Contesting Sphere Boundaries Online: Private/Technical/Public Discourses in Polycystic Ovarian Syndrome Discussion Groups

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CONTESTING SPHERE BOUNDARIES ONLINE: PRIVATE/TECHNICAL/PUBLIC
DISCOURSES IN POLYCYSTIC OVARIAN SYNDROME DISCUSSION GROUPS

by

Kittie E. Grace

A DISSERTATION

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CONTESTING SPHERE BOUNDARIES ONLINE: PRIVATE/TECHNICAL/PUBLIC DISCOURSES IN POLYCYSTIC OVARIAN SYNDROME DISCUSSION GROUPS

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The internet is fast becoming a means for people to obtain information, creating a unique forum for the intersection of the public, technical, and private spheres. To ground my research theoretically, I used Jürgen Habermas’s sphere theory. Habermas (1987) explains that the technical sphere colonizes the private sphere, which decreases democratic potential. In particular, the internet is a place for altering technical colonization of the private and public spheres.

My research focuses on women’s health because it is a particularly useful case study for examining sphere tensions. Historically, the biomedical health establishment has been a powerful agent of colonization, resulting in detrimental effects for women and their health. The purpose of this study is to examine how the internet encourages expert and female patient deliberation, which empowers women to challenge the experts and, thus, make conversations between the private/technical spheres more democratic. The medical expert is no longer solely in charge of the conversation, the layperson gains a voice.

I used PCOS (Polycystic Ovarian Syndrome) as a case to observe the changing sphere boundaries by studying the discourse that took place on multiple patient and doctor websites over a four-year period. Through my research, I found that the PCOS women challenge the biomedical model by appropriating medical language. By
understanding the medical talk, the women are able to feel confident when discussing their health conditions with the doctor and with each other. The PCOS women also become lay-experts who have personal and medical experience with PCOS. These lay-experts give their doctors more information about PCOS reducing private sphere colonization. The PCOS patients arm themselves and others with tactics to empower patients when confronting a doctor, and encouraging patients to become representatives of the PCOS community.

This case study exemplifies how female empowerment can influence expert culture. The private sphere alters the technical sphere colonization, which has residual effects on the public sphere, challenging our conventional understanding of democracy.
DEDICATION

I dedicate this dissertation in fond memory of my muse, Lauren Kosovec. Through her strength and dedication to learning more about her illness, my student helped me learn more about the PCOS community. With her help, I realized the power women possess in gaining control of their health. Lauren, you are missed.
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CHAPTER ONE:

Personalizing Democracy

Seven years ago, I was living in St. Paul, attending the University of Minnesota-Twin Cities campus, and teaching English composition. As one of the assignments, I asked students to follow a listserv or a web community for a semester and identify the variety of mediated discourses. I handed out a sheet to each student, which offered some suggestions for on-line organizations they might study. After class, one student came up to me wide-eyed. She was the oldest student in the class and she had been struggling with an “illness.” The moment Lauren saw the list she felt connected to a community. She had seen an organization to which she related. Lauren hugged me and said, “I had no idea there were others out there like me!”

One of the organizations on the list was for a PCOS web community support group. My student’s “illness” was Polycystic Ovarian Syndrome. PCOS affects an estimated 6-10% of all women (Vliet, 2006). This “syndrome” is hard to diagnose because its symptoms include large irregular cysts that appear inside and outside of the ovaries. Other symptoms involve weight gain around the midsection, having large amounts of facial hair, irregular menstruation, acne, thinning of the scalp hair, and diabetes (Sargen, 2005). Not every woman suffers from the same symptoms; some women gain a lot of weight with the disorder while others are very slender. The disease is hard to detect because every woman has her individual symptoms that often do not mirror other women. Over the course of the semester, in conversations after class, Lauren disclosed to me the pain that she experienced. Lauren had been struggling with her symptoms for years and received a PCOS diagnosis one month prior to the fall semester.
starting. Her medical doctor was trying to control the “disorder” with diet and exercise alone but did not provide her information about how to find other people with her same syndrome. Once she found the support group, through composition class, Lauren was very excited to connect with others like herself.

Lauren talked with me about her struggles with the syndrome. Doctors kept telling her to lose weight and symptoms would improve. She felt that they were morally evaluating her eating habits and lifestyle. As a result, Lauren went to a psychiatrist and was diagnosed with depression. She was given medication to deal with the depression, but the symptoms kept influencing her daily routine. She did not find comfort in the diagnosis; she only found frustration. The doctors did not listen to Lauren’s full story. The emotional aspects were not addressed fully and she felt that both the psychiatrist and medical doctor knew little about PCOS. Lauren felt like she was alone in finding information about and dealing with this syndrome. On the Polycystic Ovarian Syndrome Association website, Lauren found out about the specifics of her disease. She learned about healthy eating habits and she was able to formulate questions that she wanted to ask her doctors. By the end of the semester, Lauren was trying exercises and sleep strategies offered through the online support group and she felt more in control of her condition.

Private Issues Yearn for Public Deliberation

Lauren’s story is about finding medical information to empower and provide self-efficacy beyond professional health practitioners. Although Lauren was finally diagnosed with PCOS years after dealing with the symptoms, she was frustrated with the way both her general practitioner and psychiatrist handled her case. She was not given the
necessary resources to understand her situation. She found empowering advice not from her doctors but from the listserv resource that she discovered in my composition class. Lauren educated herself about her syndrome through the internet.

Her story is not an isolated case. Many people are turning to the internet to gain “expert” knowledge regarding issues of health (Lemire, et al., 2008). In the United States, more than half of all internet users look for healthcare information online (Rice & Katz, 2006). As more people turn to the internet, this medium is fast becoming a space for collective conversations about health and other issues that affect the individual. At the same time, this medium is expanding our sense of democratic participation in parts of our lives that have been historically labeled as private.

While traditionally democracy is understood as a concept that addresses state-citizen relationships (Schneider, 1997), in this project, democracy takes on a more personal meaning. My research argues that online discourse and deliberation provide a means for democracy. As Bohman (2000) explains, “First and foremost, democracy implies public deliberation in some form. The deliberation of citizens is necessary if decisions are not to be merely imposed upon them” (p. 4). In essence, citizens must feel that they are active agents who can participate in public conversation to make changes in their daily lives. This deliberation empowers people to challenge the experts and, thus, make conversations between the public/private/technical spheres more democratic. In other words, when individuals feel they are a part of the deliberation process they can generate results that are more democratic. The expert is no longer solely in charge of the conversation, the layperson gains a voice. My research examines how individuals challenge and resist the anti-democratic impulses of expert cultures. Specifically, this is
an analysis of a case study that follows conversations/talk about a female health issue that took place on multiple patient and doctor PCOS websites over a four-year period. I use PCOS as a case to observe the changing boundaries of the public/private/technical spheres. This research focuses on how the private challenges the technical, which has residual effects on the public sphere. This case study challenges our conventional understanding of democracy and explores how individual empowerment allows people to challenge the expert culture. Those who have PCOS have organized in ways that defy traditional sphere boundaries, sources of information, and lines of authority. When people can control their own lives and make choices that are reasonable and in their best interests, the result is less docile submission to doctor requests and the patient is more engaged in deliberating about possible health related alternatives. I use this case to analyze the internet’s potential to democratize the technical sphere.

**Introduction to PCOS**

PCOS is a hormonal disorder that can manifest itself through abnormal hair growth, abnormal menstrual cycles, ovarian cysts, acne, weight gain or loss, and/or infertility (Bussell, 2007). This illness affects women starting in their adolescent years. As suggested earlier, this syndrome has many symptoms that challenge medical expertise. Because these symptoms are biological, psychological, and emotional, PCOS is a difficult syndrome to diagnose.

Since this disorder is often unrecognized by the medical community, women with PCOS often feel marginalized. Thatcher (2006) found that doctors receive very little training about PCOS in medical school. “Generalists,” he writes, “have often failed to make, or understand, the relationship of the different faces of PCOS” (para. 6). Often
doctors do not look at all of the symptoms. Dr. Elizabeth Lee Vliet (2006), a medical
doctor who specializes in PCOS research, explains that women with PCOS become
upset because their doctors do not fully listen to them. This disorder perplexes physicians
(Minassian, 2006). Snyder (2005) pleads, “Because PCOS is a lifelong disorder with
significant long-term health risks, nurses working with adolescent patients need to keep
this endocrine/metabolic syndrome in mind, especially when a female presents with
obesity, acne, hirsutism (excessive body hair), and irregular menses” (p. 416). Yet, the
medical profession has largely ignored this plea. Dr. Vliet (2006) states that PCOS is
often missed because doctors have “problems agreeing on a specific set of diagnostic
criteria” (p. 31). She writes that too many doctors treat different aspects of female health
so they do not always connect the symptoms, leaving many women frustrated. “PCOS is
a master of disguise,” she writes (Vliet, 2006, p. 37). The symptoms are different for each
patient and they shift and change as a female’s body changes, often leading doctors to
diagnose the situation as a “female problem” arguing that the issue deals with a hormonal
imbalance relating to the uterus and ovaries. Doctors typically suggest birth control for
regulation instead of looking at the body as a whole, including the endocrine system,
which is at the root of PCOS (Hammerly & Kimball, 2003). The multitude of symptoms
that shift and change makes it difficult to fit PCOS into the biomedical model, and
currently there is no specified set of criteria used to diagnose the disease. For a disease
that has been recognized by the medical community since 1935 (Tsilchorozidou et al.,
2004), additional attention from the public and technical sphere regarding disease
awareness and management is long overdue.
The acknowledgement of PCOS as a serious condition has come mainly through internet support groups not through the medical establishment (Harris & Cheung, 2008). These groups have increased the flow of information within the public sphere pushing for patients, doctors, and the public to understand PCOS. This move influences the private/public/technical spheres surrounding the disease. Through an analysis of PCOS on-line support groups, we can map the private/public/technical sphere changes within virtual communities and discover how women with PCOS promote deliberation to increase health democracy.

Specifically, this dissertation focuses on how women with PCOS gain empowerment through online support groups and doctor websites. Consequently, this research recognizes how the increased availability of the internet changes how we receive public information and interact with the expert sphere. While the project has implications for health communication and interpersonal relations, this is not the focus. The interesting aspects of this case lie in the way individual health knowledge can challenge expert culture and influence the technical/medical discussions, thus changing how we view expert culture and deliberation.

**Expert Culture and the Technical Sphere**

To begin, one must understand the definitions surrounding expert culture and the technical sphere to appreciate the dynamics of the shifting sphere. Jürgen Habermas (1987), the German philosopher and specialist in critical sphere theory, associates expert culture with the technical sphere. Experts who use field specific or technical terminology to explain their knowledge make up the technical sphere. Goodnight (1987) defines the technical sphere in terms of argumentation. He writes, “Technical discourse is not open-
ended but requires formally coded and stipulated, field-grounding reasoning” (p. 429). The specific disciplines influence the language used within different expert cultures. The experts are individuals who have “special status” (Turner, 2001, p. 123). Those seen as knowledgeable receive authority and only certain individuals are privy to that knowledge. Atchison and Bujak (2001) explain that “expert cultures are dominated by the motivational influences of accomplishment and power” (pp. 72-73). Those who make up the technical sphere including doctors, lawyers, scientists, and individuals who have specific training within certain fields have control over the knowledge.

Experts are necessary to promote progress within particular fields. The concern is the knowledge disparity that creates division between the layperson and the expert. People rely on experts when they need guidance; however, this influence becomes negative when people take the advice without question and do not intelligently deliberate about expert recommendations. Caution is called for when receiving expert advice, because the expert ideological perspective can influence professional judgment. Turner (2003) warns, for instance, that particular belief structures influence medical advice. This ideologically influenced advice affects the way individuals understand their health and in turn affects public policy. The focus on objective, medical communication from the expert to the patient is problematic, not the expert culture in and of itself. In other words, the expert culture is important since it provides the everyday person vital information concerning field specifics; for example, seeing a doctor if you have cancer is necessary because the oncologist has field specific knowledge that can help you understand your health. The expert culture can increase layperson knowledge; when the layperson is
unable to participate in the health conversations, the technical sphere discussion becomes problematic.

By understanding the definition of “expert culture,” and how expert culture influences the technical sphere, we can move onto discussing the specific influences of the technical sphere on democracy. Schneider (1997) explains that as society evolved and gained more forms of expression beyond word of mouth, the technical sphere grew. “The production of technical discourse,” Goodnight (1987) writes, “requires communication practices that supplement and counter deficiencies of the personal sphere, thereby making practice standard and reliable” (p. 429). The technical sphere consists of standard expert communication that can overtake the other spheres as experts gain authority. As Habermas (1989) would suggest, this is a form of “representative publicness” (p. 9) were people in charge are receiving “greater emphasis,” and are considered “an enclave within a society separating itself from the state” (9). This means that a few authoritative people represent the public. These individuals are not the everyday layperson but people imbued with expertise. Therefore, the experts represent the masses, which can undermine deliberation about medical problems because the doctors assume to know what is best for the public. In other words, the experts speak for the public and represent them because of their expertise, even if the layperson opinion differs from the expert.

Each expert culture influences society and has its limitations. As Foucault (1971) explains, “Every education system is a political means of maintaining or modifying the appropriateness of discourses with the knowledge and power they bring with them” (p. 46). In other words, the forces within the expert cultures, in this case the education system, do influence the management of the discourse that occurs within that particular
system. Foucault (1975) describes the medical examination as a prime example of doctor control and surveillance. Doctors study patients; patients list symptoms and agree to procedures that they often know little about. The body becomes an object of surveillance for medical examiners while patients willingly give up their bodies to physicians’ control. The result is a reliance on expert culture that leaves little space for individual autonomy. Instead, the body’s diagnosis and treatment become normalized.

This situation creates tension between the layperson and the expert. One reason for this division is the discourse itself. Within the technical sphere, this discourse is mystifying. Not everyone can understand the codes or language used within different areas of expertise. For example, not everyone comprehends the language of law; therefore, when a situation arises in which a person needs legal counsel, an expert is needed. The same happens regarding our health; when we are not certain what is going on with our bodies, we rely on medical professionals to explain our situation. The particular language codes of the lawyer and the doctor exemplify cases that separate the individual seeking help from the expert. Lessl (1989) calls the language codes mystification, and the practitioner a “priestly voice,” where the priest or scientist or other expert “represents a reality that the audience can only superficially hope to approach” (p. 183). This expert voice is mystifying because it “speaks on behalf of an elite subgroup of society” (Lessl, 1989, p. 185) and it “elicits a reverence from the ordinary individual that perpetuates their prestige and power” (p. 186). This mystifying language often cuts off discussion between the layperson and the expert, privileging the expert authority. For example, doctors use specific terms when discussing symptoms with patients, their language has standardized meanings. This standard language allows experts to speak with
each other but does not allow a layperson to participate effectively in that conversation. In this way, there is an imbalance of quality information between the technical field experts and members of the lay public. This encounter is anti-democratic because citizens feel they have little say regarding their health.

Another reason for the division between the expert and layperson is due to the inability of the lay audience to judge expert advice. Turner (2003) explains that for democracy to occur participants must be able to discuss matters openly with “some degree of mutual comprehension” (p. 12). When individuals talk with experts, there is often little comprehension of the expert language and as a result, there is no genuine discussion (Turner, 2003). Without mutual comprehension and genuine discussion the exchange is anti-democratic; one could even assert that the expert sphere is inherently anti-democratic. While experts are necessary because we cannot be knowledgeable about every aspect of life and we need to rely on others with credible knowledge to provide sound advice, there needs to be a healthier interchange between experts and laypeople to promote a more democratic state between the technical sphere and the everyday person. Within the medical field, often patients lose autonomy over their body and passively accept the doctor’s advice. The patient loses agency as the doctor controls the patient’s medical needs. While communication between doctor and patient has improved in recent years and there has been a shift to a more patient-centered model of communication, patients must have the ability to participate in their health care needs to ensure patient satisfaction (Cegala & Broz, 2003). If patients do not feel they can understand doctor vocabulary, they cannot become active participants in their own care. “Since 2002, the Association of American Medical Colleges and the Accreditation Council of Graduate
Medical Education have made interpersonal communication one of the six core skills taught in medical schools and residencies” (Chen, 2008, p. 5). While this practice has trained doctors to communicate with patients more clearly through giving them the skills to connect with patients, in practice there is still miscommunication. While doctor-patient communication is improving, currently the technical sphere maintains dominance in conversation. Studies have found that doctors are not good judges of their patients’ emotions and often misread their patients; as a result, they “can be woefully evasive in talking with their patients” (Chen, 2008, p. 5). If the doctor is not clear in communicating diagnostic procedures, the layperson misreads what the doctor says. As a result, the patient is unable to understand medical advice.

**Private and Public Sphere Influence**

The technical sphere has influence over the other spheres; yet, both the private and the public spheres are necessary components of democracy. They coexist with the technical sphere and require explanation to ground this dissertation as a critical democracy study. The private sphere consists of the environment that all people have control over. Goodnight (1982) defines the private sphere as the events and topics discussed within an individual’s life. The conversations that occur within the private sphere are fleeting and lack preservation (Goodnight, 1982). In other words, the private sphere consists of conversations that usually happen within personal space such as the home and are undocumented. The makeup of the private sphere consists of discussions held behind closed doors; everyone is able to participate in the private sphere. These talks influence only those involved in the conversation. The private sphere talk makes up our everyday conversations. Habermas (1987) defined this as our lifeworld. Habermas (1987)
describes the three structural components of the lifeworld as culture, society, and personality. This includes societal traditions and “background assumptions that are embedded in language and culture and drawn upon by individuals in everyday life” (Cohen & Arato, 1992, p. 428). Habermas (1984) explains that the lifeworld allows for transparent communication where everyone, in principle, can understand everyone else. He defends “ordinary language” believing this is necessary for people to communicate openly (Habermas, 1971, p. 56). This is the language used within the private sphere where the lifeworld connects people and the language is easily understood. We share this interpersonal component of our lives with few people but this sphere does provide space for open talk. Issues surrounding our health frequently fit within the private sphere because the information is often confidential.

While private talk, when seen as significant by multiple people, can become public and influence the technical sphere, most conversations that occur in the private sphere stay private. These conversations rarely affect public discourse or expert conversations. This dissertation challenges the role the private sphere plays in influencing the technical sphere. The health talk of individuals with PCOS challenges expertise by asking doctors to see illness and the language that surrounds it in a new way.

The private sphere’s counterpart is the public sphere. Democratic discussions take place within this sphere. Most scholars argue that deliberative democracy comes from the public sphere and helps connect people outside the privacy of the home (Isaac, Filner, & Bivins, 1999). The public sphere extends “the stakes of argument beyond the private needs and the needs of special communities [the technical sphere] to the interest of the entire community” (Goodnight, 1982, pp. 219-220). The discussion of events and
issues that influence many groups of people generates public conversation. The public sphere is a space where “individuals of like mind and of diverging opinions can articulate their points of view, and seek to persuade, and to organize, others” (Isaac, Filner, & Bivins, 1999, p. 253). People must connect for deliberation to occur and for democracy to have a chance. The public sphere allows space for permanent records of meetings and events; it is a space where individuals connect freely and work toward a form of democracy that opens up communication for all. Studying PCOS allows scholars to understand how a private issue can move into the technical sphere and influence the public sphere, opening the discussion and empowering people to find democratic practices pertaining to their health.

**Sphere Boundaries**

Within Western society, these sphere distinctions exhibit strong boundaries while maintaining fluidity within each sphere. While Goodnight (1982) argues that the boundaries between the private/public/technical spheres are somewhat fluid, he offers a caveat explaining that there is some “breadth between personal, professional [technical], and public life [that] is characteristically American” (p. 216). Laws govern our private and public rights that reinforce sphere independence. In the United States, there is a civic tradition of separating the public and the private. When issues affect an entire society, the spheres of influence overlap. For example, the fear of a H1N1 flu pandemic in fall of 2009 challenged the sphere boundaries. Personal H1N1 stories became public and the issues brought forward by the personal stories became a public health concern since the flu was expected to kill an estimated 90,000 Americans (Goldsmith, 2010, p. 12). While H1N1 did not reach anything near such a grave death toll, when the public panicked, the
experts had to find a vaccine to keep people alive. This example reveals the overlap between the private, the technical, and the public spheres. When such major health situations occur, experts gain influence because they have specialized knowledge. The public expects these agents to provide usable advice based on their expertise, and the families who suffer expect their personal stories to help keep others from dealing with the trauma of H1N1.

In this dissertation, I document the actions and the talk that blur these traditional sphere boundaries by focusing on PCOS patient care. While rhetorical scholars have primarily focused their work on the exploration of the public sphere, I turn my attention to the tension between the private and technical spheres as a way of understanding democratic discourse. In this project, I examine online support-group rhetoric as a unique discursive space. It does not fit neatly into the public/private/technical categories. This study looks at the discourse from the private and expert perspectives. I observe the private talk of women living with PCOS through observing PCOS support-group sites, and I look at the expert discussions doctors engage in regarding this syndrome. Analyzing the two, separate sphere discourses allows for a detailed discussion of how the private/technical spheres loosen their boundaries, flow into each other, and create what Crang (2000) would call a new “public realm” (p. 301).

I argue that the development of internet communication allows for the fluidity of the spheres. Crang (2000) acknowledges that cyberspace allows for new “potential architectures” creating a “completely new kind of public realm” (p. 301). This new “public realm” provides a way to bring private issues to a larger audience and records those events so other people may view them later. In other words, one can revisit a
website to find a history of the private events discussed at an earlier time. Within the online health websites, I focus my analysis on the open internet web conversations, stories, newsletters, discussion boards, forums, and informational pages. These discourses are public and available for anyone to view. There is no need for special membership or a subscription. I chose websites that were open to the public. These conversations blur sphere boundaries because private issues are discussed through a public medium where the individuals work to maintain control of their own bodies by questioning experts. The relationship among the spheres is complex. This research focuses on how people discuss their private issues of health online within a semi-public setting and negotiate their care with medical experts. This research explores the online tensions between the private/technical spheres. Understanding the talk that is used to discuss health concerns allows us to see how individuals can re-organize sphere theory vocabulary and provides a starting point for thinking about sphere theory in a new way. The following research questions guide this dissertation:

RQ1: What does the talk surrounding PCOS reveal about the fluidity of sphere boundaries?

RQ2: How do online PCOS support groups and doctor websites influence deliberation and health democracy?

RQ3: How does PCOS support group discourse alter the rhetorical construction of the patient/citizen?

To answer these research questions, I have organized the project into six chapters. In this chapter, I define deliberation and democracy, identifying how the internet provides space for exploring these concepts. In chapter two, I discuss the private/technical/public
sphere concepts providing an organizing framework for this dissertation. I also explain the emerging scholarship regarding the internet’s influence on the spheres. In chapter three, I look at the role of women in promoting sphere boundary shifting. I complete this task through developing three areas of study. First, I explore the political history of women’s health to provide a historical framework for my case study. Second, I explain the specifics regarding Polycystic Ovarian Syndrome to give background for the role of the private sphere in this case. Finally, I explore how the internet influences issues surrounding health and women in connection to the private/public/technical spheres. In chapter four, I explain Kenneth Burke’s ratios and their usefulness as a means of mapping shifting spheres in the PCOS patient and doctor online talk. In chapter five, I look at the talk that transpires regarding PCOS and explore the ratios identifying the private/technical sphere tensions. In the last chapter, I discuss the future of sphere theory and identify implications for democracy and personal empowerment.

**Deliberation & Democracy**

Personal resistance to expert cultures is a deliberative exercise that can lead to a new form of democracy. Deliberation is a necessary democratic component. The focus on PCOS provides a case for discussion that helps shift how we understand democracy. Deliberation has two main features: it is a “social activity involving all citizens” and it is a “dialogical process” (Bohman, 2000, p. 17). In the PCOS case, patients enter a dialogue with each other regarding individual health concerns. This talk allows for the “exchange of reasons” and provides space for “interpersonal coordination and cooperation,” which is all part of the deliberative process (Bohman, 2000, p. 27). As such, deliberation leads to democracy. Dewey (1927) explains, “Regarded as an idea, democracy is not an
alternative to other principles of associated life. It is the idea of community life itself” (p. 148). That is where life is “freed from restrictive and disturbing elements” (p. 149). In the PCOS case, this means people feel unrestricted when discussing their health with their doctor and take part in the expert discussion.

To understand how democracy is used in this study, I first explain how the term is framed within this discussion. Second, I explore the communicative requirements needed for democracy to exist. Finally, I then look at how the internet influences the connection between democracy and the public/private/technical spheres.

**Framing Democracy**

The term “democracy” has multiple meanings. Saward (2003) explains, “A great many things are done in the name of democracy. Decisions are taken, institutions created and destroyed, wars fought” (p. 2). The term is thrown around in multiple contexts to justify behavior because democracy is imbued with powerful positive emotional affect. In the West, virtually no one is opposed to “democracy” (Fukuyama, 1992). In the United States, Americans often force this view on others. For example, the war in Iraq was fought in part over the desire to see the country support a democratic society where everyone has the right to speak freely and more importantly to be heard. Democracy is a complex term and scholars argue over its definition, meaning, and praxis (Shapiro & Hacker-Cordón, 1999). The term is what McGee (1980) calls an ideograph. It is value laden and “contain[s] a unique ideological commitment” (p. 6), meaning that the word possesses principles that are seen similarly within a particular culture. Ideographs are also very ambiguous and therefore they allow for different meanings of the word to move easily among different contexts. In western culture, the positive connotation behind the
term democracy allows individuals to think of freedom, open expression and individual
democracy. The word is very ambiguous; however, which results in multiple definitions.
Robert Dahl (1999) explains that democracy is difficult to conceptualize as the term
“continues to be used indiscriminately” (p. 19). Laypeople and experts alike use the term
to convey that citizens have a say in what their countries do. An ideal democracy allows
citizens to “make political decisions under conditions of freedom and equality” (Altvater,
1999, p. 41).

For purposes of this dissertation, Stephen P. Turner’s (2003) and John Dewey’s
(1927) definitions of democracy inform this study. Turner (2003) argues that democracy
is constituted through open discussion. It cannot flourish when experts dominate because
it leaves no room for “meaningful discussion” or “mutual comprehension” (Turner, 2003,
p. 12). He states:

But in the case of expert knowledge, there is very often no such comprehension
and no corresponding ability to judge what is being said and who is saying it, and
conssequently no possibility of genuine “discussion.” So expertise poses a problem
that goes to the heart of liberalism. But it also goes to the heart of every
‘participatory’ alternative to liberalism, and particularly to the normative ideas of
“civil society” and democratic deliberation. (p. 12)

Experts limit democracy because not everyone can participate in the conversation. This
limitation does not allow for full representation of ideas and therefore is anti-democratic.
As Turner (2003) goes on to say, the control of the experts over our lifeworld is
problematic because the experts influence public culture and knowledge, restricting
public discussion. Rebellion against expert culture takes the form of open conversation.
In this dissertation, the deliberation on PCOS websites questions expert medical advice and thus provides a democratic space. More voices gain legitimacy and as a result, the medical community becomes more democratic. Merton (1976) explains that when patients receive doctors’ advice they do not agree with, they see this authority as an “alien power” and will rebel against that social influence and take control of their lifeworld (p. 26). Turner (2003) argues that we need to take Merton’s advice to gain a more open democracy. This dissertation looks at the rebelling of the layperson to regain control over the self. It is through the personal that people become involved and want to converse about issues openly. Through open human interaction, discussion, and connection these aspects of democracy can strengthen. My dissertation focuses on the acceptance of individual expression that resist the pressure of expert culture. As individuals feel free to speak, then change can occur. This interaction brings our private expressions into the open influencing both the public and technical spheres.

Personal expression as a form of democracy is voiced through talk. As John Dewey writes, “Democracy begins in conversation” (Post, 1993, p. 171). Dewey (1927) argues that democracy is found through open conversation, not through the language of the experts. It is through the voices of other people that one can find an individual voice and feel empowered. For this study, the conversations of the women with PCOS and the medical experts are analyzed to explore how deliberation is constructed within an online support groups. For society to flourish we must engage one another in discussion to move our medical conversations into a more democratic space. As Barber (1984) explains, people who talk with each other have greater potential for empathy and the sharing of
common interests. This connection is important for individual growth and community support, both of which are imperative for democracy.

The public/private/technical spheres clearly influence both our talk and our democratic framework. The scholarship of sphere theory, which is ever evolving within various disciplines including communication studies, political science, philosophy, sociology and women’s studies, provides a framework for understanding the development of democracy. In fact, researchers argue that tensions among public/private/technical spheres are present in every democratic society and that they help shape the political structures within those societies (Anderson, 2003; Cole, 2003; Davidoff, 2003; Rhein, 1998). Therefore, there is precedent for thinking about democracy beyond an exclusive focus on state relations. Individual expressions are just as important for understanding the democratic aims of a civil society. What I mean is that for a society to be civil it must provide space for citizens to converse openly about topics of concern to them. In an ideal civil society, everyone speaks openly, providing equality for all. Cohen and Areto (1992) argue that civil society is necessary for democracy and is “composed above all of the intimate sphere (especially the family), the sphere of associations (especially voluntary associations), social movements, and forms of public communication” (p. ix). Within a civil society, or a civilization that seeks equality for its citizens, all three spheres of influence are present. This includes the private sphere and technical sphere, which are rarely discussed when looking at claims of democracy. Usually one views the effects of democracy through the public sphere alone. However, the individual’s voice, and conversation that occurs between the private and the technical, do influence democracy.
Communicative Requirements for Democracy

Beyond the connection to the spheres of influence, there are many communicative requirements for democracy that lead toward personal empowerment. One communicative requirement for democracy is freedom of expression (Dahl, 1989). Individuals gain agency through communicating with one another; they take the issues from a private realm to a public or expert arena. This open space for talk and expression empowers individuals to challenge the experts (and often the state). Freedom of expression is therefore not only a crucial element of democracy, but also a part of personal empowerment because it allows each individual to speak. Essentially, I am arguing that democracy starts when communication occurs between individuals.

A second communicative requirement for democracy is that laypeople must question what influences their lifeworld. Turner (2003) acknowledges that “expert knowledge presents a fundamental political problem for liberal democracy [democracy governed by discussion]” (p. 5) because experts present information that cannot be discussed by a lay audience. For communication to be productive, individuals must question the experts and examine their different perspectives. Dahl (1989) argues that for a democracy to exist individuals must have the right to seek alternative information. He states that even within the most democratic systems there is still a delegation of power and authority that influences the populace. There will always be power structures in place; however, an ideal democracy allows individuals to seek information from multiple sources so layperson participation can occur. When individuals can challenge the technical sphere, they gain control of the situation and make choices that are fitting for their personal needs. As control over one’s own life increases, democracy strengthens.
Third, for communicative democracy to occur, people must participate in discussion. Pateman (1970) explains that people must help regulate the allocation of resources. She claims that our private interests, when expressed, can integrate with the interests of others, possibly changing public opinion. In other words, talk of private matters can lead to public exchange and personal empowerment. This change can influence all spheres of life. When ideas move beyond the personal, they provide opportunity for a growing democracy as people gain agency.

Fourth, people must be willing to share examples from their personal field of experience to strengthen communicative democracy and empower themselves. It is through the private sphere that personal empowerment occurs. Without talk about our personal situations, our democracy becomes uncertain. The democratic relationships within one’s private life influence the public and, therefore, the personal is important in developing democracy. Negt and Kluge (1993) explain that there is an “interdependent relationship between that which is private and the public sphere” (p. 4), where the experience of an individual is shared and becomes a “social experience” (p. 8) of a community. Therefore, the private sphere acts as the base for democratic health. In fact, the interest of the individual is imperative for democracy. This study focuses on observing support-group conversations that come from within the private sphere. According to Schneider (1997), “a society composed of individuals who lack the skills and opportunities to engage others in discussions about public issues cannot long sustain itself as a democracy” (p. 8). We need connection, the ability to talk about issues that influence the individual, and the freedom to express opinions that challenge the state and experts if we want to sustain our democratic society.
The spheres of influence can only shape democracy through individual participation within a community. For the purposes of this dissertation, the focus is on online communities. These groups of people help constitute new democratic practices as this new internet media influences talk. Agre (2003) explains that the internet facilitates “community-building,” which helps grow a democratic culture (p. 64). He states, “…in many cases the internet is amplifying collective cognition in ways that equalize playing fields for all. Cancer patients no longer need to confront the medical and insurance systems as individuals” (Agre, 2003, p. 64). Through similar individual expression, collective forms of action emerge that provide a community of individuals to challenge the current systems. Individuals gain agency and through talk can change the way we view the technical sphere, ultimately influencing the democratic process. Schneider (1997) explains, “The will of the community in a democracy is always created through a running discussion between majority and minority, through free consideration of arguments for and against policy or idea” (p. 8). These connections are necessary to advance our social and political civilization.

These democratizing connections and conversations occur within all aspects of our lives; they are not limited to the public sphere. The democratic process occurs not only when individuals negotiate with state officials over issues; democratic practices are also apparent in discussions of many ideas within the private sphere. The democratic practices of society have gone beyond state and governance interactions and have influenced other arenas of human life. It is important to examine these other arenas in order to have a full appreciation of the complexities of expertise in contemporary life.
Kelsen (1961) argues that discussion takes place not only within formal governmental institutions, but also within informal public life such as meetings, books, newspapers, and other areas that allow for the formation of public opinion (p. 287). Democracy occurs through the connection of others. Putnam (2000) argues that our growing isolation harms our society and our ability to connect. Changes within our social structure, including at the job, in the home, and with the invention of the computer, allow people to focus on achieving individual goals alone with little social interaction, lessening our desire for face-to-face connection and increasing our political apathy (Putnam, 2000). The focus of this project acknowledges a newer form of community connection, through the internet, and explores how our definition of democracy must widen. Dryzek (2000) argues that when discussing the concept of democracy all types of communication are welcome as long as they are “noncoercive” and can connect the “particular to the general” (p. 167).

The layperson finds other laypeople to connect with online and they realize the ideologically based, and sometimes coercive, terminology of experts must be challenged. As Conant (1951) explains, all relevant arguments, from multiple sides, deserve exploration. The advancement of multiple arguments, which tend to support an experts’ position, provides more democratic support for that expert idea. This allows for a more democratic process since multiple people, other experts and laypeople, agree with the expert. Many laypersons join ideas online which explores open communal connection. The space becomes even more open as people feel anonymous when providing their input online. People feel that their physical influence does not get in the way of the online message so the communication can become more direct. Jordan (1999) explains, “It is rather that the identity we have offline, that is often marked physically, is absent online”
Jordan (1999) is arguing that certain offline prejudices do not follow individuals online, allowing for honest connection. Now, while not everyone is honest about representing their offline-self online, those invented online persona still have opinions and values in cyberspace, which provides space for many more voices, fabricated or real. Therefore, observing support group community conversations within cyberspace constitutes a place for observing deliberation that can challenge the expert sphere and open up the definition of democracy.

New space for engagement is imperative to a healthy democratic state and is available for some communities within the internet. This dissertation looks at the shifting spheres to see if aspects of the internet can provide new space for diverse human connection leading to a change in how experts and laypeople communicate and promote public action. This case study brings a private female health concern (Polycystic Ovarian Syndrome) into the technical sphere and potentially pushes the discussion into the public. This dissertation looks at how deliberation blurs the sphere boundaries and allows us to broaden our definition of democracy.

**Democratizing Potential of Cyberspace**

While arguments about the public/private/technical sphere have received considerable academic attention, the creation of the internet has only begun to influence how scholars think about spheres. I want to review how the internet shapes the arguments of sphere theory and democracy. In this section, I offer a brief history of the internet and, then, explore the mixed reception of claims about the democratizing influence of the internet. I pay particularly close attention to scholarly discussions of the internet’s potential influence on laypeople’s interaction with expert culture.
The internet originated as a national security research project during the cold war and was controlled by the Defense Advanced Research Projects Agency (DARPA) (Norberg & O’Neill, 1992, p. 1). DARPA created a network that allowed information sharing among defense researchers in different geographical locations (Roberts, 1989). By 1986, academic researchers became interested in this “relatively immediate and inexpensive communication” (Saco, 2002, p. 90). The National Science Foundation (NSF) gained access to the internet using the principle of “universal educational access.” This provided college faculty and student access to internet resources (Krol, 1994, p. 13). Then in 1994 the NSF shared its backbone services with private companies and the internet became fully commercialized (Miller, 1996).

The internet, even in its earliest manifestation, was multifaceted with complex networks that influenced community life. Saco (2002) explains, “It [the internet] has made networking at once impersonal and personal, mass mediated and popular, governmental and grassroots, corporate and individual, serious and playful” (p. 100). The internet had the potential “to create a radically more diverse public sphere,” when it moved from military control to the public (Hindman, 2009, p. 3). The internet then became public ground where anyone with access could express opinions online. Winston (2004) explains, “The digital world doesn’t prejudge ideas. It simply makes them more accessible—good and bad” (p. 141). The opening up of this textual and visual space provided a place for community connection and support. Saco (2002) argues that the internet provides “social space” (p. 124) and allows for social bonding with others. This new space reduces the power gap generated by mass media (Saco, 2002). No longer is public consumption of media restricted to those who can afford to send messages to the
public; all can participate if they have a means to get online. This provides more space to
discuss societal happenings. Therefore, the internet transformed from a space of security
to a space for connection.

