Soul Cysters Dot Net:

Configuring the Feminine Body Through the Life Writing of Women with Polycystic Ovarian Syndrome

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Introduction:

In March of 2015, a post entitled “Breaking Down Emotionally Over PCOS” was uploaded to the online health forum SoulCysters.net by an author using the handle htr12. The opening lines of the post read: “So I just found this site today, and i was diagnosed on October 31, 2008. I sort of gave up looking up info on PCOS for a month or so, because I just felt so hopless [sic]” (htr12). htr12 proceeds to tell her story of living with an endocrine disorder known as Polycystic Ovarian Syndrome (PCOS). The author’s adolescence was plagued with irregular menstrual cycles, as little as two to four periods a year, that she tried and failed to regulate with various brands of combined oral contraceptive pills. At the age of 18, htr12 recalls feeling distraught over the possibility that she might not be able to conceive in the future. This threat to future motherhood compelled the author to seek medical attention. She was advised by various physicians to continue alternative contraceptive pills in order to find the “right one”, despite jumping between not menstruating for over eight months to constant spotting. htr12 notes that “3 of the docs made me feel like i was crazy, and told me to just keep taking the pills [sic]”. The author describes a deep yearning for motherhood becoming more urgent as she began planning her wedding. She decided to attempt a physician visit again despite her past negative experiences. She writes: “I made another appointment 3 months later and the doc. gave me a preg test (which was neg) and told me that since i was not married that she should not be having this conversation with me about my period irregularities. I went home in tears and never wanted to go back to a doc again [sic]” (htr12). Sometime later, the author eventually received a diagnosis of Polycystic Ovarian Syndrome, an endocrine disorder which commonly causes infertility, among other symptoms. htr12 describes her emotional turmoil over the diagnosis and a potential inability to conceive as devastating. The author also describes how the experience isolates her from other women in her life because she feels she cannot relate to the “ordinary” experience of womanhood. She notes that some days are consumed with mourning over her “defective” body. The author describes her most recent emotional “breakdown”, triggered by her cousin and their partner’s “unplanned” pregnancy. She recalls, “I was so jealous of them, and didn’t even want to go near them… The few people i’ve told tell me they know how i feel, and they’ve had their children. No, you don’t know how i feel, and i can’t just get over it [sic]” (htr12). The author’s post signs off with an extension of gratitude for the Soul Cysters message board where she believes she can discuss her experiences with other women who understand her situation.

Testimonials, like htr12’s, are significant for understanding the ways in which some women are writing their identities in relation to a PCOS diagnosis. These testimonials also illustrate how medical institutions are failing to provide support for women with PCOS (Sterling et al. S7), compelling these women to seek alternative communities. PCOS is the most common metabolic and endocrine disorder affecting from 6% to 26% of women[1] (Lauritsen et al). Despite the disorder’s prevalence, and the documented suffering and distress reported by women with PCOS (Karjula et al. 1861-1869), the medical system has failed to provide accountable, ethical and responsible support for women with PCOS (Sterling et al. S7), including htr12. Unsupported by a medical system, some women diagnosed with PCOS have turned to online health forums as a place in which to share testimonials based on their lived experience. I began to uncover a rich and descriptive archive of first-person testimonials of PCOS embodiment in online health forum blogs. In examining the PCOS online health forum, SoulCysters.net, I seek to understand how

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[1] Although I rely on naming those affected by PCOS as women, PCOS, as it is currently understood, can affect any individual with ovaries, including girls, trans men, non-binary individuals and gender non-conforming individuals.

women with PCOS who reach out to one another online, come to understand their PCOS embodiment in new ways.

Although PCOS includes an array of varying symptoms that produce medical complications, this paper looks specifically at the condition of androgen excess (an increase of "male" hormones such as testosterone) and the ways it is written about in SoulCysters.net. This resistance to the normative medical system that is cultivated within this online space is conditional on a collective agreement to work to combat or "cure" these symptoms that produce a deviation from stable femininity. In other words, SoulCysters.net unsettles the authority of the medical institution while also reproducing a prescribed understanding of what a woman's body is and should look like. By normative medical system, I refer to the institutionalized healthcare services and facilities which are enabled and provided through the state. This project seeks to consider several questions, including: how does conceptualizing online health forums for women with PCOS, particularly SoulCysters.net, as life writing allow us to understand this writing as disrupting the authority of the normative medical system yet affirmative of stable notions of gender normalcy? In looking at the writing of women with PCOS through the lens of Judith Butler's theoretical framework, how can we understand the performativity of this writing and the ways in which it constructs the writer's body, gender identity, and sense of self? What are the social advantages of constructing, through writing, androgen excess as a disease rather than one variation of femininity? Does this stabilize an understanding of gender identity that we are reliant on? In order to address these questions, this paper examines posts on the SoulCysters.net blog by categorizing content in different themes, including what I perceive as transgressive processes which unsettle dominant discourses (writing that indicates community-building, self-expression, and alternative treatment methods) and posts that reproduce normative gender, including attempts to combat symptoms of androgen excess rather than embrace them as an alternative embodiment of femininity.

When I began conceptualizing this research, I imagined this online space was a site of resistance to the normative healthcare system, and although I found these communities do function in this way, I discovered that there are multiple, contradictory processes occurring—some of which even work to reaffirm harmful notions of normative gender. Most posts on the Soul Cysters forum show an challenging of the normative medical institution through interactions between various bloggers and their life writing. These posts cultivate community-building, foster self-expression and promote alternative treatments. These transgressive acts challenge the practices of the normative medical system and its inability to consider the subjective experience of the patient. However, at the same time, these gestures of transgression are contingent on specific normative notions of gender, more specifically an idealized femininity.

My analysis will draw from an existing scholarly discussion of women's representations of embodiment through life writing, which in itself is tied to feminist autobiography studies and disability theory. I will turn to foundational gender theory in Judith Butler's 2004 *Undoing Gender* to theorize the ways in which normative femininity is both constructed and reproduced in SoulCysters.net, but also how these processes are, in fact, necessary for survival. Ultimately, I will explore the ways in which women with Polycystic Ovarian Syndrome employ life writing practices to illustrate their experiences of embodiment and as a mechanism of transgression against a subjugating healthcare system. Through this research, I seek to understand how normative conceptualizations of femininity are being reproduced through the life writing of women with PCOS in the online health forum.

Clinical Diagnosis of Polycystic Ovarian Syndrome and the *Diseasing* of Deviant Femininity:

My own research of the clinical procedures employed in the diagnosis and treatment of PCOS has unveiled a distinct and harmful neglect of women with this condition in the North American healthcare systems. *Medscape*, the dominant online medical journal for educating physicians in North America and coordinating contemporary clinical practices, offers medical professionals peer-reviewed scholarly guides on the presentation and treatment of diseases, including hormonal disorders. I located three distinct problems in *Medscape's* PCOS clinical guidelines report which contributes to the neglect and subjugation of women with PCOS in the healthcare system. The first problem is the description of the disorder's presentation which produced a clear *diseasing* of bodies which deviate from normative gender embodiment; second, due to insufficient funding and research, PCOS seems to stand as a blanket term to categorize an array of varying symptoms and manifestations of distinct origins; and finally, clinical writing characterizes a systematic de-centering of the subjectivity of women with PCOS. In other words, there is a failure to turn to the testimonials of women's lived-experience (Lucidi).

Through my navigation of the social and societal landscape of hormonal disorders such as PCOS, I found a recurring iteration among women suffering with these conditions. Many women experience their body's deviation from society's rigid construction of binary gendered embodiment as traumatic, and this trauma is multifaceted. Many women with PCOS are experiencing feelings of being gender "abnormal". Bodily expressions of excess androgens, such as infertility, lack of menstruation, male-pattern baldness, excess facial and body hair, lowered voice, enlarged clitoris and increased muscle mass (Lucidi), work in ways which threaten our societal conceptualizations of femininity. Often, some women's attempts to address their disorders through the healthcare system are demoralizing experiences with improper diagnosis and treatment (Sterling et al. S7).

