

The Invisible Syndrome
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“When was the last time you got your period?” For most girls, this marks another routine question at another routine doctor visit. Embarrassment masquerades as annoyance as I answer in monotone, “Never have, never will.” Then through a patronizing smile I hear, “Well, honey, I don’t need my med school education to know that women get periods, and you are a woman... so when was the last time you got yours?” Well yes, Ms. Ph.D, I am a woman. I’m a woman born without complete “female” parts. But that’s a Pandora's Box I’d prefer not to open. It makes me feel as though my body is an anomaly even in the medical world as I’m forced to explain my diagnosis. Instead, I usually reply with, “I had a hysterectomy” (which is an over-dramatization, because my uterus was only meekly developed in the first place). This is the easiest way to move on from the conversation, especially when I’m there for something like a torn meniscus, and I can’t imagine my lack of menstruation matters all that much. I normally get a look of absolute pity that within seconds, dilutes to confusion as the doctor realizes my age. “Oh honey. I’m so sorry. But before that, did you have a regular period?”

Nope.

In a world where our bodies must fit within such strict physical forms just to be considered acceptable, there’s very little margin for “error”. It’s easy to internalize “difference” as falling short of an expectation -- a disappointment -- for what our human experience should be. We disassociate from what makes us individuals and in turn hide who we are from the very people we should be connecting with. In trying to mirror what we see, we ultimately create a world of illusion. Why do we try to make ourselves perfect in the least authentic ways? Perhaps we live in a paradox of comparison, where we always see ourselves falling short of physical and social expectations while simultaneously inflicting these same impossible standards onto others.

I do not have a complete reproductive system. I was born with Mayer-Rokitansky-Küster-Hauser syndrome (MRKH) which stands for nothing more than a bunch of German guys' last names thrown together. To give you the handy Google definition, MRKH *"is a Syndrome that occurs in females and mainly affects the reproductive system. This condition causes the vagina, cervix and uterus to be underdeveloped or absent. Affected women do not have menstrual periods."* One in roughly 5,000 women are affected by it. Those wishing to become sexually active must undergo a relatively extensive process either surgically or through dilation, but will still never be able to carry a child. Having an underdeveloped reproductive system has made me question my femininity in a world where rhetoric on what defines a woman often has to do with her body and its reproductive capabilities.

I'll often see self-proclaimed feminists posting artsy tumblr-esque depictions of a uterus captioned along the lines of "women are strong -- they are able to push a living creature out of this!" The central message: women are to be praised for their child-producing bodies. To play devil's advocate, this seems to adhere to the patriarchal belief that a woman's purpose is to carry children and that her body and what it can do is what ultimately defines her. Furthermore, how can I be secure in my own feminine identity within such a narrow body-centric definition of womanhood? I would like to think a woman is larger than her ability to reproduce, that being a woman does not come with an obligation to do so, and that not having children does not mean she is fulfilling her role in society any less. Because I cannot physically conform to these expectations put on women by society, cannot find bodily agency in the same way, or find my own gender identity under the typical biological definition, I've had to create a wholeness in myself through other ideas of what makes my identity and purpose as a woman.

Though infertility is something I regularly have to face in a world that really loves babies, and I sometimes catch myself questioning what the hell I'm doing here if it isn't one day to make one, infertility is a widely known, even socially accepted condition in the West. At least it seems to be when it's due to something that doesn't question your gender identity. If people ask why I can't have kids, it

would be a lot easier to only tell them part of the story -- that I have Endometriosis (a fairly common tissue growth) -- than to say it's due to the fact I was born without a space to physically be impregnated.

It is difficult to see "It's a Boy!" announcements on Facebook or get in a hospital elevator with a family bringing home a newborn because it reinforces the fallacy that I am inherently less because such beautiful, yet expected female life-events will never be peppered throughout my life (getting a period, having sex conventionally, and giving birth). It can feel as though our emphasis on these events and my innate inability to experience them conventionally represents a significant absent in my socially expected human experience as a woman.

We are socialized to believe that at some level female reproductive organs represent womanhood. Possibly because they are what allow women to keep our world populated with little homosapiens. However, I feel that this is a brutish view of a woman, because it sees her as more of a reproductive organism than as an intellectual being. As humans, it is our intellect that separates us from the animal world. Making parts of the female body represent what a woman is strips her of believing that she can be full and complete without a perfect combination of muscle and tissue in the right areas. At this point overpopulation is killing us, so when you think about it, my organs are really just looking out for the greater good.

Due to my syndrome, I'm naturally on high alert for what seems to be an abundance of rhetoric that dilutes women to their reproductive parts. As if uterus = woman. I identify as a woman, and I think most people who know me wouldn't think twice in doing the same, so my absence of a uterus could not strip me of my female identity, could it? And if my physical body is not what defines my womanhood, then no other woman should feel that she has to succumb to the same limiting belief. Though I would love to list what I feel makes me feminine, it's not tangible. I simply fall somewhere on a spectrum of open gender identity that's very similar to a lot of other "women" out there, and it's not due to anything physical or perhaps even biological.