The influence of the internet on democracy has been both positive and negative.
On the positive side, individuals have few restrictions online and are free to attain
information, provide opinions, and support policy as they wish. Saco (2002) explains,
“Cyberspace liberates individuals from the confines of apartment walls, office cubicles,
and state borders precisely by presenting users with seemingly boundless frontier
space…” (p. 189). There is space for personalized talk on the web that advances
particular perspectives and challenges certain social orders. The open frontier for talk
does enhance the means for democracy. Agre (2003) explains:

Fortunately, what the internet makes necessary it also makes possible. If the
working rules of universities will be remade through a negotiation between
professors and students, among others; if the medical system will be remade
through a negotiation between physicians, patients, and insurers, among others; if
the political system will be remade through a negotiation among citizens and their
representatives, among others, then the internet has provided tools that allow each
of these stakeholder groups to associate and, each in its own way, to press its
interests. (p. 64)

Citizens express their personal interests on the internet and forge conversations with
experts and other citizens. The individual can influence the technical. The internet
provides a good place for communication scholars to look at new possible places for
democracy.
The internet does not provide a space for open democracy in all cases; there are anti-democratizing aspects of the internet. First, there is still a clear hierarchy present within some elements of online communication. Shapiro (1999) argues that the internet may shift who is in control of information, experience, and resources if we allow for an opening of the online field but this is not a “sure thing” (p. xiii). Shapiro is arguing that while the internet provides open space for multiple voices, where colonization by the experts and state is currently at a minimum, this open arena may not last. The same structures that influence democracy offline can reconstruct online. While the medium currently has few restrictions, people have found ways to reify power structures online and the space for open communication may be in jeopardy. Hindman (2009) points out, “the extreme ‘openness’ of the internet has fueled the creation of new political elites” (p. 4). Hindman argues that the blank canvas of the internet allows anyone to paint and the picture that is forming has a similar hierarchy online as it has offline. While the artists are different in the online positions of power, the hierarchical structure remains in many areas of the internet. There are formal and informal barriers not always known to the person participating in the online experience. Therefore, some people have access and can participate while others cannot, which reifies the offline experience online.

Second, some individuals receive more respect than others do, allowing certain opinions to have more power than others. People read certain websites and not others, creating a social order based on the amount of traffic that the website receives. Hindman (2009) argues, “This hierarchy is structural, woven into the hyperlinks that make up the Web; it is economic, in the dominance of companies like Google, Yahoo! and Microsoft; and it is social, in the small group of white, highly educated, male professionals who are
vastly overrepresented in online opinion” (pp. 18-19). Certain sites gain credibility and, consequently, people read only certain cites. As a result, even when the ability exists for people to post their thoughts online, there is no guarantee that others will hear their voices. The internet does allow opportunity for more voices yet sometimes the same voices that are listened to offline receive more attention online, which can limit the democratic influences of the internet. This continues inequity in participation and weakens the argument that the internet provides a more open democratic space.

While mixed reviews of the democratizing influences of the internet will continue, it is important to point out that this dissertation does not focus on the general limiting aspects of digital democracy. This research focuses on how the private and technical spheres can influence democratic practices. Most internet research has focused on how the enhancement of online democracy does or does not occur with the development of the digital public square. I argue that perhaps researchers have been limiting their perspective and a look at other spheres is necessary to assess the internet’s potential advancement of democracy. This project shifts attention away from the digital public square and focuses on how democracy can occur on a micro level when individuals challenge the technical medical sphere and gain personal agency. It is important to look at cases such as the women with PCOS to gain understanding of what the future may hold for the private/technical sphere boundaries. This case study allows us to see how layperson empowerment may occur when interacting with the medical experts.

Regardless of whether or not the internet opens democracy to the public in most situations, the internet does influence how we view democracy from a personal level.
Rheingold (2000) explains that online users change how we communicate, influencing democracy. He warned, “Because of its potential to change us as humans, as communities, as democracies, we need to try to understand the nature of computer-mediated-communication, cyberspace, and virtual communities in every important context—politically, economically, socially, cognitively” (p. xxxi). Rheingold (2000) urges everyone to learn more about the Net and use their voices for change, which includes challenging the experts to gain personal control:

The battle for the shape of the Net is joined. Part of the battle is a battle for dollars and power, but the great lever is still understanding—if enough people can understand what is happening, I still believe that we can have an influence. Whether we live in a Panoptic or Democratic Net ten years from now depends, in no small measure, on what you and I know and do now. The outcome remains uncertain. What the Net will become is still, in large part, up to us. (p. 403)

While this was written ten years ago, legislation has moved slowly regarding the regulation of the internet. Rheingold’s argument is still applicable. The focus of this study helps to explore one aspect of power within the internet where the private sphere conversations acknowledge the importance of female health and challenge the expert doctors to see health conversations in a new way. The personal gains control.

This dissertation focuses on women’s health communication as one way to look at growing democratic space. This form of communication is important to study because health is a private matter (Frank, 1995). With the arrival of the internet, one can find information on the World Wide Web to gain knowledge about health. As such, the private information on health comes into the public consciousness and often allows
people to question what doctors say. People sometimes gain a sense of empowerment by finding health information online and they may challenge the doctors and healthcare professionals who are a part of the technical sphere. Sirigatti (2006) writes:

In recent years the Web can provide patients in-depth information about disease, and work as a medical consultant offering clinical information; until then, this information was purely the prerogative of the medical doctor. We are witnessing the encounter between medical knowledge—so far subject to the approval of a restricted scientific community—and a new behavior of the patients, who are more aware and informed about their conditions, are acquiring a more central role in the treatment process, and are less likely to play a passive and dependent role in the relationship with their medical practitioner. Both the patient-doctor communication and the decision-making process may be seriously affected. (p. xix)

This increased access to information allows for online discussion regarding health and may challenge our current sphere distinctions.

By looking at the talk that transpires between women discussing a private issue of health (PCOS) and observing how this talk resists expert knowledge, we can see in what ways the everyday talk gains power and changes the way we see the technical sphere. This project uses sphere theory to explore whether or not the internet provides spaces for democracy. This has potential consequences for understanding democracy since the voices of the everyday person may challenge and change the way we look at experts.
References


CHAPTER TWO:

Public/Private/Technical Sphere History and Evolution

With new technology, the boundaries of the spheres are blurring. The internet provides fluid space for conversation within all three spheres of influence and may challenge our traditional representations of the spheres. My research tries to expand our knowledge of the private/technical spheres through analyzing the impact of online discourse. Sphere theory literature is vast and most researchers focus on the importance of the public sphere; less concentration has been spent exploring how the private and technical spheres influence democracy. Therefore, my research offers a new perspective in which to view democracy within the private/technical spheres. In order to understand this new perspective, a historical look as sphere theory is necessary. In this chapter, I first explore these sphere tensions by providing a brief history of sphere theory as it relates to democracy. Second, I look at how democracy shifts when the technical/expert fields colonize everyday life. Third, I explain how sphere theory has evolved and explore how the internet blurs the current sphere boundaries problematizing the sphere as a metaphor. Finally, I explore how the internet may provide new possibilities for democracy.

Sphere Theory: The Habermas Vision

While I presented brief definitions of the public/private/technical spheres in chapter one, here I offer a more in-depth discussion of sphere theory. To frame this analysis, I start with Jürgen Habermas’s history of the public sphere in Western Europe and then I explore the evolution of sphere theory. While Habermas was not the first to discuss the concept of the public sphere, he was the first to give a historical account concerning the rise of the public sphere (Calhoun, 1996). While the focus of the
dissertation concentrates on the changing relationship between the private/technical spheres, each sphere influences the other; therefore, it is necessary to define and explain the components of each sphere to explore the evolution of democracy.

Habermas’s dissertation focused on Friedrich Shelling’s philosophy of history (White, 1995). From this starting point in critical theory, Habermas gained public attention in Germany when he wrote *Strukturwandel der Öffentlichkeit* (Structural Transformation of the Public Sphere: An Inquiry into a Category of Bourgeois Society, English ed., 1989) in 1962. Within this work, he “detailed social history of the development of the bourgeois public sphere from its origins in the eighteenth century salons up to its transformation through the influence of capital-driven mass media” (Bohman & Rehg, 2007, para. 4). Prior to the eighteenth century, feudalistic systems dominated Western European society. Habermas argued that through the reign of monarchs Europe participated in “representational” culture where the leaders “represented” the audience by speaking for their subjects (Blanning, 1988, p. 26). Habermas (1989) called this “representative publicness” (p. 9) where the public gained identity only through the monarch representation, and by extension through the nobility who communicated the monarch’s ideas. Essentially, the aristocracy spoke for the people calling it a representation of the people. This is what Habermas (1989) criticizes; he found this form of representative publicness to be anti-democratic. The aristocracy had control and made decisions, arguing that their choices were in the best interest of the people without considering public opinion.

The new bourgeois in the eighteenth century felt silenced by the aristocrats and began conversing in public establishments such as the salons and coffee houses. The
intellectuals and later the merchants, craftsmen and shopkeepers started to find spaces for deliberation generating more of a “critical publicity” where the talk was open and equal (Habermas, 1989, p. 188). This critical publicity transformed the public sphere, Habermas (1989) argues. It is through this discussion, free of social, economic and government influence, that everyday people are able to reach an understanding regarding matters of common concern. Newspapers, journals, reading clubs, and Masonic lodges all contributed to the shift away from state control and the opening of public space (Blanning, 1998). Habermas believed that if “free and equal” citizens had an opportunity to participate in “relatively unrestricted communication” they would gain power to influence political decisions (Bohman, 2000, p. 14). These deliberations lead to further development of critical publicity, where conversations allowed elites and common people to speak openly to one another. As Cohen (1989) explains, “…in the salons the nobility and the grandee bourgeoisie met with the intellectuals on an equal footing” (p. 24). People who were able to speak, helped shape public opinion. As Bohman (2000) explains, “Only when the sons of the aristocracy joined with the sons (and in rare cases the daughters) of craftsmen and shopkeepers could they compel political authority to legitimate itself before the tribunal of public opinion…The force of public reasons could then replace the influence of social hierarchies” (pp. 114-115). In other words, when the influences of wealth and power were suspended, conversation between classes could occur resulting in public reason or critical publicity. The voice of the public more completely represented the voice of the people.

This open discourse did not last long. Habermas argues that the mass public, including the mass produced newspapers and journals overran these open discussions by
the twentieth century in which “ideas became commodities, assimilated to the economics of mass media consumption” (Bohman & Rehg, 2007, para. 4). In other words, those in power started controlling the conversations once again. Habermas termed this return to representative publicity, “re-feudalization,” where “free exchange of ideas among equals becomes transformed into less democratic communicative forms” (Holub, 1991, p. 4). In this instance, the rise of the expert culture took power over the public voice. Professionals lead the conversations regarding what was in the best interest of the public. This is clearly seen, as discussed extensively in chapter one, in the evolution of expert culture. In many areas of communication, the technical sphere took precedence over the private sphere becoming anti-democratic, and this includes conversations regarding women’s health. To put this in the perspective of my research, for the women with PCOS the doctors pronounced a diagnosis (often a misdiagnosis) without knowing much about the disease. Still, the expert knowledge overshadowed the personal experience, muting the female voice. To stop the re-feudalization from continuing, Habermas (1989) calls for people to create open space for discussion that is “grounded only in the structural transformation of the public sphere itself and in the dimension of its development” (p. 244). In other words, to improve democratic possibilities the public (and I argue through this research the private) must influence the technical to promote substantial change. It is through the blending of these spheres (public, private and technical) that critical publicity is possible once again.

Public Sphere Defined & Exemplified

Habermas (1974) claims that a “portion of the public sphere comes into being in every conversation in which private individuals assemble to form a public body” (p. 49).
Individuals must come together and voice concern about matters that affect society within a public setting for a public sphere moment to emerge. Within this section, I fully define the public sphere, and explain how the public sphere gains its power through personal connection.

As Habermas (1989) argues, “the sphere of private people come together as a public” (p. 27). For Habermas, the private sphere includes any discussions that occur in the home between individuals. When these discussions become important enough to share with others within a public setting, then conversations move from the private to the public sphere. He argues for an idealized public sphere that occurs outside and separate from public authority (Schneider, 1997). Habermas (1989) explains, “The institutional core of the public sphere comprises communicative networks amplified by a cultural complex, a press and, later, mass media; they make it possible for a public of art-enjoying private persons [for instance] to participate in the reproduction of culture” (p. 319). The public sphere allows individuals to influence culture through open dialogue. This open dialogue allows political discussions through the “medium of talk” (Fraser, 1997, p. 70), where citizens discuss common affairs away from the eyes of the state. Therefore, individuals pull issues from their private lives to see what events would influence the most people and work to create public change that will help those individuals. For example, healthcare is a private matter when people suffer without adequate coverage. When individuals tell their private stories, citizens connect through experience and they work to promote policy changes as a result, moving a private issue into the public field.

Habermas (1984) explains that a public sphere requires public exchange. Participants must think reflexively about their cultural values; they must attempt to
understand the perspective of others; they must make a sincere effort to provide all necessary information to others; each participant must feel included and equal within the conversation; and the discourse is publicly driven, not driven by the state or economic power. Individuals must feel free to speak in public with others about issues that concern the state and government. With a strong public sphere, political power can change if the will of the populous deems change necessary. Habermas (1979) explains:

I can imagine the attempt to arrange a society democratically only as a self-controlled learning process. It is a question of finding arrangements which can ground the presumption that the basic institutions of the society and the basic political decisions would meet with the unforced agreement of all those involved, if they could participate, as free and equal, in discursive will-formation.

Democratization cannot mean an a priori preference for a specific type of organization, for example, for so-called direct democracy. (Habermas, 1979, p. 186)

Therefore, a legitimate democracy is formed in part through freedom of expression within a public venue for all who can participate.

Initially, the public gained power through having space to share ideas, but a few powerful individuals controlled the public space. Calhoun (1996) writes that “the early bourgeois public spheres were composed of narrow segments of the European population, mainly educated, propertied men, and they conducted a discourse not only exclusive of others but prejudicial to the interest of those excluded” (p. 3). Habermas wanted to see the public space include more voices. Habermas urged societies to participate in
“democratic law-making” (Chevigny, 2000, p. 310), where the public sphere provides a place for such conversations between many people.

Habermas argues that people must be able to connect within an “interactive social space,” that does not have to be face-to-face, but must allow for “public (as opposed to mass) communication and opinion formation” (Saco, 2002, p. 69). The internet may be the place to see this open public sphere because there is space within the internet public for dialogue. The free flow of information, as well as the opportunity to join group organizations and nurture political party connection, allows citizens to get involved through the internet (Schudson, 2003).

Private Sphere Connection to the Public

Second, the private sphere connects to the public. In this section, I briefly define the private sphere and explain how this sphere has struggled for acknowledgement. The private and the public spheres “stand in complementary relation to one another” (Habermas, 1989, p. 319). While the public sphere occurs within community space, the private sphere occurs within interpersonal space. Habermas (1989) explains, “The institutional core of the private sphere is the nuclear family, relieved of productive functions and specialized in tasks of socialization” (p. 319). In other words, the talk that happens inside the home, not outside where production occurs, is included in the private sphere. If many people do not experience the topic then it stays within the privacy of the home. Goodnight (1982) explains that arguments in the personal sphere “require only the most informal demands for evidence, proof sequences, claim establishment, and language use” (p. 220). The talk within this sphere is based on the personal opinions and values of individuals.
The roles within the public and private spheres are fairly defined. Familial matters are part of the private sphere while the roles of patron and voter connect to the public. It takes a long time for private topics to gain public recognition and achieve policy enactment. As Habermas (1996) explains, “Only after a public ‘struggle for recognition’ can the contested interest positions be taken up by the responsible political authorities, put on the parliamentary agenda, discussed, and, if need be, worked into legislative proposals and binding decisions” (p. 314). This process is often discouraging which continues to keep certain topics (such as personal health, childcare and interpersonal relationship issues) within the private realm. Embedded within the framework of the spheres is an economic connection. This connection helps keep the spheres separate as certain matters are considered private, such as one’s personal health and relationships and other issues are thought public, such as government concerns and war. The public must be a shared space.

The sharing of this space occurs when many people within the private sphere feel the issue is important enough to influence the public sphere. Habermas (1970) calls this “moral realization” (p. 107). This occurs when private matters have enough support and moral connection with the public that the private topics influence public opinion. To connect this concept to my research on PCOS, let us take the support groups for example. Within these support groups, many individuals tell their personal stories. When sharing their experiences, the women talk about the pain and suffering they experience due to the lack of doctor knowledge concerning PCOS. When enough women share a similar story, this raises concern for many people as this lack of efficient diagnosing could influence people without PCOS, creating a moral realization for all patients. The stories then
become a part of the shared public and a call to action urging the public and the medical community to gain education about PCOS results. The point is, if a private sphere topic gains enough interest it can become a public sphere topic.

*The Technical Sphere: Expert Voices*

Third, the technical sphere, as discussed in chapter one, is made up of experts who have control over specialized knowledge. Within this section, I outline the definition of the technical sphere, rehearse the clash between Lippmann and Dewey, and explain how the experts have colonized the “lifeworld.” Initially, arguments within the technical sphere mandate “more limited rules of evidence, presentation, and judgment… in order to identify arguers of the field and facilitate the pursuit of their interests” (Goodnight, 1982, p. 220). Expert research and field specific data is necessary to support technical sphere communication. Habermas (1989) acknowledges that individuals within the technical sphere hold more knowledge and information than the average citizen holds. This specialized knowledge is a part of the technical sphere. “Technical discourse is not open-ended but requires formally coded and stipulated, field-grounded reasoning” (Habermas, 1989, p. 429). The technical sphere requires specific knowledge. These experts use codes and language that mystify issues and information for the common citizen. Schneider (1997) states:

Habermas suggests that the increased reliance on literate materials (first, written and later, printed) gave rise to a new stratum of bourgeois people, which occupied central position within the public. The officials of the rulers’ administrations were its core. Added to them were doctors, pastors, officers, professors, and scholars,
who were at the top of a hierarchy reaching down through schoolteachers and scribes to the “people.” (p. 19)

Unfortunately, when the experts gain more influence, the voices within the private sphere have less space to discuss individual problems and policy. As Habermas (1989) warns, the influence of the media and press on the public helped forward state-based ideology and turned the private citizen into a consumer. People more readily accepted the discourse given to them and did not fully question the state’s decisions as they once had, leading to increased power within the technical sphere and a loss of power within the public sphere.

Lippmann vs. Dewey

Walter Lippmann’s analysis of expert cultures extends Habermas’s analysis of the operation of the technical sphere into the early twentieth century. Lippmann (1922/1977) was a journalist and philosopher who believed that most voters were not knowledgeable enough to make informed decisions. He felt that the public did not care to participate in the political process; or when the people participated, they would gather very little information and make decisions hastily. Lippmann (1922/1977) believed that experts were needed to influence the public into making knowledgeable and rational decisions. He writes of the public:

The lesson is, I think, a fairly clear one. In the absence of institutions and education by which the environment is so successfully reported that the realities of public life stand out sharply against self-centered opinion, the common interests very largely elude public opinion entirely, and can be managed only by a specialized class whose personal interests reach beyond the locality. This class
[the public] is irresponsible, for it acts upon information that is not common
property, in situations that the public at large does not conceive, and it can be held
to account only on the accomplished fact. (p.195)

In other words, Lippmann sought an elite class of people who could control information
given to the public. This would allow more accurate knowledge dissemination. As a
journalist, Lippmann believed this process would enhance voter education as the experts
could explain to people what they needed to know, give them the necessary details within
a complex, false information filled world. He believed that relying on the experts would
enhance the intelligence of the community. Lippmann supported the development of the
technical sphere to influence the public.

Philosopher and democratic theorist John Dewey agreed with Lippmann saying
that “the Public seems to be lost; it is certainly bewildered” (Dewey, 1927, p. 116). He
argued that the modern world was complex and it was difficult to understand all aspects
of public life. However, he did not feel that the promotion of an expert culture alone
would enhance civic engagement. He believed education was the key to advancing
democracy. He saw the public mainly as capable and rational individuals who could
come together as a community and gain education about issues that influence the public.
He saw democracy coming not from an elite class but from the public (Dewey, 1927). He
believed that citizens could learn more by talking with each other and deciding the
correct way to respond than relying on an expert to tell them how to think. “For Dewey,
face-to-face deliberation—talking, listening, and collective deliberation—is democracy”
(Jansen, 2009, p. 235). While Dewey was not around for the development of online
communication, the same deliberation outcomes can occur through cyber connections.
Dewey saw public conversation and deliberation as the crux to a democratic nation. He felt the overseeing elite made the process of voting and giving public voice less democratic, which reduced the public influence.

**Colonizing the Lifeworld**

Habermas (1987) recognizes the reality of the technical sphere Lippmann advocated for while acknowledging the need for the public to have more of a voice. However, this voice was becoming more reticent with the colonization of the lifeworld. Habermas (1987) says that there is no longer a clear division between the public and the technical spheres of influence since experts colonized the “lifeworld” which is comprised of our everyday experiences. Habermas (1987) explains, “The lifeworld is assimilated to juridified, formally organized domains of action and simultaneously cut off from the influx of an intact cultural tradition” (p. 327). The lifeworld cannot be removed from the individual; however, Cohen and Arato (1992) argue, “Individuals can neither step out of their lifeworld nor bring it into question as a whole” (p. 428). This means that the lifeworld is a part of an individual’s history and personality that is brought with each person into the public sphere experiences, but cannot be objectively analyzed. Fraser (1989) recognizes that the economic and state systems are embedded in the lifeworld dividing the lifeworld into two systems—the public sphere and the private sphere. However, with the development of modern society, current power structures and experts influence this everyday experience. The everyday is no longer central to the lifeworld because “formally organized domains” increasingly control that space. The experts have crowded out the personal.
The consequence is a professionalization of the lifeworld, which results in a greater distance between expert culture and the individuals engaged in public discourse. Wallinger (1989) explains, “Thus encroaching on the realm of public deliberative argument, technical expertise may come to replace rather than inform, public policy decision making” (p. 71). The technical sphere’s colonization lessens the potential for other spheres of influence and limits the number of people who participate in conversation. Bantz (1981) warns that the lack of “shared understanding” between private individuals and the experts may lead the public to adopt strategies that “can seriously hamper intelligent discussion of crucial public issues” (p. 87). The expert then controls the public.

Farrell and Goodnight (1981) provide a case study to reinforce Habermas’s claims of lifeworld colonization. They studied the discourse regarding the nuclear accident at Three Mile Island and found that the public shared little about the event because the technical sphere controlled it. They argue that in this instance, the “limits of technical communicative discourse are severe, recurrent, and perhaps irreparable” (p. 271). The technical sphere dominated the conversations surrounding the accident and did not allow for public reflection or communication. This is an example of how the influence of the massive public sphere diminishes while the limited technical sphere takes control. As a result, experts colonize the public sphere and the power of influence is concentrated in the elite, not in the public.

While the expert voice is an important element of society, this colonization is antidemocratic and needs public and private influence to widen the potential for
democracy. This is the crux of my argument: In the area of healthcare, the internet has empowered individuals to press back against technical sphere colonization.

**Public/Private/Technical Sphere Evolution**

To see the evolution of this democratic process, we need to address how sphere theory has evolved since Habermas’s framing of the public sphere. Many of the sphere theory scholars feel that opening up who participates in the public sphere is necessary to reduce the colonization efforts of the technical sphere. To keep the technical sphere and expert culture from dominating all talk there needs to be more space for public talk and for private talk that has potential to become public. This participation should come in the form of different types of people participating, more space for conversations, and providing a means for the private to become public. This section explores scholarly arguments regarding sphere theory development and how to make deliberative space more available for the public and private spheres to further democracy.

Within this section, I address the call for sphere theory expansion in four parts: the need to attain diverse participation within the public sphere, moving past antifeminist arguments (regarding Habermas) to include marginalized groups within the debate, furthering the expression of private ideas to enhance individual empowerment, and moving past the current sphere theory boundaries to promote democracy.

*Diverse Participation is Necessary*

Recently, scholars have challenged Habermas’s definitions of the public sphere. These critics agree that developing public talk is necessary, but they argue that the public sphere must widen in definition to allow for diverse participation. Goodnight (1987) writes, “The public sphere is made available by public space, the locations of common
meetings and discussion where the discourse of community is held open in principle to all who have a say in a matter of common urgency…” (p. 431). The sphere of public influence must include all who can contribute. This allows for a furthering of democracy because more voices help determine what is needed for the good of the community. Hauser (1997) explains that we need to move away from Habermas’s original conception of the public sphere and explore multiple publics. This is necessary to include more voices. If only the coffee shops and salons become places of discourse there are still people excluded from these places. Hauser (1997) said that if we look at the public sphere as “a plurality of publics and public spheres” (p. 278) then more discursive space results and more participants are welcomed. Fraser (1997) believes “subaltern counterpublics” (p. 81) can provide a voice for minority social groups allowing for more widespread public sphere participation. If we include individual interests informed by the private sphere, additional voices become a part of the public arena furthering democracy. Essentially, the critics argue that we cannot think of the public sphere as a single entity because this may miss voices that are able to participate in discourse outside the traditional public spaces. With the internet, a broadened definition of the public arises because the spheres overlap as private discussions become more public. This may allow for increased critical publicity for voices that have not been able to participate in former public sphere spaces.

By looking at all of the potential spaces in which people can become involved through discourse, the possibilities for what constitutes a public sphere widen. This newly defined construct may even blur the lines between each sphere of influence, creating space where the government (or the experts) no longer dominates the public, but private
issues also influence the public. My focus is on exploring those possible blurring lines, especially at the intersection of the private and the technical, where citizens may have new opportunities to assert their democratic will.

*Minority Voices Must be Included*

Second, critics have argued that Habermas is antifeminist, because he did not include in his discussion access to the public sphere for women and property-less men (Benhabib, 1996; Fraser, 1997). His arguments focus on people who had a voice during the eighteenth and nineteenth centuries: white landowning males. Fraser (1989) explains that Habermas (in his original sphere theory development) omits any connection to gender when discussing the public and private spheres. She writes:

Thus, there are some major lacunae in Habermas’s otherwise powerful and sophisticated model of the relations between public and private institutions in classical capitalism. Because his model is blind to the significance and operation of gender, it is bound to miss important features of the arrangements he wants to understand. (p. 127)

By excluding females from the discussion entirely, Habermas’s public/private sphere theory is implicitly masculinist and undervalues talk regarding the complexities of the female standpoint.

While access to actual physical public spaces is critical for developing democracy, access to participate in and influence the talk that happens within the public spaces is also imperative to the democratic process. Most of the topics accepted within the traditional public sphere are framed so men can participate but women cannot. Female and minority topics cannot receive their due attention in the public sphere. This is
important to address because my dissertation focuses on improvement of democracy for women within the private/technical sphere. This democracy has not been easy to attain. Typically, feminine terms and topics are not suitable for conversation within the public sphere. As Griffin (1996) explains:

Topics that enter into the public realm are those that are framed in terms of alienation and mastery rather than connection. War, framed as fighting for one’s position on the hierarchy, or abortion, framed as controlling woman’s body, are seen as suitable topics for public debate. The ability to see inherent connections with others, however, would make war and the need to discuss it in the public sphere irrelevant. (p. 34)

This seemingly ironic argument identifies that a topic is suitable for the public sphere if articulated in terms of a challenge. The dominant terminology is masculine in focus relying on terms of aggression, not in feminine terms of connection. Therefore, the framing of a topic makes it suitable for the public sphere or makes it more fitting within the private. Griffin (1996) argues that this essentialist view keeps men within the public sphere and women and minorities in the private sphere.

The sphere theory issues surrounding biological sex are important as well. The way societies have socially constructed language has had a crystallizing effect to keep female talk within private space. Due to the historical development of language that was constructed around “biological difference” women have had to struggle for recognition within the public sphere (Habermas, 1996, p. 425). Female topics are not seen as important arguments to address outside the home, keeping the female voice limited within the traditional public sphere space. Habermas’s research shows that little effort
was made to understand the female role within the public sphere until recently. This can disadvantage women within newer forms of democracy, such as the internet, because many minority perspectives have been disregarded in the past. Therefore, it is important to study female voices within new mediums of communication to gain a greater sense of the female role in advancing democracy.

While Habermas omits the female position within the public sphere arguments, his definition of the idealized public sphere includes anyone able to express private ideas that unite people into a public. This expands the sphere to welcome more participants (Calhoun, 1996). His more recent work argues that anyone within a collectivity should be a part of the discussion (Habermas, 1989). He writes, “Therefore, competing views about the identity of the sexes and their relation to each other must be open to public discussion” (Habermas, 1996, p. 426). Ryan (1996) argues that Habermas’s definition of the public sphere actually opens up space for women because it “freed politics from the iron grasp of the state” (Ryan, 1996, p. 261), which allowed for a more flexible parameter between the public and private. Habermas (1989) highlights the importance of dialogue to generate change within the public sphere and eventually the technical sphere. He acknowledges that if private issues affect enough people then they are discussed in the public and can promote change within the government and technical spheres. The public sphere (or spheres) researchers need to be aware of the discrepancies regarding access and ability to contribute to the public sentiment.

Expressing Private Ideas Publically, Forwarding Empowerment

Third, issues from the private sphere can become public which can enhance individual empowerment. Spheres are human constructs held in place through hegemonic
structures and therefore can change shape if radical transformations occur. The spheres are “cultural classifications and rhetorical labels” (Fraser, 1997, p. 88) that are structurally bound by societal regulations, which in turn highlight certain topics for discussion within the public sphere and keep other topics private. If the private topics gain enough recognition, they can become public. The public/private/technical sphere boundaries can shift as arguments brought forth within each sphere change through talk, altering the makeup of the spheres. As Goodnight (1982) says, arguments emerge “in concert or in opposition to ongoing activity in the personal, technical, and public spheres” (p. 215) and these relationships can be “revised through argument” (p. 220). Therefore, talk, dialogue and argumentation are necessary elements to help explore the possibilities within the spheres. Without discussion the deterioration of the public sphere would continue. Habermas (1989) explained that people become passive consumers as the media and government take over public space. Challenging the government is imperative for public growth. Goodnight (1997) agrees in writing, “Public discourse is characterized most fundamentally by controversy, not consensus, and so it is shown to give rise to on-going struggles over practice with constitutive stakes” (p. 274). If certain aspects of each sphere are challenged with enough force in the form of discussion and argumentation, the fragile lines that separate the spheres give way and the constructed spheres take on new meaning.

This new meaning does not result without resistance. Olson and Goodnight (1994) explain that past attempts to bridge the spheres (especially the public/private) have often resulted in social unrest. With their analysis of the American fur controversy, they demonstrate that anti-fur advocates “move consumer choice from the private to the public
realm” (p. 270). The notion of morality, usually seen within the private realm, is explored in the anti-fur rhetoric. This shift disrupted capitalistic patterns while creating more space for controversy. This example shows how the private sphere can become a part of the public allowing for change in political activism.

While considerable scholarship has shown the spheres do not blur their boundaries without resistance, other research within the health field has shown that there is possibility for opening the conversations between the public and technical spheres. Brashers and Jackson (1991) argue that members of ACT UP successfully got the technical sphere to listen and make changes regarding HIV/AIDS research. People within the ACT UP movement learned the medical aspects surrounding HIV/AIDS. As a result, the activists taught the doctors and researchers more about the disease. Their efforts demonstrated that “public penetration into the technical sphere is possible” (p. 287). Fabj and Sobnosky (1995) conclude that “when AIDS activists publicize technical and private issues surrounding AIDS, they invigorate the public sphere, creating the necessary conditions for democratic decision-making by an informed public” (p. 176). Fabj and Sobnosky (1995) found that people suffering from AIDS became stronger advocates for their own health as individuals, and they felt confident working “more closely with physicians and sharing the responsibility of charting a treatment for their illness” (p. 176). This is a good example of how, when information exchange occurs between the private and the technical, the lines separating the spheres of influence blur. Boyd (2002) drew similar conclusions from his study of the olestra controversy. While the FDA approved olestra, the success of the product did not last long. The public saw the negative effects of this substance on the body and put pressure on the FDA and health experts to
take the product off the market. The public sphere and technical sphere collided. As Keränen (2005) acknowledges, “science-based controversies produce shared comprehensions of scientific practice that rhetorically construct the very boundaries between the public and the technical spheres in consequential ways . . . ways that reconstitute the borders between the public and the technical” (p. 97). Our lives are directly influenced by the recommendations the technical sphere produces; as such, we must challenge experts to ensure that our best interests are in mind.

These health related research findings are similar to the PCOS case developed in this project. The previous studies show how the public interacts to influence the technical sphere; however, with PCOS the individual’s personal association with the disease influences the technical sphere. The patient helps educate and question the doctors regarding PCOS, and as a result, the technical sphere changes how it responds to the disease. This case focuses on the blurring relationship between the private and the technical sphere. This case is interesting because, while there is little media attention on PCOS, the influence of the internet has allowed the private conversations of women to inform the technical sphere.

We must view the spheres of influence as having many dimensions to move beyond the public/private dichotomy. Goodnight (1997) warns, “To read publics, not in the mix, match, and multiplicity of symbolic activities, but through the frame-frozen binaries of con (dis)sensus is likely to diminish learning from rhetorical models by overdetermining presumption and by masking risks encountered in enactments of public discourses, discussions, and performances” (p 270). He asks scholars to look at the multiple layers developed within the spheres in order to find space for discourse. The
binary view of the “public/private” sphere becomes problematic as it leaves little room to challenge the current definitions of the spheres; widening the vocabulary of what is included in sphere theory is important for opening democratic space. This dissertation challenges the traditional sphere theory vocabulary by exploring how private sphere talk can influence the technical sphere.

Moving Past Current Sphere Boundaries

Fourth, using the term “sphere” to describe the different modes of argumentation is becoming a problematic metaphor for the promotion of democratic practices. Goodnight (1982) explains that:

‘Sphere’ denotes branches of activity—the grounds upon which arguments are built and the authorities to which arguers appeal… The independence of the spheres is protected by a variety of laws protecting privacy and discouraging government intervention in private affairs. (p. 216)

With the arrival of the internet, the boundaries that have kept the private, public and technical separate have blurred. The laws are not clear that govern cyberspace and as a result the private/public/technical divide diminishes. The topics of conversation considered within each sphere of influence are evolving. This set of terms explored by Habermas, when discussing argumentation in the eighteenth century, does not have the same sense of place currently in the technical age where the space metaphor is not necessary. Meyrowitz (1985) explains:

The evolution of media has decreased the significance of physical presence in the experience of people and events… As a result, the physical structures that once
divided our society into many distinct spatial settings for interaction have been greatly reduced in social significance. (p. vii)

Place is no longer grounded in geographical space. The internet and other media influences have allowed first world communities to see space as fluid. A person suffering from PCOS, for example, can talk with her husband about her symptoms in her own home while conversing with an activist group about getting more support for PCOS research and taking notes from the PCOSA website about how to approach her doctor about changing her medication. All three spheres come together in one setting, in the privacy of the home. The spheres collapse in on themselves. Therefore, using the sphere terminology is problematic when forwarding argumentation research.

The “sphere” metaphor, while unsatisfactory, does provide us with a way to talk about argumentation and its boundaries. Crampton (2003) says, “As existing beings we live in, open up, shape, and are shaped by spaces and places. We cannot be in the first place without being in space” (p. 2). We think in terms of space and place. Therefore, it is difficult to get past the metaphor when looking at sphere theory. Crampton (2003) explains that space is problematic yet we continue to use it to describe particular contexts because it is what we know. He argues that we need to rethink the way we map space so that we do not reinstate the same oppressive structures within the online setting. By looking beyond the traditional sphere metaphors, a clearer understanding of how the internet can provide a means for democracy occurs.

Within this dissertation, I rethink how the sphere metaphor operates. While it is impossible to use terminology that is devoid of spatial references, I argue that addressing the sphere metaphor in a new way can open the possibility for viewing the metaphor. As
such, terms including “blurring boundaries,” “overlapping boundaries,” “weaving spheres,” “collapsing boundaries,” and “flowing boundaries” are used in the remainder of this project to show how the spheres blend and blur. Essentially, with the development of the internet, the spheres of argument become devoid of geographical space. As a result, the parameters of each sphere become more permeable.

The term “tension” also occurs in this project to show how there is resistance to the breaking boundaries. The “tension” re-establishes a boundary between the flowing spheres trying to claim ownership over a particular area of discourse. There are always spatial parameters trying to influence the flow between the public/private/technical. The laws that govern, the medical community that oversees the public’s interest, the privacy laws, which affect the private realm, all try to ground the spheres into particular spaces of influence. To overcome this “grounding,” the internet provides a space of flows without place that allows the everyday person to become a part of the public conversation and challenge the experts. This fluid movement is seen through the PCOS case study. The online discourse provides a means to study the sphere fluidity and through the analysis, I assess if the private/public/technical boundaries change.

**Internet Architecture: Democratic Potential**

The internet might become a strong catalyst for this change given the right situation. Therefore, to understand how the internet can change the landscape of sphere theory this section looks at internet architecture through online development and information control.

The vocabulary surrounding our sphere theory is changing and the influence of the internet is driving this shift. Thompson (1990) explains that we cannot have an
idealized public sphere, as Habermas discussed, because contemporary conditions are completely different from the ones in the eighteenth century.