PCOS presents itself in bodies through a multitude of symptoms, including menstrual abnormalities, infertility, diabetes/insulin resistance, obesity, sleep apnea, depression, anxiety and hyperandrogenism (Lucidi). The latter, androgen excess, and the diagnostic criteria's focus on clinical signs of increased male hormones in women, exposes a distinct *diseasing* of female bodies which deviate from normative gender embodiment rather than medically implicating "root causes" that may indicate health risks. I employ the verb *diseasing* to illustrate the ways in which conceptualizations of illness have been and continue to be socially constituted by the healthcare system, medical discourse and cultural ideas of gender. By using the term *diseasing*, I demonstrate how some women with PCOS—because they fail to embody normative femininity—become reduced to a dysfunctional body, an abnormal body, and a body that must be treated medically. This *diseasing* of the bodies of women with PCOS in the healthcare system is facilitated through the PCOS clinical guidelines which call for physicians to conduct a visual exam for increased testosterone. When visual cues for elevated testosterone becomes a diagnostic tool, the cause for medical concern would arise in appearance of hirsutism where, "hair is commonly seen on the upper lip, on the chin, around the nipples, and along the linea alba of the lower abdomen" (Lucidi). For physicians, visual symptoms of "abnormality" in diagnosing increased testosterone would also include signs of male-pattern baldness, clitoromegaly (enlarged clitoris), increased muscle mass, acne and deepening voice (Lucidi). Some women diagnosed with PCOS are given options of "medical treatment" for "excess" facial and body hair growth, suggesting, in conjunction with weight loss, "shaving and the use of chemical depilatories and/or bleaching cream," may be used (Lucidi). The clinical guidelines go on to explain that because plucking or waxing may cause ingrown hairs, “long-term, more permanent measures for unwanted hairs include electrolysis and laser treatment” (Lucidi). Within the framework of this diagnostic language, it is the display of gender deviation that is diseased (such as “masculine” features, infertility, abnormal menstruation, etc.), rather than the underlying source of dysfunction (if one is present). The insufficiency of both PCOS diagnostic criteria and clinical procedures is two-fold. First, the centering of “androgen excess” which focuses on clinical signs of “increased” male hormones as a diagnostic criterion indicates a *diseasing* of the bodies of women with PCOS that deviate from normative gender embodiment. Further, an institutional failure to turn to women’s testimonials of lived experience to inform clinical practices has maintained the subjugation of women with PCOS in the healthcare system. From this place, some women are cultivating alternative spaces to mobilize sisterhood and self-help. In the following sections, I discuss Butler as a theoretical framework, establish the Soul Cysters blog as life writing, outline the transgressive processes of the forum in relation to the normative medical system, then consider the reproducing of hegemonic femininity in the Soul Cysters space.

Judith Butler on Gender:

In the opening chapter of *Undoing Gender*, Judith Butler begins by positioning her analysis within a social justice framework. She poses a philosophical query, or what she names “a question for ethics” when one considers not only what makes their own life bearable, but what makes the lives of others bearable (Butler 17). Butler begins, here, unraveling her understanding of both the community and of the inter-related nature of the human and the ways in which our understandings of bodily autonomy are complex. Butler argues that “when we speak about *my* sexuality or *my* gender, as we do (and as we must) we mean something complicated by it.

Neither of these is precisely a possession, but both are to be understood as *modes of being dispossessed*, ways of being for another or, indeed, by virtue of another" (Butler 19). Thinking in particular about the dynamics of power and oppression, Butler argues that our bodies are never really our own. The body is a vessel subjected to the social sphere and imprisoned within a constant state of vulnerability. A common foundation in the perspectives of identity politics is the notion of bodily autonomy as we demand the state deregulate our bodies. Yet, as Butler argues, "it is through the body that gender and sexuality become exposed to others, implicated in social processes, inscribed by cultural norms, and apprehended in their social meanings" (Butler 20). The body becomes a place of doing and undoing within the social dimension where we are subjected to external forces such as violence and mortality. My research on PCOS life writing will benefit from Butler's philosophical and theoretical framework which contextualizes the complexity of bodily autonomy and social justice. We must begin to understand the body, as well as illness, as influenced by the larger workings of society. In this sense, the solution for women with PCOS may be turning to community resources and supports rather than solely fighting for emancipatory control over their bodies in the medical institution.

In "Gender Regulation" Butler explores the idea of how gender is constructed through its regulation. She asks: "is there a gender that preexists its regulation, or is it the case that, in being subject to regulation, the gendered subject emerges, produced in and through that particular form of subjection? Is subjection not the process by which regulations produce gender?" (Butler 41). One way, Butler argues, that gender is regulated is through its establishment as a norm. Butler's contextualization of the distinction between a norm and the process of normalization is particularly useful when theorizing gender regulation. Butler describes the nature of the norm as insidiously self-preserving, noting that although it is "analytically separable from the practices in which it is embedded, it may also prove to be recalcitrant to any effort to decontextualize its operation" (Butler 41). A norm may be discernable or ambiguous, but when norms operate as a method of normalization they become implicit and only recognizable in the effects that they produce.

Butler's perspective on norms and normalization is useful in the work of mapping gender. Butler defines gender as "the apparatus by which the production and normalization of masculine and feminine take place along with the interstitial forms of hormonal, chromosomal, psychic, and performative that gender assumes" (Butler 42). Treatments for women with PCOS which aim to lower "male" hormones directly exemplify these hormonal and performative forms in which gender assumes. Social and medical pressures to present more "feminine" and combat symptoms that are read as "masculine" function as gender regulating as they both produce and normalize the gender binary. Butler suggests that when one exists outside the norm of gender, this is a contentious place to be as you are still only discernable in relation to the gender norm. She notes, "To be not quite masculine or not quite feminine is still to be understood exclusively in terms of one's relationship to the 'quite masculine' and the 'quite feminine'" (Butler 42). This reproducing of the gender binary is evident for women with PCOS, and in particular the notion of being "not quite feminine" enough. These women are held to a standard of femininity that they are clearly not meeting, and in response the only offered solution from the medical community is to chemically and procedurally alter their bodies until the feminine standard is reached. This dilemma works to inform Butler's understanding of gender as socially produced. She argues that defining gender as existing exclusively on a binary plane of masculine and feminine misses the "critical point" that the ways in which our gender binary is produced is both conditional and comes at a significant cost (Butler 42). I understand Butler's theorizing of gender as an "opening up" of possibilities. She suggests that although there are clear and harmful hegemonic views of gender, variations of gender that are not recognized as normative are "as much a part of gender" as their normative counterparts (Butler 42). Further, she concludes that although gender is the site of production and normalization of the normative binary of masculine and feminine, gender can also be a place to dismantle and deconstruct these understandings.

From this place of understanding gender as an apparatus of production and normalization, Butler turns to Michel Foucault's theorizing of how discourse works to produce a subject. She concludes that disciplinary discourse not only regulates the subject by making use of them, but that it "actively constitutes" the subject (Butler 50). This process of constituting the subject through disciplinary discourse is evident in the way gender-variant individuals are punished and regulated through both the institutionalized state and through social encounters. Butler offers examples of this including surgical "correction" of intersexed individuals, the classification of gender dysphoria disorders including the resulting pathologization, and the state-inflicted regulations on same-sex parents or prospective parents (Butler 55). I would situate the social and medical response to women with PCOS within this gendered punishing and regulating as well. The social implications of leaving PCOS symptoms of excess testosterone "unregulated" are dire and the response from the medical system includes surgical, pharmaceutical and cosmetic interventions. Butler argues that these social and institutional regulations are producing results that remain effectively "unmarked", yet nevertheless, are constituting the boundaries of personhood (Butler 56).

