants disclosed that they have to protect their group members from the overwhelming research requests to minimize fatigue and other risks attributed to research participation.

Scope of study

The study mostly focused on the intercultural and health communication tensions surrounding PCOS. Many other themes were unearthed but were not within the scope of the research. In the future, other researchers can broaden the scope of a critical intercultural communication research to include specific ethnicity, more diverse sexual orientations etc.

Future Directions for Research

Health and Intercultural communication continue to grow and intersect towards various racial groups and health conditions otherwise under researched. This research points to an increase in the study of the communicative practices of women with PCOS. Future scholars should investigate other invisible conditions that affect men and other ethnicities. Additionally, collaborative discourse between Health care practitioners with

women with PCOS can significantly contribute to the expected health outcomes for patients.

Another critical research direction would be to explore the role of technology as a collaborative tool for health care practitioners and patients to both monitor the changes and patterns in the reproductive cycle of women as this is often reported as the indicator of PCOS.

Finally, continuous research into the intercultural communication perspective on invisible diseases will ultimately improve the health care services to women and underserved communities.

Personal Researcher Reflection

On the one hand, this paper provided me with the privilege to think like a scholar by applying critical thinking and theorizing to the data, it is perhaps the most emotionally and physically challenging research excursion I have taken so far. It is so because I was recently diagnosed with PCOS and it seemed for a split second that my life has taken a turn that I would not be able to control. However, through this research and my doggedness to not be confined to the hand that I have been dealt, I persevered, pushed further and showed up for countless women who have experienced, will experience or about to experience this journey. PCOS is a disadvantage to women who are already dealing with so much in the society.

Conducting interviews was very intense as it required a high level of vulnerability and trust from the participants which was difficult to achieve. While I could comport myself in some interviews, other left both me and the interviewee laden with tears. Psychologically, I could see myself going through the experience of my diagnosis as each participant recounted their story and again was thrown into a state of sadness, dejectedness, brokenness or not woman enough.

These all impacted me emotionally and psychologically, and I realized soon enough I needed to take breaks in between interviews to sort out my mental state of mind. I escaped several times from this project but I will attribute my determination to complete it solely based on God's grace and the need to make the voices of the women who have entrusted their most sacred stories to me to see that it is told and told loudly! Also, constant encouragement from my advisors both past and present, friends, and family kept me going and reenergized me throughout the grueling process.

Health and Intercultural communication are an intersection that has the potential to produce groundbreaking research and I am humbled and privileged to be a contributor to the body of scholarly work in the interdisciplinary. It is my uttermost desire that there is a cure or formula for PCOS so women can live to their full potential while dealing with the condition.

APPENDIX A: INFORMED CONSENT

TITLE: EXPLORING INTERCULTURAL COMMUNICATION AND HEALTH COMMUNICATION SURROUNDING POLYCYSTIC OVARIAN SYNDROME

RESEARCH PROCEDURES

This research is being conducted to explore the communicative experiences of women with PCOS. If you agree to participate, you will be asked to partake in an interview that will last between 40 to 60 minutes in which you will be asked questions about the communication challenges you are experiencing as a PCOS patient. People diagnosed with PCOS are required to participate. The interview will be audiotaped and transcribed.

RISKS

There are no foreseeable risks for participating in this research.

BENEFITS

There are no benefits to you as a participant other than to further research in the understanding of the complex phenomenon, PCOS.

CONFIDENTIALITY

The data (audio recordings and transcripts) in this study will be confidential. Each participant will be given a pseudonym as that the person's name will not be included in the research reports. All identifying information about participants will be extracted from written transcripts. Audio recordings will be deleted upon transcriptions and the transcriptions will be stored in a locked cabinet for five years in the office of Dr. Mark Hopson, PI on this dissertation. Only Dr. Hopson and the student researcher, Ayo Otusanya will have access to the transcripts. The transcripts will be destroyed at the end of the 5-year storage period. The de-identified data could be used for future research without additional consent from participants.

PARTICIPATION

You must be 18 years or older to participate in this study. Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.

CONTACT

This research is being conducted by Ayodeji Otusanya and Dr. Mark Hopson at George Mason University. Ayodeji Otusanya may be reached at 610-533-0725. Dr. Mark Hopson may be reached at 703-300-5757 for questions or to report a research-related problem. You may contact the George Mason University Institutional Review Board office at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

This study has been approved by the Institutional Review Board of George Mason University and the reference number for our project is IRBNet 1209693-1.

CONSENT

I have read this form, all of my questions have been answered by the research staff, and I agree to participate in this study.

Signature

Date of Signature

APPENDIX B: INFORMED CONSENT FOR HEALTH CARE PRACTITIONERS

TITLE: EXPLORING INTERCULTURAL COMMUNICATION AND HEALTH COMMUNICATION SURROUNDING POLYCYSTIC OVARIAN SYNDROME

RESEARCH PROCEDURES

This research is being conducted to explore the communicative experiences of women with PCOS and health care practitioners' communication challenges surrounding PCOS. If you agree to participate, you will be asked to partake in an interview that will last between 40 to 60 minutes in which you will be asked questions about the communicative challenges and strategies you utilize when treating patients with PCOS. The interview will be audiotaped and transcribed.

RISKS

There are no foreseeable risks for participating in this research.

BENEFITS

There are no benefits to you as a participant other than to further research in the understanding of the complex phenomenon, PCOS.