    [T]he development of technical media has dramatically altered the nature of mass communication and the conditions under which it takes place, so much so that the original idea of the public sphere could not simply be reactivated on a new footing. . . . If we are to make sense of these conditions and of the opportunities afforded by them, we must pay closer attention than Habermas does to the nature of technical media and their impact on social and political life. (pp. 119-120)

The new technology creates opportunities for further connection and discussion, if we understand how the media works. Habermas’s writings did allude to technology’s influence on the public sphere as he said newspapers and other forms of mass media increased potential public sphere participants (Peters, 1992). This discussion, however, focused mainly as a means of increasing the public sphere through information dissemination and participants. His writings did not focus on the impact of the medium itself. With the development of the internet, the connection of the public occurs within the privacy of one’s own home. Through cyberspace multiple conversations take place at the same time.

    The internet allows for “all to speak and all to be heard at once” (Jordan, 1999, p. 3). It restructures what a democracy can look like and provides possible spaces to blur the spheres. With the development of the internet, researchers argue that the space of democracy has changed (Friedland, 1996; Papacharissi, 2002; Poster, 1997). Space opens and free speech follows for those with access. According to Dahlberg (2001), “many spaces of discourse exist online that may be seen as extending the public sphere” (p.
The internet blurs the boundaries of the private and the public sphere because topics reserved for the home can now gain attention within a public medium. This blurring effect allows the public space to expand into the private sphere and vice versa. Jones (1997) argued that the internet illustrates Dewey’s definition of a democratic society because it develops a “new public space” generated by many people and it conjoins “traditional mythic narratives of progress with strong modern impulses toward self-fulfillment and personal development” (p. 22). Jones (1997) goes on to note that the internet provides space for political deliberation, idea exchange, and personal expression. All of these challenge the traditional notion of the public sphere because the internet opens the dialogue for many more people than the conventional public sphere. This dialogue challenges the traditionally defined public sphere because it allows marginalized voices to gain acknowledgement.

The internet highlights private issues within a public medium. The media, specifically discussion boards, blogs, instant messaging, social support networks, focuses on everyday life allowing for the infusion of the private into the public world (Hirdman, Kleberg, & Widestedt, 2005). People now have a place to share their experiences (sharing aspects of the lifeworld). Hirdman et al. (2005) write, “The media, starting in their more institutionalized mass production phase (around 1880), have interwoven the private and the public sphere, mixing the intimate with the public” (p. 110). They argue that there has been an even larger focus on the private life with the media (especially the internet) during the later years of this past century as more people gain access to the technology. The scope of the issues discussed on the internet expands what is acceptable talk within the public domain.
Anonymity of the online world provides space for a more bodiless voice. The online setting displaces the face-to-face connection of the public sphere. The voices themselves are important to create space for open talk. Taboo topics become open points of conversation within the realm of the electronic world. Rheingold (2000) contends that the internet “allows for a new kind of culture” (p. xvi). There is space for multiple voices and regulations so the fluidity of democracy and identity gains salience with the development of the internet.

The internet brings about discussion regarding the concepts of public and private because the virtual community allows for anonymity. This anonymous setting generates less fear regarding the discussion of private opinions on public issues (Fernback, 1997). In other words, individuals can participate in a virtual public discourse from the comfort of their own personal space while maintaining physical privacy. While some researchers feel that this lack of connection to the physical self can lead to deception (Jordan, 1999), others argue that this protection of physically staying in the private sphere while participating in the public sphere, is empowering (Benôit-Barne, 1999; Friedland, 1996; Mitra, 2001). Turkle (1995) explains that online space allows for identity discovery. She argues, “Although some people think that representing oneself as other than one is always a deception, many people turn to online life with the intention of playing it precisely this way” (p. 228). The individual representation is fluid within the online public sphere. This fluidity allows more individuals to feel safe when representing their ideas even if the ideologies presented do not always correspond to one’s physical space identity. This fluid movement in online identity can blur the boundaries between the public and the private spheres.
The blurring of the spheres on the internet has increased on-line connections and communities. Rheingold (2000) explains that cyberspace allows social networks to develop through virtual means. These networks provide a place for dialogue, conversation, and community building. This community building often occurs because individuals are dealing with the same problems or share the same interests (Levy, 1998). No longer bound by geographical constraints, individuals can connect based on commonalities.

The connection between the public and private intertwine as the internet develops. The increased number of social networking sites exemplifies this connection. MySpace and Facebook are among the most popular sites. They allow individuals to connect with each other through online dialogue. Individuals post pictures, music, daily journals, etc. to their pages and allow “friends” to comment. The individual profiles often tell a lot about a person’s private life showing an individual’s interests, hobbies, and weekend activities. These websites have caused a blending between the public and private space. As such, warnings have been issued to individuals looking for employment or college opportunities. It is legal for potential employers and admissions representatives to use “private” information from networking sites to gain more information about a perspective employee/student (Finder, 2006). Many people are upset that their online “personal space” might be used against them. This example shows that the line between public and private does not have strict boundaries within cyberspace. The internet provides a new layer to the sphere conversations and challenges the private/public boundaries.

The sphere boundaries are evolving. In the digital age where information is readily available and easily accessible, the definitions of private and public are not as
rigid. In fact, this new technology makes the traditional definitions of the spheres problematic. It creates new space for public issues distinct from the traditional power structures. The internet seems to provide space to further wrestle with the notions of the private sphere gaining power. Dewey (1927) explained that communication and inquiry create the foundation for a democratic society, which allows for group discussion. The internet spreads out the possibilities for discussion because there is not just one individual regulating the conversations that take place within the cyber world, thus allowing the private conversations to gain acknowledgement within the newly found public sphere. Mitra (2001) argues that cyberspace provides space for many voices because the internet is not bound by specific organizational structures; it allows for networking opportunities, is not bound by physical space, has infinite airtime, and promotes a culmination of voices from various speakers instead of only emanating from corporate entities. The internet breaks through the walls of many physical structures and leaves room for new opportunities.

Internet Promotes Democratic Space

The tension among the private, public, and the technical sphere need reconfiguration allowing individuals to reorder the expert culture. The internet has the capability to assist in this reordering but we must address issues of control to see how the internet can become more of a democratic space. As I pointed out earlier in this chapter, Habermas (1987) explains that experts colonize the lifeworld. The everyday is no longer a part of the lifeworld as “formally organized domains” control this space (Habermas, 1987, p. 327). The consequence is a partial professionalization of the lifeworld, which results in a greater distance between expert culture and the broader public.
The internet allows for this reordering, at least within certain spaces. The reason for this shift is that “computers have so thoroughly penetrated most spheres of life (particularly, but not exclusively, in advanced societies) that cyberspace overlaps with, and indeed is part of, the space of the physical world” (Saco, 2002, pp. 170-171). As this computer infiltration takes place, old definitions and boundaries regarding the public/private/technical spheres no longer apply. Who has control shifts as each sphere influences the other. The melding of the off-line and on-line self make it difficult to keep the private life muted and the public life within the conversation of the masses. The result, knowledge is shared between individuals in association with all three spheres blurring the sphere distinctions and increasing personal control.

Lowrey and Anderson (2006) explain that professionals can no longer control the knowledge available and expert authority is challenged as a result. This emergent technology allows scholars to think about the sphere categories in new ways. The new media technologies work to demystify the expert/technical sphere. Weinberger (2008) explains:

Not only can we find what we need faster, but traditional authorities cannot maintain themselves by insisting that we have to go to them. . . . It [the internet] is changing how we think the world itself is organized and—perhaps more important—who we think has the authority to tell us so. (p. 23)

In other words, the reliance on the technical sphere is decreasing. Scholars must acknowledge how the private and technical spheres may shift through these mediated conversations. My dissertation allows a glance into these shifting sphere spaces and
provides insight into how women with PCOS talk about their illness to create discussion that permeates the technical sphere.

Individuals gain personal identity and control, lessening the technical sphere power, through computer knowledge. “For the many working people whose autonomy is routinely challenged by the constraints of large organizations or the vagaries of the market, the spread of sophisticated computers holds the promise of gaining in personal control” (Clement, 1996, 383). Individuals feel that they can participate within societal discussions and get their questions answered through online means. People then start to “participate as equals in decisions about affairs that affect them” (Clement, 1996, p. 385). This means that the technical sphere does not have complete control over terminology and jargon that the sphere once had. Individuals have the means to “surf the web” to find information about the technical terms and decrease the mystery surrounding the technical sphere.

Internet access is increasing for individuals, which opens the space for a more democratic and less expert dominated culture. Expression of individual viewpoints may be recognized within the public space of the internet, providing focus on public opinion over the expert. The lack of structure on the internet allows anyone who can view the Net to have access to “the world’s cultural riches” (Stallabrass, 1995, p. 22). This includes the language that surrounds the technical spheres. People gain access to explore the different expert worlds from medicine to mechanics and the average individual gains access to the technical sphere as a result. Ess (1994) explains that individuals should partake in expert information and challenge the experts on any questionable information. He views
Habermas’s discourse ethics in cyberspace as a means to allow discussion regarding any topic:

1. Every subject with the competence to speak and act is allowed to take part in a discourse.
2a. Everyone is allowed to question any assertion whatever.
2b. Everyone is allowed to introduce any assertion whatever into the discourse.
2c. Everyone is allowed to express his attitudes, desires, and needs.
3. No speaker may be prevented, by internal or external coercion, from exercising his rights as laid down in (1) and (2). (p. 243)

These rules, according to Ess (1994), provide a more democratic and less expert dominated form of communication that is “emancipatory and non-sexist” (p. 252). The ability to question the prevailing truths and argue for a different perspective gains strength. The expert culture then changes through the influence of the layperson.

The internet is still developing. It provides digital space for democracy within all three spheres. The internet allows for structural transformation, given that actual space does not limit this medium because it is contained in the virtual. As such, it is up to the individuals that choose, and are able, to participate through the internet to develop its “architecture.” This new architecture can result in a new form of democracy through opening the potential for deliberation. Dahlberg (2001) explains that deliberation “promotes the internet as the means for an expansion of the public sphere of rational-critical citizen discourse—discourse autonomous from state and corporate power through which public opinion may be formed that can hold official decision makers accountable” (p. 616). These deliberations occur on the internet that are outside of governmental
control and expert control, which can promote ideals or policy that people in official capacity should acknowledge. The internet provides space for collective voices that can change political outcomes, influence expert opinions, and enhance one’s personal life all within the same medium.

They key to this democracy however is not in the medium itself but in the people who choose to participate. Dahlberg (2001) explains, “The public sphere will not be extended merely through the diffusion of a new technological artifact.” “People,” he continues, “must be drawn into rational-critical discourse before new technologies can be successfully employed to extend the public sphere” (p. 630). The people behind the technology develop how the internet operates as a space for democratic discourse.

**Potential Drawbacks**

There still are limitations to online possibilities. As explained previously, the internet can provide for those who have access to the technology. Without this access, marginalized voices are still muted. McChesney (1996) argues that access and computer literacy are barriers to the internet that limit its democratizing potential. If one is intimidated by the language of the computer or overwhelmed by the vast amount of knowledge available online, the internet then becomes a mechanism for intimidation rather than participation. Papacharissi (2002) identifies three barriers that accompany this new public space. He says that the lack of access, the fragmented nature of cyberspace, and the tendency to recreate capitalistic patterns online limit internet potential from becoming a full public sphere. When an individual only receives certain aspects or snippets of information from the internet the dialogues online might not forward a cohesive public space. As Sunstein (2001) explains, the internet can create information
fragmentation because of the selection process. Even if an individual has access, each user picks and chooses what to read, so, “...many people are most likely hearing more and louder echoes of their own voices” (p. 60). This again can limit the empowering effect of cyberspace. If people do not have access or have to pay for services there is limited information gained which stunts the potential of the internet as a public sphere.

The same dominant structures seem to find their way into many aspects of the public sphere. When Hill and Hughes (1998) researched Usenet and AOL political groups online, they found that the political sphere divided in a way that mirrored traditional politics where even though the liberals were the majority, conservatives dominated discourse. Hindman (2009) explains, “Because of the infrastructure of the internet, then, not all choices are equal. Some sites consistently rise to the top of Yahoo!’s and Google’s search results; some sites never get indexed by search engines at all” (p. 15). There is still a hierarchy online where certain information is privileged. Therefore, while it is encouraging to note that people are having political discussions online, the political public sphere seems to regulate itself online in organizational patterns similar to off-line communities. As Stallabrass (1995) warns, “This wondrous but specious technology threatens to act as another curtain between those who consume it and the condition of the world: as the poor are excused from cyberspace, and will appear on it only as objects, never as subjects with their own voices” (p.32). There is negative potential of the internet to exploit the poor without acknowledging their voices. The off-line dominant structures have started to colonize the internet, much as the government and technical spheres colonized the lifeworld years ago. We could fall back into the same
hierarchy if we are not careful. Consequently, it is imperative to look at possible cases that provide an antithesis to the traditional hierarchy and promote minority participation.

The PCOS Success Story

The sphere theory history and internet discussion developed in this chapter allows us to see how the concept of democracy may change through the internet. The open space provides a means for many people to speak more freely than before and may shift how we view democracy theory. This dissertation explores one such case to see what type of talk empowers a community and blurs the sphere boundaries. The PCOS case study provides a good example to explore sphere theory. Initially, this disease struggled to gain attention within the private sphere. As more people came forward with their illness stories on-line, the disorder started to gain attention. Group interest allowed private individuals to come together for support to change the way the technical sphere addressed this disease. Further explanation regarding the PCOS case study, women’s health, and the internet influence on the medical field follows in the next chapter.
References


CHAPTER THREE:

Political History of Women’s Health, and Online Resources

This chapter focuses on how gender, in relation to health issues, influences sphere theory. Specifically, I look at how female liberation can change the medical/technical sphere. Liberation, in this instance, is the notion that women gain control over their own bodies and vocalize their medical concerns to their doctors. Women feel empowered to speak about their ailments and recognize that their experience is critical in helping the experts determine a diagnosis. This liberation helps to democratize doctor-patient interactions as women are empowered to take control of their own bodies. Ruzek (1978) explains that the women’s health movement was “a challenge to professional authority” (p. 1). Women, during the late 1960’s, started to question the “traditional authoritarian medical-professional model” and this dissatisfaction encouraged women of all races to urge for health liberation (Ruzek,1978, p. 9). While I understand that women’s liberation and the health movement are more complex than seeking individual health liberation, this study focuses on women gaining personal efficacy to help blur the sphere boundaries. As Ratcliff (2002) explains:

Moving out of a passive interactional role with a doctor may require that women become more informed…. To be effective with such information, women need to enter the doctor’s office with specific questions in mind and resolve to get them answered…. Active patients are still not the status quo. (p. 36)

Liberation is seen when women become self-advocates and active patients. This liberation is slow in developing, and only recently has it influenced how women interact with the technical sphere. This dissertation explores how one group of women has gained
an understanding of their disease and has fought for control of their bodies. The online support groups for PCOS act as a modern consciousness-raising group that provides support for women’s liberation in health care. This case study embodies multiple themes of historical female liberation struggles. The challenges these women face replicate the previous fights for female liberation and empowerment.

In this chapter, I start with a detailed description of PCOS as a representative anecdote. This explanation provides a framework for looking at women’s health liberation from the sphere theory perspective. After the PCOS case study is set-up, I discuss health discourse and doctor/patient relationships. This explanation of health is necessary to understand how the PCOS case illustrates socially constructed concepts of medicine. This case negotiates the private and technical sphere interactions within doctor/patient conversations. I argue that exploring how the private and technical spheres discuss health discourse provides grounding for sphere theory research within health care. Next, I give a brief historical overview of how women struggled to gain access within the medical framework. This section provides a look at women’s struggle for medical/health liberation. Finally, I explore how online medical information has influenced women’s access to the technical sphere. With the help of support group communities, women have become knowledgeable about their health conditions. As a result, women are able to feel confident about asking doctors questions about their health and thus enhancing their own medical care. This chapter tells a story of how online access has transformed the female health liberation struggle by opening space for female voices to influence the technical sphere.
PCOS

Support groups often move private issues into public consciousness. They do so by garnering further support and understanding from people outside the support group and challenging the expert audience. In other words, the connection among individuals can create new information about a particular situation, which may change the framing of the issue in the private and technical spheres.

To explore shifts between the public/private/technical sphere boundaries, we need a challenging case with which to think. PCOS or Polycystic Ovarian Syndrome is just such a case. PCOS issues are both private and public. Until recently, PCOS garnered little media attention. PCOS did not emerge from the private sphere until the mid-1990s. Christine Gray DeZarn (2003) began to research her symptoms because she was suffering from an unexplainable health condition. She found that there was little information in journals and books. She turned to the internet for answers and there found a newsgroup called alt.infertility. These women all seemed to respond in similar ways when talking about their health. The women had irregular menstrual cycles and acne; many women had hair growth on their faces and were obese. In 1995, DeZarn started an on-line support group for women who experienced similar symptoms. The result was the Polycystic Ovarian Syndrome Association. Here women could participate in consciousness-raising efforts and generate public interest in the disease (PCOSA, 2007).

There remains much unknown about PCOS within the medical community in part because women are unsure about how to talk about their situations. It is difficult for the private sphere, in this instance a person’s experience with PCOS, to gain understanding from the technical sphere, or understanding from the doctor, especially when different
vocabularies are used. Laypeople and doctors speak a different language. Werner and Malterud (2003) have identified women who were “met with skepticism and lack of comprehension, they felt rejected [and] ignored” by the medical community (p. 1409). As a result, these women struggled to gain legitimacy for their health experiences. Doctors tend to deal with the physical symptoms separately instead of looking at the endocrine/hormonal balance of an individual. Both elements, as well as emotional and mental health variables, are necessary to understand and effectively treat PCOS. Christine Craggs-Hinton and Dr. Adam Balen (2004) explain:

Many doctors are not sufficiently enlightened about it [PCOS] to be able to make a diagnosis readily. It seems that this unfortunate fact is often compounded by women failing to describe all their symptoms to their doctor. (p. 1)

The result is often a lack of biomedical legitimacy (Barker, 2002). As Japp and Japp (2005) state, “Without medical acceptance of the validity of the illness, social, legal, and economic acceptance is difficult if not impossible, leading sufferers to experience social stigma, devaluation, and economic hardships” (p. 108). If a disease does not have a medical label, the identity of the illness and the validity of the individual’s experience are often questioned. This lack of biomedical legitimacy within the technical sphere results in frustration and self-doubt within the private sphere (Barker, 2002). The voices behind the illness doubt their experience and more health complications may ensue. According to Mahoney (2001):

In the absence of a specific etiological explanation, it becomes apparent how substantial a role normative, or value-laden, influences play in defining the
disease… In the wake of this century’s exceptional scientific and technological advances, the definition of disease, and the extent to which societal values play a role in the defining process, have become hotly debated topics. (p. 577)

The issues surrounding disease and illness are value laden because the medical community attends to certain categories of illness and not others. The medical establishment is a political field that selects certain health conditions to support financially over others.

Cyberspace has provided a more democratic space for discussion of PCOS. As a result, the disease has started garnering public attention. This media attention only happened after women told their stories to one another, formed grass-roots organizations, and took their message to the public. They have gained some recognition by petitioning the United States Department of Health and Human Services, Office of Disease Prevention and Health Promotion, to include PCOS on the Healthfinder.gov website in 2007 (Lucius, 2007). This website is a government controlled site that provides accurate and reliable health information, and it was listed as “one of the Medical Library Association’s ‘Top Ten’ most useful websites” (Lucius, 2007, para. 1). The government has now acknowledged this syndrome, which affects around seven million women in the United States alone (Medling, 2007). In October 2007, the Polycystic Ovarian Syndrome Association developed a newsletter. PCOSA Today is sponsored by Insulite Laboratories, a medical forerunner in developing medication to reduce insulin resistance (PCOSA, 2009). Advocates have even rallied support for identifying September as “National PCOS Awareness month” (Medling, 2007, para. 2). These efforts to direct public attention to PCOS are gaining ground and providing legitimacy for the disorder.
The PCOS Awareness Campaign is bringing policy issues to public consciousness and asking American citizens to sign petitions urging the House and Senate to provide funding for community outreach (Project PCOS, 2007). Additionally, television shows such as “Mystery Diagnosis” and “Jon and Kate plus Eight” are also focusing public attention on the disease. *Discovery Health* channel’s series, “Mystery Diagnosis,” covered Ashley Tabeling’s story during its first season in 2005 (Howard, 2005). Ashley suffered from a mysterious female hormonal disorder and was not diagnosed with PCOS until her late twenties. Kate Gosslin of *TLC’s “Jon and Kate plus Eight”* talks about her struggles with PCOS in her 2008 book *Multiple Blessings*. She explains how her struggles lead to fertility treatments resulting in twins and sextuplets (Gosslin, Gosslin, & Carson, 2008). More than thirty books discussing PCOS have been published since the year 2000 (Amazon, 2009), creating a slight shift in the public’s view of PCOS, as the disease is becoming more prevalent in the everyday lexicon it gains legitimacy as a public health concern. Creating a more informed public that shifts the doctor-patient relationship and alters the private/technical sphere interaction.

Once DeZarn started the PCOSA website, other women wanted to help get the technical sphere to recognize the disease so they too started communicating online and developed different online support groups. Two women with PCOS, Colette Harris and Theresa Cheung (2008), even took the language of the medical community and created a handbook about PCOS to help patients gain control of their medical experience and their health. Harris and Cheung (2008) state, “If you’ve ever sought medical help, and been made to feel you’re fussing about nothing, or that you should just take the Pill, go away and come back for more drug treatment when you want to get pregnant, this book’s for
you” (p. ix). The women use medical language to help converse with the technical sphere. The building up of lay knowledge influences the medical field. This handbook has become the ultimate resource, which even the medical community references (PCOSA, 2009). PCOS is an interesting case because it shows that doctors can gain knowledge about a disease from the people who experience it. The technical sphere goes to the private individual for consultation. This case redirects the pattern of influence.

PCOS provides a case study of online democracy. Many scholars are hesitant to make claims about internet democracy, and Dahlberg (2005) warns that democratic ideals are “being undermined by a corporate colonization of cyberspace” (p. 160). The PCOS example, however, provides a contrary case. Without the internet, these women would have difficulty finding each other, organizing support groups, and providing medical knowledge to doctors about their syndrome. The internet afforded these women the ability to communicate their private experiences to others who would listen and offer help.

PCOS serves as a representative anecdote for understanding the tensions and shifts among spheres. As Burke (1969) explains, a representative anecdote is a case that characterizes human motives and helps promote understanding of the larger picture through the case study. The case must “possess simplicity” but also “must be supple and complex enough to be representative of the subject-matter it is designed to calculate” (Burke, 1969, p. 60). The PCOS case fits these criteria because it reveals how private issues can come into public consciousness and challenge the technical sphere’s understanding of health and illness. Blakesley (2002) writes:
For Burke, anecdotes have special significance because even behind complicated theoretical formulations, there are implicit stories about human behavior or motivation that inform them. We can thus see anecdotes as containing the essential ingredients, the gist, of the more complex narratives of experience from which they may be derived. (p. 97)

Because this study centers on women, this analysis explores sphere tensions that influence the female experience. One woman in ten is now believed to have PCOS (“PCOS: A Guide for Teens,” 2009). This syndrome influences 10% of the adult female population. The websites concerned with this disease focus communication on female health and discuss how explaining symptoms and experiences, individuals can achieve self-liberation. PCOS is an ideal representative anecdote because it helps map out the changing terrain of the technical sphere.

**Health Discourse**

*Social Construction of Health*

The topic of health is a good access point for observing the fluidity of sphere theory. As such, a brief look at the connection of health and sphere theory is necessary. “Health” is a social construct that blurs the sphere theory boundaries. The meaning behind health and illness is multifaceted. The many layers allow for multiple interpretations. The many meanings influence individual understanding, public policy, and the way experts deal with medical issues. For example, with the development of the internet, more people have access to health care information and they use this public sphere to find information before making an appointment with a doctor (Tresca, 2009). As a result, doctors have had to alter how they speak about disease to the public and to
their patients. The language surrounding health has changed. More people now understand some of the technical aspects of health and use the technical language when speaking to a doctor about health issues. Health communication is a very important aspect of cultural identity as our perception of self often connects to health. Personal meaning is found through health/illness and can create common bonds between people with similar conditions (Frank, 1995; Kleinman, 1988). When individuals struggle with issues of health, they often do so in the privacy of their own homes, making health and illness naturally a part of the private sphere. Health communication is unique because it “magnifies the tension between our uniqueness and commonality” (Babrow & Mattson, 2003, p. 43). We struggle with our unique set of symptoms but we want to know that we are not alone in our suffering. Therefore, we may seek out others who have a common health condition. Individuals want to make sense of their illness, and looking to others for support can improve personal agency. Individuals find strength and reassurance when they find others with the same condition. Callahan (1993) explains, “Human beings will and must be a burden on one another; the flight from dependency is a flight from humanity” (p. 127). To understand the experience of others, individuals willingly share their own experiences. By listening or “burdening” others, individuals can come to understand their medical experiences more fully. When a community understands each other’s private experience, the health conversations move into the public sphere. The public talk is less restricted and allows individuals to enquire about the care they are receiving. As a result, people may feel empowered to question the technical sphere and garner care that will improve their private lives. These health experiences influence all three spheres in a circular pattern; private health struggles convince individuals to see if
others are out there who feel the same way. This connection to the public can spark media attention about particular health conditions, which allows more people to think about the care they are receiving. As a result, they may question expert care to help improve their personal situations.

For example, as I discussed in chapter two, AIDS and breast cancer activists brought the private experience of these diseases to public notice by promoting drug-trial legislation. As a result, the Food and Drug Administration released six experimental medicines for cancer and six for AIDS (Melcher, 1995). These activists made sense of their disease in the private sphere and then connected with one another bringing issues of AIDS and cancer into the public arena. These activists shared their stories and realized that to make a change in how the public viewed AIDS and breast cancer research they were going to have to challenge the position of experts. These activists made sense of their disease in the private sphere, and created public/political pressure that broke down opposition in the expert medical culture. These non-experts breached the separation between the expert and the layperson. In other words, public advocacy has shifted technical sphere boundaries (Brashers & Jackson, 1991; Melcher, 1995; Olesen, 2006). These examples highlight both the complexity and the increasing permeability of the private, public, and technical boundaries that shape medical discourse. The result is a shift in the ideology supporting each sphere of influence.

*Biomedical Model of Health*

The biomedical model of health has traditionally dominated the health field. Specific symptoms determine the labels given to health and illness issues. As Birke (2002) states, “We in Western culture usually invoke images drawn from science” (p.
We label diseases based on verifiable bodily symptoms. Although this health model has been subjected to a feminist critique, because more and more women resist being treated as fragmented body parts (Richman, 2000), the biomedical model retains its dominance. Quiet often, instead of looking at an individual holistically, the doctor focuses on people’s body parts to reach a diagnosis rather than really examining the whole individual. As Foucault (1975) explains, the medical examination is a prime example of surveillance. The doctor studies patients; the patients list symptoms and agree to procedures that they often know little about. The body becomes an object of surveillance while patients are supposed to give up their body to the doctor’s control. The result is a reliance on an expert culture that leaves little space for individual health stories or personal resistance. Instead, the body’s diagnosis and treatment become normalized and any bodily experience that falls outside conventional medical labels the doctors will question. Within this questioning, the medical experts may even convince the patient that the concern is a psychological one not physical. Birke (2002) explains:

We know little about how living in culture affects our bodies, partly because we do not ask (or at least we don’t ask below the surface). Just as sociology and feminism have tended to avoid confronting biology, so biomedicine tends to avoid thinking sociologically. (pp. 44-45)

The patient’s history and identity clearly need further consideration than the biomedical model allows, especially when a health concern is not easy to diagnose. When doctors cannot label the disease patients may feel frustration and self-doubt (Barker, 2002), which keeps them from participating fully in doctor visits and lessens their control over health matters.
Medical professionals recognize that the public, lay people have opinions about their health. However, these “ways of knowing” are often seen as “misguided” and are “rarely presented as enhancing understanding about explanations for ill health” (Williams & Popay, 2003, p. 34). The private sphere view of health is neither considered science nor a viable way to understand health conditions. Habermas (1971) analyzes this ideology and asserts that it does not allow different knowledge bases to enter technical discussions and therefore only the experts make valued contributions to debates about scientific and health policies. The result is a further division between the private and technical sphere.

This biomedical model has a strong hold on the medical community, but it is no longer the only orientation to health care (Sharf & Vanderford, 2003). Currently in medical schools, students diagnose illness using a more patient-centered model. Through medical training, students understand the patient’s perspective, which assists in the diagnosis. Sanders (2009) explains:

The patient’s story is often the best place to find that clue [to their condition]. It is the oldest diagnostic tool and as it turns out, it is one of the most reliable as well. Indeed, the great majority of medical diagnoses—anywhere from 70 to 90 percent—are made on the basis of the patient’s story alone. (p. 6)

Conversing with the patient assists the diagnosis and moves the interaction away from a biomedical model focus. Yet, this move of increasing patient influence often encounters resistance from both patients and doctors. As Sanders (2009) explains, “Far too often neither the doctor nor the patient seems to appreciate what the patient has to say in the making of a diagnosis” (p. 6). Doctors train to understand the private stories of patients;
yet, patients and doctors often do not give credence to those stories. Instead, both parties focus on using the biomedical model for answers. While the biomedical model is necessary, we must have diagnostic tools to help confirm and diagnose, the patient story must gain agency to provide a more complete depiction of the medical situation.

*Communal Understanding of Health*

Health and illness occur in the private sphere, which helps define their cultural meaning. The medical community needs to acknowledge that these terms derive from the private sphere. According to Berger and Luckmann (1966), when there is tension between accepted knowledge and one’s personal experience, social construction occurs. Scott (1967) supports this argument by saying that rhetoric is epistemic. Like Berger and Luckmann, Scott (1967) believes that reality is created through the process of communication. People make sense of their situations through communication. That is why health is not a static state of being but a concept negotiated by patient and doctor. When both patients and doctors realize they co-create how illness is perceived, then they can work together in helping patients recover.

Beck et al. (1997) discovered, through an investigation of various women’s health settings, that health care interactions are social constructions shaped by the communication between caregiver and patient. Through verbal and nonverbal interaction, patient and caregiver define health and illness in a given situation. Even if members of the technical sphere have more knowledge about a health condition, a patient’s personal experience is necessary for full understanding of the condition. Conversations must include technical sphere and private sphere connections. In this way, there is a communal understanding of health. Lupton (2003) explains, “Medical knowledge is regarded not as
an incremental progression towards a more refined and better knowledge, but as a series of relative constructions which are dependent upon the socio-historical settings in which they occur and are constantly renegotiated” (p. 12). Therefore, the meaning of health and illness shifts depending on the agent partaking in the conversation. Health as a construct has multiple meanings for patients and doctors. Doctor/patient communication provides an interesting case to consider when looking at how discourse is shifting.

**Doctor/Patient Tensions**

The relationship between doctor and patient is complicated. Despite over forty years of research, Street (2003) concludes, “we still do not know enough to adequately explain how a changing health care landscape is transforming the communicative dynamics of medical consultations” (p. 63). The reason, Street (2003) argues, is that the context of the medical encounter is often ignored in research. This context includes understanding the forces that act upon patients including the information patients bring to the conversation from the private sphere. Recently, the distinctions between these spheres have started to shift.

The changing nature of doctor/patient relationships contributes to the blurring of the traditional spheres. As discussed briefly above, patients and doctors communicate in different languages. Mishler (1984) argues that even though physicians and patients discuss the same symptoms, the “voice of medicine” and the “voice of the lifeworld” understand the situation differently. Doctors are mainly concerned with quantitatively assessing the symptoms while the patients are often more worried about how an illness will affect their private life including family and job (Sharf & Vanderford, 2003). As explained in chapter two, Habermas (1987) explores the colonization of the lifeworld by
the technical sphere. The doctor/patient relationship often exemplifies this colonization. Tensions may arise in the doctor’s office as the patient and doctor converse about disease from different spheres of influence. Physicians prefer the technical sphere of influence instead of the relational sphere (Baur, 2000). Patients speak from the private sphere. Lupton (2003) argues, “Medical views on health, illness, disease, and the body dominate public and private discussions” (p.1). Therefore, the expert is given more authority regarding medical issues. Patients see the doctor as knowledgeable and rely on the doctor for advice and treatment.

The medical expert traditionally has been a key influence in public policy matters concerning health issues not just in patients’ lives. Scherer and Juanillo (2003) write, “Historically, policies and actions related to community health were often decided between government and industry experts” (p. 224). Those in control made the choices for the public, calling the decisions democratic because they were intended to influence the community in a positive way. In terms of medical policy, the control of the expert has in fact short-circuited democratic practices. As the National Research Council (1989) argues, “to remain democratic, a society must find ways to put specialized knowledge into the service of public choice and keep it from becoming the basis of power for an elite” (p. 15). The concern is that the public does not always understand, or want to understand, the doctor’s choices or terminology (Scherer & Juanillo, 2003). The elite nature of the technical sphere restricts access and limits public participation. Patients can take measures to help their community only if they understand technical language and have the opportunity to voice their views.
Often this expert control intimidates patients and keeps them from understanding the vocabulary of medicine. The fear of appearing unintelligent is the number one reason patients are reticent in the doctor’s office (Padwa, 2005). The technical sphere provides information that is meant to supplement the personal sphere knowledge, but it also standardizes the discourse. For example, doctors use specific terms when discussing symptoms with patients; their language is coded similarly with each patient, expressing the standardization of medical practices. The doctor comes to the patient/doctor interaction through a particular perspective. This can be dangerous because individuals expect to receive the best personal advice when in reality a particular technical framework is introduced by the doctor and influences the interaction. Each framework has its limitations. As Foucault (1971) explains, “Every education system is a political means of maintaining or modifying the appropriateness of discourses with the knowledge and power they bring with them” (p. 46). The structures of power maintain certain controls, which selectively include and exclude voices.

The expectations of both doctor and patient must be similar or the interaction will not benefit the patient. Roter and McNeils (2003) explain, “When patient and physician expectations are at odds or when needed change in the relationship cannot be negotiated, the relationship may come to a dysfunctional standstill” (p. 123). A breakdown in communication results when private-sphere experience and technical-sphere conversations are too divergent. Dr. Joseph Caibattoni, a retired internist, found that his patients had a “lack of basic understanding of medical problems that needed to be explained in layman’s terms” (Coupland, 2010, para. 5).
Doctors respond to patients in diverse ways. Patients with higher levels of education are more inclined to ask questions and are more opinionated about doctor visits than patients with less education (Beisecker & Beisecker, 1990; Street et al., 1995). This shows that patients who feel they have agency are more likely to participate in their medical treatment. As Brown et al. (2003) argue, “Although patients may vary in the amount of involvement they wish to have, the research suggests that some level of patient involvement is necessary for patient adherence” (p. 145).

When patients perceive doctors as taking on a “patient-centered” style of communication, where physicians use terms of the lifeworld and explore whole-person issues, common ground develops between doctors and patients, and a more positive patient perception about interactions at the doctor’s office results (Stewart et al., 2000). In sphere theory terms, this means that if the member of the technical sphere uses terminology of the private sphere, the layperson feels more comfortable with the communication. If a patient has agency, then the doctor becomes a co-contributor to enhancing the health of the patient, not the sole power source dictating the treatment plan. As a result, patients feel more in control of their bodies and health.

**Intersection between the Private/Public**

The relationship between patient and doctor is critical to the health of the patient. It also provides a complex look at how the interpersonal becomes public. As Street (2003) explains, “The encounters people have with health care providers—whether doctors, psychologist, shamans, or curanderas—form an important part of human experience” (p. 82). This human experience is understood most significantly at the intersection between interpersonal and public discourse where all three spheres of
influence commune. Health is a complex terrain that people initially deal with privately; the conversation moves to the interpersonal and technical as health concerns discussions occur with friends, co-workers and/or doctors, and it becomes a part of the public domain as more people share their health experiences to promote health awareness and policy changes.

Doctor/patient relationships are not only a species of interpersonal communication but also reside in the realm of public rhetoric. The tensions between the doctor and patient occur not only inside the clinic’s walls but also outside in the public, where mediated conversations continue about health. CNN, for example, airs “Your Health with Dr. Sanjay Gupta.” Commercials are infiltrating the television media that ask patents to take control of their health and check out the resources on WebMD and other internet resources. Many of these resources ask people to visit their website and take an exam to see if their symptoms match the described disease. If there is a match, individuals print out the results and discuss them with the doctor. The interpersonal or private sphere no longer confines the medical aspects of health. This relationship becomes even more complex as people gain more control over their own bodies. Specifically, the struggle for women to move from the private sphere to question the technical has been, and continues to be, an obstacle for liberation.

Women’s Struggle for Technical Sphere Access

Sphere of Influence

The movement from the private to the public sphere was the overarching framework for the women’s movement and feminist research since the 1800’s (Wischermann, 2004). Women achieved suffrage (in the United States) by championing
the assets of the private sphere through acknowledging the moral voice of the female (Banaszak, 1996). During this time, feminists argued that representation of the moral voice should occur when making arguments about public officials. Women claimed that they could help choose candidates who embodied the moral fabric of the nation. The moral private sphere helped gain women the right to vote. The problem was that this argument also kept women’s influence within the private domain. “Ever since the beginning of industrialization, with the separation of home and workplace, American cityscapes have come more and more to resemble maps of the ideology of separate spheres for women and men” (Scharff, 1988, p. 135). Women controlled the private domain within the home and men dominated the public sphere within the work field. These domains were seen as separate spheres of influence with little gender crossover. Such boundaries were a disservice to both men and women, for males did not have a say within the private sphere of the home and women were relegated to the home (Griffin, 1996). As Fraser (1989) explains:

As long as the worker and childrearer roles are constituted as fundamentally incompatible with one another, it will not be possible to universalize either of them to include both genders…. Similarly, as long as the citizen role is defined to encompass death-dealing soldiering but not life-fostering childrearing, as long as it is tied to male-dominated modes of dialogue, then it, too, will remain incapable of including women fully. (p. 129)

This division restricted the space for female talk.