To reinforce her theorizing of gender regulation, Butler engages with the story of David Riemer who, following experiencing a section of his genitalia burning off as an infant due to a botched medical procedure, was socially raised as a girl, re-named Brenda (Butler 64). The decision to raise David as Brenda was supported by a belief of complete social constructivism from his physician and parents. After discovering his past as he got older, David chose to return to living life as a male. What is most compelling in Butler's analysis of David's story is both the way David's gender was socially and medically regulated but also the ways in which David came to understand and speak about his gender identity. First, Butler notes that the way one's body looks to others constructs the body as gendered (Butler 64). From this place, we may scrutinize medical decisions to perform gender re-assignment surgery, or hormonal therapy for women with PCOS. Butler argues that these procedures are encouraged under the guise of "looking more normal," yet they inflict scars and pain that do not align with this outcome. Butler concludes that gender-variant bodies such as David's (and I would argue some women with PCOS), are "inconceivable" to many and therefore their bodies are regulated through invasive medical practices (Butler 64). Butler stresses that her purpose in employing David's story is not because it proves or disproves either social constructivism or gender essentialism, but rather, she hopes to highlight the disciplinary mechanisms in which David had come to understand and speak about his own gender identity. This process of self-reporting by David works to unveil the ways in which his gender identity is both affirmed and denied. Because David was subjected to constant unrelenting surveillance, scrutiny and abuse by medical professionals, who collectively dangled gender normalcy just out of reach, he began to understand that he was "failing" gender. The question of whether David was "feminine" enough, or meeting the standard of feminine normalcy, was constantly interrogated. Butler argues that David had come to understand that there was a norm of who he should be, a stable femininity, and he was not that (Butler 67). This unattainable norm, for David, ensues a certain logic: the norm was distinguishable from the way he felt—it was "other" and therefore he was "other" from stable femininity. Like David, some women with PCOS recognize that they too are "failing" femininity. When their bodies express signs of elevated androgens, they experience both external regulation as well as self-regulation in order to resolve this dissonance.[2]

In Butler's chapter entitled, "Undiagnosing Gender," she explores the contentious debate surrounding a Gender Identity Disorder (GID) diagnosis and what this diagnosis means for both individual autonomy as well as access to resources (Butler 77). Butler does not attempt to establish an answer to the polarizing GID diagnosis debate, but does suggest that "autonomy is a socially conditioned way of living in the world" (Butler 77). In this sense, mechanisms of autonomy, or the opposite such as a GID diagnosis or by extension a PCOS diagnosis, may be liberating for some and restrictive for others. As Butler points out, those opposing forces usually are occurring simultaneously (Butler 77). Exploring what autonomy might look like for women with PCOS seems to reflect Butler's analysis of a GID diagnosis. Some Soul Cysters believe that further reinforcing PCOS as a medical illness will legitimize their diagnosis as a condition valid of healthcare resources including medical research, insurance coverage for medications, and development of pharmaceutical options.[3] On the other hand, there is concern (mainly from outside the Soul Cysters blog) surrounding working unilaterally to combat "symptoms" of androgen excess in the female body rather than deconstruct our societal prejudices surrounding what a female body should look like. For example, Meagan Morse in her article entitled "Young Feminist: Notes on Hair, Hairlessness, and Gender" discusses coming to terms with her PCOS illness and her bodily expressions of elevated testosterone. She writes:

> Even as I work personally at reconceptualizing the changes my body is going through, I recognize that there is more work to be done. I want to live in a society that is less rigid,

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[2] See Appendix A for Soul Cysters example.

[3] See Appendix B for Soul Cysters example.

> and less based on dichotomies about male vs. female — one in which there is a plurality of ways to be feminine or masculine, or both, or neither — and where we have language that reflects this reality. I hope we can get to the point where we celebrate diverse body types and gender presentations and create new language that allows people to better define and describe their *own* bodies.

Drawing from her previous understanding of gender as a site of possibility, Butler contemplates the repercussions of accepting a GID diagnosis as an avenue of autonomy. She wonders what happens to gender as "a mode of becoming" when we play within the confines of a masculine/feminine dichotomy. Butler ponders: "Are we stopped in time, made more regular and coherent than we necessarily want to be, when we submit to the norms in order to achieve the entitlements one needs, and the status one desires?" (Butler 82). In conclusion, she rationalizes that if a GID diagnosis is facilitating a way in which individuals can achieve their desired autonomy, we have a responsibility to locate a method which cultivates similar effects before we collectively reject a GID rationale (Butler 82). For women with PCOS, I wonder if the communities formed in the online space may behave as this "method which cultivates similar effects" Butler is suggesting, these effects including a sense of autonomy.

Butler's discussion of medical practices and the gender norm is particularly useful in understanding PCOS treatment. Medical procedures and practices that help preserve and foster primary and secondary sex characteristics can include breast augmentation surgery, Viagra, and, I would argue, PCOS treatment, including androgen blockers, laser hair removal and topical Rogaine (Butler 86). Butler questions why procedures and treatments that seek to move an individual further away from their gender norm require psychological counselling and interrogation, yet practices that position individuals firmly within their gender norm are normalized. Sex becomes culturally understood or readable on the body through these sexed bodily traits. Ultimately, Butler argues that she does not “mean to suggest that purely cultural signs produce a material body, but only that the body does not become sexually readable without those signs, and that those signs are irreducibly cultural and material at once” (Butler 87). Butler is arguing that these processes of being hailed as gendered, or having one’s body be sexually readable, function as socially constituted through cultural cues. However, although our understandings of gender are established through a combination of cultural and material signifiers, this does not delegitimize gender by rendering it fabricated. In fact, Butler argues, the significance of becoming a gender, and being recognized as such, is vital to one’s sense of personhood, one’s wellbeing, and one’s ability to “flourish as a bodily being” (Butler 100). Ultimately, Butler calls on nourishing the movement to secure transgender people in positions of medical power as a short-term solution the GID debate, but ultimately argues for an upheaval of our institutional and cultural understandings of gender norms. This call could reflect an avenue of progress for women with PCOS as well.

SoulCysters.net as Life Writing:

Upon entering SoulCysters.net, you find a conventional, unsophisticated appearing message board. A teal-colored awareness ribbon rests entwined near the top of the page within the Soul Cysters logo. Beneath the heading are several cataloguing markers within which members can post content, including “What’s on Your Mind about PCOS?”, “PCOS Treatments and Conditions”, “The Mother ‘Hood’” and “Getting to Know You.” SoulCysters.net is the “Cyster” message board for SoulCysters.com, a popular awareness movement and life-style blog for women with PCOS.[4] The website includes recipes, stories, articles and research with which readers can engage. The message board is intended to function as a health forum through which individuals can pose questions about their diagnosis and experiences while providing responses for others. Despite the simple facade, SoulCysters.net is a rich archive of over 100,000 Soul Cysters[5] engaging in discussions about their bodies and the ways in which they come to understand their embodiment of illness. The Soul Cysters forum has, indeed, marketed itself as a community of and for women. Flickers of both desperation and hope fill the pages of the message board where women are coming together to pursue and share information on their diagnoses, their bodies, and their experiences. These processes of community building are facilitated through the writing in this health forum, writing which I argue, is a form of life writing.

Life writing, and particularly life writing of illness, according to G. Thomas Couser and the definition I employ, is a literary genre of autobiography which re-centres the bodily experience and subjectivity of the author. Life writing is valuable as a tool to empower authors to re-claim authority over their bodies by moving away from statistics or diagnostic criteria (Couser 1997, 4). Canvassing the scholarly field on a particular life writing scholarship which centres disability and illness has illuminated the practice, for me, in two ways. First, life writing is

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[4] Some women of color writing in the blog have articulated that the Soul Cysters brand was, in fact, founded by a black woman. Despite this, the forum appears to be co-opted by white women where women of color have now been pushed to margins of the forum, seeking community with each other in "niche" threads (See Appendix C). In a prominent section of the blog entitled "PCOS Around the World", a space seemingly to highlight the expansive global membership of the blog's users, the forum only offers three categories of Anglo-dominated former British colonies to post within including, "UK & Irish Cysters", "Aussie & Kiwi Cysters", and "Canadian Cysters". The community building practices of the forum are contingent on other expressions of identity. The other posts in the thread reaffirm that women of color who have PCOS face compounded, intersecting forms of oppression within the healthcare system and in society at large.

