

## CHOICE/LESS, The Backstory: Loretta Ross on the Dalkon Shield Disaster

- Kristyn Brandi: A lot of my patients tell me that they get most of their information online about birth control, so I think the media is really important in informing patients. However, I'm concerned about the recent messages particularly around the election regarding IUDs and implants.
- Jenn Stanley: That's Dr. Kristyn Brandi, an OBGYN and fellow with Family Planning at Boston Medical Center. She's talking about contraceptive implants and intrauterine devices, or IUDs, which are long acting, reversible contraceptives commonly called LARCs. Dr. Brandi has been researching how and why people make decisions around contraceptives.
- Kristyn Brandi: I think it's wonderful that people are trying to find out more about different types of birth control, particularly the IUDs and implants, because they don't get a lot of press. But messages I've heard after the election were that everyone should go get an IUD, because they're concerned that they're going to lose their coverage. I think that's really problematic.
- Jenn Stanley: Following the election of President Donald Trump, the internet was abuzz with calls for women to get an IUD now, before they lose their contraceptive coverage. Publications picked up on this. BUST published an article titled "Six Reasons You Should Get an IUD Before January 20th, 2017". New York Magazine published an article "Here's Why Everyone Is Saying to Get an IUD Today". There are countless other articles like that. While birth control availability could be limited during a Trump presidency, Dr. Brandi warns against this "one size fits all" rhetoric when it comes to contraception.
- Kristyn Brandi: I think the idea that everyone should get IUDs as a protective measure from a political system or a system of healthcare that may not have coverage in the future is really scary. For one, women that get IUDs placed and they don't have contraceptive coverage after that happens, eventually a doctor will have to take that out. If they don't have coverage to get it removed, then you're putting them in a position where they might want to get pregnant and can't because they have an IUD in or they don't like the side effects of an IUD and want it removed, but don't have access. That puts people in a very coercive situation, where they're stuck with this IUD.
- I think the other thing that's problematic with that is that it assumes that IUDs are it. That's the only method that will protect people. I totally recognize the fact that people may not have coverage to get birth control pills or the ring or the patch, but if that's the best method for them, then I worry about them switching to a method that they'd like less or they may not use as well, just because they're worried about their coverage. Really these decisions should be made between doctors and women and so we can try to figure out the problems with the health care system, but we shouldn't use IUDs as a shield to protect us from the healthcare system.
- Speaker 3: Some people say it was part of eugenics. We say it was genocide.

Speaker 4: I was outraged that this doctor decided for me that I was okay with not having the ability to have any future children.

Speaker 5: They were targeted. Women were used in the trial because they were poor women.

Speaker 6: All the simple stuff have been done a long time ago. There are no simple answers now.

Jenn Stanley: For Rewire Radio, I'm Jenn Stanley, and this is Choiceless: The Back Story. Four weeks, four stories of unethical medical research, coercion and injustices in healthcare that have led us to where we are today, because pro-choice is a meaningless phrase when we assume that all choices are created equal.

Today we hear from Loretta Ross, writer, activist and leader in human rights. In 1994, she helped create the term reproductive justice and its framework to challenge the singular focus on abortion and contraception in the pro-choice movement. As we've been covering in this series, many women, particularly poor women, women of color and women with disabilities have often had to fight not only for the right to choose when to have children, but for the right to have children at all. Loretta's own multitude of reproductive experiences steered her toward a life of activism. Here's Loretta's story.

Loretta Ross: The one full birth that I had, I got pregnant at 14 through rape and incest and so I had that child at 15. I had no choice about whether to have that child, because this was pre-Roe days. It was 1969. The only choice I had in that situation was whether to keep my child. I had actually thought I was going to give him up for adoption, because obviously nobody wants to co-parent with a rapist. I had not imagined a future that that would be my pathway to motherhood. I was at a Catholic hospital, after having been stuck in this home for unwed mothers, run by the Salvation Army, and for some reason, the nurses brought my son to me the morning after delivery when they weren't supposed to, because the children scheduled for adoption was supposed to be just whisked away. When they brought him to me, I mean it rocked my world and I couldn't do it, because I kept saying, "He's got my face. He's got my face. He's got my face." I'm not sure if they did that accidentally or if they did it on purpose, but what I do know is that for the next 47 years, I ended up co-parenting with my rapist.