Ryan (1996) documents the ways in which United States women of the nineteenth-century struggled for status in the public sphere. She explains that women had
to gain access through unconventional means including volunteer associations, protest activities, and support groups. Women were even expected to facilitate others’ talk within the private sphere, such as writing all the thank-you notes and letters to the relatives (Kramarae, 1988). This helped to further gender inequality on both sides because men have little control over private domestic issues and women could do little to influence political issues. “Gender inequality,” Rhode (1989) explains, “stemmed less from denial of opportunities available to men than from devaluation of functions and qualities associated with women” (p. 61). Therefore, it is not that women cannot speak in the public sphere; it is that their talk is not fully valued.

Women’s Health

Women historically faced problems when searching for medical care (Nussbaum, Ragan, & Whaley, 2003). While women have made up the bulk of the health service workforce, they have received low pay, and little control (Dreifus, 1977). Overall, medicine has been male-dominated and women have had little say in how the technical sphere surrounding health operates (Morgen, 2002). As exemplified previously, there has been a long-standing gender dichotomy where men are accepted as the public and expert sphere voices and women are viewed as the private sphere, non-expert, childbearing voices. However, brave women have challenged this dichotomy. Women have participated in the profession of health care in the United States since the mid 1800’s, infiltrating the medical profession in small numbers. Rebecca Lee Crumpler, the first African American Woman in the United States to earn her M.D. degree in 1864 and Susan La Flesche Picotte, first American Indian woman in the United States to earn her medical degree in 1889, were both minority women sought to pave the way for other
women seeking to practice medicine (National Library of Medicine, 2008). These strong women and others including scientists, medical college faculty and midwives became a part of this ongoing process to challenge the gender dichotomy (American Medical Association 2004; Epstein, 2010). The results have opened opportunities for women in the medical field but the dichotomy still has a stronghold that women must continue to challenge.

For example, women have struggled to gain control of their own bodies. These problems range from reproductive health issues to mental health problems. Only within the last twenty years have research programs and clinical trials included women (West, 1993). Prior to 1973, male subjects determined the treatment for both males and females. This complicated health care for women because only within the past thirty-five years have women’s health needs been differentiated from those of men. Since female bodies were not studied in research programs or clinical trials, women had limited access to appropriate diagnoses and treatments. In fact, many marginalized individuals, including women, the physically disabled, and non-whites, had restricted access to health care services because they could not fully “contribute to the production and consumption of commodities” (Lupton, 2003, p. 9). In other words, one of the main purposes of the health care system in the United States is to keep people healthy enough to participate productively in the market economy. Until the late 1940’s women had little control in the economy because many women did not work outside of the home. Then once the war was over, women went back home so women’s health needs did not become a priority until women made up a substantial portion of the workforce (Yiftachel et al., 2002). Even
science 1970, when 43 percent of the workforce was female, women have struggled for acknowledgement from the medical technical sphere (Mather, 2010).

Disparity in health care continues. “Inequalities in the social and economic status of men and women disproportionately deprive women and their children of good health” (Levison & Levison, 2001). While this is mainly an economic issue, it should be acknowledged that women who are economically disadvantaged and cannot afford proper health care, tend to communicate less effectively with the medical technical sphere. Unfortunately, even today this disparity is a concern, which women continue to face and resist.

In addition, women often illustrate their health conditions through narratives that discuss emotional situations. Doctors are not fully trained to understand these emotionally based stories and tend “to marginalize contextual issues that contribute to women’s distress” (Borges & Waitzkin, 1995, p. 30). While the health experiences of women are discussed openly within the private sphere, their experiences are often dismissed within the medical field.

Not only have women had a difficult time influencing the medical field, women, up until recently, had little understanding of the unique functions of their own bodies. Male doctors controlled the knowledge about female health (Morgen, 2002). Until the mid 1970’s when women banded together they had little voice about their own health and care, even if they possessed intuitive and family knowledge passed from generation to generation. An early example of women’s desire for accurate information came in 1969 when a collective of eight women gathered in Boston for the first women’s liberation conference. They discussed how their doctors did not help empower them concerning
their health. The women said the doctors were “condescending, paternalistic, judgmental, and non-informative” (Boston Women’s Health Book Collective, 1973, p. 1). The doctors did nothing to help the women understand their bodies but instead controlled the entire health care experience from issues of childbirth to birth control. As a result, the women devoted themselves to a summer project focusing on finding out more about their bodies. The result was a book filled with women’s research papers titled *Women and Their Bodies* (later renamed *Our Bodies, Ourselves*), which has sold millions of copies and helped to change the landscape of female health (Morgen, 2002). This book marked a turning point for women. No longer were women passive consumers of their health. Women started understanding their bodies not just through the eyes of the doctor but through their own eyes. Women learned more about themselves. This move toward knowledge and empowerment inspired more women to ask questions about their bodies, which drew public attention to issues of female health. Women made their doctors take notice of them, and the medical community started thinking about women’s health in a new way. By the late 1970’s, women were becoming co-participants in their health care. These efforts have continued. *Our Bodies Ourselves* is still in print, and from this book countless specialty books have evolved on such subjects as pregnancy, childbirth, minority women’s health, and other female health issues (Morgen, 2002).

Women’s groups have also started generating public support for female health issues. The National Center of Excellence in Women’s Health, SisterSong: Women of Color and Reproductive Justice Collective, and National Women’s Health Network are a few organizations that have made women’s health issues a priority. These organizations are seeking public and governmental support for women’s health care issues. They are
currently working to mobilize and empower women. As the National Center of Excellence in Women’s Health (2010) states, “Until recently, most clinical trials included only men, missing the differences in health risks and outcomes for women. We’re working to improve prevention, treatment and care by understanding these differences among diverse groups of women” (para. 2). The fight for women to have a voice in their health care continues today.

The division between women and the technical sphere of medicine still exists and continues to frustrate women. This frustration has encouraged women to become active agents in their own care. Morgen (2002) writes, “In the past quarter century a revolution has transformed women’s health care. That revolution was sparked not primarily by technological advances, white-coated physicians, or managers of HMO’s. Rather, ordinary women conceived and reinvented history” (p. x). Women took their private lives public to help gain health care access for other women and to gain greater control over their own care. Women essentially blurred this distinction between the private spheres and the public sphere by gaining public recognition for female health (Wischermann, 2004). As Habermas (1996) explains, “Gender identity and gender relations are social constructions that crystallize around biological differences yet vary historically…. Therefore, competing views about the identity of the sexes and their relation to each other must be open to public discussion” (pp. 425-426). The female voice is gaining agency.

**Social Support**

This increase in agency can come in many forms; however, when focused on health issues women often turn to support groups. Often women put the wellbeing of others before their own needs (Kandiyoti, 1998). Through support groups, women are
able to find a community (or multiple communities) that allows them to become introspective and start paying attention to their own needs. This female support process has a long history, even though the focus on health is relatively recent. For instance, women connected with each other through the *Women’s Journal* since 1870 (Morgen, 2002). This publication covered the needs of women focused specifically on the fight for suffrage in the late nineteenth century and early twentieth century. It acted as a support group for women around the country and it “enabled them to form a community of geographically separated suffragists” (Carver, 2008, p. 15). This connection placed the thoughts of women into the public sphere.

These support groups actually helped liberate women. Hughes (1995) explains that support groups allow individuals to feel accepted, provide a safe space to gain agency, and diminish feelings of inadequacy. The support group allows women to understand their own situations more completely. Support groups are multi-faceted as they often promote education, legislation, and consciousness-raising (Kral, 2006).

Such groups often bring sensitive topics from the private sphere into the public through consciousness-raising. Berenice Fisher (2001) explains that consciousness-raising includes increasing individual awareness of “relations between the self and the world through sharing experiences, feelings, and ideas about the needs for and possibilities of liberatory actions” (p. 34). This new awareness allows the shared experiences to educate and empower. People feel connected through the stories they tell. As Pickering (2003) notes, “Feminine rhetoric…embraces inductive reasoning, which begins with a pool of individual examples and ultimately draws generalizations from those individual cases. Recognition of experience as a valid form of evidence challenges
traditional definitions of evidence” (p. 2). A feminine perspective emerges as women share their stories and learn from those experiences. This encounter connects women, which results in a “shared personhood” that builds a culture from female experience (Uchida, 1997, p. 41). Women gain a space in which they feel comfortable communicating and creating a new culture that breaks free from the isolation of the private sphere. This connection is termed consciousness-raising. These shared experiences lead to personal reflection, motivation, and empowerment. MacKinnon (1989) argues:

Women’s situation cannot be truly known for what it is, in the feminist sense, without knowing that it can be other than it is…. As a way of knowing about social conditions, consciousness-raising by contrast shows women their situation in a way that affirms they can act to change it. (p. 101)

This empowerment allows women to realize that the system can change and that they can, for instance, influence their doctors.

Connecting with people helps individuals in general articulate their needs more fully to others. Schmidt et al. (2005) studied couples in need of fertility treatments. Their study focuses on how effectively the couples communicate with one another in a support group. They found that female partners were able to find a way to express themselves to the group and improve their marital communication. Nevertheless, while women are masters of the private domain they still often experience resistance in the public sphere. While this experience has decreased with women entering the work force and public office, a majority of the female population still feels less regarded in the public sphere than in the private. For many women, connecting with others outside of the home can be
intimidating. Through support groups, women find an unthreatening space to talk and by doing so improve their communication skills both outside and inside the home. Specific to women’s health, support group influence has also increased women’s ability to share their story and not let the doctor dominate the patient’s visit. Online support groups have been especially instrumental in empowering women as they prepare to interact with their doctor. Therefore, it is important to explore how the technical sphere is addressed online, and the extent to which such communication contributes to shifting sphere boundaries.

**Medical Online Influences**

*Online Information*

The use of new technology is helping to create a democratic space for health conversations that challenge how doctors talk and respond to patients. The internet provides huge quantities of information about health-related topics and gives people the necessary vocabulary to bring an issue from the private sphere to the technical sphere.

As discussed briefly in chapter one, the development of the internet challenges the technical sphere. If individuals within the lifeworld find out more information about their health needs, then they can feel confident in using the language of the medical sphere to make changes within the public sphere. While the dissemination of health information uses one-way communication models, the internet challenges this notion and forces the health community to become interactive (Grunig & Grunig, 1991). With more knowledge about the differing sphere conversations, ordinary people become more confident about exercising their own health rights. This patient confidence has allowed private health concerns to move into public policy. When people explain personal experiences in terms
of the technical sphere, the results can change the political field. Most often, knowledge about these health matters results from access to online resources.

The internet provides an avenue of translation from technical vocabulary to lay language. As a result, patients are now more informed and have more options regarding their health. In addition, patients can compare their doctor’s advice to the conclusions of other experts online, which creates fruitful expert competition. Importantly, this comparison of various expert opinions happens at home, thus making it part of an individual’s private health experience. In other words, the private sphere can create competition between alternative technical sphere ideas. This situation also complicates the language used within the spheres. Within the privacy of one’s own home, for instance, an individual can gain multiple examples of expert terminology with which to understand the body more fully. The biomedical model is opening up to the “active patient-consumer” model where science and the layperson are making changes to the public sphere (Briggs & Hallin, 2007). Citizens are now participants in health issues and are becoming co-creators of health knowledge.

With the onset of new technologies, the private spheres are gaining legitimacy regarding health matters. Patients now play a more central role in the treatment process because they perceive themselves as understanding their health conditions. This causes an interesting dynamic in the doctor/patient relationship as some doctors comply with the patients’ requests even if the patient diagnosis is not fully accurate in order to keep a satisfied relationship (Sirigatti, 2006). There are also positive results from this new knowledge base as patients also can feel a part of the medical conversation and can participate in their own health (Rainie, 2006).
This new internet knowledge is both empowering and dangerous. This resource can empower the patient to have a voice regarding health care concerns, but it can also detract from the medical diagnosis. In the United States, more than half of all internet users look for health care information online (Rice & Katz, 2006). This growing number of online users can change how doctor/patient interactions occur and will in turn influence medical care. The new public sphere knowledge influences the interpersonal relationships between doctor/patient and may change the control the medical professionals have over the technical sphere. A national random sample of physicians reported that 85% had patients bringing internet information to office visits (Murray et al., 2003). The doctors found that if the information brought in was accurate and relevant then it became beneficial to the relationship. If the information was inaccurate, then it harmed the physician-patient relationship and the health care outcome. As stated previously, physicians would even grant requests of the patient that were not medically warranted in order to preserve physician-patient relationships (Murray et al., 2003). This study shows how the doctor/patient relationship changes with increased access to the internet. Now, both patients and doctors use biomedical information when negotiating health matters. Rice and Katz (2006) utilized Murray’s methodology and conducted a more recent study of 2,000 physicians. They found that doctors perceive the internet as a potential tool to provide information and self-empowerment:

Although physicians remain skeptical of the merits of internet health information, it appears that the internet does indeed have the ability to contribute positively to the patient-physician relationship. This remains an underdeveloped resource, however, as barriers of communication and constraints of time remain.
Technological and service innovations could help create an environment that would enhance patients’ ability to care for their health, and physicians’ ability to play a more effective role in the process. (Rice & Katz, 2006, p. 172)

While access is limited currently, more information is becoming available to many patients. Due to the interactive nature of many on-line sites including photos, animation, audio clips and videos, these “nontext” forms of communication may become more accessible to people with lower health literacy and may actually enhance the possibility of people gaining health access (Bernhardt & Cameron, 2003, p. 596). The use of other forms of communication beyond text can increase the number of people who have access to this technology and access to health information. This sphere negotiation can change how we view democracy within medicine as patients gain more of a voice in determining the way science decides health policies.

Because of this new online public sphere, doctors who use the internet as a means to connect with patients are now more aware of the language they use in discussing health concerns. The words patients choose to use in describing their illnesses influences how the experts answer in on-line settings. If a patient uses more layperson words, the doctor does as well; if the patient uses lots of technical medical terminology, the doctor modifies the language and uses the technical sphere talk (Jucks & Bromme, 2007). While this form of talk modification is not necessarily limited to on-line doctor-patient relationships, the implication is still obvious as the doctors are starting to tailor their messages to the patient to promote understanding in diagnosing. The internet allows doctors to see experiences from the patient’s perspective. As such, the technical and private sphere transform as each party learns more about the other’s position. This newly
evolving private/technical sphere interaction is speeding up the transformation from a paternalistic doctor-patient relationship to a shared decision-making relationship (Baur, 2000; Winker et al., 2000).

This shift may ultimately wear away at the univocal control of the technical sphere by trained experts. Patients who use their researched knowledge about health against their own doctor’s knowledge challenge the technical sphere. The patient uses expert knowledge against expert knowledge. They also use information they gain from fellow patients to challenge the technical sphere knowledge. Therefore, technical sphere knowledge challenges other technical sphere knowledge and is challenged by layperson experience. Lowery and Anderson (2006) found that “the spread of internet-based professional knowledge erodes the ability of professionals to control their knowledge” (p. 125). Their survey of 406 respondents found that online health information might bypass doctors regarding medical information and diagnosing. These findings challenge medical expert authority. With on-line communication increasing, the technical sphere stronghold weakens; therefore, doctors and patients must negotiate health collectively. This way the depersonalized forms of medicine cease and the consumer/patient gain agency (Baur, 2000). The internet is democratizing information, meaning that the technical sphere no longer controls the technical information of the health community (and other communities with experts). Health is becoming a co-constructed experience between doctor and patient.

*Online Support Groups*

Online support groups provide space for people to learn more about their health from a safe online place as they share private information with others. While each
support group is designed to achieve a different purpose, they all focus on helping others. Support groups promote emotional well-being and have increased disease education (Kral, 2006, Sharp, 2000; Shaw, et. al., 2006). Once this education occurs, the group participants move forward to gain recognition within a more traditional public space. “The technology provides a centralized and inexpensive space for information that is crucial to cohesive group actions, affording access to mainstream nodes in the networked public sphere” (Simone, 2006, p. 360). The web provides space for membership and consciousness-raising. Often, once consciousness-raising occurs, individuals within the group gain the confidence to mobilize beyond the online space. They use the language used from the support group to interact with the technical sphere.

Observing internet support groups is significant since individual notions of identity are infused with issues of health. Support groups provide space in which acceptance occurs individually, and problem solving is encouraged. Hughes (1995) explains, “The individuals in a support group do not take on one another’s problems. Although they face similar circumstances, they know that all must solve their own problems in their own way. Helping each other in this way diminishes their own feelings of helplessness and inadequacy” (p. 21). Individuals gain identity through their private struggles by bringing those struggles to the support groups on the internet. They find ways to talk about their private stories, which shape their spheres of influence. Harter, Japp, and Beck (2005) argue, through telling stories about health, personal and relational identities are shaped. It is through the narrative process that our notions of culture form. It is through each other’s lived moments, the “ordinary” culture, that we find connection (Williams, 1958). This connection often comes from cyberspace. Caplan (1995) says we
need to challenge what the elite health institutions define as “normal” regarding psychological issues in order to challenge the culture’s current view. Public knowledge is necessary to achieve cultural change. In other words, to challenge the current systems, individuals must connect with one another and use their individual stories to change both the mental and physical health care systems. According to Dr. Rita Charon (2006):

   New narrative practices are emerging in health care professions… Clinicians have always at least implicitly understood that the most fertile and clinically salient information we derive about patients comes from listening to them talking about their illness. (p. 192)

Charon (2006) supports the argument made earlier that in the recent past doctors resisted their patients’ stories and followed a biomedical model of health in which they only wanted to hear about the patient’s symptoms before rendering a diagnosis. The move to listening to patient stories allows doctors to understand health through their patients’ voices. Through the internet, patients are able to gain clarity concerning their own stories by engaging in dialogue with one another regarding their conditions. This communication allows individuals to share their private stories with the technical sphere, in turn influencing the health care received. This move toward online support is gaining interest and may become even more influential as patients gain personal efficacy and more medical knowledge through the internet. Using online support may liberate the people who use it as they can bring their private stories to the technical sphere and negotiate how the spheres interact.
Women and the Internet

Specifically, women can benefit from the internet as they continue to struggle to gain a voice outside the private sphere. Traditionally, technology is associated with the masculine. As Kramarae (1988) explains, “Technology is usually considered ‘big world’ talk, connected in communication research with the ‘public’ sphere, men, mass media, machines, and market prices. To connect women and technology is to challenge the private/public division present throughout ‘malestream’ communication theorizing” (p. 5). This can be challenging for women since historically, the female voice was not recognized. Herring (1996) looked at a study regarding postings on LINGUIST (the largest online linguistic resource). She found that men contributed more often to discussion of issues and posted comments more often. She said that “…when women do attempt to participate on a more equal basis, they risk being actively censored by the reactions of men who either ignore them or attempt to delegitimize their contributions.” (p. 486). When the sex of the individual was known, some of the same off-line biases infiltrated the online system, keeping women within the private sphere. Shirley and Edwin Ardener (1975) note that women have had trouble articulating their lived experience outside the home because historically men have dominated the formation of language. As a result, when the internet became available to the public, men dominated the online communication by 85 to 90 percent (Kramarae & Kramer, 1995). Women are still struggling to find a voice outside the home.

Within the last decade, this number has shifted dramatically. Women started taking control. Women started using the net as a means of connection while men continued to use the net as a tool to streamline their daily routine, to get news and for
entertainment (Pew internet and American Life Project Report, 2000). Men continue to dominate high-tech groups, but women are closing the gap. Women actually use the internet to receive health information more often than men do. Currently, 52 percent of women who use the web “research doctors and other health professionals online compared with 41 percent of men” (Pew internet, 2008, para. 2). Women are slowly finding space to participate.

The increase in female participation online allows women to feel empowered regarding their health. Through the internet, women have more access to information and are able to connect with others that experience their same health concerns. As a result, women understand their situation more and feel that they can articulate their concerns in the doctor’s office. Women are starting to feel they have a voice and as a result, this liberation infiltrates the technical sphere. Within the doctor’s office, women are starting to take control of their bodies and tell the doctors what they need as patients. This improved patient-physician exchange works to democratize medical encounters.

Female empowered online space is often found in the form of health support groups. Barbara Sharf (1997) found that doctor-patient relationships for women improve through on-line support. She studied breast cancer on-line support groups and found that the female participants exchanged information to enhance patient-provider understanding of breast cancer. The patients felt they understood their cancer more fully by connecting with others online and as a result, they felt they could speak to the doctors about their concerns with more confidence. Sharf (1997) suggests that “computer networks can be used as a forum for doctors and patients to communicate in more collaborative ways, and to gain a better appreciation of one another’s perspectives and priorities” (p. 79). By
finding common ground between patient and physician, the private/technical sphere boundaries blur even further as the two spheres develop understanding. Ratcliff (2002) explains:

Such collaboration of the doctor and the patient is not easy. Both parties to the interaction must participate, and old habits must be changed. The doctor must agree to having the patient participate, inform her sufficiently to make that participation real, and relinquish whatever remaining allegiance he has to concentrating solely on the objective, physical disease. The women’s ‘life world’ needs to be part of the discussion. The women must agree to become informed about her body and her health, be assertive in asking questions, and be willing to participate in making decisions about her health care. (p. 38)

This conscious interaction provides space for female talk and bridges the gap between the layperson and the expert. PCOS is an especially good case to observe because it deals with female sphere of influence as it enriches the way we define the public/private/technical spheres.

The next chapter focuses on how PCOS is a case study for sphere theory development. I observe specific doctor/patient websites to look at the rhetoric behind the websites that influence the private and technical spheres. My rhetorical study will reveal the type of talk necessary to change the boundaries between the private and technical spheres, promoting democratic doctor-patient encounters.
References


CHAPTER FOUR:  

Pentadic Analysis: A Methodological Description

The purpose of this chapter is to explain the methodological approach I utilized in analyzing the PCOS and physician websites. I take on two tasks. First, I explain Kenneth Burke’s dramatistic ratios and their usefulness for explaining sphere tensions. This involves understanding the theory of dramatism, the nature of the pentad, and the ratios that emerge from tensions between pentadic terms. To provide a further understanding of the ratios, I give composite stories of PCOS within the public/private/technical spheres and explain how one particular term, the dominate term, or the affinity term, influences the other aspects of the pentad. This provides an understandable illustration to set up the affinities for PCOS and explains how I looked for the dramatistic elements within the chosen discourse.

Second, I describe the texts I examined, including both patient-driven PCOS discourse and medical discourse appearing on physician-dominated websites. I explored six different sites to gain a full picture of the health conversations that surround this disease. Taken together, these sites featuring patient-to-patient, doctor-to-doctor, and doctor-to-patient discourses provide a complex picture of the shifting boundaries among spheres.

Burke’s Dramatism

In analyzing the private/technical sphere relationship between patient and doctor, I look at the tensions created between the spheres during women’s discussions of PCOS. To observe these discursive tensions, I located sites where doctors and patients discussed issues surrounding PCOS. These sites featured patient narratives and descriptions,
dialogue between PCOS patients, and dialogue between doctors. These discourses capture the human experience behind the syndrome.

I used Kenneth Burke’s dramatistic ratios to map the tensions among the spheres within PCOS discussions. Burke (1969) defines dramatism as “the basic forms of thought which, in accordance with the nature of the world as all men necessarily experience it, are exemplified in the attributing of motives” (p. xv). These motives are what move us to action. It is the feelings we have regarding situations. Our motives are purely human and require cognitive processing. Dramatism allows scholars to look at these motives, identifying what people are doing and why they are doing what they do. This provides a good way to look at sphere theory because it allows a look at the characters and stories that surround medical discourse. Dramatism, Blakesley (2002) explains, “functions grammatically as a means of articulating the relationships among ideas, how words about motives fit together to explain human action” (p. 8). The pentad provides the dramatistic terms that help the critic make sense of the world. By observing the manner in which act, scene, agent, agency, and purpose connect to one another, the critic can expose the “motivational assumptions” behind each sphere of influence. Each part of the pentad examines a different aspect of a given situation. Burke (1969) explains:

In a rounded statement about motives, you must have some word that names the act (names what took place, in thought or deed), and another that names the scene (the background of the act, the situation in which it occurred); also, you must indicate what person or kind of person (agent) performed the act, what means or instruments he used (agency), and the purpose. (p. xv)
The pentad applies equally well to the ordinary talk of everyday life as it does to the coded language of expertise. Pentadic terms “are equally present,” Burke (1969) argues, “in systematically elaborated metaphysical structures, in legal documents, in poetry and fiction, in political and scientific works, in news and in bits of gossip offered at random” (p. xv). “Dramatism,” Japp (1989-1990) elaborates, “situates human experience in the tensions between abstract and particular, situation and strategy, freedom and constraint, familiar and novel, allowing the cultural critic to trace the process by which humans symbolically define and refine those tensions” (p. 10).

These tensions are human in nature and they help define culture and our understanding of being. As such, dramatism becomes an appropriate way to analyze the shifting spheres because it focuses on the tensions within a cultural experience. “As Burke sees it,” Blakesley (2002) writes, “dramatism enables us to see not only the grounds of these interpretations, but to enable alternative ones by forcing categorical expectations to shift and thus generate new ways of seeing” (p. 41). I am able to highlight the shifting spheres by using a pentadic analysis for the PCOS case study. As a result, communication scholars may see medical democracy in a new way.

**Ratios**

By addressing the different elements of the pentad and observing how these elements influence one another through their ratio tensions, a better understanding of the spheres results. First, the pentadic terms are the terms that reveal human motives within a given situation. Burke (1969) recognizes the “act” as the element concerned with questions of what was done. The “scene” provides the background of the act. The “agent” designates the person/people behind the act. “Agency” identifies the means the agent
used in performing the act. “Purpose” is the motivation behind the act. The pentad reveals the perspective from which an audience is encouraged to understand a situation. As Blakesey (2002) explains, “The pentad—Act, Scene, Agent, Agency, Purpose—functions as a form of rhetorical analysis that can help us understand the presence of ambiguity and persuasion in any interpretation that guides action” (p. 42). Looking at the pentad allows us to understand the action of a situation more fully and as such, we can recognize the different points of view to gain insight.

The pentadic ratios, in particular, provide a good way to capture the different points of view. Burke (1969) explains that ratios “are at the very centre of motivational assumptions” (p. 11). A ratio looks at how the different elements of the pentad influence each other. Looking at the connection between the terms allows us to “multiply the perspectives” by which we view each situation (Blakesley, 2002, p. 34). Within his text, Burke explores a couple of ratios (scene-act and scene-agent) to show different viewpoints. For example, when addressing scene-act, Burke (1969) explains that Shakespeare’s Hamlet exemplifies this ratio through the Ghost of old Hamlet speaking to Hamlet. This scene of the play influenced the acts that Hamlet committed. Under this ratio, “one could not deduce the details of the action from the details of the setting” (Burke, 1969, p. 7). The scene of the ghost warning Hamlet of the corruption in the castle influenced how people responded to Hamlet’s acts. Believing that he saw a ghost, Hamlet interacted with others, and these others were convinced that he was going crazy. The ghost scene influenced the entire play, as the royal court did not believe the ghost scene actually happened, which in turn increased tension between Hamlet and others. If
that scene were not a part of the play, the tensions between Hamlet and others would not exist and the entire dramatic climax of the play would change.

Tonn, Endress and Diamond (1993) analyze the scene-agent ratio. They argue that “‘agent’ and ‘scene’ may become blurred in the concept of a community of social identity, which often includes both personal qualities and literal place” (p. 166). When connected to one’s identity, the terms may blend as they create a certain personal image. In their article, Tonn, Endress, and Diamond (1993) analyze a court case in Maine where hunters were accused of killing a woman, Karen Wood, mistaking her for a deer. Karen was gardening in her back yard and the hunters claim that the gloves she was wearing looked like a deer tail. The hunters shot and killed Karen Wood. The hunters were acquitted. In this case, the scene influenced the agent and transformed the agent’s “actions into motion, thereby providing absolution” (Tonn, Endress, and Diamond, 1993, p. 178). In other words, the hunters were Maine born citizens and Karen Wood was a transplant. The community accepts the agent, in this case the hunters, as their actions were typical of Main citizens. They hunt near private land, which is acceptable, as the citizens know to be extra careful during hunting season. The hunters gain absolution because Karen Wood was the one who did not understand the Maine rules. Within the courtroom, Karen Wood was portrayed as a careless individual who did not follow the hunting rules of the Maine community. The Maine natives had more credibility than the outsider Karen Wood did. As a result, the hunting scene rendered an acquittal for the Maine hunters. This example shows that the terms ”agent” and “scene” are interconnected, and by looking at the ratios between the pairs one can see what term has
the most influence in the situation. This can help us understand how certain elements of an experience transform other terms.

Observing the ratios is a good way to examine different points of view within the internet space. Specifically when looking at doctor and patient perspectives, it is important to have a way to observe different viewpoints surrounding the same phenomenon. By looking at the ratios regarding PCOS websites, I show the different points of view regarding this disease and explore how the different spheres discuss this disease.

In analyzing the PCOS websites with Burke’s ratios, I acknowledge the tensions created within the traditional definitions of private/technical spheres. In analyzing the websites, I looked at the five different pentadic terms and identified the ratio connection between each term within each website. Within this analysis, I found many complicated moments within the websites that created tensions between the different pentadic terms. From this tension, I was able to discern the main dominate terms that influenced sphere discussions regarding PCOS. Understanding how the dominant terms and ratios within the spheres shift in the PCOS case provides insight into how sphere boundaries are changing within health communication and may provide information as to how the sphere boundaries are blurring in other areas.

Affinities

Within this discussion, I speak of the different “affinities” that occur connecting a pentadic term to a particular sphere. These affinities are aspects within an event that highlight the essence of the situation. It is akin to Burke’s (1969) notion of the dominant term of the pentad. The term affinity, as I intend to use it for this dissertation, is defined
as an ideological bias toward a particular dominant pentadic term. Each sphere of influence seems to have a particular affinity toward a particular pentad term based on the ratio analysis. In other words, when a ratio analysis is conducted, there is one particular term that influences the others more and seems to keep the event or situation situated within a particular sphere. In the Tonn, Endress and Diamond (1993) example, the scene was the affinity or dominant term that influenced the hunters’ acquittal. I argue that different spheres of influence have an affinity term, which helps differentiate the type of talk that happens within each sphere. As I argue below, technical discourse has an affinity toward agency, private sphere toward agent, and public discourse toward purpose. However, the rise of the internet could complicate these affinities and change the ideological bias toward certain dominant terms. Analysis of this PCOS case study becomes especially important to analyze to see how the internet creates a rich interplay of sphere tensions.

Specifically, Hayden White (1973) speaks of these affinities when discussing historical representations. He argues that history representation happens differently based on the ideological background of the person re-telling the historical story. A liberal person will have a different perspective from a conservative person. As a result, when the histories are told they focus on particular forms of argument and leave out others depending on the author’s ideological perspective. In pentadic terms, this means that the particular ideological influence makes a particular term dominate. For example, Radical histories often tell tragic stories to get people to see the dire need for change. In terms of the pentad, scene is the dominant term or there is an affinity toward scene because no
matter which radical history is told the scene helps influence people toward that particular ideological position. White (1973) writes:

There are, as it were, elective affinities among the various modes that might be used to gain an explanatory affect on the different levels of composition… But, in every case, dialectical tension evolves within the context of a coherent vision or presiding image of the form of the whole historical field. This gives to the individual thinker’s conception of that field the aspect of a self-consistent totality. And this coherence and consistency give to his [her] work its distinctive stylistic attributes. (pp. 29-30)

White (1973) suggests that for different historians there are modes, or ways, of viewing history. The individual historian or “thinker’s” perspective creates tension between the events that actually occurred and the historical representation of those events, which the historian resolves by re-presenting his or her own “coherent vision,” identifiable by his or her distinctive ideology and style of presentation. These affinities help show a particular point of view and identify the “stylistic attributes” of a particular historian. In other words, history is not only made up of facts, but the style and stories of people who retell history. As such, there is a natural bias between the various discursive affinities associated with different methods of interpreting history. For example, military history would have a main affinity toward agency because the process of understanding the strategies needed to win a battle would influence all of the other pentadic terms. An example of agent-based history would be the study of modernist authors, where white, power holding males determined the literary cannon. White (1973) argues that the great philosophers of history wrote against earlier accepted affinities. These great historians’
representations challenged the then current affinities allowing for different representations and ideological perspectives. For this project, while not parallel to White’s research, there is a similar methodological connection. As I look at the current sphere of influence affinities and examine how the internet and the boundary blurring challenge these biases, I am able to assess the formation of changing ideological constructions in health care.

Currently, regarding medical discussions, the private/technical/public spheres have certain affinities. The technical sphere has an affinity with agency. When doctors talk about a patient diagnosis, agency tends to dominate. Diagnostic tests and treatment regimes are a part of medical agency. Doctors want their patients to know what they need to do to improve their health (Chen, 2009). They provide recommendations to assist patients in this process. When doctor/patient communication occurs, the doctor focuses on the treatment protocol. Doctors as agents are less important than the agency that informs doctor decisions because carrying out the standard protocol is more important than the one administering it. Doctors follow what they have learned in diagnosing and treating patients. The biomedical model frames the discussions in the technical sphere and such a model necessarily elevates the objectivity of agency over the subjectivity of agent.

To understand this concept in terms of PCOS, one should think about a story of a woman with PCOS going to the doctor’s office to obtain a diagnosis. Once in the office, the doctor goes through particular diagnostic checks asking the woman about the regularity of her menstrual cycle and the excessive hair growth on her face. The doctor also asks about her weight fluctuation and diet. The doctor looks for multiple diagnostic
clues to arrive at a PCOS diagnosis. The agency becomes the dominant term because every other facet of the situation relies on this term. Any doctor could ask these questions; therefore, the ratio between the agent and the agency shows that the diagnostic tool (the agency) has more importance than the doctor (the agent). The purpose of the encounter is to restore the patient’s health and cure the disease. Yet, this purpose is purely functional. The doctor’s purpose is to remain objective and let the diagnostic tools help determine what is wrong. The physician’s objective diagnostic tools determine disease and health. The scene is the physician’s office which facilitates clinical procedures. The patient becomes an object for study. As Foucault (2003) says, “… the patient is the subject of his disease, that is, he is the case; in the clinic, where one is dealing only with examples, the patient is the accident of his disease, the transitory object that it happens to have seized upon” (p. 59). In other words, the agency or diagnostic procedures influence the patient’s encounter. The acts of patient and doctor are choreographed around the protocols of examination, testing, and treatment. The entire visit centers on the tools the doctor uses to achieve a PCOS diagnosis, therefore making agency the affinity term.

For the private sphere, the affinity is toward agent. In chapter three, I talked about the growing importance of support groups for people dealing with health concerns. People rely on each other for assistance (Frank, 1995). Within the private sphere, individuals rely on other agents in the form of doctor, family, and/or support groups to assist in the recovery process. One’s own experience also influences the private sphere. The personal connection to one’s own health makes the term agent dominant in the private sphere.
By focusing on PCOS in the private sphere, we can clearly see the agent as the affinity term. The woman who went to the doctor to see if she had PCOS needs to find others with her same condition to gain understanding of her situation. She needs support. This support empowers her since women with PCOS feel they can talk with others openly about diet, fertility, doctors and other issues surrounding PCOS. The agent, the woman with PCOS seeks a support group. She posts online, says she has just obtained a PCOS diagnosis, and is scared and confused. She wants any information she can get to help her and her husband decide if trying for a biological child is feasible. She is in control of how much information she receives and shares. The woman can participate as much or as little as she wishes within the private sphere. This drives the pentad because each woman with PCOS, who is a member of the support site, receives information about PCOS and reacts to other agents with PCOS. The tools of medicine, which objectively measure disease within the technical sphere, are less important within the private sphere. Instead, the agent, or in this case each woman with PCOS, represents the dominant term because subjectivity is dominant in this sphere. It is individual perspectives that influence the private sphere ideology. The women with PCOS share emotions, life experiences, and coping strategies within the private sphere. The newly diagnosed PCOS woman is able to identify with others through their sharing of their individual, subjective stories not by their talk about objective symptoms. This sharing allows for unpredictability and lack of standardization in the dialogue exchange between the women with PCOS. There is a free flow of personal stories and emotions. The woman with PCOS feels free in turn to share any frustration and feeling she has regarding PCOS. The support group is a place where she can vent her feelings and gain validation for her thoughts. As such, the woman shares
different aspects of her lifeworld with many different agents, validating her experience and the private sphere. The dominant element is the agent, since the women with PCOS influence what appears on the website, and they influence the purpose of the website. The result is that agent is the dominant term.

The public sphere is more complicated in terms of affinities since media attention focuses on different aspects of health. Often there is a collective agent working to make change at the governmental and institutional levels. In this instance public is defined as a collective agent working to share information with large audiences. In other words, for an issue to become public many people must rally behind the cause. While there are many ways to approach issues of health, within the public sphere, the purpose seems to bring people together in order to enact change. The democratic public is the source of moral grounding. A collective agent occurs in the presence of a moral purpose because we often come together as a group if we share a moral purpose. As discussed briefly in chapter two, Habermas (1970) explains, “the moral realization of a normative order is a function of communicative action” (p. 107). Habermas (1970) suggests that the public and private opinion entwines through having a moral connection or “moral realization”. Only then can action take place. The public must agree on the moral purpose to gain motivation to make a change. The public wants to rally around a common purpose and wants to understand the purpose behind the choices the experts make.