[5] *Cyster*, a play on the word "sister", is a term the Soul Cysters community employs to describe themselves and each other.

inherently rooted in centering one's embodied subjectivity as the heart of validity, and second, life writing *does* something. This *doing* is performative, as in it works to transcend the act of writing in various ways, perhaps building a community, initiating self-care, organizing a resistance, embodying a transgressive act, or coming to understand one's own subjectivity in a more profound way. The writing of the Soul Cysters is performative as well, spawning discourses which are both transgressive to the normative medical institution yet reaffirms a stable femininity. It became significant to conceptualize the writing on this blog as a form of life writing in order to address the kinetic, generative nature of the Soul Cysters community. In this virtual space, women assemble understandings of their illness and identities in relation to gender. At the same time, they are disseminating information and ideas to other Soul Cysters in the community. This space is being employed as both an information portal for distributing and seeking particular epistemological perspectives on Polycystic Ovarian Syndrome, but also as a social support resource. The Soul Cysters space works in multiple, generative ways. The health forum is both producing a particular way of understanding PCOS as a medical diagnosis as well as reproducing hegemonic femininity.

I will turn, here, to the foundational analysis of Couser whose work makes evident why a significant section of scholarly texts on life writing intersect with illness and disability theory. Specifically, Couser offers the key term "autopathography" to describe autobiographical narratives of illness or bodily dysfunction (*Recovering Bodies* 5). Couser's work seeks to conceptualize autopathography and considers how life writing becomes a therapeutic, community-building, or transgressive process. Ultimately, his contribution to the scholarly field theorizes that bodily dysfunction works to provoke autopathography by intensifying one's mindfulness of mortality, aggregating introspection, threatening one's sense of identity and dislocating the perceived plot of one’s life (Couser, *Recovering Bodies* 5). Couser suggests this phenomenon occurs for several reasons, including that illness tends to heighten anxiety of our somatic self and imminent mortality, that illness is deeply entwined in identity politics, and that one becomes disillusioned with their experience in the medical institution (*Recovering Bodies* 8). Couser’s analysis made clear the ways in which “illness” incites life writing, particularly regarding the threat to identity. Grounding my research in Couser’s understanding of illness and autobiography as frequently merging reinforced the necessity of researching the Soul Cysters blog to understand the cultural work it is conducting. Many of the Soul Cysters express significant distress over their bodies’ divergence from displaying normative femininity and the ways in which these processes threaten their identity as a woman, a mother, and as sexually attractive. For example, a post uploaded to the Soul Cysters forum from the screenname kharper reads:

> I'm not really sure how to explain hirsutism to my boyfriend. I try very hard to hide the hair on my chin, neck, and chest. Yet one day he noticed a long hair on my neck. I was so embarrassed. Yet he didn't seem to be bothered by it as much as me. But he did begin to wonder what was going on. I'm not sure how to explant [sic] to him that my PCOS is causing these unsightly hair growths. Does anybody know of a way I can explain this in a simple manner?

The author expresses a level of perceived accountability to explain or apologize for her “unnatural” hair growth to her partner. Underlying this writing is a deeply embedded sense of shame rooted in the author’s perceived inability to embody an acceptable femininity. Further, I identified a recurring assertion from the Soul Cysters that they are being denied a “natural” ability of womanhood, the ability to bear children. As a post uploaded by Drie91 reads:

> For once in several years my libido is high and it's not even cuz of O coming, and last night my DH [dear husband] … said was that I'm getting crazy about all of this baby stuff. So I asked him if it had ever occured to him that I just wanted sex just to have sex. So I made the decision that this is my last cycle of any kind of fertility medication. I'm too deeply hurt that someone who was supposed to be my best friend would say that to me…I guess I'm just going to be one of those women who won't have kids. I'm really starting to hate myself. The one thing that God has designed me to do and I can't even with medication [sic].

The author's conceptualization of womanhood as synonymous with motherhood has deeply affect her sense of identity. The ideas of femininity being structured in this space normalizes bearing children for all women. In conjunction with a threat to identity, as Couser contests, the life writing in the Soul Cysters blog is, at times, incited by a dislodging of the author's perceived plot of her life (*Recovering Bodies* 9).

Thinking critically about impending mortality, Couser argues that illness is currently positioned against a postmodern backdrop, indicating a moment in time where, through biomedical and technological advancement, "healthy" is read as natural. Illness and disability, in this sense, are no longer recognised as "natural phenomena", but rather, an inexcusable and catastrophic event that is both remarkable and narratable (Couser, *Recovering Bodies* 9). Couser suggests that the same technological development that has advanced diagnosis and treatment has, paradoxically, "diverted doctors' attention toward disease and away from illness, toward the laboratory and away from the bedside, toward curing and away from healing" (*Recovering Bodies* 10). When our societal standard is now to "cure", anything less than perfect health is coded as failure. Couser argues that the advancement of medical discourse has allowed individuals to live longer, but patients feel demoralized in the process (*Recovering Bodies* 10). We can see these expressions of demoralization unfolding within the Soul Cysters blog as well. A post uploaded to the forum from Kim195 reads:

> I am 21 was diagnosed with PCOS about 3 weeks ago after going to 5 different doctors. I kept trying to tell doctors that I had it for years and no one believed me until I finally went to an endocrinologist. I was hit with the classic 'You are overweight and that's why you are having all these symptoms'. I have always felt like the odd one out because of what PCOS does to my body. Before being diagnosed I kept wondering why I didn't feel like the rest of the women in my family and in my friend group.

The author reinforces Couser's description of the demoralizing effects some life writers feel from the medical institution's delegitimizing of the patient's subjective experience of their body.

Couser describes illness as postcolonial, meaning that the experience of illness rouses a certain reclaiming of the body from hegemonic medical discourse (*Recovering Bodies* 10). Couser suggests that in the process of diagnosing and treating illness, a narrative collaboration is ignited between the physician and the patient where a "life text" is generated. When an individual is being diagnosed, often they must "offer up" a description of their family medical history and give a testimonial of their symptoms and bodily sensations. From this place, their story is no longer their own. The physician now interprets this information, commonly in ways inaccessible or shielded from the patient, and reconfigures "the sick person's illness as the patient's disease" (Couser, *Recovering Bodies* 10). Couser warns that although this process is what we generally expect and even want to happen, it is not without repercussions. This process often involves surrendering authority over one's own body and one's narrative, in a way that is objectifying. In this sense, life writing becomes a tool to repossess one's own body and life story from hegemonic discourse (Couser, *Recovering Bodies* 10). A familiar post uploaded to the Soul Cysters blog from Megb81 reads: “Hello Ladies, I am just wondering if anyone has given up on fertility? Have you accepted that maybe children are not in your future? What is your story? I say this because I am almost at that point. Here's my story...” This post continues with a chronological description of the author’s experience with PCOS. Often posts on the Soul Cysters blog begin with a statement such as “this is my story,” or “my PCOS story.” Story telling seems to dominate the life writing within the blog as a method to centre one’s subjectivity as a source of authority, or as Couser argues, as a reclaiming of one’s life narrative from institutional objectification (*Recovering Bodies* 10).

Through Susannah B. Mintz’s foundational text in feminist autobiography studies and disability theory entitled *Unruly Bodies: Life Writing by Women with Disabilities*, I came to understand the ways in which life writing can both produce and dismantle cultural understandings of identities of illness. Mintz profiles several different narratives by women with disabilities. These women employ life writing methods to demonstrate the damaging experiences of bodily divergence not by the physical limitations of their illness, but rather, through cultural fallacies that code those conditions in reductive or normative ways (Mintz 1). Mintz describes the processes of identity re-formation as an inherent effect of life writing, particularly for women with disabilities and their coming to critically understand the ways in which their gender and illness intersect to generate a distinct subjectivity. Similarly, Couser mirrors this argument in his description of life writing of illness, or autopathography, as inherently tied to identity politics (*Recovering Bodies* 8).