Nonetheless, we have a very detrimental stigma around “imperfect” bodies, and though MRKH doesn’t get in the way of my daily life, constant social reminders give agency to an internalized conclusion that something is broken within me, that I, when defined by my physical self, am incomplete.

Last year on December 5th, a girl living in Subhash Nagar, India doused herself in kerosene and lit herself on fire after being diagnosed with MRKH. Especially in other cultures, the idea of infertility is a death sentence for a woman. This and many other stories like it show just how much pressure is on women to reproduce.

However, infertility is only part of the complete picture for an individual with MRKH. Common public rhetoric about MRKH only talks about the infertility -- lack of a uterus -- part of the diagnosis. When the syndrome isn’t fetishized on television shows like *Embarrassing Bodies* (yes, that was a thing) that profit from rare and potentially humiliating diagnoses, the woman with the condition only shares certain aspects, mainly the mechanics behind the uterus’ absence or underdevelopment. I want to expand the conversation to include the more more sensitive part of my condition that typically isn’t publically talked about -- the part where I was born without a complete vagina, and therefore, unable to have sex (though -- because we *are* going there -- I have undergone the process to make it so I can).

In a world where a woman’s body is hypersexualized, where she must cover up because her body has been socially commodified as a sex object, where rape culture dominates and hearing a sex joke is as common as hearing “how are you?”, the manifestation of these messages and the constant, degrading rhetoric towards a woman’s body presents itself to a technically intersex individual as a series of unrealistic expectations. I was born unable to have sex... is that too shameful a topic to even make a joke about?

I learned through watching romance movies and attending a number of fraternity parties that we hold sex on a pedestal. It represents the pinnacle of what can happen in life, in a relationship and wherein we enter

some supposedly special realm with another individual and become our most vulnerable, intimate, exposed selves. “Did you guy... do it?” was something I heard daily growing up, in hushed whispers in public school bathrooms, as if the thing itself was so private, so magnificent, it couldn’t even be named. In other words, that sex is... everything. As somebody who was born unable to have sex, and have ingrained this as such a shameful incapability, I find myself avoiding intimacy. I think after my diagnosis at the age of 16, I began to employ the belief that I couldn’t even give people what they want anyway so why bother getting close to somebody if rejection is the only reasonable outcome? Of course, there are people whose relationship horizons broaden wider than sex, but I often felt debilitated, or inherently unable to experience what society classifies as the literal climax of human life -- like I had a body that was deficient at the deepest level and who would want to share that with me? I learned how to be a mask of myself so that even in intimate situations I was acting. I could pretend to be that hot girl everybody wanted, but I knew that beneath the surface I didn’t have what they cared about most. I was never able to be myself even after months in a relationship. I felt that the consequences of displaying my vulnerabilities, not just emotionally, but especially physically, would leave me a definitive social and emotional casualty. My depressed high school self couldn’t fathom taking that on too.

Sex has become this thing that gives people validity. Like you did it -- you were able to please a man. Congratulations, you now know that your body has accomplished what you feared you would be bad at. But what if you can’t *even* be bad at it without undergoing surgery, or the physically and emotionally painful process of dilation? It is as though having that experience with somebody justifies something about ourselves. Perhaps that we are capable of being wanted in such an intense and intimate level down to the very core of our physical and soul beings. So, in not being able to have sex and living under the pressure to have such an experience, it’s scary to meet people and not know their intentions or how they would react to my “coming out” about MRKH. I fear rejection and embarrassment. I fear telling

somebody and having them react cordially but slowly stop texting me back. And I fear the moment after telling them. Will their entire vision of me change? It's a conversation I don't want to *have* to have.

When I was 16, I still hadn't gotten my period. I went to the first of many doctors who were stumped by what could be wrong. On the outside, MRKH is not visible, but once the doctor actually tried to look *inside*, she realized she simply couldn't. She ordered an ultrasound whose black and white screen showed nothing but mush where all my reproductive organs should have been. I think the man administering the exam thought that the machine was broken because he kept messing with it, trying to make it give him some direction as to what he was seeing. Ultimately, he could hardly make out a single organ. An MRI was ordered, then another, and a few tests later, they were checking my chromosomes to see if I was even genetically female. As a teenager who already dealt with a lot of insecurity and depression, having my own gender identity be questioned by blood tests and finding out several of my organs were just *absent* within the same week was overwhelming. "Born without complete female reproductive organs" would become a label even harder to hear, to live with, and to try to comprehend, let alone accept.

