

## **Cutting Edge Treatment: Pain and Surgery in the Ashley X Case**

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*Pain and surgery are phenomena that have frequently been mentioned in the discussions of the Ashley X case. This article describes how pain and surgery have been used selectively to argue for or against the Ashley X procedures. Few if any of the many publications discussing the merits of the Ashley-X procedures can be said to strike a reasonable balance between the pros and cons of the procedures. This lack of balance and extreme polarization may result in part from the lack of precedents and weak research foundation for making decisions around this kind of treatment.*

In "the Unkindest Cut of All," Heidi Janz (2009, this volume) describes how surgery and pain were constructed in discussions of the killing of Tracy Latimer. Surgery is described as an invasive torture that mutilates the body with little prospect of relief and likely to result in catastrophic complications. While the primary purpose of the surgery proposed for Tracy Latimer was to relieve pain, there was little discussion of surgery's role in mitigating pain and great emphasis on the role of surgery as a cause of pain. In short, those who supported the killing of Tracy Latimer did so because they believed that the surgery prescribed to relieve her pain was actually a fate worse than death. This paper explores images of pain, suffering, and surgery in another case involving a child with severe disabilities, the Ashley X case.

### **History**

Gunther and Diekema published "Attenuating growth in children with profound developmental disability: A new approach to an old dilemma" in October 2006 in *Archives of Pediatric and Adolescent Medicine*. Daniel

Gunther, the first author, was the pediatric endocrinologist who was involved with the case, and Douglas Diekema, the second author, was an ethicist who was also involved in the case.

There were two major parts to this article. The first part described a case in which medical and surgical procedures were applied to a six-year-old girl who had severe and multiple disabilities. These procedures that were described included administration of very high-dose estrogen after surgical removal of her uterus but not her ovaries. While not mentioned in the initial article, it was subsequently revealed that the Ashley-X procedures, as they came to be called, also included the removal of both of the child's breasts as well as an appendectomy performed along with the hysterectomy.

The second part of the article was presented under the heading, "the ethical debate," presenting arguments for and against the use of these procedures and concluding that they are appropriate for some children with profound disabilities, provided the family and physicians approve and "preferably after review by the institution's ethics committee" (p. 1017). Gunter and Diekema suggested that, after attenuating a child's height and consequently the child's weight, she would be easier to care for and receive better care. They suggested that this would increase the prospects of the child remaining in the care of her family.

By the time the study was published, the procedures had already been applied to the child who was the focus of the case study. While there was some immediate reaction from members of the medical community, disability advocates, and members of professional organizations concerned with the welfare of people with disabilities, this response was relatively low-profile prior to January 2007, when the case began to receive much wider attention. On January 2, 2007, the parents of the child who was the subject of Gunther and Diekema's case study launched a blog (Ryan, 2008) about their child and the procedures that were performed. On their blog, in which their daughter would become known as "Ashley X" and "pillow angel," her father, as spokesperson for the family, presented her family's perspective on the case. While the parents were in basic agreement with the authors of the original study, their blog reached a much broader segment of the population, presented

a much more personal perspective, disagreed with some points made by the earlier publication, and provided a much fuller perspective.

On January 6, 2007, the Washington Protection and Advocacy System (Carlson & Dorfman, 2007) commenced its investigation of the case to determine if any of Ashley X's rights were violated. Like other protection and advocacy organizations across the United States, this organization has authority under Federal law to investigate instances of abuse or violation of the rights of individuals with developmental disabilities. Around this same time, there was further acceleration of interest in the case after it began to receive attention from national and international news organizations. For example, *Time Magazine* (Gibbs, 2007) and CNN (Burkholder, 2007) ran stories early in 2007.

In the following months, many individuals and organizations expressed opinions regarding the Ashley X case. The board of the American Association on Intellectual and Developmental Disabilities published a strong statement condemning the practice as "Unjustifiable Non-therapy" (Bersani et al, 2007). TASH (Undated), an organization that advocates on behalf of people with severe and multiple disabilities, passed a "Resolution on Unnecessary and Dehumanizing Medical Treatments" affirming "the right of all persons with disabilities to freedom from being provided with medical treatments that are not necessary for their health, but rather designed for the convenience of the care-providers."