Jenn Stanley: Loretta attended Howard University early, at age 16, to study chemistry. All students under 18 needed written parental consent to access birth control. Her mother, who she describes as a fundamentalist Christian, wouldn't sign her birth control permission slip.

Loretta Ross: She, of course, saw sex and sexuality as sins and since I already had a baby, she thought that I should never have sex again until I got married. Guess what happened? Freshman year, a thousand miles away from home, I got a new boyfriend and that was my first time engaging in voluntary sex, so that was pretty

special to me. We only had sex three times and I ended up pregnant again. I was kind of frustrated, because I'm like, "I haven't even gotten to the point where sex doesn't hurt and I'm already pregnant for a second time?" This just didn't seem fair. This wasn't what the romantic novels said it was going to be like. Fortunately for me, because it was in Washington DC, DC legalized abortion three years before Roe v. Wade and so I was able to seek out a totally legal, totally safe abortion at Washington Hospital Center and my law school headed boyfriend was very eager to pay for it, so it was not even a matter of the cost or anything like that, but again, I needed parental consent.

My mother really refused to sign the permission slip for me to have an abortion. Basically, she told me, "Well, if you're pregnant again, just come on home. Drop out of school, come on home and raise your kids." I could kind of see why she said that, because my mother had two children at 16 and here I am, 16, faced with two kids, so that's what she knew, except I wasn't going for that deal. It took a long time of arguing with her and finally, my older sister, who's nine years older than me, Carol, just literally forged my mother's signature to the slip. I never had any regret at all. I've searched my soul to see if I regret that decision, not at all. It was my attempt to try to prevent future pregnancies that I accepted implantation of the Dalkon Shield.

Jenn Stanley: The Dalkon Shield was an IUD that was developed by the Dalkon corporation and marketed by A.H. Robins Company starting in 1971 in the United States and Puerto Rico. It was first promoted as a safer alternative to birth control pills, because at the time, there were concerns that the pill caused blood clots and increased cancer risk. The Dalkon Shield had a unique shape that made it difficult to take out, so it had multi filament strings for easier removal. Loretta said getting the Dalkon Shield inserted was relatively painless and at first, she didn't notice any problems, but a few months in, she started experiencing extreme pain.

Loretta Ross: I kept going to the doctor and unfortunately, I wasn't able to use my private OB-GYN, which I had been with ever since my days at Howard University, was a Howard graduate and everything. I had gotten a job with an HMO and so they forced me to use their system and my doctor, through the HMO, was head of OB-GYN at George Washington University Hospital, so I actually kind of thought I was in good hands. It turns out that he had all kinds of racist and sexist stereotypes about me, because I'd already had a baby. When I started developing the infection, he assumed and literally told me that I had some rare venereal disease that the GIs from Vietnam had brought back to the United States and he kept treating me for an STD when I had acute PID. That went on for six months and I was in extreme pain. My stomach was getting distended and at no point, did he remove the IUD. I was naïve enough to trust a doctor. I actually believed his stereotype about me, but I kept saying, "I don't know any GIs. How can I get something from a GI? I don't know any GIs. I'm not having sex with any GIs."

He prescribed something else and I'd take that for a month and then come back. It wasn't working, so he prescribed something else and something else and something else, so we kept trying these different regimens, but never did he consider removing the source of the infection in the first place. Actually, my

boyfriend when was a medical student and he's the one that recommended that, "Loretta, you really need to go see what else is going on with this, because this doesn't sound right." I said, "Okay, I'll make an appointment next week and I'll go again." Well, before I could get to that appointment, I passed out in my apartment one day. Fortunately, Eric, my boyfriend, was there when it happened, so he called the ambulance for me and they took me, unconscious, to the hospital. When I woke up, I'd had a complete hysterectomy, because I wasn't even conscious to sign the permission slip.