The purpose animates the collective agent. The purpose behind the agent, act and scene generates some type of health change. Toulmin (1950) suggests that moral reasoning informs all logical people. For people to come together in a community, they must “recognize a duty to one another and have a moral code” (Toulmin, 1950, p. 135).
When people have the same moral purpose, “the desires and actions of the members of a community are harmonized” (Toulmin, 1950, p. 136). In order for reasoning to become a collective act, communities, or collective agents must agree on what will improve human satisfaction. If the public feels morally obligated to participate then they become a collective agent. From health care reform to drug policies and AIDS research, the purpose highlights the issue and gets people to respond. In order for the public to acknowledge an issue, ordinary citizens must form a collective to demand institutional change. ACT Up drives this demand for AIDS research, breast cancer activists for medication, and Go Red for Women for heart disease research for women (American Heart Association, 2010; Brashers & Jackson, 1991; Melcher, 1995; Olesen, 2006).

Ultimately, these collective agents, driven by strong moral obligations to improve health research and services, motivate people to support change regarding health care and health care policy (ReachMD, 2009). Without the focus on the purpose, the audience does not understand the push for policy reform. The dominant pentad term in the public sphere is purpose. Until recently, the dominant pentad terms assisted in keeping certain discussions within certain spheres.

For PCOS, the purpose is what brings the topic to the public. For example, the woman who just found out she had PCOS feels that doctors and the public should have more information about this syndrome so that others like her will not have to suffer for so long without knowing what is wrong. As such, the woman looks for activism support. She finds others on the Project PCOS website that want to promote education for all regarding PCOS. The women all share a moral purpose, to help others understand PCOS.
As a result, the woman signs her name to the email petition on the Project PCOS webpage that asks legislators to promote knowledge about PCOS. The petition states:

To: House and Senate Leaders of the United States of America

Dear House and Senate leaders:

...We believe there is insufficient community outreach, health resources, services, providers and other barriers that prevent women and girls with PCOS, (Polycystic Ovary Syndrome) from obtaining necessary diagnosis and treatment of this syndrome. The cost of such inadequacies comes at the expense of the women and girls with PCOS who languish needlessly jeopardizing their health while the healthcare system unfairly remains uneducated and ill-equipped to deal with the complex treatment needs of this population....

We call on Congress to enact legislative proposals that will improve access to essential health services, insurance coverage and educational programs, through promotion of guidelines for proper diagnosis, treatment and care for women and girls with PCOS. There are small steps that can be taken to obtain this goal including; improved coordination of local and state health programs; increasing funding of community programs and health services to support and research PCOS; allowing expansions of federal health entitlement programs; fostering state and local collaboration programs to connect women and girls with PCOS to health services; mandating insurance coverage for women and girls with PCOS and other proposals that seek to avoid a host of adverse outcomes for women and girls with PCOS who are unable to access the proper diagnosis, treatment and educational resources. (Tabeling, 2007, para. 2 & 4)

The point of this petition is to lobby for PCOS legislation, moving PCOS into the public sphere. From the framework of moral reasoning, this is a concern that affects not only women but everyone because the cost of medical coverage influences us all. Additionally, we all have a moral responsibility to help end human suffering. This suffering should create a common interest, or common purpose, to promote change. As Dewey (1927) says:

Then there arise purposes, plans, measures and means, to secure consequences which are liked and eliminate those which are found obnoxious. Thus perception generates a common interest; that is, those affected by the consequences are
perforce concerned in the conduct of all those who along with themselves share in bringing about the results. (pp. 34-35)

The purpose is what connects people and helps bring about practical results that can support a community. The public petition could help women inspire others to sign the petition and legislative action could motivate the medical community and the media to pay more attention to this disease. The purpose is what unites these individuals. The purpose influences the act of the petition and the scene. When media covers PCOS, they talk about how people need more information about the disease. This is the main purpose. The agent is collective so it does not matter if the doctors who support PCOS research, or the women, or both, are fighting for recognition; the purpose of getting more information to more people supersedes the agent. Additionally, the purpose influences the way in which the collective agent conveys the information. With the legislative petition, the purpose becomes disseminating accurate PCOS information to the doctors and the general population. This moral reason would create a common community interest, which Toulmin (1950) discusses, ultimately improving human satisfaction. The result, public PCOS stories promote the moral purpose.

The technical/private/public affinities do not remain dominant without a challenge. While the above composites show stories of how PCOS cases represent the corresponding sphere affinities, these affinity boundaries are not static. Within my analysis, I look at these different dominant terms and examine how people communicate against these affinities. By observing different ratios pertinent to each website’s discourse, a new affinity may emerge or at least a ratio may provide tension enough to
challenge the current dominant term. I argue that the rhetoric of PCOS shifts and changes the cultural understanding of the spheres.

For this dissertation, I looked at discourse between patients and between doctors to see what tensions formed when communicating about PCOS. Once each ratio was established, through the online dialogue, I identified the most influential terms. I then looked to see how each term influenced the sphere affinity and whether there was resistance to that affinity. The next chapter focuses on the analysis of these affinities. Ultimately, this study explores the many ways the affinities disrupt the private/technical sphere boundary.

**PCOS Online Discourse**

Before exploring these tensions fully, a look at the procedures I used to obtain my data for analysis and an explanation of the online PCOS discourse is necessary. First, I explain what online discourse text I included for my analysis and provide a rational for analyzing these texts. Second, I explain why one must look at the discourse from both the patient and doctor perspective. This gives a better understanding of how both the private and technical spheres are operating within this case study. Third, I provide descriptions regarding the patient and doctor websites I used for this analysis.

PCOS online discourse occurs in many forms, from dialogue between members to online newsletter articles. In different ways, the women share their experiences with others in acts of mutual support. One way women explain their illness is through stories. By looking at the PCOS narratives on the websites, we can come to understand the strategies these women use in explaining their health condition. One can also see how online support groups express cultural meaning. Fisher (1984) identifies that humans, or
homo narrans, are storytellers. Stories are used “to give order to human experience and to induce others to dwell in them to establish ways of living in common, in communities in which there is sanction for the story that constitutes one’s life” (Fisher, 1984, p. 6). We can gain cultural meaning from texts by looking at the online stories.

Japp and Japp (2005) write:

For the reader or listener, narratives forge connections to another person and his or her world and reflexively provide insight into one’s own world. If readers share the illness, they find reinforcement and community. If not, they learn how others experience the world of illness, and prepare for the day when they too will need to adjust to an illness of their own or one they love. (pp. 107-108)

Narratives allow individuals to connect with the stories others tell. Through the story’s fidelity, people feel connected to the storyteller and learn from another’s experience. As Frank (1995) explains, “In stories, the teller not only recovers her voice; she becomes a witness to the conditions that rob others of their voices. When any person recovers his voice, many people begin to speak through that story” (pp. xii-xiii). Stories help unite individuals and provide common ground for experience. Therefore, the stories the women and doctors tell are included as discourse within this analysis because it provides the common ground needed to explain a medical situation. However, stories are not the only form of discourse in online communities. I considered any messages that provided rhetorical meaning in my analysis. I observed any messages posted online that were open for public reading from the homepage to the message boards. These messages provided over 3,200 pages of web text for this analysis.
Physician language and dialogue is also important to this analysis because they offer insight into how the technical sphere discusses this disease. The private sphere perspective, in the form of support group talk, is not the only way individuals express PCOS information. Physicians also talk to one another and to patients regarding PCOS. Schneider (1997) explains that looking at both multiple texts from different perspectives increases ideological understanding. Using multiple websites featuring discourse from many perspectives provides a broad look at sphere negotiations.

To understand how this culture evolves and blurs the public/private/technical sphere divide, I examine PCOS internet texts from both the patient and doctor perspective. I selected multiple organizational websites for analysis. I collected data, consisting of the PCOS discourse posted to the website, for over four years. The main PCOS online support groups I analyzed were Polycystic Ovarian Syndrome Association (PCOSA), SoulCyster support group, and Project PCOS. From the doctor’s side, I analyzed American Academy of Family Physicians, Doctors Lounge, and Revolution Health. To understand the substance of each website, I provide a brief description of each below.

I followed ethical procedures in analyzing the online text. I observed the message board discussions on each website, which did not require a membership; therefore, the information was public. I also analyzed the online public PCOS newsletters. When obtaining and analyzing the narratives and text from all of the websites, I followed Sharf’s (1999) ethical guidelines in studying naturally occurring discourse on the net. I first reflected on whether the research would “benefit the group in some way” (p. 26). Second, I introduced myself to the website organizers and explained my purpose. Third, I
asked for the site’s consent to use the narratives posted on the website. Finally, I tried to demonstrate “a respectful sensitivity toward the psychological boundaries, purposes, vulnerabilities” (Sharf, 1999, p. 27) of the individuals behind the shared stories.

**PCOSA**

I analyzed the PCOSA webpage dialogue, stories, and text to see how women navigate the online space. The Polycystic Ovarian Syndrome Association is the oldest PCOS support group and it is dedicated to helping women around the world who have PCOS (PCOSA, 2009). As I explained in chapter three, PCOSA was established by Christine Gray DeZarn in 1997 (Pro, 2000). Christine suffered from PCOS herself but could not find any information about the disease. She states:

> It became clear to me that I would need to take the driver’s seat in attending to my own health care. But I also wanted to help others avoid the frustration I had encountered in my attempts to learn about PCOS. I wanted to help others sit in that driver’s seat as well. (DeZarn, 2003, pp. 2-3)

Within a week, DeZarn had over 200 women signed on to the website to learn more about their condition (Pro, 2000). The site provides support for others. This website gave women a space to talk about their private issues through a public medium.

By reading the narratives recorded on the site, by examining the discussions in the message board archives, and by exploring the online newsletters, the critic has access to materials that document the navigation of public, private, and technical sphere boundaries. There were over 1,300 online narratives reported to the site by 2007. Within the stories, the women explained their experiences to varying degrees providing short paragraphs to pages regarding their personal situations with PCOS. The women
represented 18 countries around the world including Australia, Bangladesh, Canada, England, Greece, India, Ireland, Israel, Italy, Malaysia, Mexico, New Zealand, Philippines, South Africa, Sweden, United Kingdom, United States of America, and Yugoslavia.

*SoulCysters*

This PCOS support group, SoulCysters, has over 37,000 members from across the globe and “is the largest online community for women with PCOS” (SoulCysters, 2009, para. 2). The website allows women diagnosed with PCOS to find space to speak. The website’s motto is “Women with PCOS speak from the heart!” (SoulCysters, 2009, title). The site includes multiple forums that address issues from acne to conception. The purpose of the website is to provide support for those with PCOS. As the website states, “Here, at SoulCysters.com, we also believe that we help ‘each other’. Many of our members have become lifelong friends, helped each other lose weight, and kept up with the birth of our children (yes, you CAN get pregnant with PCOS!” (SoulCyster, 2006, para. 3). The website started in 2000. At first there were only five pages, now it has over fifty pages with numerous links, and a message board with over thirty forums each with 110-32,149 threads, making SoulCyster the largest online PCOS community. The site has been featured in magazines, newspapers, and television programs, including *Redbook*, *Woman’s World*, *Family Doctor*, *USA Today* and *The Oprah Winfrey Show* (SoulCysters, 2009). SoulCysters provides a look at how online communities talk about medical experiences with the expert culture. This provides very recent information that looks at the ways the PCOS community is conversing with one another regarding the medical community.
Project PCOS

The activist website, Project PCOS, began in November of 2006 (Tabeling, 2006). The founders of the site were frustrated with medical professionals because they “lack an understanding of the syndrome” (Harvey et. al., 2007, para. 5). The result was this website. The following mission statement is published on the site:

Project PCOS envisions PCOS being recognized as a significant public health concern. This site aims to invoke, inspire and incite the PCOS Community and its supporters to be vocal proponents in the media, advocacy coalitions, and educational forums, both online and within health related communities. People with PCOS, their families, supporters, the medical community and the general public will all be active participants in this effort. (Project PCOS, 2007, para. 1)

The goals of this organization include obtaining legislative action for better diagnosis and providing comprehensive online resources for better educating others about PCOS. The website’s Board of Directors believes that lack of knowledge has created an urgent need to educate medical professionals who treat women with PCOS. As such, the education of the technical sphere has become a priority of this organization. Though based in New Jersey, this organization is “truly a virtual entity” that works with patients and doctors worldwide (Project PCOS, 2007, para. 6). Within the website, women share their narratives and highlight information regarding PCOS. These women also work to educate those in the technical sphere by providing data regarding PCOS that allows for a new negotiated vocabulary between patient and doctor. They work to shift the private/technical sphere interaction. In analyzing this website, I observed the narratives of the women and organizations that have influenced the PCOS community through
advocacy and support. Additionally, I analyzed the “Getting the Word Out” section to document the website’s move from support group to political activist organization, pushing the boundary between the private and public sphere.

There is not one particular support group or forum that reflects the physician’s perspective regarding PCOS. The doctor organizations cover multiple health topics and few cover PCOS extensively. For the purposes of this study, I analyzed three doctor sites. Each one covers the basics about the disease and provides suggestions regarding health matters for women with PCOS. These sites offer information and advice about PCOS. They also suggest other resources to gain further information regarding the syndrome. On these sites, doctors interact with fellow health professionals and with potential patients.

*American Academy of Family Physicians*

The most comprehensive physician site is the American Academy of Family Physicians website. This site represents “more than 94,600 family physicians, family medicine residents, and medical students nationwide” (“About Us”, 2009, para. 1). The website provides primary and secondary research information concerning PCOS and offers physicians a patient-centered model of medicine to follow. Over 45 documents focused on PCOS research. “It is a way for a physician-led medical practice, chosen by the patient, to integrate health care services for that patient who confronts a complex and confusing health care system” (“Practice Management,” 2009, para. 4). This website provides a more patient-centered model that allows for a comprehensive look at the language that connects doctors and patients. In my analysis, I examine both the PCOS information and the patient-centered model discussions.
Doctors Lounge

Two physicians developed this website, Doctor’s Lounge, in 2001. The website is updated daily. The site connects doctors, nurses, and health care professionals through discussion boards. The website members have “written over 10,000 articles and answered over 30,000 medical questions” (“Welcome to Doctors Lounge,” 2009, para. 1). The website includes medical content, doctor’s forums, and educational tools with the goal of providing “humanitarian service to patients from around the world” (Fouad, 2009, para. 4). The focus of this website is to help medical professionals, students, and often patients, find medical support online to enhance “rather than replace the doctor-patient relationship” (Fouad, 2009, para. 3). When analyzing the text on this website, I followed the discussion boards relating to PCOS and I analyzed the PCOS medical information. There were 286 documents on the site explaining different concerns regarding PCOS.

Revolution Health

The website, Revolution Health, has fast become a “powerhouse in the online health space” (“About Revolution Health,” 2009, para. 2) since it merged with Everyday Health, Inc. on October 3, 2008. It is now the leading “consumer-centric health company” (“About Revolution Health,” 2009, para. 1). The purpose of the website is to “transform how people approach their overall health and wellness. By putting individuals at the center of their own health care, Revolution Health allows them to make informed choices and offers more convenience and control over their individual health care decisions” (“About Revolution Health,” 2009, para. 1). The website tailors its information mainly to women and other caregivers. An eight person executive board with business degrees controls the website. Prestigious medical organizations such as the
Mayo Clinic Health Information and the Cleveland Clinic control the website. Numerous non-profit organizations also provide support for this website. Therefore, many medical professionals provide information to the website. Revolution Health has over 150 tools that a visitor can use to gain health information including community blogs, live forums, a health video library, expert led groups that can help people reach personal goals such as losing weight and quitting smoking, and news information about a multitude of health topics. Revolution Health currently has 878 responses, articles, and forum discussions that focus on PCOS. I explored each of these discourses in my analysis. All of the information was part of the public domain and I did not need a membership to access it.

These different websites constitute the various voices within the public/private/technical spheres of health communication. They provide a window on the changing relationship between doctors and patients in the internet age. These website spaces provide rich data sets required to understand the tensions between the spheres and explore the blurring of boundaries which promise to give the layperson a new self-efficacy.

The next chapter identifies how the pentadic affinities, developed through analyzing PCOS doctor and patient discourse, enhance argumentation theory. Within this chapter, I discuss the emerging space of flows that occur within the private/technical spheres due to online communication. I specifically analyze the ratios that occur in the support group websites and the doctor websites. The analysis shows that boundary shifting occurs in the pentadic terms that surround the affinities within both the private and technical spheres. The result allows for a more democratic medical encounter.
References


CHAPTER FIVE:

Understanding Private/Technical Sphere Boundary Shifts:

Analysis of Polycystic Ovarian Syndrome Websites

By observing the six websites, with over 3,200 documents discussing PCOS, I argue that the private sphere does influence the technical sphere in this case study. The result is a blending of the spheres when discussing women’s health. There were eight main themes relating to sphere theory conversations regarding the PCOS condition. The private sphere and the technical sphere rely on the influence of each other. The result is greater public sphere knowledge that comes from both technical and private spheres. For example, a doctor will describe the symptoms of PCOS and then use personal patient stories to help anyone understand the disorder more fully and to help patients cope with the mental anguish that accompanies such a diagnosis. The technical and the private spheres often work together informing the public.

In this chapter, I explain these private/technical sphere themes in detail. Each theme shows how the private-technical sphere boundary is a flowing entity that, at least through online communication, allows the private sphere to permeate the technical sphere and provide space for the lay voice. The current sphere affinities strengthen even as different ratios permeate the spheres. In chapter four I argued that the private sphere affinity was toward agent and the technical sphere affinity toward agency, this case study ratio analysis highlights the importance of agency within the private sphere and purpose within the technical. The current affinities of each sphere (agent in the private sphere and agency in the technical) remain but “agency” in the private and “purpose” within the technical both become critical ratios to understanding how the particular sphere affinities
remain within online space. What results from these ratios is a weaving together of the private/technical spheres, which creates a more democratic space for discourse. The themes presented in this paper articulate these shifting boundaries and exemplify the fluidity of the spheres.

**From the Private to the Technical Sphere**

The three support/advocate groups analyzed shared many features. The support moved in a pattern from welcoming new members to providing information then eventually asking the members to become self-advocates and advocates for others. The discourse starts with personal testimony then moves to questioning the medical community; finally, the conversation influences people to empower themselves. Initially, the women with PCOS spend a lot of time talking about their life circumstances. This helps provide other support group members an understanding of each woman’s personal struggles with PCOS. A typical post looks like this:

Imagine... you know there is something wrong with your body, however, convincing your physician is a war in its own. That was my life for 5 years, while trying to have a baby with no success [sic]. My physician said there was nothing wrong with me, and actually scolded me for not trusting his word. That's when I came across an article in a magazine. You know those little one paragraph inserts in those woman magazines?.. there was my answer in black and white!.. needless to say, after a simple ultrasound from my doctor (who claimed it was all in my head), it was confirmed that I indeed had PCOS! After firing him, I found a great doctor who has been helping me deal with the symptoms that come along with PCOS, and I am glad to say, I have 2 children… don't get me wrong I did endure
a long battle with infertility, and did take a lot of medication...but it can be done...you can have a child with PCOS. Of course, the hair you grow with PCOS can make you a great candidate[sic] for the bearded lady in the local circus, but hey, face it..(no pun intended), it won't kill you. I have been on an emotional roller coaster with this blasted syndrome... but I have realized all I can do is share my story, and fight for a cure. My advice - listen to your body, talk to your physician and use the internet!!!! (Jenny, 2006, para. 71)

The private/interpersonal conversation weaves in with the technical sphere questioning which eventually results in a call to action for educating others about PCOS. Online support groups help promote medical democracy by encouraging patient participation. The themes, to some extent, follow the structure of Jenny’s post. They show authenticity, welcome members, work to humanize the technical sphere, and promote PCOS advocacy.

At first, when I observed the PCOS support group/advocate group websites the initial images stuck me. Women were shown working together, standing with family members and feeling connected to the online community (PCOSA, 2009; SoulCysters, 2010b). There were also images of women standing, smiling, alone expressing that they can take personal control (PCOSA, 2009; ProjectPCOS, 2007a; SoulCysters, 2010b). The images seemed to express welcoming environments for women. This comforting climate continues through the language used on the website. The women participate in seemingly open and authentic communication.

Agent Vulnerability

At first glance, each of the websites shows the authenticity of the private sphere within the public realm of the internet. The women not only post their user names but
also identify other very personal characteristics about their relationships and health.

Expression of this vulnerable information occurs in many forms. The women present their identity within each post. Starting from the first time the women dialogue on the forum sites, they share very personal information. For example:

mammah: Okay, so, I’m new here. Well, duh, right? [She is posting on the new member forum] Anyway, for the last 2-3 weeks I have felt that something just “wasn’t right” so, went to the dr. He said, “I think you may have PCOS.”… The emotional kink in all of this is the infertility issue b/c my boyfriend and I have great plans for marriage and family but, at 36 that clock is ticking so loudly that sometimes I can’t hear anything else. That’s me in a nutshell: Crampy, moody, emotional, weepy, and hopeful. Thanks for letting me share. (mammah, 2010, para. 1)

The women express who they are and explain the situation they are in right away to help show the other members that they suffer from a similar health story.

Within the profile section of the message, the women share what they want the other observers to know about them personally. Each post centers on PCOS and explains a woman’s medical history, marital status, and pregnancy status among other information. For example:

Angelbear: MY NAME IS TRICIA MY HUSBAND IS SCOTT
I AM 35 HE IS 37
WE HAVE 2 ANGEL BABIES [These are fetuses who have miscarried or been born as still births]
MED I TAKE ARE
1500 MG METFORMIN ER AT BED TIME
LEXAPRO A LITTLE DEPRESSED AFTER BABIES DIED
YASMIN BCP’S [birth control pills] FOR ONE YEAR
STRESS TAB WITH IRON VITAMIN (Angelbear, 2006, para. 1)

mrsmiaow: Danielle
email me at mrsmiaow@soulcysters.com
10 years TTC [Trying To Conceive] (but only married 5 of those year
LOL [Laugh Out Loud], SHHH! don’t tell)
Diagnose 1998
Have all the classic symptoms, no periods, very hairy, overweight, acne, diabetic…etc
mrsmiaow: Glucophage, Actos, Lopressor, Norvasc (BP), Aprion, Lipotor [drugs she is taking] Adoption will be done REGARDLESS of ability to conceive. (mrsmiaow, 2006, para. 1)

The statements express the “hide nothing” attitude of many women on each PCOS website. The women discuss their most vulnerable moments as they bring issues of the private sphere into the public. Women talk about experiences from trying to get pregnant to dealing with depression and relationship issues. PCOS influences not just the women’s health but their entire personhood. The disease is a female disorder and as a result, the women are socialized to keep this talk within the private realm (Scully, 1994). The health issues envelop the women with PCOS. The agents’ health condition dominates their domestic scene. They talk about how PCOS influences their relationships, work, environment, etc. A clear view of each woman’s private, domestic life is exposed through each post.

These support group websites give women a means to bring reproductive health and mental health issues into the public. They become authentic with each other, as the face-to-face barriers to embarrassing conversation do not exist. For example:

Timara: I have read a lot of your posts and feel for you all. Please don’t lose hope like I am. I write this while tears pour out of my eyes. I remember not only being the tallest but the only girl in high school with a beard. I used creams/shaved/waxed etc… I found a man who can grow a beard faster than me, I am still so depressed. I am an ape with hair growing where no woman should have hair… P.S. PCOS Sucks!!! (Timara, 2010, para. 1)

Conversations, usually reserved for the closest relationships, are exposed and explored through the PCOS support group forums. The women connect with each other through their similar experiences.
No topic is off limits for these women. They connect through the perceived authenticity of their posts. As one member said, “The last day DH (Dear Husband) and I had sex was April 14th. That’s more than two months ago!!! (Seeing that typed out on screen makes it seem even more depressing. *sigh*)” (wokeuplaughing, 2008, para.1). As a result, the women feel open with one another. They seem to gain trust from one another through exposing their vulnerabilities. While this may not be true for every woman who participates on any of the support group websites, through my observations I feel that most of the women are searching for online support to help survive their off-line lives. I cannot argue with certainty that the women represent themselves completely; there could be inauthentic representations, or people representing false identities; however, given the nature of this syndrome, it seems unlikely that many people would understand the disease well enough to fake true PCOS membership. As a result, the women feel comfortable in the online public space to discuss very private matters. As LadyBug78 (2008) explained, “Well, once again I’m feeling full of TTC[Trying To Conceive] anxiety… and throwing it out on the internet feels like a good way to get rid of it” (para. 1). The women use this connection as a therapeutic way to share private space with others and help support other members of the PCOS community.

_All are “Welcome”… If You Can Talk the Talk_

The women provide a welcoming environment for new members. Many of the members are nurturers, counselors and friends to other members. They provide emotional support for the community. For example, after each new member recognizes herself, the other women say “Welcome,” “Hello,” “**hugs,**” “Good luck!” (PCOSA, 2009;
Many members also give suggestions about how to become active patients and PCOS support group members. For example:

**Leonsbabymaker:**

Hi my name is leonsbabymaker. I am 24 years old. Me and my husband have been ttc [trying to conceive] for 5 months. I was dx [diagnosed] with pcos in 2006. I do not ovulate on my own at all. I want a baby so bad and it’s like everytime [sic] I turn around one of my family members are pregnant. I was on vitex but it seems like that makes my af [aunt flo (menstruation)] super long. I just want some help with ttc my first child. This has been a heartbreaking journey. I don’t want to give up but I have been through alot I [sic] my life and I just can’t take much more heart ach. A baby would be a blessing just need some help getting him/her here. Please help me with any advice u have. Thank u and godbless [sic].

U won't believe what he told me! Me and my husband were talking about having a baby and he asked me how far was I willing to go to get pregnant. I told him as far as I had to. He asked me about adoption and I said that that was an option but I want my own baby I have been taking care of other people children all my life and I just want someone who looks like me. He then turned to me and said maybe ur not suppose [sic] to be a mother did u ever think about that. What if it's not for you. Mother hoods not for everybody. My mouth dropped open and my eyes filled up with water he said dont be so sensative[sic]. My heart is soooooo hurt by what he said and I haven't said a word to him in days. He asked me for a baby then he turns and says something like that. He keeps asking me what's wrong and I leave the room. He knows how bad I wAnt a baby and all the things I have done to have one. How could he say something like that. What should I say or do for that matter. I'm so lost and I don't want to talk to him right now. They never lied when they said it's a thin line between love and hate.

**MissChrystal:**

I think there’s 3 things you need…

1. Support from your spouse because this journey SUCKS and can take the wind out of your sails like nothing else. Comments about not being meant to be a mother is not the positive influence you need to get the job done. So start there and work out the issues with DH [Dear Husband] comments on you not being a mother.

2. A good doctor who is willing to help you get pregnant and support you along the way. If you don’t ovulate, get charting and temping, but OPK’s [Ovulation Predictor Kit’s] and get
MissChrystal: Clomid or another ovulation inducing medication. If you don’t O, then you won’t get pregnant on your own, so become proactive!

3. Find your inner strength because this may take years and years for you and it’s painful, so you need to prepare for what’s to come. Find support group like on these forums and ask a million questions and read read read read! Good luck! (Leonsbabymaker, 2010, para. 1-6)

The women welcome the new voices and try to get new members into the private conversations by helping them feel a part of the support group. They often exchange insight about their own personal conditions to show the new women that they are not alone. They encourage women to overcome their relationship and personal difficulties by providing steady support. These women are strong agents of the domestic scene. These websites use many different ways to show the private sphere within online space or as Burke (1969) would say, the women use many “agencies” to connect people together. For example, there is a Facebook site linked to the PCOSA website that has over 4,000 members (PCOSA, 2009). Each new member is encouraged to join the Facebook group. After connecting with the women of PCOSA, one of the members, Sasha Ottey, even started a PCOS Challenge website where she “challenges” new members to start a fitness routine. Her website offers “16-week fitness, nutrition and mental wellness programs, a weekly radio show, local offline support groups and a support/social networking website that attracts 25,000 visitors per month” (Lord, 2009, para. 1). Through multiple venues, or agencies, the women are welcomed into a PCOS diagnosis and given ways to help themselves and others. As Sasha Ottey says:

I was motivated to create PCOS Challenge because of my own hardship with the condition and knowing that so many other women and their families were impacted in similar ways and needed an integrated support system….
Our company's goal is to serve as an inspiring and motivating force that encourages women with Polycystic Ovarian Syndrome to take control of their lives and to apply appropriate measures to prevent other diseases and illnesses that stem from PCOS. We will continue to seek out partners, experts and sponsors to deliver highly effective, leading-edge programs that support women with PCOS. (Lord, 2009, para. 5 & 7)

The purpose of this private space is to help women find ways to take control of PCOS and live healthier lives.

As new members on the websites connect to the online communities, they must learn the language of the communities to experience full inclusion. For example:

Karol:  Hi thin ladies, I’m a thin cyster too. I’m 5’10”, and I weigh about 155. I’m actually heaver now that [sic] I’ve ever been in my life. A more typical weight for me is more like 140 (which is too skinny – I like the little bit of curves that I have now.)

My RE [Reproductive Endocrinologist] recently started me on a no-refined carb diet & 1+ hrs of exercise 7 days/week. I met with him today & he wants to put me on Metformin too. I was on met for a while during the summer, and it made me feel HORRIBLE! I really don’t want to start taking it again. But since DH [Dear Husband] & I are ttc [trying to conceive], I guess I need to do what the dr says.

So I’m wondering what all of you are going through to control your PCOS. Any success?

Tabsies2006: Well, even if your RE [Reproductive Endocrinologist] is great, don’t be afraid to ask questions/challenge him. If you’re not comfortable with something, don’t hesitate to tell him and see if there is an alternative… (Karol, 2006, para. 1-5)

This excerpt identifies a common communication pattern that occurs on the PCOS websites as women use particular fertility terminology to connect with one another. This conversation between Karol and Tabsies2006 use this specific language such as RE [Reproductive Endocrinologist], DH [Dear Husband], and ttc [trying to conceive] to show their identities as women who struggle with fertility issues. The new members that
come onto each website often have to ask what a term means. The women are gracious in
supplying the answer and they often suggest that the new member check out the glossary
on the website to learn the language. The terminology list helps to make a new member
feel a part of the group. Without it, a new participant would feel excluded because the
language is unclear. It is interesting because this private sphere uses specialized language
like the technical sphere to create inclusion. This technical language, much like the expert
culture, selectively includes some of the women and excludes others. This language use
seems almost a resistance to expert culture by using the same means as the technical
sphere. What I mean is that if the layperson can use the same technical jargon as a doctor
then there is less medical intimidation and the women within the PCOS community feel
more empowered when in a doctor’s office. Essentially, the women can talk the doctor
talk.

The women not only use the doctor talk, but also the women appropriate it and
make it their own through. This is evident in their play on language and in some of the
acronyms they use. For example, the SoulCyster website is a play on sister where the
women have used a symptom of PCOS to suggest that these women are connected like
sisters through their disease. The women also use different medication terminology and
generate acronyms to help the women speak of these difficult medical words and
procedures in terms understandable to them. For example, Lins79 (2010) was discussing
the process of pregnancy and had a question about implantation bleeding, blood that can
occur when the fertilized egg settles in the uterus. She said to the SoulCysters website
pregnancy forum:
Hi ladies, congrats on your pregnancies! I am not one of you lucky gals yet, but hopefully that won't be for long! I posted in the infertility forum, but only got one reply! Has anyone experienced IB [implantation bleeding], if so, what did it look like and how long did it last? **Any responses would be greatly appreciated** as I am only 6-7 DPO [days past ovulation]. (Lins79, 2010, para. 1)

The women use fertility terminology to speak with each other about their situations. They also develop their own language to speak of fertility and emotional issues. This language consists of acronyms that are more personable such as “BD” for “Baby Dance (sexual intercourse),” “DH” for “Dear Husband,” and “CIO” for “Crying It Out.” The women support each other in comprehending the medical talk behind PCOS as a disease, understanding the process of fertility, and supporting the emotional side of the syndrome. They feel comfortable with the doctor language, and make the language their own so it blends the technical with the private.

As discussed in previous chapters, within the expert culture, mystification occurs due to technical language use. The same situation occurs within the private sphere websites as some women are included and others feel excluded from conversations based on shared terminology. While the old members work to include the new members and help them learn the terminology, it seems as if the women are using the technical sphere language in order to determine who is included in the fight. If you know the language, you are one of us. This is an interesting way to challenge the technical sphere, as the women seem to resist the medical sphere by using the medical sphere. While this move allows the women to see who understands the PCOS lingo, it might marginalize some voices and intimidate those who are unable to learn the abbreviations and the lingo.
Therefore, the women who can use the terminology of the technical sphere feel most included within the website conversations, or at least they are the ones who post most frequently. This language connection does provide a start for the PCOS women to generate a certain identity within the group. This identity says that they are comfortable speaking of their illness in technical terms.

*Humanize the Technical*

Beyond using the language of the technical sphere, the PCOS support group sites also work to humanize the doctors as the women prepare to enter the medical scene. Once the women enter the world of medicine, they talk about the medical encounter in a more subjective way while using the objective medical diagnostic terminology. They show the humanity (or lack thereof) of the doctors encountered. This shows that the women use aspects of the private sphere when discussing an encounter with the technical sphere. Almost every diagnosis story starts with the woman seeing multiple doctors before she gets a PCOS diagnosis. A typical PCOS story speaks of the doctors in this way:

I got my first period when I was very young, I was 8 years old. I continued to have my period regularly *sic* until I was about 16. It then started to come only about 2 or 3 times a year. I went to the doctor and they told me I just needed to lose weight *sic*. I have always been pleasantly *sic* plump. So I went home and tried everything to lose the weight but the harder I tried the more I would gain. I went to the doctor about 10 times in five years always to hear the same thing. Then one day I was talking about it with a friend and she mentions PCOS to me, so I looked it up on the internet and started to cry. I had it all, the facial hair the missed period the thinning hair the obesity as well as type 2 diabetes. I went back
to my doctor and told him what was wrong with me, at first he told me not to self diagnose and that I obviously just ate too much, I did not give up and demanded to go see an endocrinologist \[sic\]. I am ok now I am eating right and exercising \[sic\] I get my period about 4 or 5 times a year, I have lost weight and I am controlling my diabetes with diet and exercise. And one day hope that I can have a baby. My biggest hope is that awareness of PCOS increases with laymen as well as Doctors who just think we are lazy. (Jeweleen P., 2006, para. 1285)

The women are frustrated with the lack of knowledge about PCOS and frustrated that they must jump from doctor to doctor to find one that understands the symptoms well enough to provide a definitive diagnosis. As one woman sarcastically exclaims, “What do you get when you combine 4 doctors, 2 dermatologists, a gynecologist and 15 years of telling PCO symptoms? Well, eventually, you get a PCO diagnosis!” (Michelle, 2006, para. 269). Many of the women within the private sphere support websites waited many years to gain a diagnosis. The doctors did not understand the syndrome well enough to give women appropriate advice. As a result, physicians who said that the symptoms were psychological or that they would go away if the women lost weight often just dismissed the female experience.

In posting after posting, PCOS women explain how doctors dismiss the female experience. PCOS women clearly believe the medical encounter should not just consist of objective diagnostic practices but that the doctor should engage the entire person and understand the subjectivity of each individual case. In their posts, the women show disgust in their posts with the doctors because they do not convey the empathy the women need. The women speak little about the protocol the doctor follows and speak
volumes about the doctor’s quality as a person and clinician. The women also speak extensively about how the doctor interacts with the patient. Furthermore, the women judge their doctors, not as professional diagnosticians but as people with little understanding or compassion. For example, Diana (2006) explained her horrifying doctor experience saying:

I am the face of a PCOS sufferer. I suffer from PCOS, as well as having to suffer with doctors who would dismiss my pain and complaints simply because they didn't know what to do or what to look for. My ex-OB/GYN dismissed my pain by saying the pain must be related to having a full bowel and all I needed to do was use the restroom and my pain would be gone! She said if that didn't work I should go see an internalist[slip] because it could be a stomach problem. I guess she should have listened when I said the horrible pain was located in the pelvic area where my ovaries were. There was not even a suggestion of getting an ultrasound, blood work or anything else! She refused to believe there was anything wrong with me other than my being overweight and trying to pass me off to doctors that had nothing to do with my problem. I was ashamed and suffered for 5 horrible years of sheer pain until my general practitioner listened to what my complaints were and decided to follow up on what she believed to be the problem. (para. 1243)

This particular doctor interaction was not pleasant and as such, the OB/GYN becomes somewhat of a counter-agent because the patient is evaluating her subjectively. Ironically, many OB/GYN specialists know very little about the disease and an accurate diagnosis often comes from a general practitioner or endocrinologist. Dr. Vliet (2006)
says that because OBGYN is considered a surgical field these doctors will often give a
wrong diagnosis because “the problems causes by PCOS just don’t seem as serious in a
busy surgical practice” (p. 33). In addition, hormones are not typically tested unless
someone is trying to get pregnant. As Dr. Vilet (2006) says, “individual specialists are
not likely to look at the whole symptom picture. Not only are few of them trained to
recognize (or treat) PCOS, but each doctor’s specialty brings with it unique blind spots
(p. 33). General practitioners, on the other hand, have a wider range of symptoms they
must deal with and will often look at the whole symptom picture to achieve an accurate
PCOS diagnosis. Now, once a woman receives a PCOS diagnosis, then the specialist can
help provide better insight to the disorder and give more accurate and effective treatment
plans then the general practitioners usually do. The specialists gain their credibility as
effective doctors once the women are diagnosed with PCOS.