On May 8, 2007, The Washington Protection & Advocacy System released its report on the Ashley X case (Carlson & Dorfman, 2007). They found that the hospital had acted illegally and in a manner that raises significant discrimination issues:

The Washington Supreme Court has held that a court order is required when parents seek to sterilize their minor or adult children with developmental disabilities, and that the individual must be zealously represented by a disinterested third party in an adversarial

proceeding to determine whether the sterilization is in the individual's best interests.

Courts have also limited parental authority to consent to other types of medical interventions that are highly invasive and/or irreversible, particularly when the interest of the parent may not be identical to the interest of the child. Thus, the other aspects of the "Ashley Treatment" – surgical breast bud removal and hormone treatments – should also require independent court evaluation and sanction before being performed on any person with a developmental disability.

The implementation of the "Ashley Treatment" also raises discrimination issues because, if not for the individual's developmental disabilities, the interventions would not be sought. State and federal law expressly forbid such discrimination against individuals because of their disabilities. (pp. 1-2)

According to the report, Seattle Children's Hospital acknowledged that they had acted illegally and agreed to measures to prevent future occurrences including:

Develop and implement a policy to prohibit growth-limiting medical interventions on persons with developmental disabilities without a court order. The policy will ensure that all appeal periods and appeals, if any, are exhausted before any procedures are performed. (p. 2)

In a press release, the Hospital indicated that they had violated the law when they relied on legal advice from the parents of Ashley X to decide that they did not require the judicial review of the courts before the procedures were carried out and promised to implement safeguards including:

- Children's will require a court order for growth attenuation through hormone treatment, and for breast

bud removal and/or hysterectomy when it involves a child with a developmental disability.

- Children's will not schedule procedures either to attenuate growth or perform hysterectomy or breast bud removal in children with developmental disabilities without review and approval from Children's legal counsel, who will assure a court order is obtained before allowing a procedure to be scheduled.
- Children's will appoint someone with a disability rights perspective as a full member of the Hospital's Ethics Committee, and will require committee review and guidance when a court order has been obtained by parents. (Fisher, 2007)

As they claimed they would, Seattle Children's Hospital did publish a policy prohibiting "Growth-Limiting Interventions for Patients with Developmental Disabilities" without prior court approval (Children's Hospital and Regional Medical Center, 2008).

The controversy might have ended there; it did not. Although Daniel Gunther, the endocrinologist and first author of the original publication, died in September 2007, Douglas Diekema, the ethicist and second author continues to advocate for growth attenuation (Allen, Kappy, Diekema, & Fost, 2009; Diekema & Fost, 2010). The Treuman Katz Center for Pediatric Bioethics, which was founded by Douglas Diekema and supported, in part, by Seattle Children's Hospital, established Seattle Growth Attenuation and Ethics Working Group to further explore the use of these procedures. In January 2009, this group convened a public session to report on some of their deliberations. As of January 2010,

Seattle Children's Hospital still maintains a summary of the original Gunther and Diekema article on their website, concluding:

We suggest that after proper screening and informed consent, growth-attenuation therapy should be a therapeutic option available to these children [children with profound developmental disabilities] should their parents request it. (Seattle Children's Hospital, 2006)

There is no note or caution about the fact that the case study was found to have operated outside the law or that the hospital had agreed not to engage in these procedures without judicial review and approval. Diekema and Fost (2010) continue to argue that a court order should not be required for these procedures to be used.