The literature on life writing is also attuned to concerns of ethical positioning, particularly rooted in bioethics, ethnographic ethics and feminist autobiographical ethics.

Conventionally, published autobiographical narratives are situated within a medium reserved for privileged demographics (namely white, male and middle-class). Couser maintains that we must ask: whose stories are being told and whose histories are being recorded (*Recovering Bodies* 4)? In thinking about publication accessibility, it becomes significant to reinforce SoulCysters.net as life writing. The online space is not as heavily subjected to the rigid boundaries of formal publication and theoretically holds potential to both combat privileged authorship and contest the authority of the medical institution. In practice, and what seems to be unfolding in the Soul Cysters blog is anonymity and accessibility by default. The health forum opens ups life writing to authors who are certainly less represented in the formal publication of autobiography. The unregulated use of language, the dissemination of alternative epistemologies, and the employing of pseudonymous screennames all contribute to the emancipatory potential of the life writing genre in the online space. Although, it seems, the potential of deregulation is paradoxical in nature within the Soul Cysters blog, particularly when these processes of deregulation employed by the authors work to reinforce certain regulations of gender and identity. Further, feminist autobiographical ethics discourse raises concern over processes of interpretation and transcription, particularly in terms of consent of marginalized demographics. Through a cultural studies approach, the scholarly field considers the implications of various methods of life writing readership and the factors that must be recognized, including agency, audience, authority and authenticity, relationality, temporality, privilege and oppression, and the larger sociopolitical context of the topic (Smith & Watson 236). Situating my research within a feminist autobiographical ethical framework was significant particularly when considering the work of interpretation. Because the use of language and syntax is employed freely by the Soul Cysters, it was a meaningful practice to incorporate direct quotations from the women to capture the nuances of the writing.

Online spaces do not reflect normative autobiography texts that are first subjected to publication constraints and subsequently mass distributed. Rather, processes of generative collaboration are continuously building dynamic converging and diverging autobiographic encounters in the online forum—posts build from and interact with each other, lists of medications and dosages are posted next to excerpts of poetry, and so on. In order to capture the performative nature of the life writing on SoulCysters.net, I began understanding this writing through the language of Tammy Spry and her discussion of a methodological framework that she names autoethnographic performance. According to Spry, autoethnographic performance represents the junction between “autobiographic impulse” and a particular “ethnographic moment” in critical self-reflexive performative discourse (Spry 706). Employing autoethnographic performance as a scholarly method first calls on the body as a site of analysis while simultaneously positioning the subjectivity of the subject’s lived experience as a source of authority—this is what I detect is happening in the Soul Cysters forum as these women are employing autopathography as a writing method. Spry claims that what allows autoethnographic performance to transcend beyond autoethnography as a methodological praxis is in the action of *doing* (Spry 706). The generative nature, or the *doing*, which I found crucial to understanding life writing, was further reinforced by the performative description of autoethnographic performance. Spry’s description of the performative aspect as a process of *doing* speaks to the online health forum as a “space” of “performing” life writing. Like Spry, Mintz’s analysis is also rooted in a recognition that life writing is generative or *does* something, and concludes by romanticising the emancipatory potential of this authorship by women with illnesses. Ultimately, she argues for hope where she envisions life writing playing a part in reimaging or reinventing what gendered disability and illness means and how it can produce liberated rather than subjugated identities (Mintz 22). For the Soul Cysters, Mintz's argument for the emancipatory potential of life writing may mean an avenue to re-imagine identity through writing bodily experience.

Transgressive Acts of Community Building, Self-Expression & Alternative Treatments:

Couser and Mintz, in line with other scholars of pathography, argue for the emancipatory and resistant potential of autopathography that re-centres the subjectivity of the author. As a significant portion of the scholarly field of life writing argues that autobiographical narratives are intrinsically resistive, transgressive or subversive, I aim to identify exactly in which ways SoulCysters.net challenges oppressive structures—particularly the healthcare system. The Soul Cysters blog was deliberately constructed from the ground up, with enough women having to first recognize dissatisfaction with their experience in the healthcare system. The site's designers and administrators, then, built the site and the community of members sought out this alternative space to address their illness. I use the term transgressive as the Soul Cysters consciously have organized in this blog and found ways to circumvent the medical system. In a society that normalizes institutionalized healthcare as the pinnacle of expertise and authority, generating an alternative space to address health becomes a transgressive act. The Soul Cysters are both seeking and disseminating information on their illness in the blog and subsequently employing their knowledge to challenge their physicians' opinions, they are rehearsing narratives to perform to physicians in order to receive the prescriptions they desire, and they are re-centering bodily experience as a source of authority. Amid a medical system that cannot fathom a patient's subjectivity, occupying the online space to generate alternative treatments, discover modes of self-expression and build a community is transgressive.

I turn to an example of women's autopathography in practice, Audre Lorde's 1980 *The Cancer Journals* through Diane Price Herndl's chapter in *Feminisms Redux* entitled, "Reconstructing the Posthuman Feminist Body Twenty Years After Audre Lorde's *The Cancer Journals*". Lorde's writing is an autobiographical account of the healthcare system's inability to comprehend her experiences as a self-identified black lesbian with breast cancer and the solace she finds in speaking about her experiences with other queer breast cancer patients. Herndl describes Lorde's motivation to write her experiences of illness as a gripping struggle to fight against the threat of becoming effaced—effaced by the cancer that may kill her and effaced by a subjugating health system which holds no space for her identity (Herndl 479). Like Couser and Mintz, Herndl discusses the concept of storytelling as a form of resistance and ultimately suggests that life writing in general, and Lorde's autopathography in particular, is inherently resistant (Herndl 479). For Lorde, writing resists the threat of her effacement (Herndl 479). Lorde's desire to write her perspective came out of a search to find others like herself. Lorde asks: "where are the dykes who had had mastectomies?" (Herndl 50). In writing *The Cancer Journals*, Lorde seems to answer her own question by declaring: "we are here". Like Lorde, the women in the Soul Cysters blog are building a community which also refuses their effacement. The community building occurring in the Soul Cysters blog works in ways that legitimize these women who feel as if their identities are dissolving under the authority of medical discourse.

Herndl discusses the themes of Lorde's journals as "meditations on fury and mourning", silence, and the falseness of prosthesis (Herndl 479). Thinking in particular about prosthesis, as Lorde outlines her experiences with mastectomy and a refusal to wear an artificial silicone breast, Herndl describes Lorde's theory of prosthesis as a means of silence (Herndl 479). Prosthesis, and by extension I would argue medical procedures and cosmetic practices of "normalization" that are offered to women with PCOS, work as a way of dividing and hiding women from each other and therefore preventing them from knowing there are others like them. This division ensures that there is no voice given to women to share with each other their rage and pain which actively depoliticises their injustice. For Lorde, we can deny breast cancer as political because methods such as prosthesis veil the illness from our collective awareness (Herndl 479). A prevalent theme in the Soul Cysters blog is an astonishing recognition from the Soul Cysters that they have finally found others, suffering in silence, just like themselves. For example, an administrator of the Soul Cysters blog outlines a basic guide of PCOS for newly diagnosed women entitled, "NEW TO PCOS? START HERE! Making PCOS Less Confusing" (KatCarney). Over 100 responses follow from women just beginning to navigate their new diagnoses. One user, diamond.chica, writes: "thank you so much for the posting im new here and I feel lucky ! thank god i found this forum by CHANCE ! ahh feel much better knowing whats going on in my body after these detailes iv just read ! thanks again [sic]." As Herndl argues, the emphasis to appear normal after a mastectomy works to confine women within a stable femininity, treating their bodies as aesthetic objects (Herndl 478). Like prosthesis, procedures and methods prescribed by physicians to "treat" PCOS symptoms of excess testosterone work to shroud women with PCOS and isolate them from each other. Within a medical system committed to a strict gender binary, it is unacceptable, and in fact often dangerous, for a woman in public to have a beard, a male-pattern bald spot or a muscular body. Moreover, medical discourse is actively expunging these expressions of PCOS from the narrative of womanhood. The community driven practices of Soul Cysters works to validate women with PCOS as real and creates space for these women to connect with each other. For example, a Soul Cyster named warriorchick1506 writes a post entitled "I just need someone to tell me it'll be okay," that reads:

> Today at our ultrasound we were told although I have not had any cramping or bleeding that our baby has passed. This is so hard to accept and I feel like those with PCOS are the only ones to truly understand why i'm so sad… I feel so much grief right now and I don't know how to accept this. It took me almost 8 years to accept I had PCOS and now I feel guilty for not pressing my doctor to treat me differently.