The next morning, after they do this, what they call a total hysterectomy ... They actually did a sub total and then they came back and removed even my remaining ovary. After he did it, the doctor comes in the room, and says "Oh, aren't you a lucky girl I caught that? Aren't you lucky you already got kids?" I was bewildered. I said, "Are you telling me I can't have any more kids?" He said, "No, we had to do a hysterectomy on you to save your life." At first, again, I was grateful, because I thought he had saved my life, but Eric told me. He says, "Something's not right about this. Something's not right." Based on his urging, back then you could actually get copies of your medical records, so I got a copy of my medical records from George Washington University Hospital, took them to my former OB-GYN, who was practicing at Howard University Hospital, and my former OB-GYN took one look and said, "The first thing he should have done was remove that Dalkon Shield. There's so much medical literature now showing that that filament is dangerous."

Jenn Stanley: This was in 1974. By that time, more than two million women were using the Dalkon Shield IUD. Reports were surfacing about the increased instances of pelvic infections and septic abortions among those who'd had the Dalkon Shield inserted. That summer, the medical director at A.H. Robins published a letter to the editor of the British Medical Journal that said that while the company was aware of the increase in septic abortions and four fatalities among users, they didn't see evidence of a direct causal link between these cases and the Dalkon Shield. But medical journals were already publishing articles saying that the porous, multi filament string that made the Dalkon Shield easier to remove appeared to allow for bacteria to travel up into the uterus.

Loretta Ross: I was angry. I was angry and I think the thing I was most conscious of was that I had lost my chance to be voluntarily pregnant. Yeah, because I really had the experience of parenting in all the worst ways with that, but I was looking forward to getting married and seeing what voluntary pregnancy looked like. Like I said, I had a whole discovery of what voluntary sex felt like, so I really wanted to do the whole thing. I was most conscious of a sense of loss and then I got enraged as he started delving into the medical records and telling me all the missteps that this head of OB-GYN had done and then he was ... When he said, "He just assumed because you were black and poor and you were already a mother, that he did not have to provide you quality care." Based upon that, I sought out a lawyer and we ended up suing A.H. Robins, the maker of the Dalkon Shield and folded in the doctor.

- Jenn Stanley: Loretta was one of the first to sue A.H. Robins for complications caused by the Dalkon Shield.
- Loretta Ross: I hired this lawyer who counsels me to settle, because he basically told me. He said, "Because you're already a teen mother, they're probably not going to give you a lot of money anyway." Of course, I found out that that was his racism, his sexism on my story, because the settlements that happened after me were multi-million dollar settlements and I got a whole lot less than that, because I was being urged to settle by him. He was creating a body of cases where he could become one of the class action lawyers.
- Jenn Stanley: About 200,000 women sued A.H. Robins in a class action lawsuit claiming that the Dalkon Shield caused physical injuries, miscarriages, infections and emergency hysterectomies. Collectively, they won about 2.4 billion dollars and A.H. Robins had to file for bankruptcy. At least 18 women in the United States died from complications likely caused by the Dalkon Shield and many others were left permanently sterilized.
- Loretta Ross: That was my entree into even thinking about reproductive rights activism, because we hadn't created the term reproductive justice then. I was outraged that this doctor decided for me that I was okay with not having the ability to have any future children. He didn't know anything about my story.
- Jenn Stanley: Loretta's experience with the Dalkon Shield and her subsequent unauthorized sterilization procedure began her journey into reproductive rights activism. She was surprised to find out that long after the device was deemed unsafe for American women, the United States Agency for International Development had been sending the device overseas for use by women in low income nations.
- Loretta Ross: I went to South Africa and I got there and found that the Dalkon Shields that they'd been prohibited for distributing in the United States were being dumped in South Africa. The women in South Africa were offered the worst deal, either control your fertility or we will not employ you. They were risking their own sterilization in order to get employed under an apartheid government and jobs are, of course, scarce and minimalist and marginalized back then. That's when I really got mad, because after I'd been sterilized, for A.H. Robins through a bankruptcy reorganization still able to promote a defective product around the world--that should have been illegal. It was already immoral, but it definitely should have been illegal.
- Jenn Stanley: But it wasn't. During a 1978 congressional committee hearing on whether contraceptives deemed unfit for Americans should be promoted abroad, representatives from pharmaceutical companies, US aid and private population control agencies presented what they called a humanitarian argument that the risk of dying in child birth was greater for women in poor countries than the risk posed to them by these dangerous contraceptive methods. The pharmaceutical companies had money to be made in these contraceptive dumps and the US government was still promoting eugenics population control policies abroad. The Dalkon Shield was dumped in more than 40 countries around the world. Only one