In January 2010, *The American Journal of Bioethics* published a new article by Diekema and Fost, titled "Ashley revisited: A response to critics," along with commentaries from a number of other authors. In their article, Diekema and Fost argue that criticism has been unfair, that the "Ashley Treatment" was in the patient's best interest, that court review should not be required, and the procedure should be made available for use with other children with severe and multiple disabilities. Their paper is published along with nine peer commentaries discussing the case and most of these (Asch & Stubblefield, 2010; Goering, 2010; Lantos, 2010; Lillie, 2010; Lyons, 2010; Ouellette, 2010; Sobsey, 2010) are highly critical or skeptical of Diekema and Fost's arguments. The two other commentaries included with the article neither endorse nor condemn the procedures. Instead Spriggs (2010) argues that the merits of the case cannot be resolved by best-interest arguments, and Hester (2010) argues that our moral intuitions should not dominate our rational analysis of the case.

A number of other scholarly articles have been written about this case. In addition, there have been many editorials and general discussions in the

mass electronic and text-based media. Supporters of the procedures argue that there is little harm to the child, that risks are small. They suggest that the primary benefit to the child is indirect and, that by attenuating her growth, she will also remain lighter, making it easier for caregivers to provide care for her. In turn, they believe this will result in a better care, a better relationship with her primary caregivers, and a greater likelihood of remaining in her natural family.

Critics argue that the procedures are unnatural and harmful to the child. They believe that harm and risk of harm outweigh any potential benefits to the child, and that these procedures violate the universal rights of children and should not be permitted.

In writing this article, I must clearly state that I am an opponent of the Ashley-X procedures and cannot pretend to write from an unbiased perspective. In previous articles, I have written my own reasons (Sobsey 2007; 2010) for objecting to the Ashley X procedures. These include: (1) that these procedures violate the child's right to development as put forth in the United Nations Convention on the Rights of the Child, (2) that there is no evidence that families are more likely to institutionalize heavier children than lighter children, (3) that estrogens have been shown to stunt the growth of children but lead to weight gain not loss, (4) that the harm and risk of harm to the child are substantial, and (5) the use of invasive and atypical procedures for children with or without disabilities must be justified by clear and compelling benefits. The present article, however, does not address most of these issues. Instead, the present article deals only with how pain and surgery are addressed by proponents and opponents of the Ashley X procedures.

#### **Constructions of pain and Surgery in the Ashley X case**

Like discussions of the Tracy Latimer case, discussions of the Ashley X case were populated heavily by references to pain, suffering, and surgical procedures. In strong contrast to the Latimer case, however, advocates for the procedures have discussed their potential to produce pain much less frequently. Proponents of the Ashley X procedures frequently justify surgery as a means to prevent pain and suffering. These justifications were based primarily on preventing the pain or

distress that might possibly occur in the future, rather than alleviating pain that actually exists in the present.

It is useful for this ethical discussion to categorize pain into several categories. The first category of pain is pain that already is present or already has been present and known to recur. As such, it may or may not be reduced or managed by an intervention. The second category refers to pain that is an expected and predictable consequence of intervention. Surgery almost always produces some degree of post-operative pain, which varies in intensity and duration. The duration and intensity of this pain varies, but it can rarely, if ever, be prevented entirely. The third and final category is potential pain that may or may not occur as a result of an intervention or in the absence of intervention. For example, proponents for the Ashley X procedures identified the risk that pain might occur from a poorly fitting wheelchair upper body harness if Ashley's breasts grew larger, while opponents identified the risk that chronic pain syndrome might be a consequence of hysterectomy or mastectomy.

### *Pain and Mastectomy*

One of the most controversial elements of the Ashley X growth attenuation procedures is mastectomy. Although the initial ethics committee discussion for these procedures included the topic, "How will Mastectomy improve Ashley's quality of life?" (Carlson & Dorfman, 2007, Exhibit L, p. 3) and a bilateral mastectomy was performed, there was no mention of mastectomy or any other procedure involving the breasts in Gunther and Diekema's initial publication. The procedure described, carried out, and paid for by health insurance was identified as "bilateral simple mastectomy" (Carlson & Dorfman, 2007, Exhibit R).

Since this procedure was part of the original ethics discussion and actually carried out as one of several surgical procedures (i.e., total hysterectomy, bilateral mastectomy, appendectomy, and bilateral fallopian tube destruction) carried out collectively, this omission appears to be a serious one.