In response to this post, a user named mrsmeeks writes her own experience with miscarrying her first child and notes "I'm sorry, I know this isn't what you came here for but I thought if nothing else it might be helpful to know you're not alone, that someone else is experiencing the same emotions right now." The thread ignited by warriorchick1506's initial post follows with 13 similar responses of solidarity from women recalling their experiences with pregnancy and loss. This thread is only one of hundreds in the section of the blog labeled "Mother 'hood'".

In thinking deeper about the transgressive methods of women's autopathography in practice, I began engaging critically with a twentieth century modernist author championed by some feminists, Virginia Woolf. In particular, I was informed by the way Woolf effectively employs stream of consciousness as a narrative device. She centres both the experiences of the body and the subjectivity of mental illness as reality and this "new" reality subverts medical discourse. Janine Utell's work on Woolf in relation to autopathography, entitled "View from the Sickroom: Virginia Woolf, Dorothy Wordsworth, and Writing Women's Lives of Illness," shows how life writing becomes a tool of transgression against the everyday experience of illness (Part I). At stake for Utell is the question of "how writing renders a transgressive space beyond the 'normal' rhythms of life in which to work through a subject's altered relation to her mind and body and the ways writing can be restorative for a subject grappling with how she has been othered within the context of her most intimate relationships and everyday life" (Part I).

Utell argues that autopathography becomes an avenue to reimagine phenomenology, or the conscious and individual experience of disease and the patient's subjectivity in relation to it. Woolf's writing privileges her own perceptions as truth while the others she encounters are treated as illusory objects to be determined by her perception rather than subjects with agency (Utell Part II). Woolf's writings work in opposition to the harsh, sterile medical examination as a way to construct the experience of the self. Utell notes that Woolf's essay begins with the shift of awareness that accompanies certain dissociative illnesses: "How astonishing, when the lights of health go down, the undiscovered countries that are then disclosed…what precipices and lawns sprinkled with bright flowers a little rise of temperature reveals" (qtd. in Part II). Ultimately, Woolf's use of language is figurative and relies on imagery. Her perceptions are almost hallucinatory (Utell Part II). In this sense, Utell argues the experiences of the body which are given authority in this writing have the potential to generate new ways of understanding and of producing knowledge (Part II).[6]

In the Soul Cysters blog, Utell's argument of life writing as grounded in phenomenology and in opposition to medical discourse works in multiple ways. Women on the blog write about their illness in ways that privilege bodily experience as a more legitimate authority than discourses adopted by physicians. Further, women in the forum seek and disseminate information on alternative treatments to the practices of the normative healthcare system, informed by the "results" they examine on their own bodies. Writing in Soul Cysters is centered around a collective faith in alternative treatments to Western medicine. Women write lines such as "I've browsed through the messages about vinegar and it's impact on insulin resistance. I want to try it" (earcmra) or "I am trying to treat my PCOS naturally, and avoiding Western Medicine,

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[6] For other work on Woolf's writing as autopathography see Jane Marcus' "Pathographies: The Virginia Woolf Soap Operas."

because I do not think it will fix the hormone problem that is causing my hair loss, and I believe that the long term side affects of some of these meds is horrible" (Hope4022).

Utell discusses "the sick room" as depicted by Woolf, as not only a space to marinate in illness but as a site of transcendence to envision a new reality. Utell describes Woolf's writing of illness as an art rather than a case (Part II). For Woolf, the sick room hails creativity and a particular ingenuity which has the potential to reimagine the self through writing one's bodily experience. Woolf writes, "But to return to the invalid. 'I am in bed with influenza'—but what does that convey of the great experience; how the world has changed its shape…the whole landscape of life lies remote and fair" (qtd. in Utell Part II). At stake, here, is the inadequacy of medical discourse to capture subjective embodiment of Woolf's illness, leading her to employ figurative and symbolic tools (Utell Part III). Therefore,

> the disordered body and the sensations it engenders are 'astonishing,' literally, stunning, filling with wonder, beyond reason or logic…Writing becomes life, living becomes imagining, and perceptions are sustenance. The sickroom is thus transformed into a generative space of imagination, even in confinement" (Utell Part III).

Illness transcends the confines of medical discourse and is only able to be engaged with through writing, and the freedom writing offers, by its ability to bring into comprehension lived experience. Utell's discussion of the "filling of wonder, beyond reason or logic" which illness incites informed my understanding of the creative life writing on the Soul Cysters blog as an instrument of transcendence. I see this in the way the Soul Cysters use poetry to describe their bodies and their embodiment of PCOS. One poem, authored by KatrinaAnne reads:

The Key to Happiness

I wake up often and I hear my inner critic
He tells me I am ugly, worthless and there is no reason to stick with it
I hate to admit it but sometimes he really gets to me
He makes me so sad and with this it is hard to set myself free
I begin to really believe everything that he has to say
He tells me I am fat, I am hairy, and I will never find my way
But I am trying to beat my inner critic and outsmart him with my mind
I will not let him win, NO not this time
I know this journey is going to be hard, so far I have been on it for three years
But I will continue to work on this to overcome my insecurities, my low self esteem and my fears
I may not be able to change everything physically about myself that I really dislike
But I will keep on working on my mind in order to tell my inner critic to take a hike
With the love of my cysters, Salem, my family and my friends
I really think that I can beat this thing and I will fight it until the end
I know I have to learn to love and be compassionate to me
Because this is the key to happiness and this is what will set me free

I love you girls and thank you for reading

In this sense, the Soul Cysters blog becomes the sick room. It is a site to both wallow in earthly illness, yet transcend beyond. The forum, like the sick room, becomes a transgressive site of possibility for women with PCOS to rewrite their reality.[7] Through Woolf, a failure of medicine to recognize the lived particularity of "diseased" bodies is uncovered. We see that the medical

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[7] See Appendix D for Soul Cysters example.

system does not have the capacity for lived experience, it cannot comprehend the subjectivity of the patient. Therefore, Soul Cysters—and Woolf's "sick room"—must exist to bring the phenomena of lived experience into reality.

Reproducing Normative Femininity:

Despite the transgressive nature of the Soul Cysters life writing and the ways in which the blog re-centres the lived experiences of women with PCOS, the Soul Cysters community is contingent on a collective goal to "achieve" femininity. The practices of the medical system which dehumanize women with PCOS are challenged but the aspects of the disease which are grounded in the regulation of gender are not. The Soul Cysters come together to write about alternative treatments or methods that work to combat symptoms of PCOS, they discuss relationship advice for when a woman understands she is not meeting a standard of femininity, and they share alternate ways to infiltrate the healthcare system to obtain the medications they desire. Although, the Soul Cysters understand, through both their interactions with the healthcare system and their social encounters, that their body is an unnatural deviance of femininity. These women recognize that they are required to resolve their gender dissonance but they are unable to do so through the healthcare system—this is what ignited the creation of SouCysters.net. The Soul Cysters blog, then, has become a space of gender regulation. It is by engaging in the heath forum that the Soul Cysters are reproducing a normative femininity. The Soul Cysters narrative is clear: the Soul Cyster is strong, the Soul Cyster is defiant to a healthcare system which has no space for her embodied experience, and the Soul Cyster will "beat" this "bodily infestation" of masculinity which does not belong to her.[8]

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[8] See Appendix E for Soul Cysters example.

