

THE PUZZLES OF INFERTILITY: A PATIENT ADVOCATE'S VIEW

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MS. COLLINS:

Well, thank you so much for having me here today. It is a pleasure to be here.

I am here to represent the patient's perspective. I went through two years of treatment for secondary infertility while I was a lawyer, and it has now become my cause.

In the ten years that I have been in this field I have noticed recurring ironies and contradictions and today I would like to present five or six of them. I call them the puzzles of infertility. And what started as personal for me has become very political as you will see.

By the way, do you know who that is? Robert Edwards the Nobel Prize winner in Medicine. . .

So let's go through a few of these puzzles.

Puzzle Number 1. Since reproduction is inarguably essential to the human race why isn't there insurance coverage for it? My goodness. Well—oh, I should also pause to say I am on the Board of Directors of RESOLVE, the National Infertility Association. But I am speaking today as an individual and not on behalf of RESOLVE. RESOLVE is completely neutral on certain questions about which you'll find that I personally am not neutral. Not neutral on much.

Okay. So 7.3 million people in America are affected by infertility. That's a huge number. It is a very treatable disease. But how many states—in how many states is insurance coverage required to be provided for this treatable disease?

Comprehensive insurance coverage is available in only five states. New York is not one of them. What are the justifications?

I have a whole list, but I will just talk about a couple. They range from, well, “Infertility won’t kill you,” as if we only insure for fatal diseases?

At the other end of the spectrum is, well, “There are just so many needy children out there already, why don’t you just adopt?” As if we people with infertility are being charged with solving one of the world’s great social problems and we need to be denied medical treatment that we could have, in service of that goal.

Snarky, aren’t I?

But I say the bedrock misunderstanding is that many people fail to understand that infertility is a disease. It is dysfunction of the reproductive system, which is one of the major bodily systems like your circulatory system or your digestive system.

The World Health Organization finally has recognized that infertility is a disease, but it came to that realization less than a year ago.

And here’s the importance of infertility. You know, if everybody in the country eventually got cancer or eventually got heart disease it would be tragic, but if everyone got my disease the human race would end. (I have to give a footnote, Peg Beck, a social worker in Massachusetts, came up with that one, but I think she is exactly right.)

And here’s something really important to know about insurance coverage: when there is insurance coverage there is better practice of medicine. With insurance coverage, patients don’t feel the financial pressure to perhaps transfer more embryos than they should in the one cycle that they can afford.

Single embryo transfer is really fair and possibly only when there is insurance coverage, and with single embryo transfer we virtually eliminate the problems of triplet and twin births that make fertility treatments seem expensive.

But there is a new layer of irony to this. Health care reform may pose a great threat to the little insurance coverage that we have. It turns out that H.H.S. Secretary Sebelius is going to be defining an “Essential Benefits Package.” And if infertility or any other mandated benefit is not included in that Essential Benefits Package, then a state that wants to keep that mandated benefit is going to have to finance it itself. So we at RESOLVE are very concerned that in the next months and years we’re going to have to devote our energy to try and keep what little coverage we have.

Puzzle Number 2. Why are religious political groups that claim to be pro-family willing to throw infertility patients under the bus?

Infertility is under attack. In the past few years my organization, RESOLVE, has been engaged regularly in battles to try to keep IVF legal.

Now, you would not think that there would be many efforts to try to stop American women and men who want to have babies from having them, but surprise, there are. There has always been this fringe of people who were opposed to IVF because they were opposed to embryos outside of the body. But this extreme view started getting mainstream airtime, at least so far as I have seen, in 2003 with the President's Council on Bioethics under President Bush.

The President's Council on Bioethics decided to examine reproduction and law and said that their goal was to protect the dignity of human procreation. As if our IVF children were not dignified.

The Council proposed nonconsensual governmental tracking of the procreation of people with infertility, including tracking of our embryos by the government. It does not make me feel especially dignified. I mean, sex offenders are subject to nonconsensual government tracking.

And in their early writings they referred to embryos as "nascent human life" or, more to the point – as "babies to be."

So RESOLVE and others fought against this and we did get the Council to back off. But, their initial antipathy toward infertility and reproductive medicine, believe me, was unmistakable.

But then came Nadya Suleman, the so-called "Octomom," and at the same time in a perfect storm, a spate of legislation called Personhood Legislation. Now what is Personhood Legislation? This is legislation that declares that a microscopic embryo or an egg from the moment of fertilization is a full human being, deserving of full human rights. And Personhood Legislation has been making its way into a lot of bills in a lot of states, sometimes overtly— sometimes sneakily. But it poses a real threat to the way IVF is practiced today.

So what does Personhood Legislation look like? I am going to just pause and let you read examples of Personhood Legislation, the language that is used.

Now, I could—I could go into great depth about each of these,

but I am not going to, I am going to make two points. Okay, three points.

First of all, I did not put up there legislation that has been proposed in Kansas, Michigan and Mississippi.

But the Arizona bill that RESOLVE and others fought against was really kind of nefarious because it prohibited—what it prohibited in the name of protecting embryos was very, very vague. But doctors who, unwittingly perhaps, violated the law faced prison terms: six months to one and a half years. It was a Class 6 Felony to violate the law. And since the prohibitions were very vague, the law was obviously meant to discourage the practice of reproductive medicine in Arizona.