CONFIDENTIALITY

The data (audio recordings and transcripts) in this study will be confidential. Each participant will be given a pseudonym as that the person's name will not be included in the research reports. All identifying information about participants will be extracted from written transcripts. Audio recordings will be deleted upon transcriptions and the transcriptions will be stored in a locked cabinet for five years in the office of Dr. Mark Hopson, PI on this dissertation. Only Dr. Hopson and the student researcher, Ayo Otusanya will have access to the transcripts. The transcripts will be destroyed at the end of the 5-year storage period. The de-identified data could be used for future research without additional consent from participants.

PARTICIPATION

You must be 18 years or older to participate in this study. Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.

CONTACT

This research is being conducted by Ayodeji Otusanya and Dr. Mark Hopson at George Mason University. Ayodeji Otusanya may be reached at 610-533-0725. Dr. Mark Hopson may be reached at 703-300-5757 for questions or to report a research-related problem. You may contact the George Mason University Institutional Review Board office at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form, all of my questions have been answered by the research staff, and I agree to participate in this study.

Signature

Date of Signature

APPENDIX C: RECRUITMENT MESSAGE

Dear Friend,

My name is Ayo Otusanya and I am a third year PhD student at George Mason University. I am conducting a research for my dissertation on Health and Intercultural Communication surrounding Polycystic Ovarian Syndrome (PCOS). I am seeking to interview women diagnosed with PCOS to share their lived experiences coping with the condition. The interview will take 40-60 minutes at a convenient location or by telephone. The interview will be audio taped and transcribed. All identifying information about participants will remain confidential.

This study has been approved by the Institutional Review Board and the reference number for our project is IRBNet 1209693-1.

This research is being conducted by Ayodeji Otusanya and Dr. Mark Hopson at George Mason University. Ayodeji Otusanya may be reached at 610-533-0725 and adaphere@gmu.edu. Dr. Mark Hopson may be reached at 703-300-5757 for questions or to report a research-related problem. You may contact the George Mason University Institutional Review Board office at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

To participate please sign up using the link below:

https://gmuchss.qualtrics.com/jfe/form/SV_bmi8PQFdQDE1n1j

Thank you for your time.

APPENDIX D: INTERVIEW INSTRUMENT

1. What is your nationality?
2. In which state do you currently reside? Outside the U.S.?
3. What is your age range? Over 18? Over 30? Over 40? Over 50?
4. What is your highest level of education?
5. What is your occupation?
6. What is your income range? Under 20k annually? 20-30k? 30k-40k? 40k-50k? 50k-60k? 60k-80k? 80k-100k? Over 100k annually?
7. Are you married/single/civil partnership/in a relationship?
8. When were you diagnosed with PCOS?

CULTURE-CARE QUESTIONS

9. How would you describe your experience with PCOS?
 - a) Do you communicate with anyone about PCOS? Why or why not?
 - b) Have you experienced any communication challenges due to PCOS?
 - c) What communication challenges do you experience because of PCOS?
 - d) With whom in particular do you find it most difficult to communicate around PCOS issues?
 - e) Why do you think it is difficult to communicate about PCOS?
10. How does PCOS impact the overall health-related quality of life for women?
 - a) Do you experience any specific emotions and moods relating to PCOS?
 - b) Have you experienced challenges in daily life due to your emotions and moods?
 - c) Do you think PCOS has affected your physical looks? For example, has it impacted hair growth or hair loss, weight, skin condition (or acne), or other physical issues?
 - d) When was the last time you thought about your weight? How often do you think about your weight? Can you share an experience with weight after being diagnosed with PCOS?
 - e) Do you feel having PCOS is a disadvantage to you as a woman?
 - f) Do you worry about childbearing? If so, how often do you worry about childbearing? Not often? Often? Very often? All the time?

- g) Do you experience any communication tensions/challenges/obstacles regarding your reproductive health? With whom? A significant other? With family and friends? With healthcare professionals?
- h) With whom do you have the most difficulty discussing your fertility or reproductive health?
- i) Do you experience communication tensions/challenges/obstacles about your weight and/or menstrual cycle? If yes, please describe.

11. How do women with PCOS seek health information before and after diagnosis?

- a) What was your initial understanding of PCOS before you were diagnosed?
- b) After diagnosis, where did you go for more information about PCOS?
- c) Did you make any lifestyle changes after being diagnosed?
- d) If yes, what lifestyle changes did you make?
- e) If no? Why not?

COMMUNICATION PRIVACY MANAGEMENT QUESTIONS

12. Do you think women with PCOS are likely to disclose their condition to others? If yes, under what circumstances will they disclose? If no, why not?

- a) Do you communicate with others about your PCOS diagnosis?
- b) If yes, with whom do you communicate? What do you communicate about?
- c) If no, why not?

CO-CULTURAL THEORY QUESTIONS

13. What communication tensions/challenges/obstacles are experienced by women with PCOS? Please describe.

14. What communication strategies are used to overcome tensions? Please describe.

15. How do women with PCOS employ communication strategies to navigate specific health-related dominant spaces? Can you offer an example?

16. Do women with PCOS perceive any stigma and/or discrimination based on their symptoms? Can you offer an example?

HEALTH CARE PRACTITIONERS QUESTIONS

17. What specific tensions/challenges/obstacles do women with PCOS raise while getting PCOS related treatment?

- a) What is PCOS and how can one be diagnosed?
- b) In your experience, how often are women diagnosed with PCOS? Not often? Often? Very often? All the time?

- c) What treatment plan (or information) is most often provided to women after diagnosis?
- d) In your experience, what specific communication tensions/challenges/obstacles are encountered by women with PCOS?
- e) How do health care practitioners communicate with PCOS patients?
- f) How do health care practitioners respond to questions or inquiries of women with PCOS?

18. During treatment for PCOS, do women reveal their specific communication strategies? Can you describe a strategy?

19. While receiving PCOS related treatment, do these women use any specific strategies with you? Please describe.

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