set of instructions and 100 applicators accompanied a box of 1,000 unsterilized devices, rather than the standard in the United States have one applicator per sterilized device. Many of the women receiving these IUDs lived in places with limited access to healthcare, so if they did develop an infection, they were at a much higher risk of death. It's estimated that hundreds, if not thousands, of women around the world died from the Dalkon Shield IUD.

Loretta Ross: I talked to a lot of South African feminists and they said they were offered the devil's bargain. And you're dealing with black women who are already marginalized and pushed out of the economy and who are told that if they're at risk of getting pregnant, then they will not be employed. Well, you're choosing between possible risk to your fertility and feeding your children. What kind of choice is that? At the same time, I was having these really contentious conversations with members of the family planning movement that literally were saying, "Well, the risk of sterilization is so much less than the risk of having an unsafe pregnancy and so we don't actually see a problem with this." These are supposed to be the people on our side. That's when I started taking a very critical look at reproductive technologies, because it wasn't just about the Dalkon Shield, but that body of ideas, that ideology that is persuaded that women don't have the right to remain reproductively fertile under their own control. This happening on our side really bothered me.

Women do need reproductive options. They do need birth control options, but they also need the full information about the risk and benefits of these options. Distributing birth control drugs and devices in the context of where people lack even access to basic healthcare is a form of population control and why they think that what worked in the United States is not applicable globally is, again, part of imperialism and racism and all the jargon that we talk about. I still offer a critical idea of LARCs, the long acting reversible contraceptives, because with the attacks on the Affordable Care Act, we have more women turning towards long term contraceptives like LARCs and all of that, because they are afraid that their other methods will not be covered any longer if the ACA is repealed. If you create coercive conditions, then women are going to make the most rational decisions they can make within those conditions. I'm not into criticizing their decisions. I'm into criticizing the conditions that produce those decisions.

Jenn Stanley: The Dalkon Shield gave IUDs a bad reputation for years, but a lot of that damage is starting to be undone. LARCs have become increasingly more popular over the last decade and IUDs are much safer than the Dalkon Shield was. They're made with a monofilament string that drastically reduces the risk of infection. But medical decisions are supposed to be made based on what's best for a patient's health and there will always be some level of coercion involved in a medical decision made to protect oneself from a political system. Loretta Ross is still very active in the reproductive justice movement. Her new book, *Reproductive Justice: An Introduction*, which she co-wrote with Rickie Solinger, is available now through University of California Press and wherever books are sold.

Choiceless: The Backstory is produced by me, Jenn Stanley, for Rewire Radio, with

editorial oversight by Marc Faletti, our director of multimedia and executive producer. Cynthia Greenlee is a senior editor at Rewire and she's a story consultant and contributor to this series. Laura Huss provided research and fact checking. Jodi Jacobson is our editor in chief. Brady Swenson is our director of technology. Music for Choiceless is by Doug Helsel. Thank you to all the staff at Rewire, especially Rachel Perrone, Lauryn Gutierrez and Stacey Burns, our communications and social media team, for getting the word out about Choiceless. Tune in next week to hear more on sterilization abuse in the United States. Thanks for listening.