Due to this doctor frustration, some of the women with PCOS critique doctor
agency. They disagree with the professionals’ response because they argue that the
doctors focus too much on medical protocols and do not see patients as individuals.
Essentially, the women with PCOS critique the main affinity of the technical sphere,
agency, because it is too objective. The women on the PCOS websites judge the doctor’s
qualities as people and as clinicians regardless of the encountered medical procedure.
They see the practitioners as failing not only in their diagnosis, but also and more
importantly for the women, the doctors fail to listen and critically evaluate what the
women are saying. The PCOS support group websites critique the doctors’ objective
evaluation based on limited information, which is fitting for conversations that start
within the private sphere. Within this sphere, subjectivity, including personal stories and
anecdotal evidence, is valorized. PCOS sufferer Robin Brooks Radel (2007) exemplifies this critique through the story that she shared with Project PCOS:

…Thus began the parade of doctors. Over the next 7 years, I saw 17 more doctors. I saw internists and Ob/GYNs and even a psychiatrist. They all said my problem was weight based. If I just ate less and exercised more, I would be all fixed.

I found an article in Women’s Day Magazine, about a woman named Wendy. She was losing weight with this new diet, nicknamed CAD, and she had an interesting story. She told of a rapid weight gain, a velvety brown mark on her skin, hair loss on her head and excess hair everywhere else. Oh, and skipped periods, just like me. I felt as if I were floating; the idea of someone else like me was so foreign, so exciting and so validating! I wasn’t crazy, this was a disease! It had a name! It was called Polycystic Ovarian Syndrome, or PCOS. I searched books and magazines and the internet until I was armed with enough information to take to a doctor. I took a recommendation from a friend and went to her family doctor, Dr. Karen Woods, MD.

I often think that had one of those 18 doctors looked a bit harder, or listened a bit, or did some research, I might not have become diabetic. Sadly, it seems none of these respected physicians knew what to look for regarding PCOS and even misdiagnosed symptoms. (para. 3-5)

In addition, these PCOS support group websites tell the story of how women use the information about PCOS found within the public sphere to help gain an understanding of their private struggles, and then use their personal knowledge to discuss a PCOS diagnosis with the doctor experts in the technical sphere. This medical scene provides the perfect space for all three spheres to converge: it is spearheaded by the PCOS sufferer, otherwise known as the agent; the private sphere also recognizes the public sphere influence (where information about PCOS is found) and as a result, the women use their knowledge to impact the technical sphere—they share their knowledge with doctors.

The PCOS women have become proactive and they fight for disease recognition within the technical sphere. Permeating private sphere online PCOS communication is the lesson that doctors are human and they make mistakes. Instead of placing
responsibility for an individual’s health within the hands of the doctors, the women of the PCOS websites argued for self-efficacy to obtain optimal health because the doctors are fallible. As PCOS sufferer Claire (2007) explains:

The lesson I learned from this ordeal is that you always need second opinions! Doctors are certainly not gods or goddesses. They are human and they make mistakes too. It was very easy to be tempted to trust my first doctor who said I didn't have a problem and to get rid of my irregular periods with birth control pills. Sure, that is the treatment I eventually took but if I had started taking the pills before I got the real diagnosis, I wouldn't have realized that I have PCOS. The diagnosis really has changed my lifestyle and I will be prepared when I am ready to have children to know that I might encounter some obstacles. (para. 2)

The women were honest with each other and suggested that sometimes the first expert is not the best. They helped each other realize that they must find someone who is willing to provide the type of care each woman needs, a doctor who does not just focus on the agency or medical protocols, but considers the human side as well. As the SoulCysters website specifically suggests, “If you are not happy with your doctor, find a specialist who will listen to your concerns. Women with PCOS often have special concerns about their appearance that are directly tied to their condition. You and your doctor must act as partners to manage all aspects of this complex condition” (Dunaif, 2006, para. 8). The medical technical sphere agency stronghold is weakening and the demands of the private sphere are strengthening as women recognize their need for care that respects and acknowledges the individual.
Beyond showing their frustration with doctors and the human limitations of the doctors, the PCOS support groups express how important personal control is within the technical scene of the doctor’s office. In other words, the women must become the agents who influence the physician’s use of agency. The support group websites teach the women to be prepared when entering the medical sphere. As Christy R. (2006) says:

I know that I can be very pro active about my healthcare and seek out the medical professionals to help ME stay healthy and have a wonderful, normal life. I cannot urge other women enough to be pro active in their own healthcare and seek out the healthcare providers that are right for you, to keep up with all of the research being done. Do not let anyone make you feel as if you do not deserve the best healthcare you can get. I took back so much of the power in my life when I became a more active participant in my own healthcare, instead of just a patient who did whatever I was told. Stay healthy and strong, ladies! (para. 33)

The women challenge the medical community by advocating for a pro-active encounter with the doctor. The result is the private sphere gaining more legitimacy as the women ask to share the power over their bodies with the doctor. The women are no longer passive consumers of health care; instead, the women feel empowered as they become knowledgeable about the disease through PCOS resources.

Through the private sphere, women gain knowledge to help educate others. The women become the lay-experts. They have experienced PCOS for years and understand how to influence doctor-patient interaction. All PCOS websites tell new members to seek different information from the sites and to ask anyone on the sites if they have questions.

*PCOS Lay-Expert*
Most of the women offer suggestions for materials women should read before going into the doctor’s office. As the SoulCysters (2010a) website says:

If you haven’t yet downloaded the Medifocus Guide to Polycystic Ovary Syndrome, I HIGHLY recommend it. It is one of the most comprehensive and up-to-date resources on PCOS treatments, research, physicians, etc (after SoulCysters, of course) Keep a copy for yourself, and make a copy for your doctor (they'll need it).

Seriously - if you don't ever get another book (or anything) on PCOS, you and your doctor should have the Medifocus Guide. Once you download it, you'll get FREE updates on any PCOS research that comes out for the next year. It truly is a must have. (para. 1 & 2)

Women with PCOS created this document, with the help of medical professionals, to teach doctors and patients the details of living with PCOS. The book itself becomes the agency for change for both the patient and the doctor. There are different resources recommended throughout each of the websites from articles in magazines to the book A Patient’s Guide to PCOS by Dr. Walter Futterweit who has 25 years of experience treating women with PCOS (Medling, 2007-2008). The purpose is the same in each case, use these resources to educate yourself then educate your doctor. The activist site, Project PCOS, changed its original mission to promote PCOS advocacy within the medical community. As the mission states:

Over the past year, The Project PCOS board of directors have been reviewing and defining the needs of our community. As such, Project PCOS has begun to change our focus and mission to better serve these needs…

Going forward, Project PCOS will be concentrating much of its effort on educating the physicians, reproductive endocrinologists, family doctors, obstetricians, gynecologists, nutritionists, medical professionals, and alternative healers about the syndrome through a series of events, partnerships and educational materials.
Project PCOS will engage PCOS patients in this new mission to help educate and inform medical professionals. With the help of our community, we will get up-to-date information and research into the hands of those working directly with PCOS patients.

Please continue to visit the Project PCOS website, PCOS message boards, PCOS Today Magazine and the many PCOS advocacy and informational sites available for updates about this new focus. Exciting times are ahead as we push PCOS awareness forward! It is only through education and awareness that PCOS will gain the attention it needs to be understood. (Harvey, 2007, para. 1, 4-6)

While Project PCOS is most articulate about its activist mission, each website highly encourages women to learn as much as possible about PCOS before engaging with the medical technical sphere. Therefore, the women will know the language and understand the syndrome well enough to help the doctor understand the situation. This results in knowledgeable patients who often supplement the doctor’s knowledge. Shannon’s (2006) story from the “Share Your Story” section of the PCOSA website reveals how doctors can benefit from information brought in by patients. She said, “I recently gave my doctor (Ob/Gyn) copies of the [PCOS Today] newsletters and she was very excited to have them. She recently had two teenage girls become patients that have PCOS and needed the information to pass along” (para. 62). The information that comes from the private sphere into the technical sphere helps promote female health.

The main contributors to the PCOS websites are women who stand astride the technical and the personal spheres. They act as agents of change who influence the medical community and challenge their medical protocol, or agency, ensuring better healthcare for all women with PCOS. This creates a strong case for female empowerment, as the women understand the medical agency, including diagnosis and treatment. They have had personal encounters that make them lay-experts. With this experience, they form critical opinions about the adequate or inadequate approach the
doctor uses which, in turn influences the information that they take back to the support groups. This information is then given to other women with PCOS so they can also become agents for change.

**From the Private to Public Sphere**

The weaving of the spheres is also present as the private sphere influences the public sphere. While these infiltrations are not yet observable on a massive scale, the PCOS women are gaining recognition in multiple online capacities and making progress with the general population. The focus of Project PCOS includes a campaign to raise money for PCOS awareness. The campaign is called “One Million for PCOS” and it urges members not only to donate money for the cause but also invites them to sign a petition that is addressed to members of Congress asking our representatives to “promote community outreach” and health resources (Tabeling, 2007, para. 2). The goal is to “call on Congress to enact legislative proposals that will improve access to essential health services, insurance coverage and educational programs, through promotion of guidelines for proper diagnosis, treatment and care for women and girls with PCOS” (Tabeling, 2007, para.4). Currently, the petition has 9,983 signatures. The website also gives suggestions for how to write emails to legislatures. The website suggests that an email is an appropriate form of communication; when written formally, the email provides a “paper trail, physical evidence that the public has taken notice of an issue” (ProjectPCOS, 2007b). The result is a private issue coming into the consciousness of the government and the public.

The PCOS support groups help shape public opinion regarding PCOS. Habermas (1989) suggests that for communication to form a “public opinion,” it must generate
“structural transformation of the public sphere itself and in the dimensions of its development” (p. 244). While Habermas (1989) spoke of the coffee houses and salons acting as spaces to promote public opinion resulting in conversations that influence the public sphere in the eighteenth century, in this instance, the internet acts as the starting point for promoting PCOS information. Without this space, the PCOS women would not have found each other so easily and promoted their cause. The PCOS websites work to make the private information into a public opinion issue by transforming the public’s view of this disease. In this case, the “structural transformation” comes in the form of people becoming aware of the disease and generating awareness at a governmental level. The women are hopeful that eventually Congress will take up the cause of these women and promote PCOS informational campaigns across the nation. As the Project PCOS petition invites, “The undersigned organizations, campaigns and individuals look forward to working with Members of Congress to enact these reforms that will help address this widespread national problem” (Tabeling, 2007, para. 5). The PCOS organizations are willing to work with Congress to transform the image of PCOS from an unknown disease to an illness that affects the entire nation.

The PCOS women also implement different agencies to get the word out to the public about PCOS. The websites each have press packets with information about the syndrome that women are supposed to download and share with their local papers. The women can also print the PCOS Today newsletter and share it with others. They encourage each other through the forums to participate in PCOS related activities such as starting support groups or “Walk the Walk for PCOS.” This walking campaign acts much like a cancer walk, where the purpose of the event is to promote awareness and support.
The women want to get the word out that PCOS is harming everyone if not personally at least financially. As the Project PCOS Press packet asserts:

Polycystic ovary syndrome (PCOS) – the most common endocrine-related condition of reproductive-aged women, and a disease that causes male pattern balding in some women affects nearly 4 million women in the U.S. and costs $4.36 billion annually, according to a report released by The Endocrine Society. According to the Endocrine Society, screening for PCOS may reduce the overall economic burden associated with the condition. Following are highlights from the study:

- Costs from PCOS-associated diabetes = $1.77 billion
- Costs from treating menstrual dysfunction/abnormal uterine bleeding associated with PCOS = $1.35 billion
- Costs from treating hirsutism (excessive hair growth), a side effect of PCOS, = $622 million. (Excess hair typically appears on the face and extremities, while hair on the head thickens.)
- Costs from providing infertility care for PCOS patients = $533 million

These costs are compared to the costs of the initial evaluation of PCOS, which are estimated at $93 million. (Project PCOS, 2010, p. 6)

The women will use a financial component to their rhetoric to help the public realize that PCOS does influence them even if they do not personally suffer or know someone who suffers from the syndrome. The women use agency, the information in the press packet, as the means to disseminate information to the public. This tactic is useful because it creates what Burke (1969) calls “common ground” (p. xix), where individuals find particular “substance” that they can connect with, whereby individuals can be transformed or see experiences in new ways (Burke, 1969, p. xix). If people understand that it costs them money when doctors do not accurately diagnose women with PCOS, then the public will be more likely to do something about the situation.

Women with PCOS use this knowledge to influence public opinion. This resonates with Habermas’s explanation of “public opinion,” as the talk must become important to a group of people by appealing to “the needs and interest of bourgeois civil society” (Baker, 1996, p. 192). In other words, for talk to become public, common
ground must occur. The women appeal to males and females through using the financial information from the press packet that influences everyone.

The women use other means to speak with the public about PCOS. The newest technological tools implemented by the support group sites are social networking opportunities and video streaming. The women have been sharing their stories with open discussion on Facebook and YouTube. This helps to generate public sphere recognition within online spaces outside the support group pages. The YouTube videos give a face to the disease as people not only read about the horrors these women experience but see the sadness, the tears and the frustration. Project PCOS explains the purpose of the YouTube videos project:

> Often the best way to understand what someone is going through, is to see it through their eyes. The following women, families and supporters have graciously shared their personal stories and lives with Project PCOS to help people understand the very real and often very painful reality of life with Polycystic Ovary Syndrome (ProjectPCOS, 2007c, para. 1)

One of the YouTube videos has over 22,500 hits. A fifteen-year-old female who goes by Krazykat5216 generated the video. She said, “So many people don’t know about Polycystic Ovary Syndrome. I was inspired to do this because I saw other videos with the same message” (Krazykat5216, 2008, para.1). The response to her video has been overwhelming. Over 100 messages have posted to her YouTube comment wall. The video continues to gain viewership and is still pertinent for its audience.
As one commenter, with the user name willowjana, said:

Beautiful video! You made me cry lol. I have been living with PCOS for about 15 yrs. Mine began at the start of puberty and I am now almost 31 yrs old and still continue the struggle. This disease can make you feel so alone, so I am very proud of you for posting this vid. And to all those posting comments, remember you aren't alone. There are alot[sic] of women out there with this, so find one and make a friend on this journey to share, learn, and cry together. (willowjana, 2010, para. 1)

The women bravely share their personal information with the YouTube public hoping to forward their cause and help bring about public awareness for PCOS. Each of these different agencies help forward a pro PCOS awareness message for patients, doctors, and the public.

When analyzing the different elements of the pentad operating on the support websites, I noticed that the agent was still the primary affinity for the private sphere. In comparing the ratios of the agent with scene and act, the agent was still the focus because the act and the scene remain relatively vague in the discourse. The doctor’s office is the main scene present but the importance of the office and the act of going to the office is not critical to the discourse of the websites. One just assumes that the typical events that happen in the doctor’s office take place. The critical pentad components were the agent, purpose, and agency. The agent remains the main affinity because the perceived authenticity of the person with PCOS helps convey the many PCOS messages to others. While the purpose, to educate and provide knowledge about PCOS, was imperative to focus the websites toward similar goals, the means of conveying the purpose became
more important in determining the reception of the message. Therefore, the agent-agency ratio became the most critical in forwarding medical democracy. This occurs because the women use many different strategies, from on-line discussions about finding the right doctor, to using medical fertility terminology in talking with other PCOS “cysters,” to signing legislative petitions in promoting PCOS knowledge. The women educate within the private sphere but the support group discourse does not stop there. The women want to reform the technical sphere. They want to fix the technical agency so the doctors do not just pay attention to protocol but to the personhood of the patient. These websites point out that the PCOS lay-person agency experts are willing to help fix the technical sphere. The women, through the online websites, seem to suggest that the experts cannot, or will not, fix themselves and change the protocol to become more patient centered and PCOS knowledgeable. As a result, the PCOS women give others the means to help shape the technical sphere. They also provide information to the public, encouraging others to become knowledgeable about the health effects and financial ramifications of this disease. Through their online conversations, the women gain the attention of participants within the private, technical and public spheres. It is through their use of agency that this private sphere case study is able to create space for dialogue within the other spheres. The result is a more democratic online space that promotes democracy within the technical sphere.

**From the Technical to the Private Sphere**

The three doctor websites analyzed had many similarities that helped promote medical democracy. The sites used expert language within many of the medical reports but also connected with laypeople using common language. The websites reach both
doctors and patients. The technical sphere’s main affinity toward agency influenced the design of the websites because the main goal is to use any means possible to make sure the audience (which includes health professionals and patients) receives answers for the health questions asked. The websites used many different means or agencies to provide information to those who need it. These diverse agencies include medical reports from journals, basic information pages, Q&A sessions where nurses, doctors, and patients answer health questions, forums surrounding PCOS/gynecology, and the sites provide other places and resources for patients to seek information.

The goal of each of these websites is to provide information about different diseases to the individuals who inquire with the understanding that the information should not replace expert medical advice. As the main disclaimer from Doctor’s Lounge says, "The information provided on www.doctorslounge.com is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her physician" ("DoctorsLounge – Gynecology," 2010, para. 1). The websites intend to inform the audience, help the audience use the doctor language, and understand the syndrome before they encounter the doctor’s office for the next visit.

Within the websites, four distinct themes emerged from the analysis. The doctor-authored websites provided information, argued for a specialized technical approach, used community collaboration and validated the private sphere. Each of these themes highlight the importance of the agency used to promote a particular purpose, providing medical information to all who inquire. What results is the agency/purpose ratio, which dominates the technical sphere in these websites. The means of dissemination influences information sharing. Ultimately, the different ways of reaching the audience all converge
on the same goal to help doctors, patients, loved ones and anyone who has access to the information understand the PCOS condition.

Information Providing

The main purpose of each doctor-controlled website is providing information. There are multiple agencies used to get accurate information across about PCOS. To reach a diverse audience, the websites utilize both clinical information and compassionate information. Most of the clinical information is provided through links to medical journals, which give doctors information about PCOS using medical terminology. Anyone can access the information but the audience intended is a medical audience. For example, an article by Dr. Richard Sadovsky (2002), posted on the American Family Physician website, looks at how the drug Metformin reduces insulin resistance better than other medications. The language in the article helps the doctors understand the study, where 15 obese adolescent females lost weight and lowered their insulin resistance through the Metformin medication. There are numerous links to various PCOS related journal articles all written from the year 2000 to the present. These articles help reinforce and valorize the biomedical model. The articles focus on doctor diagnosis and treatment, which shows the importance of agency within the technical sphere. The articles focus on different procedures and medications to help attain an accurate PCOS diagnosis and treat it. One of the more recent articles by Dr. Linda French (2004) found that the ultrasound is not foolproof in diagnosing PCOS. Other diagnostic procedures are necessary to get an accurate diagnosis. French (2004) studied 22 females all trying to conceive. She found in “the group with polycystic ovaries, 84 women who had no other signs or symptoms associated with PCOS had a mean time to pregnancy similar to that of women with
normal-appearing ovaries” (para. 2). In other words, women with cysts got pregnant in the same amount of time as women without cysts. Therefore, French presented support for the position that women participating on support group websites have been arguing all long: cystic ovaries alone do not identify PCOS sufferers. That is one of the symptoms but others must be present to receive a PCOS diagnosis. This information helps show both doctors and laypeople how difficult it can be to diagnose PCOS because of its many and varied symptoms. The point is that within the medical technical sphere agency is significant to gain an accurate diagnosis and new research enhances understanding about how misdiagnoses occur. Attentiveness to both agency and new research helps to make the medical community more aware of the complexity of PCOS.

The terminology used on the doctor websites shows that the PCOS diagnosis is a diagnosis based on exclusion. Within the content of the websites, the doctors explain that to receive a PCOS diagnosis the doctor must exclude other disorders to arrive at PCOS. The problem is that the symptoms vary significantly between each female so the diagnosis is complex and may take a while to determine. While the support group websites show the frustration with the doctors for not figuring out a diagnosis sooner, the doctor websites explain why that frustration happens. Essentially, the doctor sites show that medical professionals must run multiple tests to determine a PCOS diagnosis. These tests include blood tests to check insulin levels, an ultrasound to look for ovarian abnormalities including cysts, a physical examination looking for excess weight and body hair, and obtaining a history of the patient’s menstrual cycle. Each of these symptoms alone could promote an alternative diagnosis. Therefore, a doctor must eliminate other disease possibilities to render a PCOS diagnosis. The doctor websites help the patients
become more sympathetic to the doctor’s position as they explain the many alternative
prognoses which must be dismissed before arriving at a definitive diagnosis of PCOS. As
Dr. Marilyn Richardson (2003) explains:

Although there is no consensus as to which laboratory tests should be used to
diagnose PCOS, most physicians agree that the evaluation should screen for
hyperandrogenemia [masculinizing hormones] as well as for abnormalities that
have serious health consequences. Often, the clinical picture is readily apparent
from the history and physical findings.
In the author's opinion, the evaluation should follow these principles: exclude
other etiologies… (para. 18-19)

Therefore, what the women in the support group websites say is true, doctors cannot
agree on the diagnosing procedures, but it is because doctors use many different medical
options to eliminate other disorders in order to determine if PCOS is present. Both
support group and doctor group websites show the complexity of obtaining a PCOS
diagnosis.

The doctor websites acknowledge the complexity not only through explaining the
diagnostic procedures but also by explaining the medical terminology. When the websites
use clinical talk, most often there is a hyperlink to definitions of many of the terms used,
which helps promote further understanding of the information provided. These links
move the audience to another page of information that allows them to get a better
understanding of the highlighted term. An example of this is on the Revolution Health
website:

The cause of polycystic ovary syndrome (PCOS) is not fully understood, but
genetics may be a factor. If you have PCOS, your sisters and daughters have a
50% chance of developing PCOS.

The first signs of PCOS are usually after a girl's menstrual cycle begins
(menarche). A teen with menstrual periods over 45 days apart may need to be
seen by a doctor to make sure she doesn't have PCOS. (Normally, the first periods
and ovulation are hard to predict. They become regular within the first 2 years
after menarche. For more information, see the topic Normal Menstrual Cycle.) In some women, PCOS starts after a big weight gain.

PCOS problems are caused by hormone changes. One hormone change triggers another, which changes another. This makes a "vicious circle" of out-of-balance hormones in your endocrine system, including:

- Ovary hormones. When the hormones that trigger ovulation are not at the right levels, the ovary does not release an egg every month. In some women, cysts form on the ovaries. These cysts make androgen.
- High androgen levels. High androgen in a woman causes male-type hair and acne problems and can stop ovulation.
- High insulin and blood sugar levels. About half of women with PCOS have a problem with how the body uses insulin, called insulin resistance. When the body doesn't use insulin well, blood sugar builds to high levels. If not treated, this can lead to diabetes. (Davis & Gallagher, 2008, sec. 2)

The complex terms that need further explanation have hyperlinks. The audience then can click on the link to gain further information. This provides more support for the affinity toward agency because it is the means of getting the information across that becomes important. The doctors and board members in charge of the websites want people informed before they go and see their area doctors. Using the hyperlinks is one way to keep from overwhelming individuals as they read a current page but to provide other information if the person needs further clarification.

*Compassion vs. Protocol*

The doctor websites not only present accurate PCOS information, but they also promote understanding of the syndrome through compassionate and accurate responses to patient questions. The individuals that respond are doctors, nurses and people suffering from PCOS. When looking at the responses, it is clear that the nurses and fellow PCOS patients especially show a human side when they answer while the doctors are often more objective when responding, focusing their answers on medical protocol. Within the
forums on each website, at the end of each post, the respondents say “Good luck,” “Good luck in your efforts,” “Keep us informed on your progress,” “I hope this information has been somewhat helpful,” and “To all my soulcysters out there, hang in there!!!” (DoctorsLounge, 2010; RevolutionHealth, 2010). These responses show a more personal side to the technical sphere. It seems as if the nurses and fellow PCOS sufferers want to connect with the individuals asking the questions, and they give answers in companionate ways. Much as the support group websites worked to provide “common ground” (Burke, 1969); the doctor sites intend to accomplish the same purpose as the nurses and fellow PCOS patients show a human and not just clinical side.

Communication with the nurses is especially patient focused and often compassionate. The nurses are the ones who stand in-between the patient and medical agency. They exhibit a balance between emotional and diagnostic talk. For example, “sallyanne” is concerned about her daughter’s health and possible depression and asks Doctor’s Lounge for help. Sandy Tracy, RN, responds to this worried mother with compassion saying:

Dear Sallyanne,

Thanks for writing in, I am sorry to hear your daughter is having problems. At 15 she is noticing her peers more and wanting to fit in. it appears that your daughter is definitely dealing with depression. Although there is no history of depression in your family your daughter is dealing with very unique issues. I encourage you to get your daughter assistance as soon as possible. These are the years that your daughter is the most impressionable and self harming is no way to live.

It is great that your daughter is not having problems at home. Is she open to you? Does she know that she can talk to you without repercussions? How about a different school one that specializes in special needs. It sounds like your daughter is not receiving the support needed at her current school.

It sounds like you have been very supportive of your daughter and her issues, continue talking with her and reassuring her that you are looking into ways to help
her. In the meantime I encourage you to get the appointment with the pediatrician as soon as possible. Your daughter may need medication for depression.

I hope this helps, please do not lose hope and continue to assist her. If you feel she is going to hurt herself or someone I encourage you to take her to the emergency room so she can be evaluated.

Thanks again for writing in and God Bless you. (“Concerned,” 2007, para. 12-17)

Nurse Tracy not only gives suggestions for the mother in helping her daughter, but she also asks questions regarding what is going on within the domestic sphere to assist in the diagnostic process. The nurse uses compassion to help encourage a medical encounter.

When using compassion, the nurses are sympathetic to the PCOS women and their need for answers. As the liaison between the doctor and the patient, between the private sphere experience and the technical sphere medical terminology, the nurses make suggestions that assist the patient. This includes recognizing a poor doctor diagnosis and suggesting alternative care. For example:

wallsy: …it may have been the 3rd possibly the 4th time i was admitted into hospital that i remember one of the doctors saying that i could have polycystic ovaries but saying this nothing further was said and i haven’t been tested. Could there be a reason for them not to send me for any tests at that time?

Theresa Jones, RN: …The only explanation I could think of for the lack of evaluation during your previous hospital stay is due to the fact that you were admitted specifically for Diabetic Ketoacidosis and their focus was to achieve control of that particular crisis. However, in my opinion, taking into consideration the frequency of your hospital admissions, referral to an Endocrinologist should have already been suggested and arranged. Below is a link for some information regarding PCOS, and again, I would encourage you to have an evaluation by an Endocrinologist. Best wishes.

Sincerely,
Theresa Jones, RN (wallsy, 2006, para. 1 & 2)
The nurse points out, in a subtle way, that the doctors might have focused too much on controlling the immediate health situation and failed to acknowledge the possibility of other issues causing “wallsy’s” troubles. The nurse suggests that an endocrinologist would be helpful in gaining an accurate diagnosis. The nurse indicates that the previous doctors, if following appropriate medical protocol would have made a PCOS inquiry. The nurse is willing to, at least subtly, speak to the fallibility of the technical sphere doctor and suggest that “wallsy” find a specialized doctor. She also provides information about PCOS to help her educate herself about the disease. This way she can approach the doctor well prepared to enter into dialogue about her concerns.

On the other hand, the doctors respond with formulaic and objective responses more often then companionate responses. Their well wishes often resemble the closing to a letter. Statements such as “Best wishes,” or “Best regards” can come off as generic responses rather than statements full of compassion. This standard closing may be another element of medical protocol. The doctors seem constrained by the agency. For example, Dr. Safaa Mahmoud posts nearly identical responses for most women who ask questions about PCOS. She might provide a slightly different opening paragraph but then she moves into the lists of the symptoms and says “Best Wishes” at the end of her posts (imjellyfish, 2007, para. 7). For example, we can compare two different inquiries and the responses to each by Dr. Mahmoud:

**fattycat:**
female 26 years old.
In the past few months I have been experiencing hair loss and have been being treated but the underlying cause for the hair loss has not been identified. I had several pre existing medical conditions, reactive hypoglycemia, borderline high blood pressure, and parasomnia. During tests it has recently been found that I have an irregular heart beat and high level hyperlipidemia. I am beginning to suspect that rather than being separate medical issues that these (minus the parasomnia) are somehow
fattycat: related. If so what could it be and should I be seeing someone about a heart condition or about my blood sugar levels?

Dr. Mahmoud: Hello,

How about your menstrual cycle? Is it regular? Do you have any pelvic pain?

There might be a hormonal disturbance that explain your symptoms, but there are many causes that give similar clinical picture. Thus a thorough history and physical examination is essential to direct physician for certain causes.

One of these causes that is common at your age is: Polycystic ovary syndrome - PCOS - is a condition in which females may have problems in their menstrual cycle, fertility, excess hormones including insulin production, heart, blood vessels, and physical appearance (obesity). acne, oily skin, or dandruff obesity and high blood pressure hair loss in specific parts due to high androgen level

Cause of PCOS are not known yet and diagnosis is confirmed by Abdominal US in addition to the other labs. I advised you to seek direct medical (gynecologist or endocrinologist) consultation.

Keep us updated.
Best regards. (fattycat, 2006, para. 1-9)

imjellyfish13: I am a 26 year old female. I am always hot and sweaty and I've gained 20 lbs in the last few months. I have acne worse now than I did in my teens and I'm always tired. Could I have a hormone problem? I am not taking any medications and I don't know of anyone in my family with these problems.

Dr. Mahmoud: Hello,

How about your menstrual cycle? Is it regular? Do you have any pelvic pain? There might be a hormonal disturbance that explain the changes in your habits and your symptoms, but there are many causes that give similar
Dr. Mahmoud: clinical picture. Thus a thorough history and physical examination is essential to direct physician for certain causes.

One of these causes that is common at your age is: Polycystic ovary syndrome -PCOS- is a condition in which females may have problems in -their menstrual cycle,
-fertility,
-excess hormones including insulin production,
and physical appearance (obesity).
acne, oily skin, or dandruff
obesity and
hair loss in specific parts due to high androgen level

Cause of PCOS are not known yet and diagnosis is confirmed by Abdominal US in addition to the other labs.

I advised you to seek direct medical consultation.

Best regards. (imjellyfish, 2007, para. 1-7)

Dr. Mahmoud’s responses are almost identical even though the women making the inquiries are asking different questions. One woman was asking if she should seek help for her heart condition and blood sugar. The other woman was asking about her hormones. This example reveals a tremendous distance between the possible PCOS sufferer and the doctor expert. The women are asking for assistance to make their private health better and the doctor responds with a PCOS description, which is part of the medical protocol. The doctor stays removed from the domestic scene. She does not speak to the patients’ emotional needs. The focus is on the possible diagnosis. The patient speaks to the doctor from the private sphere and the doctor responds with technically formatted information focused on agency, not on each woman as an individual agent.

While not all doctors on the websites respond with such formulaic answers, some are more compassionate than others are; the focus of the talk is always on the diagnostic
Dr. Shoemaker’s answer recognizes the fear that women may have when dealing with reproductive issues and she validates that fear. Yet, her answer is firmly grounded on medical protocol. She uses other research to back up her arguments and suggests that the individual should be aware of other ovarian issues. This response is typical of the forum sections of the three doctor websites where the PCOS sufferers’ fears are often validated, and then the focus turns to factual medical information. The doctors suggest that the women seek more information and they may even suggest a visit to a specialist.

As part of the information-providing component of the websites, which follows the medical protocol, a majority of the posts suggest that the women find a doctor and specifically one they can trust. For example, Debbie Miller, RN (2008) says:

I'm glad to see you are progressing in your diagnostic process. Metformin is a very safe and effective medication…

Good luck in this. I know it can sometimes be a trial and error process to get the right balance but I trust your doctor will stay with it until you achieve the results you need. Best wishes. (para. 1 & 3)
The underlying suggestion here is that the doctor does know best and if a patient sticks with the prescribed diagnostic treatment then she will eventually find the health balance she needs. Each of the answers to the patient questions suggests that treatment should not be a rogue endeavor but should be discussed with the physician. As the Cleveland Clinic (from the Revolution Health website) stresses, “Specific treatment options should be discussed with your physician” (Cleveland Clinic, 2006, para. 2). The information given on each of the websites is to supplement the knowledge a patient has to help empower her when she is in the doctor’s office. The doctor websites provide the tools to help the women understand medical diagnosis, in essence understand medical agency, but they do not give them tools to deal with the complexity of their emotional situation. The focus of the website is on understanding the technical sphere and encouraging women to seek help from the medical community.

Specialized Technical

The PCOS patient must find the right professional within the medical community. The doctor websites do not valorize all doctors but suggest that the specialized doctors might be most fitting for this syndrome. This may seem slightly ironic because, as I stated in chapter three, often the specialists are not the right doctors to discover PCOS because they are not trained to “look at the whole symptom picture” (Vliet, 2006, p. 22). However, the specialists often have extensive experience dealing with PCOS symptoms once all of the symptoms present together. In other words, the specialists have practice treating each of the PCOS symptoms but they are not trained to look for them all at once to render a PCOS diagnosis. Therefore, if a general practitioner considers PCOS as a possible diagnosis then the specialist can explore that diagnosis and determine an
effective PCOS treatment plan. Still, it seems interesting that this example of the technical sphere would suggest a more technical expert to assist in the diagnostic process. As the women suffering from this disease look for help, the doctors are suggesting that the women see gynecologists and endocrinologists to gain a more accurate diagnosis (DoctorsLounge, 2010).

The interesting argument here is that the medical professionals, on the websites, suggest that particular experts within the technical field would be more effective at handling PCOS patients than others. This seems to say something about the medical technical field in general: the more specialized the expert the better chance a woman has to receive an accurate diagnosis. The need to appeal to a more advanced specialist shows that doctors continue to focus their attention on agency. If a doctor does not understand the medical situation, it is because there is ineffective agency, which means that the doctor is insufficiently technical. Therefore, the patient is charged with the task of finding a doctor who has the appropriate amount of technical knowledge, and has sufficient agency, to meet the needs of the patient. The websites seem to reinforce the technical sphere hierarchy, saying if a general practitioner does not give you the answers you need, continue up the specialist chain. Dr. Chan Lowe (2007) reinforces this suggestion when he responds to patient “Lissa_K”. He says, “Seeing your OB is a good place to start. If your OB has trouble an endocrinologist will be appropriate. Best wishes” (para. 4). This advice suggests that the more specialized the language the better the chance of an accurate diagnosis because the doctor-specialist will more likely understand all of the symptoms associated with PCOS. While the support group websites work to breakdown the formalized medical language and use it as their own (especially the medical language
concerning fertility), the doctor websites at times do the same, but also suggest that if a
generalized perspective is not enough, the specialized-technical is needed to help the
patients improve their health. In other words, the specialists are the ones who possess the
most specific knowledge and in turn the potential for the most mystification in their
language use, creating what appears a higher level within the technical sphere.

The failure to diagnose accurately is not seen as a failure of the doctor, but is
recognized as a procedure issue because PCOS, due to its complex set of symptoms, is
not easily recognized. Therefore, the fault of an incomplete diagnosis is attributed to the
disease itself not to the doctor-agent. What this means for the private sphere is that the
doctor and the protocol are not viewed as inadequate; the disease is viewed as
challenging which requires more specialization. As a result, language that is even more
specialized must be learned to understand fully the doctor’s suggestions, continuing to
widen the distinction between the private and the technical spheres.

This suggestion for seeking a more specialized doctor does not come without a
disclaimer. The doctor’s websites do explain that the doctors are human, much like the
support group sites pointed out. The difference is in the approach. The women on the
support group websites showed their frustration and anger at the doctor’s lack of
compassion and lack of appropriate medical answers. Within the doctor’s websites, the
humanity limitations of the doctors are by suggested when the women are urged to seek a
second opinion. For example:

CT617: Hello, I am a 20 year old female who has recently been having
some pain in what seemed to be my ovaries… I finally went into
the doctor’s and have since had a external/internal ultrasound as
well as several blood tests. My ultrasound showed that I have fiber
cysts covering both ovaries, and since I have had recent weight
[sic] gain, some mild facial hair, infrequent/absent periods, and
CT617: pain all signs were pointing to PCOS said my Doctor. Well we checked all sorts of things including my insulin and the only thing that has come back irregular is my FSH level was low. And of course she said that it is possible to still have PCOS but unlikely since my insulin was normal.

Debbie Miller, RN: I believe this could be PCOS, even without insulin problems. People are very different in their response and you certainly have enough symptoms for me to suspect this. Rarely does one present with all the possible symptoms in any given condition. More commonly, it is enough symptoms to raise red flags for further investigation. There are medications, such as Metformin, that are effective in treating PCOS so I would see a doctor who is comfortable and experienced in treating PCOS (most likely OB/GYN or endocrinologist) to get another opinion about this… At any rate, getting an evaluation with a specialist could only help. Good luck. (“Fertility,” 2007, para. 1-5)

The answer here shows that the nurse does not validate the first doctor’s response but instead suggests that “CT617” find a doctor that is “comfortable” and has experience with PCOS. She does not negate the first doctor’s diagnosis, but she does suggest a specialist. This example shows that the health of the woman is more important than loyalty to a particular doctor.