After it was revealed that the initial article and “ethical debate” published by Gunther and Diekema failed to include mention of the mastectomy performed on Ashley X, the authors responded by saying that they had not included it because it had nothing to do with the growth attenuation procedures that were the focus of the article:

Breast bud removal was a completely separate request and raised a different set of issues that were unrelated to growth attenuation (as was the incidental appendectomy that was performed). (Gunther & Diekema, 2007, p. 616)

They are careful to distinguish between the hysterectomy, which was described in the original article because it was partially justified as means of controlling a side effect of the estrogen treatment, and mastectomy which was not. Writing in 2010, however, Diekema and Fost now include “breast bud removal” as part of the growth attenuation procedures, describing Ashley X as:

a young girl with profound and permanent developmental disability who underwent growth attenuation using high-dose estrogen, a hysterectomy, and surgical removal of her breast buds. (p. 30)

In this article, rather than claiming that mastectomy was irrelevant to growth attenuation, they now justify the mastectomy along with hysterectomy because of “the high-dose estrogen side effects...which include heavy menstrual bleeding and rapid advancement of breast development” (p. 31). In fact, they suggest that the estrogen therapy required that a mastectomy be carried out without delay:

Since high-dose estrogen results in breast development and breast bud removal is a significantly less risky procedure than reduction or removal of a fully developed female breast, there were also reasons for not

delaying that procedure. (Diekema & Fost, 2010, p. 35)

Ironically, the authors dispute the claim that the effects of “high dose estrogen applied to a six year-old child are likely to result in highly atypical physical appearance that is at least as dramatic as simple amputation” (Sobsey, 2007, quoted in Diekema & Fost, 2010, p. 39) and argue “there is nothing atypical about the physical appearance of someone who has been treated with estrogen” (Diekema & Fost, 2010, pp. 39-40). Sobsey’s claim of atypical appearance was based on the rapid and massive breast enlargement that might be expected in a six-year-old girl treated with very high doses of estrogen and was written prior to the disclosure that the child’s breasts had been surgically removed.

In fact, Diekema and Fost actually support the original claim that fully developed breasts on a six-year-old would appear at least as atypical as their amputation, suggesting that her mastectomy could easily be concealed by clothing, while large breasts on a young child would be noticeable. Since Gunther and Diekema (2006) did not reveal that the girl’s breasts were in fact amputated, the claim of atypical appearance was based only upon the information that Gunther and Diekema chose to disclose. Diekema and Fost (2010) suggest that the high-dose estrogen would result in rapid and extreme development of the girls breasts to a point where it would be preferable to remove her breasts completely than allow her to live with such large breasts.

Once having acknowledged that mastectomy was a part of the growth-attenuation procedures, however, Diekema and Fost continue to shy away from the use of the word mastectomy and prefer to use the term “breast bud removal.” Proponents of these procedures use this terminology, which appears to make the procedures more acceptable. In sharp contrast, opponents of the procedures have used terminology that Diekema and Fost consider inflammatory, such as “cutting off the girl’s breasts” (Picard 2007), “chop off her budding breasts” (Brew-Parrish, 2007), and “lopping off her breasts” (Caplan, 2007). Diekema and Fost (2010) suggest that breast-bud removal is a better term than mastectomy because the procedure was less invasive and less traumatic than a typical

mastectomy and that “breast bud removal is a significantly less risky procedure than reduction or removal of a fully developed female breast” (p. 35). There is unquestionably some degree of truth to this claim. There is less tissue to be removed and somewhat less blood supply to the area. Since most mastectomies are performed to treat malignancies, radical mastectomies involve surgery removal of lymph nodes that would not be required in a simple mastectomy required for the removal of healthy breast tissue. In addition, some of the postsurgical pain experienced after mastectomies may not be the result of the surgery, but may result, at least in part, from radiation or chemotherapy used around the time of the surgery.

