Normalized Abnormality: Living with PCOS

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Abstract

This autoethnography explores my experience navigating Polycystic Ovarian Syndrome (PCOS) within a healthcare system that often dismisses women's symptoms as "normal." Through personal stories of embarrassment, ineffective treatments, and emotional tolls, I confront the frustrations of dealing with PCOS while being met with indifferent and gender-biased medical advice. This narrative reflects on how these experiences have shaped my identity, fears about motherhood, and perceptions of women's healthcare, ultimately calling for a more empathetic and informed approach to women's health.

Keywords: Polycystic Ovarian Syndrome (PCOS), menstruation, hormonal imbalance, female healthcare

First Menstrual Experience

"That's normal" has gotten to be one of the most frustrating phrases I've been told. I got my period at fourteen years old; it was light back then. Three months passed from my first cycle and it did not start again. "That's normal. It happens," my mom used to tell me. The next time I got my period, it was the opposite of how it was the first time. I remember feeling very uncomfortable in class, I stood up to go to the bathroom and I saw a huge blood stain on my seat. I turned to my friend sitting beside me and asked her if she could hide it with her bag since there was a boy right next to my seat who could clearly see it. A stain that size could not go unnoticed.

"I can't, it's impure," she deadpanned.

I did not know what to reply and put my bag instead and scurried outside the classroom. I spent the next 45 minutes desperately trying to get the school to contact my mom or at least give me other pants to wear with no avail. They argued that the school day was almost over, and I would go home in a bit anyway.

Panicked, I returned to class, and I heard said boy whisper "Look, Ghalia *jeyeeta*, and there's blood on the seat."

Riding the school bus home, I sat at the edge of my seat. I could not afford to expose myself on the bus as well, although I still managed to stain it just a bit so that it would go unnoticed. Shameful, nonetheless. My mom was sympathetic and shared some experiences

of her own to comfort me, but I just did not want to experience menstruation again. They say be careful what you wish for, and it is true because I indeed did not menstruate after that.

It is normal for teens to have irregular periods in the first two years of menstruating, and it does not necessarily require an evaluation from a doctor (Seattle Children's Hospital, 2022; Torborg, 2017). However, I kept spotting blood for a whole month, and I think my mom took me to the doctor to comfort me, or she knew there was something unusual. So, at 15, I was prescribed birth control, antiandrogens, and progestins. I finished my doses, and my period became normal.

First Signs of PCOS

At 16 years old, I went on an exchange program to the USA for eight months. That period was the worst for my hormones. I did not menstruate for the entirety of my time there. I had a litany of other apparent ailments as well: acne breakouts on my face, neck, shoulders, and back, intense cravings, heavy sleep that never seemed enough, unreasonable weight that made my face look swollen, and I had excess hair growing on my body and face. These symptoms are typical ones for hormonal imbalance in women (Roop, 2018). With hormonal imbalances, the lifestyle plays a major role (Bokar & Joshi, 2023) – I had been eating a lot of processed food, take-outs, and snacks; I was overworked, homesick and stressed. All these factors are usual causes for the symptoms mentioned (Roop, 2018).

I revisited my gynecologist upon my return home. I really liked her; she always treated me like one of her daughters and she was also my mom's obstetrician. I only had to mention that I had not menstruated in almost nine months, and she immediately performed an ultrasound and asked me to do a bunch of tests to evaluate my hormone levels. At my age, I did not think that one would be so familiar with seeing her uterus on a screen and taking a picture of it back home with her, but that was how it was for me. Then, again, I was back on medications.

First Diagnosis of PCOS

Fast forward to 18 years old, the same problems, symptoms, and anxieties resurfaced. I did not want to hear the word "normal" about my menstrual health anymore. I was fed up with my body's incapability of being normal without medication and blamed the doctor for it. I asked my mom to take me to another one, and we did.

I remember sitting across from him and my mom beside me. "I haven't been getting my period, there is hair on my face and my chin-"

"Are you Arab? You speak broken Arabic."
"Yes, I am." He only nodded so I continued describing what I was experiencing, disregarding his clear disinterest in what I was saying: "I am having acne breakouts and—"
"You're gaining weight, yeah that's typical. Let's check your ultrasound image." I got up and a woman led me to a breakout room, he followed us and started examining the screen. "A lot of women experience this, you have PCOS, it is prevalent in 23% of women. Let's go back," was all he said.

What was PCOS? What was causing it? What did that mean for my health? All these were unanswered questions.

We went back to the doctor's office, and he asked me if I exercised, then he told me that I needed to lose 10 kilograms of weight, exercise, and of course, take the same medicine as always. Hearing the same medication prescribed to me, I felt myself checking out mentally from the room and withdrawing into having to relive the same experience again knowing that it won't work out but hoping I'd be proven wrong this time.

Hormonal imbalance is a symptom of PCOS; however, PCOS is distinguished by having many small cysts on either or both ovaries (Zehra & Khursheed, 2018). I did not know this at the time or where these cysts showed on my ovaries.

