Two months ago I received a diagnosis that was hard to believe, understand, and accept: a "bag" trapped in my lower abdomen. It is shaped like a mango, 20 centimeters in diameter, and filled with thick liquid to the point of nearly bursting. It is neither "malignant" nor "benign," but something else, of a different order. It is the sequel to a surgery that took place 40 years ago.

I was assigned female sex at birth, and raised as a girl. When I didn't menstruate upon reaching puberty, a series of medical consultations led to a diagnosis: I had been born with MRKH, one of the many variations of intersex sexual characteristics. MRKH can have different expressions; in my case, I had been born with a vulva but without a vagina, uterus, or fallopian tubes.

As happens most of the time in almost every part of the world, that diagnosis was followed by the supposed urgency of surgery to "fix the problem." My father was worried about my chances of being "a real woman," and a surgeon assured him that a vaginoplasty would make me "truly a woman." It was at that moment that I spoke with both of them to explain that I had no interest in being a woman. My father found that conversation extremely alarming, but the surgeon told him to stay calm: my identity "malformation" was merely a symptom of my physical "malformation," and my male identity could be "cured" with a surgical intervention. What's more, it was essential to do it as soon as possible.

The weeks that followed were hell; the pressure ultimately came down to an ultimatum: either surgery, or psychiatric hospitalization. That is how I ended up "consenting" to an intervention that, according to the surgical team, would be simple and without major consequences for my health. The operation is known as the "modified Baldwin," and it consists of cutting a piece of intestine and placing it where the vaginal canal would have been.

Months after that surgery I had a generalized infection. The neovagina constructed from intestine had closed in the middle, like an hourglass. The tissue from which the neovagina was made had continued producing intestinal fluid, and that fluid had become trapped in the upper portion of the "hourglass"; it had become infected, and that infection had spread throughout my entire body. I nearly died.

I then learned that when a vagina is surgically constructed it must be used, to prevent it from closing and, as in my case, putting life at risk. I again stated that I had no intention of having vaginal sexual intercourse, and that I preferred to have everything removed so as not to be in danger again. I then learned that it could not be removed without risking the function of the bladder and/or the rectum. The only thing I could do to avoid another case of septicemia was to "dilate" the neovaginal canal (that is, to open it with a medical instrument called a Hegar dilator). My body had become a time bomb that had to be defused again and again. Since the dilations turned out to be painful, it was necessary to perform them under general anesthesia, several times a year, for several years. My father spent years furious about the expense each dilation represented; the surgeon spent years repeating that my resistance was purely psychological — resistance to "being a woman." After six years of torture, the neovaginal canal finally closed completely. Or so it seemed.

And here we are, 40 years after the first surgery, "simple and without consequences" — apparently, the upper end of the vaginal canal remained open, if only minimally. And that tissue, which had come from my intestine, continued producing intestinal fluid — very little, and very slowly. This is how what I have trapped between the rectum and the bladder is the same time bomb that nearly killed me 40 years ago.

In a few days I will have to undergo another surgery — this time, yes, to remove all the intestinal tissue. The surgery that could not be performed before because it was dangerous must now be performed even though it is dangerous. The tissue that must be removed is literally fused to the walls of the rectum and the bladder, but also to those of the intestine; scar tissue, nerves, muscles, and blood vessels are all tangled in the same place. They are so tightly bound together, and the pressure is so strong, that all it takes is wanting to urinate for the pain to split me open.

As I said at the beginning, I share this information not only because it is personal, but because, and above all, because it is political. When intersex activism says that bodily "normalization" interventions are medically unnecessary, it is speaking precisely about this: no one's life is at risk from having been born without a vagina. When it says that interventions must be freely and informedly consented to, it is also speaking about this: even in adolescence, consent can be obtained under threat. When it says that interventions have negative long-term effects, it is also speaking about this — for example, 40 years. When it says that these interventions negatively affect our mental health, it is also speaking about this: I am a 54-year-old man, forced in his adolescence to undergo a couple of surgeries and years of dilations (in my experience, the closest thing in the world to being raped again and again, naked and asleep on a metal table), forced these days to deal with horror that does not cease.

Since its beginnings, intersex activism has questioned two related assumptions. The first assumption holds that innate variations in sexual characteristics must be normalized so that intersex people can be happy. The second assumption holds that innate variations in sexual characteristics can be normalized. The first of those assumptions is based on endosexism — that is, on assuming that happiness lies in having a body that is not or does not appear to be intersex. The second assumption is based on medical omnipotence, incapable of recognizing that every intervention that modifies our innate sexual characteristics produces acquired sexual characteristics. My body is the result of the combination of both assumptions made flesh: instead of a different but healthy body, I have a different but sick body.

I began doing intersex activism in the late 1990s, and I have had the privilege of seeing in my lifetime everything we have achieved up to today. However, stories like mine continue to happen; somewhere in the world, right now, there is a surgeon who prides himself on being a "sculptor of bodies," a father who is angered, frightened, or horrified to learn that his child is "different," a society that believes simultaneously that "that doesn't happen" and that "if it does happen, it's not wrong," an intersex person who will pay for the rest of their life the cost of a "normalization" they did not consent to — worse still, who will pay with their body the cost of someone else's fantasy.

I know that some of you will be sorry for all of this, some of you write to ask how I am, will offer your encouragement, your support, and your help. I thank you in advance, as I also thank those who have made it this far in reading, whether or not you contact me afterward. The most important thing you can do after reading me is to remember that this message is not about me, but about you — about what you can do to prevent other intersex people from going through the same kind of experiences, suffering the same kind of pain, and enduring the same kind violence. While I'm undergoing surgery again, do something. Speak up, get involved, make it as political as you can: make it personal.

In solidarity,

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