Nevertheless, the invasiveness of this procedure on a child with or without disabilities should not be trivialized. The well-refuted notion that children and people with disabilities suffer less pain because they do not articulate their suffering well has been shown to be dangerous as well as false (e.g., Oberlander & Symons, 2006). Since pain receptors are fully developed in children of this age, there is little reason to believe a child suffers less from surgery. In addition, a bilateral mastectomy is clearly more invasive than the removal of a single breast. Clearly, if the size of the breast removed is to be considered in determining the invasiveness of the procedure, number must be at least as important. Table 1 lists some of the terminology used by proponents and opponents of the procedure. It should be noted that all of the terms used have the same denotation but differ strongly in connotation.

Table 1. *Euphemistic terminology used by proponents of the Ashley-X procedures and dysphemistic terminology used by opponents of the Ashley-X procedures.*

<b>Proponent Terminology Euphemisms</b>	<b>Official Terminology For Procedure</b>	<b>Opponent Terminology Dysphemisms</b>
[Not mentioned]	Mastectomy	Cutting off the girl's breasts
Breast bud removal	Simple                      Bilateral Mastectomy  Breast Amputation	Lopping off her breasts  Chop off her budding breasts

On their blog, Ashley's parents made a point of explaining why a breast

bud removal should not be considered to be the same as a mastectomy:

This operation involved removing Ashley's subcutaneous, almond-sized breast buds, which contain the milk glands, while keeping the areolas and nipples intact. This surgery was done with small incisions below the areola, the slight scars almost disappeared a month after the surgery. This operation is akin to removing a birthmark and is a very different surgery from a mastectomy on an adult woman with developed breasts. (Ashley's Mom and Dad, 2007)

It has also been suggested that *breast bud removal* is a better term to use with the public since *mastectomy* is a medical term that may be unfamiliar to the public and/or misunderstood by the public (Diekema & Fost, 2010). In reality, the opposite appears to be true. A simple database search confirms the fact that *mastectomy* is a term widely used in mainstream as well as medical literature, while *breast bud removal* has been rarely used anywhere outside discussions of the Ashley X case. The repeated use of the term *mastectomy* in the ethics committee report and the billing of health insurers for a *simple radical mastectomy* makes it clear that the physicians involved felt no need to differentiate their procedure from a mastectomy for internal or billing purposes, but advocates for the Ashley-X procedures have clearly felt the need to do so in communicating with the public. Table 2 indicates the frequency of the terms *mastectomy* and *breast bud removal* in selected mainstream media, academic, and medical databases, when used to refer to the Ashley X case and without reference to the Ashley X case. Clearly, the term *mastectomy* is used frequently in all three areas. While the phrase *breast bud removal* has been rarely used outside the context of the Ashley X case. Simply put, most people never heard the phrase breast bud removal before the Ashley X case and it has been used hundreds of times more frequently in referring to the Ashley X case than in all other uses combined. The term *breast bud removal* seems to have exploded into the English language lexicon in January 2007.

Table 2. The frequency of articles using the terms mastectomy or breast bud removal in mainstream, academic, and medical media.

	<b>Terminology</b>	<b>Mastectomy</b>	<b>Breast Bud Removal</b>	<b>Database</b>
<b>Mainstream Media</b>	With Ashley X, Pillow angel, disabled daughter	292	458	<b>Google</b>
	Without	5,770,000	3	
	With Ashley X, Pillow angel, disabled daughter	5	5	<b>NewsLibrary</b>
	Without	53,377	0	
	With Ashley X, Pillow angel, disabled daughter	4	20	<b>Factiva</b>
	Without	49,137	0	
	With Ashley X, Pillow angel, disabled daughter	0	12	<b>Canadian Newsstand</b>
	Without	6,454	0	
<b>Academic Journals</b>	With Ashley X, Pillow angel, disabled daughter	0	2	<b>Academic Search Complete</b>
	Without	2,799	0	
<b>Medical Journals</b>	With Ashley X, Pillow angel, disabled daughter	1	1	<b>Medline</b>
	Without	22,654	0	