I opened an online search on my phone once I got into the car to answer my own questions. I found that PCOS can develop into a metabolic disorder, cause infertility, and other psychological issues (Louwers & Laven, 2020). Reading this terrified me. I had to lose 10 kilograms, eat healthily, take pills, sleep well, or else I would not be able to fulfill what I had always dreamed of: motherhood. I do not remember when I stopped taking pills because the doctor never specified the duration of the treatment and I never asked, so I decided for myself that maybe this time I can rely on my own body to function the way it was supposed to.

Living with PCOS

A couple of months later, I was texting my friend about my PCOS and how I was terrified of infertility. The subject of my excess hair came up, and I explained why I had it, what PCOS was, what it could lead to, and that I had stopped the medication.

"Every month I am terrified of not getting my period. I don't care about all the other symptoms I just want kids so much. I literally would lose my purpose in life if I couldn't have them. Everything I do and plan is centered around how it will affect them when I have them."

My friend tried to comfort me, saying that there was much more to me and to life than the medical condition I had. Their words were not very convincing; if I could not have children then there would be a massive gap in my life and heart. It is a type of grief I do not think I can handle.

I obsessed over tracking my ovulation, making excel sheets of everything I was experiencing, and I feared eating. Being in university dorms, and always feeling tired made it difficult to cook food, so I slept instead. Every time I was hungry, I would think of the weight I needed to lose and how the food I ate would make things worse for me. So, I had naps for meals and temporarily turned off my constantly tired body and mind.

There was one time back home where we decided to order from a Turkish restaurant. I decided to order a baked potato, thinking that it would be better than a Donner. When the food arrived, I had my baked potato and just stared at it. *It was coated in butter; how many calories was this?* My mom noticed and I told her that I didn't want my food. She started sharing her beef Donner with me by giving me the beef slices on a fork. With tears in my eyes thinking about how fatty this food was, I forced myself to eat but could not do more than three bites.

As a natural consequence of disordered eating, months passed without me menstruating. Again. My hair started thinning and I was losing weight but by the wrong methods and

for the wrong reasons. I went from 65 kilograms to 53 kilograms in a month, meaning I accomplished what the doctor asked me to do. Yet, I was not menstruating.

Realizing the Flawed Healthcare System

I went back to my old doctor; she told me that my uterus had no cysts whatsoever and that my ovaries were very healthy. She suggested I start getting laser hair removal for my face accompanied with antiandrogens and birth control for a year. I did as was told and yet, the same issues rearose four months after completing my medication dosage. The cycle repeated and I went to another doctor who told me that I did in fact have PCOS of an average level. I tested my hormone levels and was prescribed the same medications. Again. Shockingly, when I finished the dosage, my menstruation stopped again.

I now stand at a point in life where I cannot find a trusted doctor to guide me to health. I have found my own answers and a better cure for my condition with no support of a doctor but rather from the women in my life with the same experience. I have grown up lost between doctors who diagnose and un-diagnose me with chronic illness, and between the people around me telling me that it is "normal" or that once I get married, I will miraculously be healed because of course a man would be the cure for a female's sexual reproductive health issues.

I now understand PCOS more; 70% of its cases go undiagnosed (WHO, n.d.). PCOS works as a vicious cycle. What happens is that the cysts on the ovaries lead to elevated levels of androgens that in turn elevate insulin resistance. This insulin resistance is the factor that causes PCOS to be considered as a metabolic disorder. Ironically, the rise of androgens that leads the increase of insulin resistance also drives higher levels of androgens. Consequently, ovulation halts and these non-ovulated eggs or follicles turn into cysts. So, the cysts themselves are non-ovulated eggs that stop the ovulation of more eggs. Hence, it is comorbid with insulin resistance and can lead to gestational and type 2 diabetes. The feeling of fatigue stems from this fluctuation in blood sugar. Moreover, elevated insulin levels cause more water retention that leads to inflammation in the body. This inflammation increases cortisol levels, making PCOS associated with some mental health issues. Therefore, PCOS is a complex chronic illness, and I am still trying to accept it and live with it.

Without the support of the women around me experiencing the same experiences as mine, I would still be lost over how to deal with my health to this day. I discovered Myo-Inositol and Dcheiro-Inositol as a possible solution for PCOS through my friends. Myo/Dcheiro-Inositol aids in controlling insulin resistance and works on the symptoms of PCOS without the side effects that the usual prescribed medications have (Greff et al., 2023).

Conclusion

These seven years of navigating misdiagnoses, repeated treatments, and gendered assumptions have shown me that the normalization of suffering in women's healthcare is anything but harmless. Living with PCOS is not just about hormonal imbalance, it is about enduring a chronic illness within a system that too often dismisses women's pain as "normal." Persevering through the emotional toll of confusion, shame, and fear of grieving potential futures and doing the work doctors should be doing, would have been exponentially more difficult without the support and solidarity of the women around me; without feeling seen and heard by them. I now understand that healing is not linear, and empowerment often comes not from medical authority but from the women around me,

those who shared the same story as I, who helped me begin to take control of my health. While PCOS is a complex and individual condition, the healthcare system continues to offer one-size-fits-all solutions. Women's health deserves nuance, empathy, and a commitment to seeing and hearing those it aims to serve. My story is just one among many, but I share it with the hope that what is deemed "normal" in women's health will no longer be silenced, but validated.

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