

Ethicist in Ashley case answers questions

By Amy Burkholder
CNN

(CNN) -- Dr. Douglas Diekema is director of Education at Treuman Katz Center for Pediatric Bioethics in Seattle, Washington. He led the ethics panel that evaluated the controversial growth attenuation therapy for a severely disabled girl identified only as Ashley. In 2004, Ashley's uterus and breasts were removed and she was given high doses of estrogen to keep her small and to retard her sexual development.

Dr. Diekema talked to CNN about the therapy.

CNN: Describe Ashley when her parents and her pediatric endocrinologist came to you with this controversial request.

Diekema: Ashley was a little girl approaching her seventh birthday. She was profoundly disabled: She would never talk, never walk, and was dependent on her parents to meet all of her needs. Her cognitive function was the equivalent of that of an infant, and it's not likely it will ever change. When you see Ashley, it's like seeing a baby in a much larger body.

CNN: When your ethics review committee sat down to evaluate the case, what were the core issues discussed?

Diekema: There were two main aspects to the parents' requests. We looked at whether we should permit growth attenuation to occur and whether we should permit a hysterectomy. The first issue was, do these things have the potential to improve this little girl's quality of life? Will they make her life better? And the second issue was, what's the potential for harm here and is it significant [enough] that even with the prospect of some benefit we shouldn't allow it to move forward? It was the consensus of the committee this did in fact actually have potential to improve her life significantly and there was very little actual harm.

CNN: Describe for us what was done to Ashley in 2004.

Diekema: The growth attenuation was accomplished simply by putting her on high-dose estrogen. It's like being on a super birth control pill, and shortens the period of time she's capable of growing. Whereas a normal woman might stop growing at the age of 16 or 17, Ashley stopped growing at the age of 9. The hysterectomy involved a surgical procedure where her uterus is removed. They kept her ovaries in, so she could continue to produce hormones like a normal person would.

CNN: How big will she get?

Diekema: Ashley's about 4 feet 6 now and she's achieved her final height, so she's no longer being treated with high-dose estrogen. She's finished with the treatment.

CNN: As a doctor and an ethicist, what was most troubling to the ethics panel?

Diekema: The ethics committee struggled with trying to understand what potential troubles might come to a little girl from this sort of thing. Would someone in Ashley's position for example, ever really care if they were 12 inches shorter? The conclusion was in Ashley's circumstances, where she would never walk or talk, that height had very little value. We needed to look at the different meaning these sorts of things might have to a little girl who is as profoundly disabled as Ashley was.

CNN: You pledge to do no harm, but this was the first case of its kind. How do you proceed knowing it was without precedent?

Diekema: One of the difficult things about being a physician is sometimes you don't know for sure. We strive to do no harm, but that has to be balanced against what good you might do for a patient. Ashley had a surgical procedure and that involves some pain and risk, but it was our assessment after very careful consideration that the potential benefits would ultimately outweigh the risks.

CNN: What are the benefits for Ashley?

Diekema: When you look at the growth attenuation, the primary benefits are by being a smaller girl, it will be easier for people to lift her, and will allow her to receive a more personal level of care from her parents for a longer period of time. They really want to be able to pick up their daughter and give her a hug and put her in a chair. It will be easier for them to move her to the car and go on outings rather than thinking about leaving her behind with a caretaker when they go on vacation. As far as removing her uterus with a hysterectomy, there are many profoundly disabled children who are traumatized by menstruation. They don't understand why there is blood coming from that part of their body, and it's impossible to make them understand. Unlike a normal 11- or 12-year-old, you can't explain to them this is a normal part of your development. The family wanted to spare Ashley that drama. Ashley's a little girl who already had experienced being terrified of blood.

CNN: Ashley goes to school. She has peers. Is it at all concerning to you that here's a little girl who will never grow?