The other one that I want to point out is Colorado. This Tuesday they're voting on that. Amendment 62 is on the ballot, and if a majority of Colorado voters vote for it then the term *person* is going to apply from the beginning of biological development, which is meant to be fertilization.

Now, this is the second time it has come up in Colorado. It was defeated approximately 25 percent to 75 percent last time. So it is not actually expected to pass, but I think they are going to keep coming.

Now, if embryos have full human rights it creates big questions about when can be done in reproductive medicine, and the effects are far ranging.

Now, some of these seem a little farfetched. For example, could a couple and their embryos be adversaries in a legal proceeding? Is this desirable?

They may seem a little bit farfetched, but you know that case, *Shirley v. Sebelius*, where the judge entered an injunction prohibiting Federal funding for stem cell research just a few weeks ago? Embryos were plaintiffs in that case. Do you know this? Yes, Nightlight Christian Adoptions was a plaintiff on their own behalf and on behalf of all the frozen embryos in the U.S. that were not going to be used for actual medical treatment. So what seems a little “out there” sometimes is real.

The other thing I want to mention - I'm going to go back a slide with any luck - as I mentioned, some of this language also seems a little extreme. You might think to yourself, “Ah, no one could ever pass a law like that,” but indeed there is a law out there on the books that reads a lot like these—and you have probably heard of it: the Dickey-Wicker Amendment. Raise your hand: Have you heard of the Dickey-Wicker Amendment? You have

heard of it? Okay. It prohibits Federal funds for quote, “research in which a human embryo is destroyed, discarded or knowingly subjected to risk of injury or death greater than that allowed for research on fetuses in utero.” It is not so different from the language of personhood legislation.

Do you see the equivalence between microscopic embryos and fetuses, and the attribution of human qualities to microscopic embryos?

And I have to say, people who have infertility, we pay the price of the Dickey-Wicker prohibitions. Scientists in this country know a lot more about mouse embryos than they do about human embryos. And when it comes to our treatment and in particular the selection of the right embryos to transfer in treatment, it is incredibly inefficient and primitive because we have not been able to have Federal funding to study embryos.

Now, personhood laws are clearly anti-abortion and they are anti-stem cell pretty obviously, and some people believe that that their effects on IVF are purely incidental. We are just the collateral damage, they did not really intend that. I do not think that is so.

I found this on the website of “Personhood Colorado” earlier this month, and the description of fertility treatment and reproductive medicine is harrowing. They say that it is the mass extermination of human beings at the hands of fertility clinics.

Those of us with infertility who are trying to have babies, we think of ourselves as motherhood and apple pie. So, this is deeply shocking.

I will tell you, the brilliance, though, of the personhood strategy is that it wipes out abortions, stem cell research, many forms of contraception and IVF all at once. It focuses exclusively on the embryo and it does not balance, it does not even pay any attention to, the rights of the woman as is done in *Roe v. Wade*. It is just all about the embryo; the people do not even come into the picture.

So, who is going to defend us? The feminist organizations, right? They are going to come and defend us. Not so fast. In a stunning twist the National Organization for Women and Our Bodies Ourselves have recently sided with the embryo rights movement to try to wipe out some forms of infertility treatments.

You think this is crazy, right?

Two weeks ago I went to a showing of a film called *Eggsploitation*, E-G-G, *Eggsploitation*, at Harvard Law School.

This film was made by a former pediatric nurse named Jennifer Lahl who has started her own bioethics center.

Now, a few days before the showing, Ms. Lahl was profiled in the Boston Globe; it was kind of a puff piece where she expounded her beliefs that all Evangelical Christians like herself should oppose not only abortion and stem cell research, but also IVF. IVF is wrong. That is a quote.

So, this film *Eggsplotation* is part of a campaign to stop medical treatment via egg donation, and the film is really in my opinion just a biased, one-sided view, a series of interviews with about five women who engaged in medical egg donation and suffered some unfortunate physical consequences. In my opinion it is a smear piece.

But here is the thing, Harvard Law School invited her, Ms. Lahl, to come because it was recommended by the people at Our Bodies Ourselves. And who accompanied Ms. Lahl, but someone from the National Board of the National Organization for Women. And she introduced herself, thereby lending feminist “cred,” if you will, to someone whose aims were actually to wipe out not just egg donation, but also abortion. So they are sort of supporting someone who plants the seeds of their own destruction.

Puzzles, puzzles, puzzles.

Well, I have a little bit more that I’m probably not going to tell you. Well, how about if I just share the puzzles? This will take about 45 seconds.

Why is disseminating accurate information about the limits of female fertility so darn threatening? When ASRM did a campaign to enlighten people about causes of infertility, it received unbelievable bad press. The National Organization for Women was also against this as I recall.

I could not resist passing on important information about the female fertility decline, and I hate the fact that women who do pay attention to their biological clock are routinely mocked, routinely mocked for what is indeed biological fact. IVF does not materially extend female fertility.

Number four, the fact that people with infertility are regarded with insensitivity and scorn, I think you have sort of got that message from me already.

But here is my most important one for you. So: “As between manmade conventions about education and career paths, and hard wired limits to female reproductive biology, why do we

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spend more energy trying to change the biology, freezing eggs, things like that?" I think we have to look as a society at what is important.

Thank you.