The doctor websites suggest that women find specialists who are right for them. The doctors and nurses on the websites suggest that the women must be empowered to seek what is right for their health. They ask the women to become participants in their healthcare and democratize the doctor/patient experience. As Nurse Debbie Miller (2007a) said, “I know it can be difficult but I would be politely assertive in this. Tell the doctor you are not satisfied that your problems are diagnosed and treated and you believe you should see a specialist for a second opinion” (para. 1). The websites even suggest that doctors encourage people to seek a second opinion so the patient feels most comfortable. As Miller (2007b) says, “Your doctor knows your situation better than I do
but it would seem to me that you may want to get a second opinion. It is a good idea whenever you are still worried about something after seeing your doctor and most physicians welcome these” (para. 3). The point here is that the technical sphere is using private sphere language to help encourage women to find a doctor who is right for them. The language I am referring to is “be politely assertive” and if you “are still worried” then look for alternative care. The responders provide suggestions that encourage the women to empower themselves and take note of their feelings to determine if an alternate course of action would better serve their health. The point is, the doctor websites suggest that the women seek specialized technical knowledge regarding their health; however, this knowledge will only become useful when the women reflect on their personal health concerns and feel empowered to seek alternative opinions. What I am seeing here is that doctor websites combine the private sphere conversations with the technical as health care experts asking women to think about their personal experiences to determine what type of further expert help they need. This analysis suggests that the technical is designed to meet the needs of the personal as the women can continue getting different expert advice until the expert’s expert satisfies the medical needs of the patients.

*Community Collaboration*

The blurring of the technical and personal continues within the many different discourse opportunities within the doctor websites. Often when women accesses a website to ask questions at least one professional answers. A nurse or a doctor gives specific responses to the questions. In many instances, both a nurse and a doctor respond. For example:

Dietpro1: I am a 38 year old female who has suffered from SEVERE PMS since I was 11!! (Before they even labeled these symptoms!) Over
Dietpro1: the years, since about 9 ½ when I started my onset of menses, I have suffered with severe hormonal related problems (mood swings, depression, acne etc) that would come on me like a ton of bricks (around ovulation) and then miraculously disappear the day of my period...

I am truthfully at my wits end here and I don't know what else to do!

My priority has to be hormone regulation, because these symptoms are becoming unbearable: 6-7 pounds weight gain per month for approximately 10 days, mood swings, acne, hair, back ache and feelings of fatigue, anger and sadness without much cause.

I do believe that this imbalance has caused the infertility and I just want to feel well!

I am willing to pay a fee for your time! You guys, as a profession, are underpaid as it is!

Please advise, Donna

Theresa Jones, RN: Hi Dietpro1,
Endometriosis in some women exhibits no signs or symptoms. However, when symptoms are present they cause severe menstrual cramps, heavy menstrual bleeding, pelvic pain, low back pain, and infertility. Advanced edometriosis may cause adhesions that involve other structures including the ovaries causing midcycle pain and produce ovarian cysts such as endometriomas/chocolate cysts. Diagnosis of this particular disorder is usually discovered during a pelvic exam and by a laparoscopic view.
Simple/functional cysts containing fluid without debris are much less disconcerting or worrisome than blood filled and solid cysts...

I would also suggest a referral to an Endocrinologist to identify any hormonal/metabolic disorder. I hope this information has been somewhat helpful.
Sincerely,
Rntdj
Dr. Shank:  

Hi Dietpro1:

I agree with Rntdj that you need to see an endocrinologist. Endocrinologists are the hormone specialists. Ob-gyn's are primarily trained as surgeons, and few have an in-depth knowledge of hormones.

As an endocrinologist who has co-authored a review on PMS, I would like to add to Rntdj's excellent comments… (“A Hormonal Mess,” 2005, para. 1,5-12)

Dr. Myron Shank goes on to explain the specifics regarding premenstrual syndrome, elevated androgen levels (elevated male hormones), PCOS, insulin resistance and other endocrine disorders. Again, this example shows how the focus remains on the diagnosis, recognizing the importance of medical agency within the technical sphere. Dr Shank provides the details of each disorder and at the end of his post says, “I hope this information has been helpful for you” (“A Hormonal Mess,” 2005, para. 21). This example is typical of the doctor website responses; the doctor usually supports what the nurse suggests. This example shows that there is collaboration between the medical professionals, suggesting that the responses from the nurses are just as valid as the responses from the doctors. While the doctor validates the nurse’s response, this illustration also provides a clear example of the hierarchy; as the doctor not only adds his perspective, which is similar to the nurse’s response, but he directs “Dietpro1” to his article. Collaboration exists but viewers of the doctor websites still know that the doctors have more expertise credibility then the nurses and the specialists have even more expertise.

The observed hierarchy does not limit the voices on the doctor websites. Validation for responses on the doctor websites is not just given to the doctors and nurses, but this validation also includes those who are personally affected by PCOS. On
the doctor websites, the women with PCOS are considered experts because of their experiences with the disease. As long as their information they provide is accurate, the layperson response is allowed to stand unchallenged as an answer to the woman’s question. For example:

**teenie331:** I have been told that I have PCOS and Metabolic syndrome X. Based on my lab values and symptoms, I am willing to believe those diagnoses. I honestly think that I may also be somewhat hypothyroid, and that that might be contributing to my symptoms. I am well aware that my TSH is normal, but I am suspicious of my somewhat low Free T4… Is there anything else you would like to tell me regarding my symptoms and lab values? Any new ideas?

Thanks so much for any help and advice.

-Christine

**lucky2185:** Christine -
I have the same symptoms and it is horrible - I haven’t gone to a doctor yet - I just figure it’s somehow my own fault although I eat well and exercise and wasn’t always this way … If you wouldn’t mind telling me about what worked for u and how u r doing with this, I would appreciate it!!

**teenie331:** I don’t know how long it’s been since I last posted, but I think it was before I started seeing the endocrinologist. When I visited with her, she really just told me more of the same (basically, why don’t you just lose weight.. SLOB.) I am always amazed at how insensitive health care practitioners can be in regards to the weight issue. No, I don’t [sic] want them to tell me it’s okay to be fat, I know it’s not, but it would be very nice if they could be more supportive and less demeaning. :roll: I’m probably going to be clinician some day (probably a physician assistant), so that’s a goal for the future....

We need to find a better answer. We need to find a CURE. I’m about ready to call this my life’s work. As I complete my bachelor's in physiology, I have decided that I will spend my research hours studying the causes and possible cures for PCOS and related disorders (that's if I get to pick the subject). Maybe I will be an endocrinologist... an understanding one who CARES.
teenie331: No, in short, I'm just as desperate as I ever was. So far, I have found no adequate answer [sic], and there is certainly no cure. There are some medications that may help you which have not helped me, but nothing is going to make it all go away. Not yet. I would recommend [sic] that you do go to a doctor (I hope you have a really good one), so that you can discuss the issue and start exploring the various symptomatic treatments that are available.

I understand.

Best wishes to you, and remember, you're NOT alone.

-Christine

sugarpie: Hi there...

Just to let you girls know too.. I'm in the same boat. I hadn't got my period yet, and I was 18 almost 19 years old. I was gaining wait... by tests were all out of wack. I went to the doctor after I researched PCOS and mentioned it to her, and she said without a question thats what I have. She put me on Yasmin birth control and within 2 months I dropped 25 lbs... no effort from me. My hormones were so out of control. I now get my period regularly [sic] and its very light when i do get it. THis is definitely[sic] something to go to the doctor for. TThere is a lot they can offer you. It's a common common thing too. Good luck girls... any questions, feel free to ask. I was through it all ;)

teenie331: I'm not saying that you shouldn't go to the doctor... by all means, you should. I'm simply saying that there isn't necessarily anything that anyone can do about PCOS.

Because it is an endocrine issue, everyone will have different symptoms, and it is guaranteed that treatments will range from completely ineffective in some to miraculous in a few…. I guess what I really wanted to say is that what may have worked well for you will NOT work for everyone. It may work for some, but please don't tout it as the universal answer, because it isn't. There isn't one.

I'm glad that you found something that works well for you, but I'm afraid that the rest of us are still looking. I suppose I'm unrealistically looking for the miracle pill that will cure all of my ails. Ha.

And thus, we continue.

-Christine. (“PCOS, Metabolic Syndrome,” 2005, para. 3-8, 12-18, 22-25)
This exchange is very similar to the dialogue found within the support group websites where the women discuss their experiences, provide support, and correct each other using their personal experiences as evidence. Therefore, I argue that this exchange exemplifies the blurring sphere boundaries. The boundaries seem to weave together. Within the technical sphere examples, evidence of the private sphere exists, as PCOS layperson experts answer PCOS health questions. The women with PCOS use the doctor websites to share their knowledge about the disease, and because the doctor sites are seen as expert space, the women and their private experiences gain legitimacy. The PCOS lay-experts are able to offer procedure explanations, and they can fully validate other women’s experiences and emotional needs. Therefore, the lay-experts bring elements of the private sphere into the technical to provide emotional support for the agent, not just diagnostic support for the medical agency.

The women not only share PCOS stories and give advice, but they also help empower each other. For example:

*terri1977:* Hello, I read a previous post regarding a brown discharge. I have something similar going on with me, however, it may be a little bit different and I would like some advice….

During the second week of November 2005, I began experiencing the brown discharge once again. No pain at all this time. The difference was that it has been going on for 2 weeks. Again, the discharge is very minimal. I was wondering if this could be due to the change from Desogen to Yasmin. The discharge did not start until after I was on Yasmin for 2 months. I've never had any abnormal discharges when I switched the birth control before years ago. Should I be concerned and see the doctor again?

Thank you for your help.
Terri
Buddysgirl2b: Terri, I am not a dr. but if your [sic] having female problems and don't know what's going on you should get a second opinion. Be aggressive it's YOUR body not the dr.'s. You know when things aren't right, find out & keep digging. (“Should I See a Dr. Again,” 2005, para. 1, 4-7)

This example reveals the vulnerability and honesty of an individual asking questions regarding PCOS. “terri1977” gives very personal information to gain advice. The response she receives is from a fellow PCOS sufferer who acknowledges that she is not a doctor but that she is an expert about of her own body, so she encourages “terri1977” to claim a similar expertise about her body and actively seek a second opinion when she has a question. Within this post, the doctors and nurses did not feel that they needed to respond; the layperson suggestion was enough to provide the correct answer: get a second opinion and listen to your body. This willingness of the technical sphere to accept lay-expert expertise truly reveals a positive blurring of the boundaries between the private and the technical spheres.

It shows that the medical community can change and a more communal relationship between doctor and patient is possible. The example above reveals shifts in the online conversation between patient and doctor. This blurring of the private and technical spheres then influences the public sphere as women feel empowered to speak with their doctors, get a second opinion, and advocate for their rights as patients. The democratizing move to allow laypeople experts to respond to patient questions suggests that the spheres are fluid. These websites support the conclusion that a public response to a medical issue (such as PCOS) would not just come from the medical community but would come from the collaboration of medical experts and lay-experts.
Validating the Private Sphere and the PCOS Lay-Expert

This community response is not only seen through the collaboration of the doctor, nurse, layperson dialogue but it is also seen as the website authors validate the private sphere PCOS support groups. The doctor websites each connect to the private sphere support groups through suggesting that women who find information on the doctor websites also visit the support group websites for more information and for emotional encouragement. All three websites have multiple listings that reference the Polycystic Ovarian Syndrome Association and the SoulCysters website. Each doctor website provides the support group website address and often gives the address and phone number for the Polycystic Ovarian Syndrome Association. As a result, women have multiple ways to connect to the support groups. For example, Nurse Debbie Miller (2007c) says, “I can direct you to a good site that explains PCOS and includes a quiz to help you decide if you might have it. http://pcosupport.org/medical/whatis.php” (para. 1). As cheryldecarlo (2007) said to Revolution Health, “I encourage anyone who has at least 2 of the illnesses listed to go to PCOSA.com, and take the assessment and contact your primary care doctor if you need. To all my soulcysters out there, hang in there” (para. 1). The nurses and the laypeople on the different sites all support patients looking to the support groups for help. This example shows that any possible PCOS patients should search the PCOSA site for help, while “cheryldecarlo” also references the SoulCysters website. Importantly, women can use the doctor websites as self-diagnostic tools, in that they can check the number of symptoms they have before connecting with the doctor, and they can use the doctor websites for information about support groups. With expert information about terminology and procedure, in conjunction with additional
information, emotional support and personal validation, the women feel more prepared to participate in health discussions with their offline doctors.

The doctor-supported websites validate what the support group sites say and provide them as a means to obtain more information. As Revolution Health suggest:

It can be hard to deal with having PCOS. If you are feeling sad or depressed, it may help to talk to a counselor or to other women who have PCOS. Ask your doctor about local support groups or look for an online group… The Polycystic Ovarian Syndrome Association (PCOSA) provides a central and comprehensive set of resources for information on polycystic ovary syndrome (PCOS). PCOSA also provides an advocacy network, including social support, for women with PCOS and for their families. (Davis & Gallagher, 2008, sec. 1 & 14)

The support group sites thus become an agency for information that the doctor run websites fully support. However, the reverse is not true. The support group websites suggest particular practitioners and highly recommend that women see endocrinologists, or other specialists, but they do not suggest that the women go to doctor websites for informational assistance with PCOS. Instead, they suggest that the women look at the handbooks or PCOS guideline books on their own websites and give links to other useful books written by women with PCOS or doctors who have dealt with this disease for at least 20 years. Doctor websites encourage women to check support group sites, but support group sites do not direct women to doctor websites. There is clearly an infiltration of the private sphere into the technical sphere. The infiltration of the technical sphere into the private is apparent as well, on the level of specialist language, but the permeability of the boundary does not seem to operate in the same way. The permeation
occurs in keeping with the affinity of the private sphere, individual agents learn specialized language and protocols and share with other agents demystifying the technical language. The PCOS layperson expert has credibility within the expert sphere. As a result, the medical community websites allow for the layperson voice and suggest that women find help through the support groups. The collaboration between the private and technical spheres becomes more apparent.

This shift in acceptance of the private sphere by the technical sphere helps highlight that the agency/purpose ratio is critical to the functioning of these doctor supported websites. The authors of the sites want to help women understand and get the best help possible for a PCOS diagnosis. The purpose is to give enough information so the women are empowered to be active agents in their health care. By using the layperson perspective and offering the support groups as credible information websites for learning more about PCOS, American Family Physician, Doctors Lounge, and Revolution Health, all validate the private sphere and suggest that there is more of a connection between the technical and the private. As Revolution Health states:

Many people are more satisfied with their health care if they share the responsibility with their health professionals. Your health professional is an expert on medical care, but you are the expert on yourself. Often there is more than one option for diagnosing or treating a condition. By being a partner with your health professional, you can help choose the option that best fits your values, beliefs, and lifestyle. You also will feel more confident about carrying out the chosen treatment. (Golonka, 2007, para. 1)
Ultimately, you are the expert of yourself. The doctor websites suggest that the expert does not just come in the form of a medical degree but also comes in the form of experience. Therefore, the private sphere merges with the technical when individuals have the illness experience. In other words, the private becomes technical in a special way, as there is collaboration between the medical degree expert and the PCOS personal experience expert.

This move influences the public sphere because more agents feel they can participate in the democratizing of health. When the private individual shares her opinion about PCOS and gains validation from the experts, then this private experience grows into a collaborative process. Exploring where doctors collaborate with PCOS patients generates a type of, what Habermas (1989) calls, “critical publicity” (p. 188). While Habermas (1989) urged for such spaces of deliberation within the public sphere, finding these moments of collaboration within the technical and private sphere opens spaces for deliberation regarding matters of common concern. Through the technical sphere websites, the audience understands that medical personnel and laypeople can converse. The public therefore recognizes that one needs the personal story and the expert to get something accomplished, in this case change people’s understanding about health situations.

This analysis teaches us that support group websites use technical terminology to connect with the doctors and the doctor websites suggest that women use the support group sites to gain information and emotional support. The result is each website example shows a shift: the technical/private spheres permeate each other but maintains their own essential affinity. The private support groups reach into the lexicon of the experts to gain
legitimacy and commonality between women. The doctors suggest that the women connect to the support groups for help and at the same time suggest that specialist may help one gain more health answers. The result is a blurring of the spheres where the private sphere starts sounding like the technical and the technical sphere encourages even more technical expertise yet pays heed to the private sphere examples. This creates a complex identity for both sphere components. The ratios then shift some, where the affinities remain the same (private=agent, technical=agency) the stronghold that those affinities have is altered some as agency becomes important to the private support groups and the purpose combined with the agent becomes essential to the doctor websites.

Ultimately, these ratio shifts influence the relationship of the private/public spheres with the public sphere. While traditionally the public sphere consists of individuals who can speak and generate change within the system, this definition changes as the internet becomes more influential within our everyday lives. According to Research and Markets (2010) over 221 million people in the United States, about 71% of the total population, are online. This number will grow to over 77% of the population achieving online status by 2014 (Research and Markets, 2010). This medium is fast becoming a space for public advocacy. As such, when we see spheres weaving into one another, such as with the doctor and patient websites analyzed in this project, the public observing this blurring affect understands that they can influence the way people interact. Conversations flowing from one sphere to the next, through spaces provided on the internet will have a significant impact on how we view democracy and may help democratize other areas of our life.
References

A hormonal mess for the past 28 years, and I can’t take any. (2005, Sept. 4).


CHAPTER SIX:

Between the Spheres: Blurring the Sphere Boundaries and Forwarding Democracy

After observing how the PCOS and doctor websites allow for communication between the spheres, I return to my research questions and address the changing nature of sphere influence. I will first address each research question, second reflect on the limitations of the dissertation, and finally discuss implications for future research. To start, let us return to the research questions posed in chapter one:

**RQ1:** What does the talk surrounding PCOS reveal about the fluidity of sphere boundaries?

**RQ2:** How do online PCOS support groups and doctor websites influence deliberation and health democracy?

**RQ3:** How does PCOS support group discourse alter the rhetorical construction of the patient/citizen?

**Between the Spheres**

When addressing the first research question, I first return to the sphere metaphor itself and explain how the traditional distinctions are not working with online structures. Second, I address four conclusions that explain what the talk surrounding PCOS reveals about sphere boundaries. 1.) Increasing access to expertise and expert language challenges the sphere distinctions. 2.) PCOS women gain strength through personal connection to blend the sphere boundaries. 3.) Validating the expert’s expert reveals a hierarchy within the technical sphere that questions the make-up of the technical sphere. 4.) Endorsing the lay-expert hierarchy blurs the private/technical sphere boundary.
After exploring patterns of PCOS discourse, I argue that the spheres still maintain a strong connection to their particular original affinity. The private sphere still valorized the agent, especially the lay-expert. For the PCOS support group websites, individuals find each other and tell their personal stories in order to understand their disease and find emotional support (Kral, 2006). As for the technical sphere, doctors still argue for their position by suggesting particular diagnostic procedures and articulating specific symptoms that the women should look for when considering if they have PCOS. They also suggest that women make appointments with specialized experts, individuals who have very specific medical knowledge and a greater understanding of the procedures behind that particular specialization. While doctors are often adhering now to a more patient-centered model, their primary focus is to diagnose the patient using the scientific measurements they have available (Katz, 2002). The medical community focuses on objectively gaining information from a patient in order to make a diagnosis. The diagnosis drives the doctor encounter not the subjectivity of the doctor-patient relationship. As such, the means of rendering a patient treatment protocol is most important to the doctor. The few examples of the public sphere also show that PCOS women unify around the same purpose, PCOS education, urging the government and medical community to pay more attention to this syndrome. The point is that for a complete sphere shifting to occur, those different sphere affinities would have to change. Instead, what I observed through the discourse was a more blended form of talk that could not be categorized as solely private or technical, but instead represented a more
“between the spheres” talk that defies the space/place articulation of sphere theory. For example, SoulCysters member J&J Doepel (2010) said of her experience with PCOS:

Hi everyone my name is Jamie and this is my story about living PCOS and trying to conceive. A little back story, my first signs of PCOS were at the age of 13. My mom rushed me to the hospital thinking my appendix was bursting only to find out that I had developed cysts on my both of my ovaries causing me great pain and irregular periods…. I married my boyfriend of 5 years last October and now we have decided that we want to start our family. So the search for a doctor ensued. We finally decided to see Dr. Haas in Oklahoma City. We had our first visit on Jan 26th. I was given an ultrasound and blood work was done. I was started on Metformin, Prenatal vitamins, Provera (7days)…. 3 days after I ended the Provera regiment I started! I then started taking my Basal temp reading every morning before I get out of bed. My next appt with Dr. Haas is March 1st. I am very pleased with Dr. Haas and do recommend him to anyone woman trying to conceive with PCOS. (para. 1)

This example starts with personal information about J&Jdoepel. Then she moves from the public talk to discussing what doctor worked for her and what medical protocol she was under to start trying to conceive. She uses medical fertility terminology and personal examples in her post. This exemplar reveals a more blurred sphere dialogue because it shows her technical sphere knowledge weaved in with the vulnerable personal information.

Through the development of the internet, worldwide human interaction has increased, connecting people between the spheres, allowing for inter-sphere social
interaction. This is what I would call “between the spheres” talk, which is discourse that has aspects of the private sphere, the technical sphere, and possibly the public sphere, although that was not often observed in this discourse. This blending sphere metaphor recognizes the traditional affinities within each sphere of influence but also acknowledges that conversation provides ways to create tension with the alternate sphere’s affinity term. What I am suggesting is that the technical sphere recognizes the private sphere PCOS women as agents but then massage the discourse to revolve around agency when providing advice. The private sphere PCOS patients do the same, where they use the protocol agency talk that the experts discuss and focus the discourse on the PCOS women as agents. The private sphere agent and technical sphere agency affinities creates tension between the two when they encounter the same space.

Let me provide examples to clarify. Within the technical sphere, the medical community takes an individual’s private story and turns it into an example that can help future patients connect with others and feel better about their disease. As discussed in chapter five, the doctor websites valorize the private sphere by suggesting that women dealing with PCOS seek out the support group websites. Revolution Health says:

It can be hard to deal with having PCOS. If you are feeling sad or depressed, it may help to talk to a counselor or to other women who have PCOS. Ask your doctor about local support groups or look for an online group… The Polycystic Ovarian Syndrome Association (PCOSA) provides a central and comprehensive set of resources for information on polycystic ovary syndrome (PCOS). PCOSA also provides an advocacy network, including social support, for women with PCOS and for their families. (Davis & Gallagher, 2008, sec. 1 & 14)
This example shows that the medical community acknowledges the female patient agent by saying, “It can be hard to deal with having PCOS…,” and then they focus the conversation on suggested ways to management the syndrome by seeking out PCOSA and/or other support groups. The doctor website’s focus shifts from the female agent to the suggested remedy, which in this case is the PCOS support group websites. The medical community acknowledges the PCOS agent but shifts the conversation from private agent centered talk to agency-centered discussions on treatment to help the patient improve.

To explain the agent/agency tension from the private sphere, we return to J&J Doepel’s (2010) post. The personal story starts the post, and then discussion of the treatment Dr. Haas suggested follows. Finally, she moves back to focusing on agent through suggesting Dr. Haas as a reputable doctor agent and she gives her opinion. The focus shifts from the technical agency talk to more personal/personal opinion talk. The point is that by observing the PCOS discourse, I recognized aspects of each sphere affinity within the other but the weaving of the two sphere affinities resulted in a type of talk that seemed neither public nor private but between the two.

This shift from observing strict sphere boundaries to analyzing discourse between the spheres is analogous to the communication studies discipline struggle. As Cohen (1994) explains when the speech teachers divided from the English instructors in 1914, creating the National Association of Academic Teachers of Public Speaking, a new area of study was considered. Since that moment, the discipline has been arguing about the boundaries regarding how one can study communication. As Sproule (2008) explains:
But if the full story of communication has yet to be written, we may at least depend on its having safely metamorphosed from loose concept on the 1930s to borderline field in the 1950’s to full-fledged discipline at the beginning of the twenty-first century…. Clearly, the final verdict on communication’s circuitous route to disciplinary catholicity has yet to be written. Yet despite varieties of selective memory, and continuing disputes over purposes, concepts, and methods, the discipline variously succeeds in synthesizing its humanistic, social-scientific, performative, and professional strands. (pp. 174-175)

As the discipline advances, the lines between the different fields of study are blurring and different types of methods and objects of study are considered appropriate. This synthesis allows more space for studying different forms of communication. As with our discipline struggles, we need to quit strictly categorizing how we speak by using the spheres of influence to classify our talk. We interact through informal social structures in which clearly defined boundaries are difficult to articulate; and therefore, we must allow for more weaving between the argument fields in order to understand our actual social arrangements and move toward a more democratized society. The point is that having “between the spheres” talk provides space for more fluid discourse that weaves together the different sphere distinctions. This weaving generates space for actors in the different traditional spheres to interact and understand each other’s language, providing more of an open field for democracy.

The women with PCOS, before 1995, had few PCOS resources (DeZarn, 2003). With the development of the internet, the women were able to find each other. While Hindman (2009) argues that many hierarchies reify through digital structures, especially
through the way search-engine protocols are designed to privilege certain blogs/websites over others; this is not fully the case for women with PCOS. These women were able to generate space that weaved the private sphere, and technical sphere language together resulting in conversations that were not fully private or technical. These women needed the development of the internet to find each other and create the support websites that have such strong followings. As Harris and Cheung (2008) excitingly report, “With the fantastic rise of websites, from Verity in the UK to PCOSupport [PCOSA] in the US and Australia, and chat rooms where women from all over the world can share their thoughts and questions, the world of PCOS…is a very different place” (p. vii). The resources are vast. What this case study teaches us is that the private sphere conversations start to appropriate technical sphere talk and the experts start sharing the internet space with laypeople to provide differing voices on their websites.

**Increasing Access to Expertise and Language Appropriation**

With the development of the internet, expertise has been divorced from privileged locations such as the lab, office or hospital. Additionally, no longer do credentialed experts have exclusive access to medical information; the internet increases the access for many. The everyday person, who has online capability, has access to the technical information. The architecture of the internet makes this possible because an individual can just click on the web address of the support group sites and toggle back and forth between the doctor websites and the support group websites attaining information from both the technical and the private sphere representations. As such, the medical language does not hold the mystery it once had. Habermas (1987) explains that, as the technical sphere was able to take over the lifeworld in part because it generated more mystery in its
language that was not clearly understood by non-experts. Now, when the personal and the technical come together, the language that used to separate the two spheres blurs for PCOS patients.

Since the blurring of the private sphere talk and the technical sphere talk, the PCOS women now speak not only with the doctor using medical terminology, but also speak with each other using technical terms. The women use the medical agency to help inform the private agents. For example, they use terms such as “Clomid [a drug used to encourage ovulation]” and “ttc [trying to conceive]” to connect with both the text savvy community and the fertility doctor community. The point is the agent who has complete control in the private sphere uses a distinct agency to reach out to others with the similar condition. Through appropriating the language of the medical community and use it in their own way, the women gain a better understanding of the medical community. The women provide a glossary of terms on the websites to help the new people acclimate to the websites, and they offer encouraging words to help the women share their personal stories. They entwine the acronyms and language of the medical communities with ones of their own. For example, on the SoulCysters website, there was a discussion thread titled “April’s BD bring May BFPs” which means “April’s Baby Dance (sex act) bring May Big Fat Positives (positive pregnancy tests). Within this discussion, miasal2003 (2010) explains, “It’s official I’m pregnant! CD1 [Cycle day1] was April 11, HCG [Human Chorionic Gonadotropin, an ovulation stimulator] shot april [sic] 21, IUI [Intrauterine Insemination] April 23, 82 million sperm 90% motility” (p. 1). She goes on to explain the specifics regarding her insemination and at the end of the post, miasal2003 says she is scared to lose this baby but is hopeful. The women play around with the
private language such as BD (baby dance) and use technical terms such as CD1 (cycle day 1) within their discussions. The point is that the private uses the technical sphere language in a way that other female agents can relate. The PCOS agents get comfortable with the medical terms and in turn understand the medical agency. This talk strips away the mystery behind the authority rituals from the medical community; as a result, the patient feels the doctor visit becomes a more democratic process.

**Strength through Personal Connection**

Women have historically pressed for greater autonomy and empowerment over their bodies. As shown through the many editions of *Our Bodies Ourselves*, and other such works, women have challenged the medical establishment well before the internet (Boston Women’s Health Book Collective, 1973). The open architecture of the internet has allowed for the acceleration of these social forces as women find many connections with one another. The sharing of personal experiences is no longer restricted by location. This medium allows individuals to connect with people who are dealing with similar situations. Before the internet, one might find one or two people with similar symptoms; now, one can find thousands of people with similar characteristics and interests.

This public medium, the internet, allows people to compare experiences giving many women confidence as they realize they have other people’s stories as evidence upon which to base their claims. For example, OneStarTattoo (2010) tells PCOS patients to resist doctor advice that does not work for them. She explains:

Hi everyone, it gets me so angry the way we are treated by doctors who either don't know enough or don't care enough or maybe both. I am sorry for that. It took me many many years before I found a good doctor and I live in NYC, there is a
Dr. on every corner. I thought I saw somewhere on this site resources for finding a PCOS-"friendly" (for lack of a better word) doctor. Look around and see if there are any in your area. (OneStarTattoo, 2010, para. 1 & 2)

The women feel empowered to share their experiences with others and give suggestions to look on the support group websites to find PCOS knowledgeable doctors in their area. The PCOS women feel comfortable sharing their experiences with others and may even resist doctor’s influence offline because of their newfound confidence and understanding of PCOS. As Kathryn Carney (2010) explains:

Then, after talking to my doctor, I went off my medications, and requested a prescription women with PCOS). He said, “No!” So, I went to 3 more doctors until I found one that would prescribe it, providing I came in for regular liver testing. OK!!! (para. 13)

Kathryn Carney is making a decision about comparative PCOS risks. She wants to make the best health decision for her and not let that decisions be usurped by physicians. The support group websites in particular allow individuals to share their stories and draw confident generalizations about their experiences. These experiences provide a sufficiently robust knowledge base to challenge expert conclusions. Within the PCOS support group websites specifically, women spend a lot of time explaining their stories to each other. As discussed in chapter five, the PCOS stories told on the support group websites usually explain the frustration the women have experienced with the doctors because they are not knowledgeable about PCOS. The PCOS women’s stories are familiar to one another as they find common ground with each other based on a common symptom or a negative experience with the doctor.
Through their stories, the women can connect. As a result, the patients, both new and experienced, feel a bond. The agency the women use is story-telling, sharing personal information to help connect the women together. For example, Nan2010 (2010) says:

Like Marianne [a fellow PCOS SoulCyster] said, knowledge is power. Ever since I was diagnosed I try to read up on PCOS. There's a wealth of knowledge on the internet for free, if only you can make time out to read about it. There are websites such as this, blogs and Newsletters that you can subscribe to. If you can implement one positive life-changing act per week, you'll see a turnaround in just a month. Your symptoms will improve and your quality of life too will get better. Your hair will grow back and those annoying ones will thin out and eventually disappear.

No action is too small. Make a resolve to change your lifestyle and believe me, you will be happier. You are not alone my dear, I feel your pain too. You have to be strong, and see this as a challenge. If you visit www.ovarian-cysts-pcos.com/, and click on hirsutism there's a wealth of info there that you'll find very useful. Try them out, you might feel you're getting nowhere in the first couple of weeks, but hang in there and you'll soon see changes in your life.

And don't suffer this alone. You NEED someone you can talk to. If you can't talk to anyone you know, start a blog, vent your feelings. If you keep them bottled up you will find it hard to move forward. (para. 1-3)

These stories create a depth of personal experience for each woman individually and yet the similarities in the stories allow the women to challenge the expert advice, or lack of expert advice, they have been given. The women see their personal stories in other people’s stories, and they feel supported which allows them to provide sound emotional advice and as a result the women often question expert advice. The strength the women find through each other allows for talk that informs the experts who are unfamiliar with PCOS issues.

Beyond providing information from the private sphere to the technical, through the websites, the women have the ability to compare different expert opinions. Each woman has different doctor stories to share and there is plenty of material on the support
group websites, as well as other informational websites, to help encourage and or
discourage women from seeking out particular doctors. This provides a means for
comparison. The women read the critiques regarding the different doctors and decide
which expert is right for their particular case. The individual agent voices make it
possible for the stories agencies to resonate and allow the women to seek the right type of
help.

These first two themes help show that increased access to medical information
and patient connection are critical to encouraging a blurring between the technical and
the private spheres. It is the subjective experience of the patient agents, made possible by
the internet, which diminishes expert authority. The access to more medical information
and the ability for patients to understand many similar patient experiences demystifies the
technical sphere and provides space for the private to influence the technical.

Validating the Expert’s Expert

Beyond showing evidence that the private sphere has infiltrated the technical
sphere, this study also provides support for promoting the technical sphere itself. As
addressed in chapter five, the women with PCOS are continually looking for better
experts. They constantly search for more experienced and better-trained physicians who
know the best treatment regimes for PCOS patients. As explained earlier through
OneStarTattoo’s post, the support group websites even have discussion boards where
women give doctor referrals to women struggling to find adequate care. The SoulCysters
website has a forum titled “Find a Doctor.” Within this forum, women have posted names
and locations of doctors in different states who they consider “PCOS specialists” (“PCOS
Friendly Doctors,” 2010, para. 1). These specialists are doctors who provide accurate
diagnostic and treatment advice while treating the women as individuals with specific individual needs. The point is the women do support the biomedical model if doctors use the right, refined protocol to diagnose and treat PCOS. Therefore, when connecting back to the ratios, when finding the right doctor, the PCOS women valorize the doctor’s agency over other pentad terms because using the right protocol will provide women with productive results concerning PCOS. This focus on proper diagnostic tools or agency then allows women to give their personal stories of how the right doctor helped them, which focuses conversation back on the agent and her opinions regarding the doctor.

Finding the right doctor agency can improve the personal PCOS agent. This shows that the agent/agency ratio is present within the PCOS website discussions, which result in the PCOS agent informing others about the agency used by the best PCOS doctors. This again expresses more of a “between the sphere” talk because the technical doctor sphere agency is discussed as a part of a personal PCOS agent’s story. When sharing their personal stories, the women say the lack of adequate diagnostic protocol and doctor humanity is what has frustrated the women in the past. As a result, the women fully support a doctor who can give them understanding as well as concrete suggestions to improve their health situations.

The doctor websites also suggest that the PCOS women go to specialists, endocrinologists or gynecologists, to achieve a more accurate prognosis. This means that the doctor experts even suggest that women seek more expertise to achieve an accurate PCOS diagnosis and proper treatment. The physicians and nurses on the doctor websites and the women experienced with PCOS, all suggest that the specialized doctors have a more advanced protocol and more experience in dealing with diseases such as PCOS. The
point is, the expert’s expert still has high credibility and the protocol, which the specialized expert uses, is considered legitimate by both the private sphere and technical sphere participants.

What this says about the weaving sphere boundaries is that while the private sphere discussions influence the technical sphere, there is still a desire for technical sphere authority within the private sphere. There still are distinctions between the three spheres but as people continue to share their personal stories, specifically within online spaces, those personal stories gain acknowledgement from the other spheres making the talk within each sphere blend and become less specifically technical or private.

*Endorsing the Lay-Expert Hierarchy*

The lay-experts assist in making sure the talk surrounding the PCOS support groups infiltrates the technical sphere, helping personal stories gain acknowledgement from the experts, democratizing the medical experience. Many different types of experts participate in PCOS discussions. Based on the different expert influences, I have generated the taxonomy of PCOS related “experts” based on perceived credibility. This taxonomy is patient driven where the women with PCOS recognize the individuals who are most trustworthy and knowledgeable in giving the women medical and emotional support. O’Keefe (2002) explains that, “Credibility (or, more carefully expressed, perceived credibility) consists of the judgments made by a perceiver (e.g., a message recipient) concerning the believability of a communicator” (p. 181). Many factor-analysis studies have occurred in determining the “dimensions underlying credibility judgments” (O’Keefe, 2002, p. 182). The two main dimension of credibility are expertise and trustworthiness. Coupled with this is trustworthiness, an individual will lack credibility,
or ethos, if they cannot be trusted, or if they seem insincere. The point is that expertise does not just come from having a title and credentials but another factor that influences credibility is for an individual to have perceived competence and sincerity. People’s differing perceptions result in multiple “experts” given any situation. As such, the women with PCOS have their own perceptions regarding credibility and talk about this perceived expert hierarchy informally through the discourse on the support group websites.

The PCOS case study in particular generates a unique expertise taxonomy. This taxonomy consists of individuals on the doctor websites as well as the PCOS support group websites who are viewed as credible agents at improving the health of people with PCOS. Each within the taxonomy has some type of “scientific ethos” (Segal & Richardson 2003, p. 138). According to Segal and Richardson (2003), this means that the individual:

…typically involves the mastery of a specialized theoretical vocabulary or experimental equipment, proper certification and institutional position, and a specific sense of the construction of scientific explanations and of where explanations are no longer to be sought. It also involves a set of gestures, tropes, and norms that govern appropriate moments of the properly scientific production of persuasive speech and action. (p. 140)

For strong ethos to be present, the individual needs to understand the medical language, feel knowledgeable about scientific protocols, and use appropriate “persuasive speech” when convincing others how to take care of their health. Segal and Richardson (2003) warn that this credibility is perceived. She says, “Even the most ardent believer in an infallible scientific method understands that such a method produces credible knowledge
only insofar as it guides the activities of people who use it in the production of knowledge” (Segal & Richardson, 2003, p. 139). For the women with PCOS, their perception valorizes emotional support over doctor credentials. The result is that the individuals who can cross the spheres and add a personal touch to the medical information have more credibility.