When I was first diagnosed I wasn't given a name for my syndrome or told that it affects 1 in 5,000 women -- only that I didn't have a complete vagina, cervix, or uterus -- and that there was no future hope I would ever be able to have sex or have children. I felt immediately burdened with a shameful stigma upon hearing this because the problem itself was so private and unknown. Whereas when somebody gets cancer diagnosis, typically there is no humiliating connotation attached to it. The patient will receive supportive information like a specific name for the condition, along with a prognosis and a network of doctors who had definitely heard of it before. This isn't to belittle cancer, but rather, to stress the importance of providing a name, a plan and information, and stigma-less compassion when delivering a diagnosis. It was hard to just hear, "You don't have x,y and z -- there's nothing you can do about it and you may possibly be the only person to have been born this way," especially when you type "born without

a uterus” into Google and MRKH is the first result. In fact, it wasn’t until a year later when a friend’s mom Googled these “symptoms” my original doctor had given me, that I found out I wasn’t alone, that there was in fact a name to my condition, and specialists, oh, and the hope of being able to have sex without surgery. She made a blue folder filled with medical articles and information, sat me down in her car and said “You have MRKH.” Now knowing that what I had had a name, had options and was a ‘real’ thing, I started calling around to doctors. It turned out I actually did need surgery to remove the remnants of “uterine horns” (the hysterectomy I was talking about). I had to travel bi-annually from my hometown in Colorado to see a Harvard-educated specialist at Boston Children’s Hospital throughout the rest of my high school experience. That year of feeling alone before receiving my Google diagnosis, with no support medically, but especially socially, did a lot of harm as I began to internalize the notion that I was “damaged goods”. That feeling of being so isolated by my difference provoked me to start this dialogue as a typical teenaged girl would -- in an Instagram post senior year of high school. Previously, my worldview had been created by society’s determined fixation on sexual agency, and on a strict ideal body image where there was no room for variance. Had it been infiltrated with other people being honest about their imperfections and about their differences, I probably would have felt like, frankly, I sucked a lot less.

I’ve struggled for years with an eating disorder largely due to my (false) conclusion that my body is lacking in the most vulnerable way it could be and in a way I feel I could not have an open dialogue about until recently. This change was due to a slow, yet steady epiphany that pretending that my body functions in a way that it doesn’t -- or more generally that pretending to be somebody I am not -- will never lead to personal happiness. Destroying myself for not having the body I so badly wanted was never going to ultimately give me what it was I was searching for. The more I try to fulfil this image of what is female and what is “attractive” to compensate for what I can’t control, the more I hurt myself and avoid the

opportunity to start this potentially beneficial conversation with the broader MRKH community and anybody who feels left out of mainstream society's expectations. My battle with accepting MRKH, though highly specific, was a universal tale of self-acceptance. I want somebody to read this and, cliché or not, feel like the world has space for their difference too. We aren't all as crazy as we think we are -- we just don't open up in honest ways enough to feel like we have room to breathe with our genuine experience. No matter if I'm starving myself, or punishing myself for not succumbing to an image I feel obliged as a woman to fit, I still won't have been born with a complete reproductive system, so I may as well stop running towards an image of perfection that will always shadow me. By living with gentleness towards our bodies instead of pressuring them into being what society deems ideal (or punishing them for not meeting that standard), we can stop perpetuating our addiction to making ourselves suffer. Instead, we can become addicts to habitual kindness and in doing so we open up the space for others to end their own incessant torment towards themselves for things outside of their control --things that don't need to feel heavy in shame because they aren't absolutely perfect.

You may wonder why I am so comfortable speaking about this. I'm not. Even though there aren't many people born within the vast realm that is intersex (though almost 1 in 50 people are), almost everyone suffers from something that makes them deviate from the expected human experience. I believe it's important for there to be a more open and honest dialogue that our bodies' stories don't have to be skinny or sexual or white or hairless or clear-skinned. We create standards and expectations of sex, gender, and body image that do not serve the greater good -- and quite frankly, I'm sick of it. So there you go: I'm intersex. I believe that opening up a dialogue to unmask difference and shed light on what we all hide, also opens up a space for acceptance. Not that we have to glorify our problems, but we could start by refusing to silence our true voices. In thinking, speaking, and acting with truth we can all live in a more authentically nuanced society where this perpetual obsession with fitting the mold isn't the only way to feel legitimate and worthy. Whatever it may be that you potentially struggle with accepting as part of

your life, embrace it, because hiding it or pretending like it doesn't exist isn't going to make it go away. In doing so, you will plant the seed for somebody else to see difference not as a hindrance but as an enabler for some kind of growth and expression of their own story.

Though I cannot live the “conventional” female life by giving back through childbearing, I hope to have a hybrid career in the film industry partly devoted to telling genuine stories whose central themes can help people at home feel less alone and secondly to making documentaries that shed light and gather funds for a variety of global inequalities. I also dream of opening up a free mental health facility domestically with a radically different approach to treating mental illness that is founded out of Buddhist philosophy. Instead of entering the typical mental health facility where the patients won't feel their unique needs/individual situations are being assessed, where they can't even hug those around them, or even tell the other patients their names or stories, they will find an alternative here. My approach to treatment is devoted to cultivating a sense of self love, and gentleness within the individual with a personalized approach that is tailored to addressing the problem, instead of masking it and where the individual can expect to leave with a strategic plan for them to feel successful emotionally, socially, and either academically or professionally. Essentially, it will be a center open to anybody to come feel loved, accepted, to make friends with their demons, and find sanction with the Buddhist idea of loving-kindness and leave understanding their own basic goodness and with a strong sense of purpose in the world. Fingers crossed, I can accomplish some of this without a pregnancy.