Many proponents for the Ashley-X procedures express concern that she may develop large breasts that could be painful and indicate that the harness used to secure her into her wheelchair could cause irritation to her breasts. Carlson and Dorfman (2007) quote the original ethics committee as follows:

the restraint strap that holds Ashley in the wheel chair

goes right across the area of her body where the breasts would be if they develop. (Exhibit H)

The implication is that, since the strap is currently where her breasts will be "if they develop," and this might result in irritation, a surgical solution is justified. Terry and Campbell (2008) write:

To sit up and be moved in a wheelchair requires the use of chest strap, which could be uncomfortable with large breasts; wearing a bra could distress Ashley who is upset by even a hair on her face... (p. 21)

Many women and some men and young children who use wheelchairs, drive, or ride in vehicles with seatbelts, have experienced nipple or breast irritation from seatbelts. In fact this problem is not unique to individuals with large breasts, and there are many useful remedies to this problem that do not require breast removal. In addition, it appears rather one-sided to express concerns about preventing discomfort as minor as a hair on the face while dismissing post-surgical pain as irrelevant.

It is not surprising that people acquainted with disability studies' perspectives or the social construction of disabilities find this approach particularly problematic. They have long argued that medical models of disability place problems unreasonably within the bodies of people with disabilities and fail to recognize the contributions of the physical and social environment. It would be difficult to hypothesize a more extreme or absurd example, than suggesting that we amputate a body part rather than refit a wheelchair harness to make it more comfortable.

Approximately 60% of mastectomy patients report severe post-operative pain and 10% report that severe post-surgical pain persists at least 6 months after surgery (Fecho, Miller, Merritt, Klauber-Demore, Hultman, & Blau, 2009). In this study, 23.9% of women reported significant levels of pain at least 4 days per week one-and-a-half years after mastectomy.

Chronic pain after mastectomy has been reported frequently, and there is

no evidence to date suggesting that children, men, or women with small breasts are immune from this problem. In fact, research suggests that the younger the individual is at the time of mastectomy, the higher the incidence of chronic pain. Gartner and colleagues (2009), for example, report “the most important determinant of persistent pain and sensory disturbances was young age” (p. 1990). Another study reports that the earlier a mastectomy is performed, the greater the risk of chronic pain syndrome (Vilholm, Cold, Rasmussen, & Sindrup, 2008).

A study of chronic pain after surgery compared patients who underwent mastectomy (511 patients), inguinal hernia repair (351 patients), and open-heart surgery (1348 patients) on their reports of continuing pain longer than 3 months after surgery. The frequency and intensity of chronic pain was similar among all three groups, but the most frequent and most intense pain was reported among those who underwent mastectomy. Forty-three percent of mastectomy patients experienced chronic pain longer than three months after surgery compared to 30% of hernia repair patients, and 39% of cardiac surgery patients (Bruce, Poobalan, Smith, & Chambers, 2004).

Another study (Gartner, Jensen, Nielsen, Ewertz, Kroman, & Kehlet, 2009) reported that 48% of women who underwent mastectomy were experiencing chronic pain an average of 26 months after surgery. More than two-thirds (69%) of women who had mastectomies reported discomfort or sensory disturbances an average of 26 months after surgery, and this included 92% of women in the youngest age group. Not surprisingly, there were no patients as young as six-years-old in the study so it remains unclear how these findings apply to children. While chronic pain after mastectomy has been discussed most frequently in terms of pain lasting several months to a year or more after surgery, few studies have considered even longer-term outcomes. One study, however, followed women who reported persistent pain after mastectomy. Of women who initially reported persistent pain, 52% reported they were still experiencing chronic pain 7 to 12 (mean = 9 years) years after surgery (Macdonald, Bruce, Scott, Smith, & Chambers, 2005).

*Pain and Hysterectomy*

Gunther and Diekema (2006) justify performing a hysterectomy in part by saying it might reduce the potential for future pain and discomfort.