In coming to understand the collective objective of the Soul Cysters blog (achieving a normative femininity) I turn to alternative message boards online where other PCOS communities, including those occupied by trans men, write about their identities and embodiments of illness.[9] In the life writing I examined of trans individuals with PCOS, a stable femininity was not being reproduced. I identified an engagement with PCOS as a way to both legitimize and understand trans identity through a biological and essentialist means. The ways in which a PCOS body exhibits symptoms of "excess" androgens and elevated testosterone are employed in these writings as "evidence" for a "born-this-way" narrative. Because trans individuals face injustice, abuse and violence when society "reads" their gendered body as deviant, exhibiting PCOS seems to offer trans individuals a way to turn to "biological" explanations for their gender identity. This includes mainly a false belief that elevated androgens and the corresponding symptoms of excess body and facial hair, male-pattern baldness, enlarged clitoris, increased muscle mass and lowered voice, produces a male gender identity. For example, one blogger named Quicksand argues that experiencing a "surge" of male hormones in utero triggers a PCOS illness, and this would explain why a trans man now "feels" like a male. Quicksand notes:

> So let's say your mom has excess testosterone. She becomes pregnant with you (somehow despite having PCOS) and is unaware that she has PCOS, therefore you, a developing female fetus, receive a hefty dose of testosterone while in utero. This affects your brain development in such a way that it becomes more congruous with the brain of the male gender. Voila! A transman in the making. So I guess what I'm trying to say is,

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[9] Examining this particular community becomes significant when considering that there is a perception of a high PCOS prevalence rate in trans men. There is also strong criticism of this perspective claiming a lack of supporting evidence (Baba et al).

> yes, there could be a correlation [between PCOS and trans identity], but it is irreversible. Luckily, it makes passing ten times easier before starting testosterone...as in, I have a beard in my before AND after pictures. Good stuff!

This explanation acts as a way to legitimize, through the medical system, their gender identity. Despite "born-this-way" narratives being valid and representative for some trans and gender non-conforming individuals, biological explanations for gender become dangerous when they work to both delegitimize people who experience gender fluidly and feel different at different times, and to reinforce biology as indicative of gendered behavior (for example, beliefs that men are inherently violent due to the effects of testosterone). As Quicksand notes, some bloggers discuss a concept of "PCOS privilege" in the trans community where trans men with PCOS are perceived to "pass" as male more convincingly than those who do not have these symptoms of excess androgens. Similarly, one anonymous user begins to conceptualize PCOS as socially constructed by asking, "If a cis woman has PCOS, and her body produces a lot of T [testosterone], she gets things like acne and androgenic body hair, loss of cycle and possibly other male traits. If I, a trans man takes T I get these things too.....how is it healthy for me but unhealthy for her?" ("FTM Advice"). This user highlights how bodily expressions of elevated testosterone may be perceived as an illness in some bodies but as achieving gender normalcy in others. Through looking at the ways in which trans men come to understand their illness with PCOS in complex and varied ways in relation to the Soul Cysters, it becomes clear that the outcomes of reproducing a stable femininity in Soul Cysters is an effect of cultural pressures.

Turning back to the work of Mintz, I desired to know what was unique about the life writing Mintz profiles and how those women were able to subvert and resist hegemonic understandings of illness. In attempting to locate where the perspectives of Mintz's authors diverge from those of the Soul Cysters, I found it was in the former's collectively subscribing to a social model of disability (Mintz 2). Where both categories of women are engaging in life writing to better understand themselves in relation to their illnesses, the Soul Cysters portray their bodies as abnormal to a substantial extent, and disregard this abnormality as produced by discursive cultural expectations of femininity. Mintz argues that the authors which she is profiling prescribe to a social model of disability which she defines as positioned in opposition to hegemonic medical discourse. Mintz's authors view disability not as a malfunction of the body which requires surgical or pharmaceutical intervention, but rather, as produced by our structural development of normalcy (2). Mintz suggests that while writing about their experience of gendered disability, these authors are actually re-writing disability in terms of "power and discourse rather than genes or physiology" (2). Unlike the Soul Cysters, the authors Mintz is profiling come to assert a form of activism through their understanding of their gendered identities as subjugated, ideologically produced, and without inherent flaws. Rather than remaining merely ignorant of their gendered identities as both political and socially constituted, it seems the Soul Cysters thoughtfully sidestep this way of thinking. The larger narrative embedded in the Soul Cysters forum is an acceptance of the PCOS body as deviant, abnormal and requiring medical intervention. Large sections of the forum are dedicated to investigating symptoms, exploring alternative treatments, and discussions of which medications were "successful" in reversing a perceived deviancy, allowing them to "return" to normalcy.

Mintz describes her authors as "compelling precisely because they write their bodies—their gendered, disabled bodies—as textually produced but also phenomenologically alive," because they focus their writing on the multitude of generative factors that work to construct their identities. The factors include family workings, medical treatment, cultural representations and systemic oppression, as well as the “really real” impairments of their bodies (4). In other words, these women are writing about the ways in which their disabilities are culturally produced without succumbing to erasing the “real” impairment and the hardship it causes. The Soul Cysters, on the other hand, champion activism mainly around challenging the practices of the healthcare system to ultimately elevate awareness of PCOS as a disease in the medial community. There is little mobilization in the Soul Cysters space around challenging cultural understandings of femininity. Despite Soul Cysters’ apparent transgressive resistance to the normative medical institution, the healthcare system and the Soul Cysters forum have a shared urgency for altering the PCOS body to reinstate a stable femininity.

Mintz argues that “cultural messages about illness and dysfunction, like regulatory norms of gender, wield a fierce and tenacious hold on us” (22). She notes how surprising it was to find in her analysis of these authors, as women who hold overt feminist and progressive agendas, a constant undermining of their political activism by routinely surrendering to the very ideologies they were attempting to destabilize. Mintz concludes that structural understandings of identity are overpowering. Despite the self-awareness of these authors, she located routine instances of deeply internalized and unrecognized shame of the body (Mintz 22). This “fierce and tenacious hold” for the Soul Cysters is about survival. Similarly, David’s story, and Butler’s subsequent analysis also informs an understanding of the motivations of women with PCOS and their treatment options. If the question is: why are the Soul Cysters striving to attain a standard of femininity when these practices are seemingly not in their best interest, the answer is: normative femininity is, in fact, in their best interest of survival. Through constant social persecution and medical interrogation, some women begin to recognize that they are “failing” gender. Like

David, to varying extents some women understand that they are not meeting the standard of feminine normalcy and rectifying this incongruence becomes integral to their sense of identity.

Conclusion:

Despite the transgressive ways in which Soul Cysters works to defy the practices of the normative healthcare system, the forum is ultimately reproducing hegemonic epistemologies of gender. The community building practices, discussions of alternative treatments and modes of self-expression are contingent on either working towards achieving normative femininity or lamenting one’s inability to do so. The ways in which Soul Cysters becomes transgressive is complex. The women who write in the forum stand in solidarity with authors such as Lorde and Woolf who actively criticize the dehumanizing practices of the healthcare system, but for the Soul Cysters it seems they are achieving the same outcome as this problematic institution. Both the normative medical system and the Soul Cysters community are mandating a standard of femininity for women with PCOS to meet. In the same way healthcare policies enable physicians to prescribe medications and perform procedures that “combat” masculine bodily expressions, the Soul Cysters community reinforces these same objectives. Physicians look to “treat” the bodies of women with PCOS through prescribing androgen blocker medications such as Spironolactone, oral and topical Minoxidil for male-pattern baldness, hair removal procedures such as laser and electrolysis or hair growth prevention cream like Vaniqa, and the combined oral contraceptive pill (Lucidi). Despite the community of the Soul Cysters forum working in transgressive ways which re-centers the subjectivity of these women, the objective of discussions in this space is to discover new ways to attain normative femininity. Women in the Soul Cysters blog are sharing alternative treatments used to lower androgen excess, to re-grow hair on their head and diminish the hair on their bodies. These women are sharing collective pain and mourning over their inability to become pregnant without a collective resistance to essentialist notions which inherently link womanhood to motherhood. The Soul Cysters are rehearsing false narratives to perform to physicians so that they may receive the diagnoses and accompanying prescriptions they desire. This subversion however is ultimately to obtain more efficient and accessible ways to "combat" the perceived masculinization of their bodies.