Within this taxonomy, there are the “expert’s experts,” who as discussed previously, are trained, licensed professionals with credential authority. These are the reproductive endocrinologist and other specialized doctors who have earned the trust of their PCOS patients because they understand PCOS as a syndrome. Even within this definition, there are specialists that have more credibility with the PCOS women then others because of their connection with the private sphere. The specialists who take the time to know the women and meet their emotional as well as physical needs have more credibility than the doctors who just have a strong medical knowledge of PCOS.

Individuals who take both the personal and medical aspects of a patient into consideration would be considered a “sphere-crosser,” because they are able to speak the language of both the technical and private spheres.

The second on the hierarchy list is often the “PCOS lay-expert” who has had medical encounters and knows how to speak the terminology. This expert is also a sphere-crosser who speaks the private sphere and technical sphere PCOS language. She has also lived with the disease for years and has empathy for the other women. The lay-expert has expertise in PCOS issues and is believable because she can talk using both the doctor language and the vulnerable language of someone with PCOS. The lay-expert often becomes a voice for PCOS advocacy, moving the message into the public sphere.
Third are the “nurses” who often have expertise in providing emotional support and informative PCOS information to the women. They too are “sphere-crossers” because they are trained to listen to the patient and provide empathy. They also give proper PCOS medical advice.

There is also the “PCOS coach/counselor” who helps people deal with the private sphere issues surrounding PCOS. They may be sufferers of the disease or they may just be supporters. They gain their expertise through having high emotional intelligence in which they know how to relate to people and are sympathetic to the different PCOS experiences. These individuals are good at dealing with private sphere discussions and helping the women feel supported.

The “doctor experts” also have some authority within the PCOS expert taxonomy. These individuals have legitimate authority derived by their credentials. Sometimes this trust is questioned if the doctors give poor advice or do not know enough about PCOS to make a diagnosis. Other times these doctors gain the trust of the PCOS women who enter their office and further their credibility by providing a sound diagnosis. Most of the “doctor experts” are not “sphere-crossers” as they solely use the biomedical model to render a diagnosis.

There is also the “self-expert,” individuals who know their own bodies and are able to share their personal stories with the online support groups. These individuals are not “sphere-crossers” either. They gain credibility through the private sphere alone as they feel brave enough to share their story within the public online support groups.

This taxonomy is not exhaustive, but through these illustrations, one understands the many levels of expertise from within the technical/private spheres, influencing how
people respond and deal with PCOS. The individuals with the most credibility are ones who can speak the language of both spheres providing accurate diagnosis and emotional support. PCOS women recognize credible experts as individuals who blend the private and technical spheres. This means that credibility is given to the doctors who pay attention to the private stories and the women with PCOS who understand medical procedures and accurately use the medical language, demystifying the doctor encounter. Additionally, this taxonomy does not limit an individual to one category. An expert’s expert could also be a PCOS patient expressing specific medical knowledge as well as personal knowledge to patients with PCOS. The point is that expertise comes in many forms and influences the spheres in different ways, which results in an alternate online hierarchy.

As seen through the explanation of the previous theme (validating the expert’s expert), these PCOS websites are not anti-expert. They still give credence to advice given from specialists and experienced females with PCOS. However, the PCOS women listen to experts who share their PCOS stories; the women pay attention to the agents who provides advice that is personalized. The PCOS case creates a reversal from the typical technical power where the lay-expert’s knowledge of the terminology and protocol increases her power. In this instance, the emotional connection and understanding of the patient’s syndrome trumps credentials. The lay-expert women are often more knowledgeable about PCOS than the doctors, while the doctor has expertise in the medical realm the patient has expertise in living with PCOS. This expertise is based on the lay-expert’s personal experiences, and ability to demystify the technical sphere so other women with PCOS can understand the medical terminology. Through the study of PCOS as an online case, I found that the women gained power because of their own
personal experience. Usually, personal experience is not perceived as having “scientific ethos,” the objective medical protocol is more important to obtaining accurate scientific results. However, the PCOS community sees the personal as a means to get the doctors to listen because the women have information about PCOS that can help inform the doctors and the PCOS community. When the private spheres and the technical spheres blur, the doctor’s office becomes more democratic for the women with PCOS. As Shannon’s story, from chapter five, exemplifies, “I recently gave my doctor (Ob/Gyn) copies of the newsletters and she was very excited to have them. She recently had two teenage girls become patients that have PCOS and needed the information to pass along” (Shannon, 2006, para. 62). The PCOS lay-experts supplement the doctor’s information and help provide assistance to others with PCOS. The result is that the lay-expert women with PCOS become a part of the medical agency to help a PCOS patient become healthy.

Given this taxonomy, while the lay-expert has great credibility with both the PCOS and medical community, one can see how the expertise from both fields becomes important when addressing issues related to PCOS. Each of the doctor websites in this project rely on the expertise of the women with PCOS to provide information to the PCOS community. The doctor websites do so by suggesting that the women go to PCOSA or SoulCysters for more information regarding PCOS and valid places women can go to gain emotional support (Davis & Gallagher, 2008). In other words, the expert websites consider the private stories of the women as part of the expert advice given to new PCOS patients, because the women are specialists in dealing with PCOS. Revolution Health especially supports this message saying, “Your health professional is an expert on medical care, but you are the expert on yourself” (Golonka, 2007, para. 1). Women with
PCOS share their stories on the doctor websites. Additionally, not only do the doctors and nurses respond to inquiries, but the women with PCOS also provide advice. Therefore, the women with PCOS are framed in a way to show that their expertise; the private sphere is what gives the PCOS women credibility within the technical sphere.

When putting this in Burkean terms, the lay-expert agent knows how to speak the language of the doctor office agency. As such, agency is still the main affinity within the technical sphere, but who can endorse this agency shifts. In this instance, the female PCOS patient becomes influential in the discussion between the doctor and the patient as the private stories of the woman help to inform the doctor’s visit.

For women with PCOS, the lay-expert patients possess authority and credibility that surpasses the doctor’s scientific ethos. The authority behind the doctor/lay-expert carries less weight than the good outcomes that occur for good PCOS management advice. This is a departure from traditional sphere relationships where the technical sphere structure is based on the amount of authority an expert has. In this instance, women listen to experts who will provide positive results. Authority is denied to doctors who do not make positive changes in the lives of women with PCOS, as the patient will find someone else for her medical needs. This generates a form of female empowerment that encourages women to share their stories with the doctor, fostering deliberation between patient and physician.

**Deliberation and Health Democracy**

The deliberation that occurs between doctor and patient within this case study promotes a more democratic space regarding health communication. Returning to Dewey’s definition of democracy, he suggests, “Democracy begins with conversation”
(Post, 1993, p. 171). Dewey (1927) warns us, “No government by experts in which the masses do not have the chance to inform the experts as to their needs can be anything but an oligarchy managed in the in interests of the few” (p. 208). In other words, the masses must be able to have a voice in the community for democracy to exist. While not perfectly analogous, because Dewey was talking about communication between people within the public sphere, and this study focuses on the private sphere demystifying the technical sphere to forward democracy, Dewey’s warning relates to PCOS because the patient must be able to participate at some level in technical sphere conversation for democracy to occur. The example of PCOS provides a case for female empowerment and provides a case for democratizing the medical experience, which brings us to the second research question. The answer to this question, “How do online PCOS support groups and doctor websites influence deliberation and health democracy?” is that the websites challenge colonization for both the private and the public sphere through conversation, ultimately increasing deliberation and democratic potential for the technical sphere.

Expanding on this answer, I first review our discussion on colonization. Second, I explore how the private sphere resists technical sphere colonization through the PCOS case. Finally, I briefly explain how the internet provides space for public opinion outside of the technical sphere influence, decolonizing the public sphere.

Colonization Review

As explained in previous chapters, experts colonize the private and the public spheres, which diminishes personal autonomy and hinders the development of public opinion. As Habermas (1987) said, we must be cautious of technical sphere advancement because the result is “a colonization of the lifeworld by system imperatives that drive
moral-practical elements out of the private and political-public spheres of life” (p. 325). Within the health field, the technical sphere has the most knowledge and therefore influences the patients and the public regarding what they should think concerning health issues. The technical sphere colonizes the public and private spheres regarding medical issues because the health care professionals are experts regarding medicine, limiting who can participate in discussions of health. The language used by the medical experts often creates mystification for the patient making it difficult for an individual to feel comfortable, or knowledgeable, enough to participate in the discussions that occur in the doctor’s office. However, with the development of the internet, patients change how colonization occurs for both the private and public spheres.

When relating the second research question answer to the Burkean ratios, it is the private sphere agent and the public sphere purpose that make challenging technical sphere colonization possible. As explained earlier, “agent” continues to be the affinity term for the private sphere because it is through the stories of individual women with PCOS that others are able to feel they can own their stories and express their voices. The PCOS website contributors give women the means and the language to participate in the discourse at the doctor’s office. For the public sphere, the agent is still a very important term as the women with PCOS connect with people outside of the PCOS community by sharing their personal stories. It is the individual stories that intrigue people without PCOS and as a result, these individuals, who make up the public, want to learn more about the disease. While the PCOS stories, and the individual agents, connect the public to the disease, it is the unified purpose that helps push the public into action. The unifying purpose: to promote PCOS education and make sure every population is aware of this
syndrome. This purpose is what focuses the audience toward action because the audience knows that when people gain accurate information they can participate more completely within the public sphere and within the doctor’s office. The increase in PCOS knowledge provides a means for people to deliberate effectively regarding their health. The focus on purpose helps open space for health democracy. With an understanding of how the private sphere agent affinity and public sphere purpose affinity remain stable within the PCOS example, we can now look toward what this means in terms of colonization concerning health democracy.

_Private Sphere Colonization_

The PCOS patient has combined knowledge about her personal situation and knowledge about the medical protocols, which results in the patient co-creating democratic space within the doctor’s office. The patients use their personal experiences to gain understanding of medical expertise and then use that knowledge to inform their doctor visits.

The PCOS women have demystified the technical sphere by understanding medical language and procedures, which is a form of decolonization. However, in some ways, colonization increases within the private sphere. For example, the PCOS women use the medical language surrounding fertility and PCOS, and they now use it in when talking about their private situations on support group websites. As a result, new PCOS support group members who do not understand the medical terminology have to learn the language or they cannot fully participate in the PCOS discourse. The colonization and mystification of the support group websites occurs when new members join. Now, the women, as explained in chapter five, support new individuals and help them learn the
language through answering questions and giving the new members a glossary of PCOS website terms, but if the women are intimidated by the language or talk of medical procedures, they may not join. The PCOS women also do not resist the biomedical model, they learn the medical procedures and they trust in the specialists to give appropriate advice regarding PCOS issues.

The appropriation of the medical terminology and reliance on the biomedical model to nurture PCOS women to health makes the PCOS case complex because it demystifies the medical establishment while colonizing the private sphere with technical language. This case is similar to the ACT UP activist group; the members of ACT UP, an AIDS activist group, were not satisfied with the medical establishment’s decision to use traditional protocol when testing new AIDS drugs. People with AIDS were dying quickly and the ACT UP group wanted to make sure that everyone received the actual trial drug and not a placebo. The members of ACT UP learned the language of the medical establishment to push forward changes concerning AIDS drug research (Brashers & Jackson, 1991). While they were working to change the medical establishment, they still relied heavily on the biomedical model to help save their lives. While the ACT UP group is an example of “public penetration into the technical sphere” (Brashers & Jackson, 1991, p. 287), and the PCOS case is an example of private penetration into the technical; both cases show that some form of colonization was necessary to learn to talk the talk of the medical establishment. By accepting the biomedical model, the AIDS and PCOS patients were able to improve their lives.

This increased use of doctor language and understanding of medical procedures, while increasing the medical influence on the support group websites, has allowed the
women to resist colonization in other ways. The women, as discussed earlier in this chapter, have taken the doctor language and appropriated it for their own use. The PCOS women do not just allow the medical terms to take over the support group discourse. Instead, the support group members communicate with each other through the terms and acronyms to make the terminology more personal for the women. They have come up with acronyms such as RE (reproductive endocrinologist) and AF (Aunt Flow or menstruation), and BMS (baby making sex) to discuss the “medical” process using their own language. This shows that while the doctor terms have influenced the private sphere, the women still make the support groups websites their own and are able to use language that helps validate the personal story while at the same time providing understanding of fertility. By comprehending the language, women can feel more confident speaking to the doctors.

While the technical language acceptance and acceptance of the biomedical model increases medical influence for PCOS support group members, the appropriation of language and ability to deliberate when in a doctor’s office reduces the technical sphere’s control over the private. The collaborative discussion allows for what Turner (2003) calls “mutual comprehension” (p. 12) where both the doctor and the patient understand the diagnostic conversation and promote a more democratic exchange. Through opening the exchange of ideas between doctor and patient, the medical practice becomes more democratic.

This form of private sphere deliberation within the technical sphere has occurred in other diseases as well. Fair (2010) explains that individuals with Morgellions disease, a medically complicated illness that consists of disfiguring skin lesions, fatigue, and
significant memory problems, have connected with each other, telling their stories through online resources. The patient feels empowered to challenge the doctor’s authority because the patient knows more about the disease than the doctor. It is the personal story, and the connection to others through personal story, that allows the patient personal autonomy. No longer is the personal story colonized by the technical; the doctor must listen to the patient’s story as the “patient” is seen as a “personal expert” who knows more about the disease than the doctor knows. As a result, patients are able to be a part of the medical deliberation and the medical encounter becomes more democratic.

*Public Sphere Influence on Colonization*

Regarding the public sphere, the internet provides space for public opinion outside of the technical sphere influence. Traditionally, the technical sphere greatly influences public opinion because, as Bantz (1981) explains, there is little “shared understanding” between experts and the public which “can seriously hamper intelligent discussion of crucial public issues” (p. 87). The women on the PCOS support group websites try to reduce the impact of public sphere colonization by promoting shared understanding between the doctors, patients and the public. The websites provide space for deliberation because the internet blurs the distinction between the private/public spheres. Women come together in private to fashion a force of public will. The support group websites provide space for women to rally together as a collective. The women with PCOS often have individual encounters with people to discuss the disease, and in return, these encounters become a force for forming public opinion. As viewed through the discourse that transpired in the doctor websites and through the personal PCOS stories, one can see that the medical community is encouraging people to gain more
knowledge about PCOS from the support group websites and from others with the disease. The doctors, at least within the discourse analyzed for this project, are not opposed to the private sphere gaining and expressing accurate PCOS knowledge to others. The medical community is in support that the public should be more aware of PCOS. As Dr. Futterweit (2006), co-chief of the Endocrine Clinic and clinical professor of medicine at Mount Sinai School of Medicine in New York City, says to his patients “…take control of this condition instead of it controlling you. To see women with PCOS smile again, feel better, be more assured and self-confident, and eventually achieve their goals in life—that must be the aspiration of any physician treating them” (p. xviii). This results in a collaborative effort to encourage information dissemination and healthcare practices.

The public opinion that the PCOS women share is that everyone, especially doctors, need to be more aware of PCOS and support women who have the syndrome by educating others. This opinion is then delivered to the public through petitions, campaigns, walks, YouTube videos, Facebook, etc. The public then learns about the struggles of women with PCOS and questions how the medical field is responding to this syndrome. This public opinion may challenge the audience to reflect on their personal experiences with the medical community and empower individual patient behavior. As a result, deliberation occurs in the form of critical reflection because the public learns more about PCOS and critically evaluates the medical field’s responsibility for providing care. This move promotes deliberation between the public and the physicians working toward greater PCOS understanding. As Dr. Elizabeth Vliet (2006), practicing women’s health physician, says, “Together, we all make a difference. Together we continue to make
positive changes toward a healthcare model for the future that will incorporate our unique hormone makeup as women into all of our health assessments and treatment planning” (p. x).

**Patient/Citizen Construction**

In answering the third research question, “How does PCOS support-group discourse alter the rhetorical construction of the patient/citizen?” the focus shifts from looking at the spheres and democracy potential toward issues of citizenship. The construction of patient/citizen alters in two ways: the patient becomes a more proactive agent, and generates community interest to foster citizenship.

*Proactive Agent*

First, the construction of patient changes because the internet allows the patient to become a knowledgeable agent of health care information. The patient/citizen voice however cannot be ill informed or respect does not occur. Therefore, the patient knowledge must be accurate to influence doctor communication. As Murray et. al. (2003) found in their study, well-informed patients who bring in accurate and relevant information about their health concerns benefit the doctor/patient relationship. However, if the information was inaccurate, then it harmed the physician/patient relationship and the health care outcome. The point is that for the construction of the term patient to gain legitimacy in the technical sphere, the patient must have accurate information regarding health situations. The PCOS patients learn the agency of the technical sphere, feel empowered enough to speak the doctor’s language, and gain control over their bodies.

It is not knowledge alone that allows the internet to alter the construction of “patient,” since anyone can gain knowledge from books, journals, and other resources,
but the support group and doctor websites tutor women in the tactics they need to become active participants in the medical field. One tactic the support group websites suggest is to ask the women to bring PCOS literature to the doctor’s appointment. SoulCysters suggests that patients bring the *Medifocus Guide on PCOS* to their doctors (KatCarney, 2005). This way the women have a tool they can use to start the conversation about PCOS. They negotiate the right treatment that will work for them and feel that they have a say in the outcome of their care. Other websites, not directly affiliated with the PCOS support group, suggest that women bring in any accurate literature they find about PCOS to the doctor’s office. As step one suggests, “Get the facts. Do as much reading as you can about PCOS so that you can have an educated conversation with your doctor. There are many books and websites dedicated to PCOS, and it would be beneficial to bring some of the literature with you to your doctor’s appointment” (“How to Talk,” 2010, para. 2). While agency is the main affinity in the expert culture, when the women with PCOS are able to speak about that agency and understand the diagnostic procedures needed to determine a PCOS diagnosis, they become empowered agents.

A second tactic the support groups endorse is for women to promote PCOS education, influencing both the technical and the public spheres. As Ashley Tabeling (2006), the founder of Project PCOS explains, “It is my personal goal to ensure every medical professional makes the proper diagnosis. Furthermore, I think girls who are coming of age should learn about PCOS when they are learning about sex education in school” (p. 15). To help reach her personal goal, she provides a press-packet on the Project PCOS website for women to give to their doctors and to anyone who needs PCOS information. The packet includes facts about PCOS and stories by women who have
suffered from the disease, including the explanation of her own struggles with PCOS. Women are encouraged to understand this information and give it to others helping disseminate PCOS knowledge to others. The rhetorical construction of patient changes from a passive consumer of medical advice to a knowledgeable, questioning agent.

Community Citizenship

Not only does the construction of patient alter when the women become proactive agents, but also because they generate a community through the support group discourse. The women are not alone in their fight to educate others about PCOS; they create a community of support for each other. The women want to help others learn more about the syndrome, and they want to provide emotional support for their fellow “Cysters.” Through the influence of the lay-experts, PCOS coach/counselor, and self-expert, the women feel the support of the PCOS community.

The women act not in self-interest, as most of the lay-experts on the website have found a means to control their personal dealings with PCOS, but instead they act out of community interest to help all women with PCOS. As Dewey (1927) suggests, education is key to advancing democracy and by talking with each other, the women generate “collective deliberation.” They are able to learn more about their own personal situation by listening and talking to each other. The women connect with each other to form a community. Toulmin (1950) called this connection a “moral code” (p. 135), where a group of people has the same moral purpose, which allows for a “harmonized” community (p. 136). The point is that the definition of patient changes rhetorically through the development of internet communication because the patient comes to a doctor situation with a community of support behind her.
The patient is no longer a singular entity but a collective community agent because the PCOS support groups generate information that the patient brings to the doctor’s office. In return, the patient brings back information from the doctor encounter to the support groups, informing the community. This means that the PCOS women never enter a doctor’s office alone. They use the tools, tactics, and stories learned from the website to inform their doctor interactions and then they return the favor by explaining what they learned (or did not learn) from their doctor. The “collective deliberation” allow the PCOS women to be seen as a collective citizen. The evidence of this collective citizenship comes in the form of doctor’s websites suggesting that women who need PCOS information go not to other doctor websites for support but to the different PCOS support group websites. The women are viewed as a collective group that supports PCOS knowledge.

The PCOS example provides a case that is different from patient empowerment campaigns that many medical institutions encourage. With patient empowerment, doctors encourage patients to gain information about their condition and ask their doctor’s questions. They may even provide formalized support groups for cancer patients and others to connect concerning their treatments. The technical sphere controls this space. For the women with PCOS, the support groups provide a free space. Sara Evans and Harry Boyte (1986) explain that free spaces are places that are open for all to participate and help generate “democratic movements for change” (p. 17). Evans and Boyte (1986) define free spaces as:

Environments in which people are able to learn a new self-respect, a deeper and more assertive group identity, public skills, and values of cooperation and civic
virtue. Put simply, free spaces are setting between private lives and large-scale institutions where ordinary citizens can act with dignity, independence, and vision. (p. 17)

This free space becomes an antonym to colonization, as individuals are able to participate outside the private sphere. The PCOS support groups allow women to freely tell their stories and reflect on their experiences, which gives this group an identity and provides space for consciousness-raising. These PCOS patients become citizens because they learn tactics to gain confidence and assertiveness when dealing with the technical sphere. These tactics do not come from the medical establishment but from the PCOS community and are designed to help the women take action to enhance their personal health.

Additionally, the women focus on the building of the community in order to make sure as many people as possible know about PCOS. They help women think about the medical establishment more critically and encourage the women to become active patients representing the PCOS community. They are able to speak freely within the support groups and take their message to others.

This case shows that the internet can create a patient who is more of a citizen than would be possible through other forms of communication. Online communication creates a shared experience that is immediate: when someone posts information, another person reads, and the connection is continuous. This connection does not just allow for consciousness-raising but it provides a means for activism. The women do not just learn about their health but they find ways to improve their lives and the lives of others by using their voices and getting involved. The websites do not just act as self-help literature but they influence the women to become activists. This is similar to the original women’s
health movement where women gathered to make changes for female health resulting in the collective work *Our Bodies, Ourselves* (Morgen, 2002). Now, this citizenship and activism occurs more readily through the internet because the online medium connects women together from all over the globe. The result is a move from self-help information toward political activism to gain a democratic voice within the health care process. The internet provides a means for private issues to gain acceptance within a semi-public space; a collective then forms which generates citizens who speak out about the healthcare needs of the collective.

**Limitations of the Dissertation**

As with any research, there are limitations to my work. When looking back at the process, this study presented a few challenges. I will discuss two main limitations in this section. First, this research focuses on doctor-patient textual examples only. Second, this particular study may be an eccentric case with which to discuss issues of deliberation and democracy.

**Limited Textual Examples**

First, this analysis focused on textual examples surrounding doctor and patient discourse. The six websites were my only unit of analysis for this project. Therefore, it is unclear if the women always acted on the empowering messages they promoted in their online dialogue. The stories told may be romanticized versions of the doctor encounters they experience. As such, the texts may not fully represent how an individual acts within a doctor office setting. Future study should focus on qualitative interview data to see what actually happens in doctors’ offices to hear the dialogue between patient and doctor.
This would allow for a more complete picture of the tensions and collaborations that exist as the private and technical sphere interact.

Second, voices are still missing, even within the PCOS case, because not everyone has access to the internet. While in the United States over seventy percent of the population is online (Research and Markets, 2010), still thirty percent of the population do not have the ability to gain support through online resources. While this does not automatically presume that individuals who do not have access cannot empower themselves when in doctor-patient situations, it decreases the ability for women to have the support from others, and the correct terminology necessary to generate democracy within a doctor visit. It would be interesting to study women who do not have internet access and assess whether they feel able to challenge the boundaries of the technical sphere or feel relegated to the private sphere.

Third, the doctor-to-doctor voices are missing from this project. The doctor websites I analyzed did claim to reach other doctors but the audience also included patients, medical students and other health care professionals. As a layperson, I was not able to gain access to the doctor only websites. As a result, the technical sphere to technical sphere discourse is absent from my study. In other words, I do not know how doctors talk among themselves about PCOS and their patients. To make the study more nuanced, a look at the doctor rhetoric where the doctors have a difficult time diagnosing patients would be helpful. This would allow researchers to see how doctors negotiate their expertise when traditional diagnostic procedures are challenged through a difficult case. Having the doctor-to-doctor data would provide a stronger means to look at
technical sphere communication and would influence how democracy is negotiated from the expert’s perspective.

Looking at the male perspective would also help build significance to the discourse. While men do not have PCOS, either a look at the men who support women with PCOS or a look at a different disease that influences both genders would be useful in observing sex differences in negotiating the sphere boundaries.

_Eccentric Case Study_

This case study may be an eccentric example of democracy. While I have argued throughout this entire dissertation that looking at democracy broadly by including the private and technical sphere talk is necessary for furthering deliberation and democratic practices. This case study may be a little too narrow in its demographics (female, PCOS patient, reproductive-hormonal health) for the general population to gain an appreciation regarding its influence on democratizing health.

The PCOS case study is intensely personal, as women have to share embarrassing information about a strictly female condition. Moving from the private sphere to the technical sphere, women share their personal stories and emotions not only with close friends and family members, but also with doctors. This is the main way women communicate their health concerns, through their personal stories (Borges & Waitzkin, 1995). Many women feel comfortable sharing their personal experience with the doctor. They become experts about their own health situation and are willing to express their situation to the medical community.

Women are active patients, while men might still struggle for control within the technical sphere of medicine. Males will see the doctor less than females within their
lifetime. In a recent study, Bertakis (2009) found, “Female patients make more medical visits and have higher total annual medical charges; their visits include more preventive services, less physical examination, and fewer discussions about tobacco, alcohol and other substance abuse (controlling for health status and sociodemographic variables)” than male visits to the doctor (p. 356). This study points out that women feel more comfortable than men do in seeking a doctor for medical help and as a result women often live longer. Dr. Robert Sobut (2010), a psychiatrist at Northwestern Memorial Hospital and clinical instructor of psychiatry at Northwestern University Feinberg School of Medicine, explains that males’ resistance to health care is socially constructed. He explains that women and men receive different messages from an early age regarding health. Sobut (2010) states:

Women get encouragement to be nurturers…. A woman is so used to giving and taking care of others it’s not too much of a leap for her to take care of herself. For men the act of nurturing can be an unfamiliar concept, therefore they tend to be more neglectful of themselves…. A man is acclimated from an early age to tough it out, so they tend to not like to ask for help…. When they start to feel weak or unwell, it messes with their invincible masculine identity. For women their gender role has much more fluidity. (para. 2-4)

It is this nurturing aspect, found within the private sphere, which, in part, allows women to seek medical help more easily than men.

Women often embody their personal experiences and explain those illness experiences to the doctor, which allow the women to feel empowered so they can “resist physician applications of medical power” (Lorentzen, 2008, p. 49). Women feel
comfortable telling their stories. This is an interesting perspective since men have a major public sphere presence, and women, until recently, have been relegated to the private sphere (Griffin, 1996). Historically, women have had control over the private sphere not the public (Wischermann, 2004). Women have had ample practice sharing their personal stories with other women within the privacy of their own home. As a result, women often feel comfortable expressing their feelings to others even in the medical field.

The gender influence, intensely personal stories, and the heavy reliance on the communication between the support group participants and the technical sphere may limit the impact of this case study on democracy theory. While PCOS affects an estimated 6-10% of all women (Vliet, 2006), it is still a case with very specific criteria. However, this is not to say that other case studies might have similar results when they challenge the technical sphere. I am just suggesting that it would be useful for communication studies scholars to study other cases that promote democratic practices within online research. As this case is a good study in dealing with patient/doctor power differences, further research is needed to see how these differences are experienced in other discourses. This way we could see what other type of talk can generate deliberation and forward democracy.

**Implications for Future Research**

Habermas (1989) wanted the public to have more of a voice and not just a “representative publicness” (p. 9), where the ideas of the few represented the many. He wanted to reduce the colonization of the public/private sphere by the technical sphere and generate space for deliberation (Habermas, 1987). The PCOS case study provides a glimpse into the possibility of democratic discussion that allows patients to become
active citizens who represent their perspectives to the public. This study revealed that when individuals feel they are a part of the deliberation process they can generate democratic results. There are three implications from this research that I argue deserve further scholarly attention. The first concerns the influence of gender on sphere theory research. The second explores the importance of the layperson expert in forwarding democracy. The final implication suggests the importance of subjective research when studying online democratic spaces.

**Gender Influence**

First, an area for future research suggested by this study is gender’s influence regarding the weaving sphere boundaries. This study points out that female patients might have an advantage over male patients in gaining empowerment within the technical sphere because of their connection to the private sphere. Therefore, this study identifies that the rhetorical construction of the female patient, in particular PCOS patients, alters, promoting patient self-awareness and activism.

Since women have been masters of the private sphere domain for so long, the PCOS women now, through the help of support group websites, can discuss their personal issues within the technical sphere. Ashley Tabeling (2006) explains that through her work she hopes to “inspire and empower the PCOS Community to speak very openly about their struggles, symptoms, and trials to overcome the illness, to help other women and girls understand the syndrome and seek the proper resources to help them manage their lives with PCOS” (p. 14). Women are encouraged to tell their stories to the medical professionals. This occurs in all of the PCOS support group websites and doctor websites. As a result, women are experienced in sharing their personal health stories. Undeland and
Malteraud (2008) found that when studying female patients who had medically unexplained illnesses, the women’s illness stories helped the diagnostic process. Undeland and Malteraud (2008) found that “…the doctor assumes a provisional standpoint in the decision-making process when the diagnosis is not immediately cut. Yet, talk—intricately intersubjective—is the most significant instrument for the clinician towards a diagnostic conclusion” (p. 222). In other words, the female patient’s story helps make sense of the illness and can enhance doctor-patient interaction.

Men do not have the same historical connection to the private sphere as do women. As such, beyond refusing to seek help from the doctor, males often are not trained to know how to share their personal stories. Historically, men have been socialized to keep their personal experiences and emotions private making it difficult to share these aspects of self with others. Dr. Carlyle Stewart, an internal-medicine physician on the medical staff of Baylor Medical Center at Plano explains that, “Men tend to be sensitive about discussions that relate to emotions, especially when it comes to sharing feelings of depression or anxiety that may be perceived of as a sign of weakness or loss of control” (Churnin, 2010, para. 8). As a result, Dr. Stewart very seldom discusses feelings directly with men. “Instead, he asks casually about how life has been in general and more specifically, whether there been a lot of stress at work or at home. If the men mention marital problems or layoffs, he explains how a patient's mood or emotional state can cause biochemical or hormonal changes, which may affect someone physically and mentally” (Churnin, 2010, para. 10). Most men are more comfortable within the public sphere then the private, helping to generate support for a collective not for their
personal health experience. This creates a reversal in control where women have more of a say over their health and as a result over the technical sphere than do men.

This PCOS research helps provide support for women’s health liberation, much like the eight women who gathered in the summer of 1969 to create *Our Bodies, Ourselves*. The fight persists as women continue to learn more about the female body and urge the medical establishment to acknowledge female conditions and experiences regarding health. Women, who have access and ability, are making strides to democratize their health.

*Lay-Expert Influence*

Second, lay-expert influence is an important criterion for developing democratic practices. While the lay-expert women cross the private and technical spheres to empower others, the term “lay-expert” is problematic. This term, “lay-expert,” produces rhetorical concern, it is an oxymoron where “lay” refers to “layperson,” defined as “a person who does not have specialized or professional knowledge of a subject” (Collins English Dictionary, 2009, para. 4). The PCOS “lay-experts” do have specialized knowledge about living with PCOS and they have learned medical knowledge. Therefore, this term is not ideal to describe this knowledgeable PCOS advocate. I encourage anyone studying this type of expert in other case studies to find a less rhetorically problematic term. However, for discussion regarding this dissertation, “lay-expert” provides a clear description of how the private lay-experience weaves together with expert knowledge. Regardless of the terminology, women with PCOS are experts regarding their disease, and they help others understand the syndrome.
For women with PCOS, the lay-expert gives them a starting point at which to speak the language of disease. The lay-expert provides a vocabulary from the technical sphere and blends that vocabulary with everyday knowledge and personal stories that relate to other PCOS sufferers. In other words, the lay-expert connects with other PCOS patients by sharing common ground personal stories, and she weaves into the story the expert vocabulary. As a result, new members of the support group websites do not feel intimidated by the technical sphere jargon but find comfort in the personal stories. To insure that the women feel connected and not isolated the glossary of terms is available on each website to help a novice member navigate the talk. The lay-expert becomes the liaison between the private support group talk and the technical doctor terminology.

Future research should focus on other online groups that use a similar lay-expert liaison. This research could help forward argumentation theory regarding the shifting sphere boundaries.

Not only do fellow patients benefit from the lay-expert, but the doctors benefit as well. Through this specific case, the doctors become knowledgeable about PCOS most often through the PCOS lay-expert discourse. The result is that the private and the technical spheres connect as the private patient expert and the technical doctor expert discuss the best health plan for each woman. This “between the spheres” discourse blends the private and technical sphere, allowing for deliberation. Empowerment provides a more democratic medical encounter. As such, we must continue to watch and study this trend, observing where the lay-expert influences the traditional expert in other situations.
Subjective Research

This dissertation highlights the importance of subjectivity. Within this section, I address the importance of subjective research and then provide suggestions for future communication studies research. I argue that this project provides support for subjective ways of knowing that move beyond the typical objective responses. I am not suggesting that we need to rid research of objective ways but there should be more harmonization between the objective and subjective paradigms to gain a more nuanced view of the world around us.

For issues surrounding health, this means the conversations move beyond the biomedical model and include patient’s subjective medical histories. For a medical encounter to move into a space that provides deliberation, the expert doctor and patient must rely on subjective means of discovery in conjunction with objective diagnostic procedures. Often, patient-centered doctor encounters are already occurring, but within our research, the collaboration between objective medical procedures and subjective patients’ stories deserves further scholarly attention. This important finding will continue influencing and revamping of the medical system. The biomedical model is still necessary since objective diagnostic procedures help experts understand the same terminology; however, the private, more subjective experience of the patient also must be considered if the medical community wants to foster healthy collaboration with the private sphere. What I mean by this is that through the development of online spaces more voices are present and influencing others; we need to research these voices through subjective means to understand their potential for deliberation and democratization.
The communal websites such as Wikipedia are growing in popularity, with user status up 46% from 2009-2010 (Freierman, 2010). More people are using those communal sites to gain “credible” information. A study conducted by Dr. Yaacov Lawrence, at the Kimmel Cancer Center at Jefferson in Philadelphia, compared Wikipedia entries for ten forms of cancer to the National Cancer Institute entries. Wikipedia was accurate and was written at a college level while the National Cancer Institute entries were written at the ninth grade level (Huget, 2010). Therefore, we are looking to the community more and more for answers and finding reliable answers; as such, we rely less and less on the experts. This example shows that the objective, medical model is not going to continue to control the medical community and doctors are going to need to speak a vocabulary that is more subjective to each case in connecting with patients. The private sphere just might engulf the technical sphere resulting in a lack of confidence in the experts and an increase in patient confidence. The communal control is forwarding democracy.

Therefore, communication scholarship must continue to study online communication as a means for promoting democracy. I encourage the study of more case studies to observe where the private sphere resists the technical. By analyzing cases that highlight resistance, we can see where the internet generates space for deliberation and lessens the stronghold of the expert culture. In time, a new metaphor may emerge to replace the sphere theory. Until then, we need to focus scholarly research on analyzing how discourse between the spheres changes our current democratic interactions.
Tribute to Lauren

The women with PCOS are a representative anecdote for observing democratic evolution in private/technical sphere relationships. Through their personal connection, appropriation of technical language, lay-expert influence, and promotion of community collaboration, women with PCOS are able to change the technical sphere and empower themselves. A democratized technical sphere results as women gain control over their bodies.

As for my student Lauren, I encouraged her to take her PCOS knowledge and become an advocate. One of her major assignments for class was a written proposal. Students had to identify one item they wanted to change about the university. I suggested to Lauren that she propose an awareness campaign to the university about PCOS. Lauren took my suggestion and developed a comprehensive PCOS education plan.

When the class ended, I received a Christmas card from Lauren thanking me for helping her become a better writer and PCOS advocate; more importantly, she wanted to thank me for listening and for taking the time to support her. That January, Lauren suffered from a pulmonary embolism and she passed away. I found out the day after her funeral as I returned to the numb Minnesota air. Her mom and sister contacted the school looking for me. They wanted the rest of Lauren’s papers. I gave them the final proposal that she had turned in, and I shared with them the Christmas card she had sent. We cried, hugged and planned a way to support Lauren post mortem. Her sister proceeded to have the proposal published on the PCOSA website and we worked together to develop PCOS awareness at the University of Minnesota.
Through this life experience, and through this dissertation, I learned that the private sphere does influence the technical sphere and that the voice of a female collective can be powerful. The infiltration of the private into the technical, especially through the experiences of the lay-expert agent, generates space for personal democracy. The more voices within the private sphere that speak out, the stronger democracy may become.

Thankfully, my student Lauren was able to find a niche within the PCOSA support group before passing away. I hope that by sharing her story and developing this dissertation, the syndrome will gain a greater presence within the public sphere, finding a multitude of listeners and support. I will carry out Lauren’s legacy and help discover empowerment possibilities for PCOS keeping her message in the public eye and her private memory alive.
References