Diekema: It would be more concerning to me if she were a little girl who was running around on the playground. I think ultimately being shorter than she would be in comparison to her peers makes less of a difference when she's in a chair and interacting at that level. She will still mature at the same level as her classmates. If you look at her face, it will continue to age appropriately. We haven't attempted to change her outward appearance. What we've done is made her shorter than she ultimately would be.

CNN: What about the risks of high-dose estrogen? Your paper identified risks including blood clots and deep vein thrombosis.

Diekema: The primary risks of high dose estrogen are similar to those of oral contraceptive pills. It's a risk many women are willing to bear for contraception. In Ashley's case, it was the decision the potential benefits we felt she would derive from being smaller justified that small risk of a blood clot.

CNN: How has Ashley changed in the two years since her treatment?

Diekema: She hasn't changed a great deal. She's still the same little girl. The only difference now between what she's like and what she would have been like is that she won't be increasing her size.

CNN: What about when she's 19?

Diekema: When she's 19 she will look like a short 19-year-old.

CNN: What about her cognitive development?

Diekema: The expectation is that her cognitive development will remain where it's been her entire life. The treatment she underwent will have no impact whatsoever on that development. I think it's important to note the committee felt very strongly that there were certain aspects of Ashley's condition that justified this sort of treatment, that her condition would not change.

CNN: Ashley, it seems, is frozen as a little girl. She will remain tiny, with no reproductive capacity. Was that at all concerning to you?

Diekema: I wouldn't characterize her as being frozen as a little girl, because certainly that wasn't the intent of the parents and I don't think it's anybody's expectation. But the reality is, she will always be a little girl mentally and nobody can change that. Nothing we did changes that.

CNN: Ashley's parents call her their "pillow angel." Is there a danger of infantilization, that Ashley will be treated as a child her entire life? Is that fair and dignified?

Diekema: I'm not sure that's inappropriate. If Ashley's brain is the brain of a 6-month-old, then Ashley should probably be treated as a 6-month-old. It's not clear to me it would be appropriate to treat Ashley like an adult. You treat people appropriately for how they appreciate being treated, and if she responds to the world like a 6-month-old, treating her like a 6-month-old may actually be the dignified thing to do.

CNN: Are there other children you are considering for growth attenuation?

Diekema: Not that I am aware of. We have a mechanism in place at the hospital where anybody who decides they would like to proceed with this type of treatment will need to have that case carefully considered. It's most justifiable in a child who is profoundly developmentally delayed at a level similar to Ashley's, where they're unlikely ever to go beyond the capacity of an infant mentally. Somebody who will never walk. If those factors change, I think it becomes harder to justify doing this.

CNN: What will suggest this was the right thing to do?

Diekema: I don't think there is any way to prove this was the right thing to do. You have a little girl who you will never be able to ask, "Do you think this helped you?" The closest thing is asking the people who care the most about her and that's her parents. What her parents will tell you now is this was the right thing to do. We would have been disturbed if Ashley had had a complication. Fortunately that hasn't happened.

CNN: To critics who say, "we have the technology to do this, but we're intervening and doing things nature has not intended us to do," you'd respond?

Diekema: We do that all the time. Everything I do in medicine alters the way nature intended things to happen. What's important for us to do is think carefully when we do that. Is this justified? Do I have a really really good reason for doing this? Is it ultimately benefiting this person in an important way and not undermining some other aspect of this person's being? That's the justification.

CNN: Is there a potential for abuse?

Diekema: Yes, there is the potential for abuse, as there is potential for abuse with a lot of things we do in medicine. This is the kind of treatment we used very carefully. I would be distressed to see this be used more widely. I would not at all agree with somebody that suggested using growth attenuation therapy in a child who has Down syndrome, for example. I don't think the potential for abuse is a reason never to use it for anybody.

CNN: You say meeting Ashley and seeing her interact with her family helped form your opinion. How so?

Diekema: They are very intelligent individuals. They're very thoughtful. They care immensely for their family, and are devoted to Ashley. A disabled child can be a big challenge for a family, and this was a family that clearly has devoted their lives to making life as good as possible for their daughter.

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