This is not to say that regulating gender is not imperative to the livelihoods of women with PCOS, because it is. Nor is it to undermine the severe injustice women with PCOS face in the healthcare system or the lack of funding or mobilization PCOS draws for medical research. As the structures of oppression currently stand, these injustices for women with PCOS mean discrimination, alienation, and punishment of their bodily expressions insofar as they destabilize our societal understandings of gender. As we come to understand that the Soul Cysters blog is replicating the gender regulations of the healthcare system, we also come to understand why. As Butler contests, achieving gender normalcy is an effort of survival (Butler 100). Ultimately, our practices for reading a sexed body are socially constituted, but this does not mean that gender, as a process of becoming, is trivial. Gender affects us in deeply meaningful ways and there are serious implications when the sexed body is read "incorrectly" or when it is unreadable at all. These implications include both social persecution where performing gender "appropriately" becomes a mode of survival, and internal disarray when one's process of becoming is stifled or halted. It is understandable then why the Soul Cysters are reproducing a standard femininity. Meeting this standard becomes either a process of survival or a mode of becoming. In spite of this, Butler's conclusion points to the political and social justice potential of PCOS. Gender as a site of possibility gives hope to women who may feel imprisoned by their diagnosis and desire new ways to respond to PCOS which are not rooted in reproducing a normative femininity.

Holding dear the hope of emancipation offered by both Butler through the apparatus of gender and Utell through the deconstruction of the “sick room”, SoulCysters.net has the potential to be a site of possibility as well.

Appendix A

“I'm exhausted. I'm just so exhausted with trying to work with my body, and constantly feeling like nothing helps. I felt I had finally found the right remedy with my body, for the first time in my life, last year, I had 12 cycles!!! It was far from regular, but was encouraging. Then I had 2 cycles in December. 1 cycle, and another exactly 2 weeks later, then nothing until June and the same thing happened.

I feel bloated and inflamed, all the time. I'm emotional. I'm tired. I'm so sick of my hairy face, and my body being fit, except for my huge fat stomach.

I try so hard to eat right, exercise, do yoga, meditate, acupuncture, I take vitamins, but NOTHING WORKS longterm. It seems to work for a bit, and then not at all... then I stress over the expense of it all. It's a vicious cycle.

I feel like I'm at battle with myself, by myself.

It's been such a hard year. My Grandpa passed away from cancer, my husband and I have been going through an immigration process, so doing the whole long distance thing, my sister is transitioning... further- found out, in my province, they pay for my sisters surgery if she wants it, but I can't get IVF if I need it?!

PCOS is so frustrating. Life is hard enough, and it feels like all those coping tools we as humans should have are debilitated from PCOS. I just wish so badly I could have been born with a normal functioning body.

I'm so sorry for venting all of my toxicity... I just feel so frustrated and alone this week and needed a safe place to expel all these thoughts” (adt83).

Appendix B

"…It [PCOS] is amazingly badly diagnosed, and treatments for symptoms are lacking or doctors are ignorant. Even those at well regarded establishments. Very frustrating.

I would love to start a foundation FOR PATIENTS RUN BY PATIENTS.

Just think how many women are affected in the world. Millions. If 10% of them, joined a foundation, became members and donated even $1.00 per month (how much do we spend on treatments with little results) we could have millions of dollars to allocate to research and therapy development. Research based upon what patients want answers for, not geared towards the researchers getting published in some academic journal so they can get the next grant and stay employed. Research geared towards changing lives.

Think of how we could change things. I don't want to have a foundation which just does educational conferences based upon what the existing medical establishment is doing. I want to direct the research. I want to build a database of patients, with their unique hormonal parameters (because people are so different), start doing DNA screens on ladies based upon those hormonal parameters, start logging which treatments had which results on which type of cysters (followup bloodwork after). Log which patients would be willing to participate in studies. Log family inheritance patterns. We could do so much. But we're going to have to do it ourselves" (maddy17).

Appendix C

a) “Hey Sistahs!

I was inspired to start a fresh new thread after finding out that the founder of SoulCysters.com was founded by a Sistah! I mean I am elated to see that she is African American!!!

I am so proud of her and after reading her highly inspirational personal story about PCOS I feel even more motivated to stay on track to a healthier me. A healthy me I'm sure will increase my chances of obtaining and maintaining a healthy pregnancy that results a healthy baby. I am so emotional right now, lol, my PCOS mood wings have been in kick ass mode the past month and I am prone to crying at any and everything! lol! This is definitely one of those moments.

I'm new to being active on the site & TTC and I must say I truly enjoyed the post of so many Sistahs sharing their stories, their struggles, their joys, their BFP's and everything else 😊

This is how we heal. We heal by sharing and being open with one another. This is how we learn. This is how we as Sistahs will overcome PCOS. So chat it up ladies!” (MissPerseverance).

b) “Hi ladies. It's great to be able to talk to someone else of color. Most women I get to talk to about these issues are Caucasian and Latino so it will be good to have another perspective. It seems so many African Americans won't talk about pcos and infertility. Thanks you for having the courage to do so” (edswife05).

Appendix D

“When My Son Smiles

When I look at you
I see my past, present and future collide
Years of wanting
And waiting
Meet sleepless nights and tired eyes

When I hold you I feel blessedly complete
All the years of aching emptiness melt away
And I know my heart will hold you all the rest of my days

Your laughter is food for my soul
Your tears cut me like the sharpest of blades
I’d trade my life to give you a hundred thousand happy healthy days
And fade away peacefully knowing you’d be safe

Your touch on my cheek warms me as no fire ever could
And the look on your face when you gaze up at me- adoringly!
Makes me ache to be the person you see

I hold you cradled in imperfect arms
And trace my finger down your soft cheek
Your eyelids blink open sleepily- more brown than blue
And you look at me as if I have every answer you’ll ever need

A tear runs down my cheek to land on yours
And your small pink lips turn into a tiny bow smile
And in that moment I know true joy
For there is no pleasure greater
Than the euphoria I feel
When my son smiles up at me.

Written when I brought my son home from the hospital” (Bigsmama).

Appendix E

“Hi all,

since I know I have PCOS I finally know the cause for me why my body looks so disproportionate for a female. I'm a thin cyster and I look very dudish: broad shoulders with a massive ribcage, very long torso and short limbs and of course the PCOS belly. :/ Besides that, I noticed that my facial structure had become much more masculine. Comparing pictures of my 16-year-old self to now (I'm 20) there is a significant difference: very pronounced brow bones, a big jaw and a overall wide face. The left half of my face looks even more manly than the other one. I know that when I'm ovulating it is mostly the left side of my ovary so maybe there is a connection. I know that all of this is due to the excess amount of testosterone. I've tried to control it with a holistic lifestyle and natural medicines but nothing of it worked apparently, just a whole lot of money going to waste. So I guess that I have to go back to BCPs in order to shut my ovaries down before it get's worse. PCOS can really be frustrating when it comes to looks.. It is hard for me to accept myself the way I look now. I identify myself socially as a woman but looking at my body I feel like something in between male/female which I hate. ☹ I really don't know what to expect from this depressive post, I just wanted to get this off my chest.. Maybe we can share our experiences together?

Best wishes & lots of love,
chloejolie” (chloejolie).

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