This onetime procedure eliminates the complications of menses, and in many cases, will spare the individual and her caregivers the expense, pain, and inconvenience of a lifetime of hormone injections. (p. 1015)

Diekema and Fost (2010) also use the possibility of menstrual pain as a rationale for hysterectomy, suggesting that medication might prove a poor alternative to control the discomfort of menstrual cramps:

some women report that medication provides little or no relief from their menstrual cramps, while others experience relief only from a hysterectomy. In Ashley's case, it might be difficult to ascertain whether she is having cramps or getting relief from them, simply because she is incapable of communicating the reasons for her agitation or distress. (p. 40)

However, neither of these discussions mentions the fact that hysterectomy results in very significant post-surgical pain (e.g., Keita, 2009; Wilder-Smith, Arendt-Nielsen, Gaumann, Tassonyi, & Rifat, 1998). In addition, their concern that menstrual pain might go undetected due to her limited communication and therefore be untreated would apply to post-surgical as well as to menstrual pain. Of course, while post-surgical pain is virtually inevitable and often severe, its occurrence is also highly predictable and its duration is typically limited. Unfortunately, chronic pain after hysterectomy is common and occurs in approximately one of five patients. A review of research on chronic pain following hysterectomy finds the lowest reported level is 5% of all patients and a high of 32% of all patients reporting chronic pain after uncomplicated hysterectomy (Brandsborg, Nikolajsen, Kehlet, & Jensen, 2008). Adding to this problem is the risk of complications. For example, in the Ashley X case, her uterus was removed while her ovaries remained in place.

Residual ovary syndrome occurs in a significant number (approximately 5%) of women who have this procedure (Rane & Ohizua, 1998), and the younger they are at the time of their hysterectomy, the greater the risk of its occurrence (Dekel et al., 1996). When this occurs, the retained ovaries enlarge as a result of the formation of masses that are occasionally malignant but more frequently benign. This syndrome is very painful, can lead to serious health threats, and typically requires additional surgery. In an individual who cannot report the location of her pain, these masses may grow very large and form adhesions to other organs before they are discovered, making surgical removal much more complicated.

Although complications of hysterectomy resulting in death are rare, approximately 1.9 deaths occur for every 1000 surgeries. The lifetime risk of dying from some form of uterine cancer is approximately 4.7 deaths per 1000 women. So the chances of dying as result of hysterectomy are much less than the chances of dying as a result of uterine cancer. The number of life years at risk in the case of hysterectomy in childhood, however, is much higher than those at risk due to the possibility of uterine cancer because the median age of death for cervical cancer is 57 and for other cancers of the uterus, 72. As a result, on average about 140 life-years would be lost among 1000 six-year-olds as a result of hysterectomy compared to about 66 life-years lost as a result of uterine cancer among 1000 women, those who did not have a hysterectomy at age six.

Another complication of hysterectomy resulting in additional pain is infection (Gunnarsson, Rizzo, & Hochheiser, 2009; Molina-Cabrillana, Valle-Morales, Hernandez-Vera, Lopez-Carrio, Garcia-Hernandez, & Bolanos-Rivero, 2008) at the surgical site or of the respiratory tract resulting from intubation. Overall, the risk of some complications following hysterectomy is high. For example, one study reports (Salom et al., 2003) that among 100 women undergoing hysterectomy with prophylactic appendectomy, the procedures reported in the Ashley X case, 39 had post-operative fevers, 6 developed urinary tract infections, and 12 had wound- healing complications. Postoperative hemorrhage occurs in about 2% of cases and accidental injury to the bladder, bowel,

or other organs also occurs in about 2% of cases (Maresh et al., 2002). Overall, most women who have hysterectomies are satisfied with the results, but 12% report that they have not recovered from surgery after a year, 7% report that they have not recovered after two years, and more than 5% require subsequent hospital admission within two years after surgery (Kjerulff, Rhodes, Langenberg, & Harvey, 2000). More than 25% report at least one post-surgical complication within two years of hysterectomy.

Without hysterectomy, it is extremely likely but not certain that Ashley X would experience some degree of menstrual pain or discomfort. The onset of menses is somewhat unpredictable in girls with severe disabilities; it can be early or very significantly delayed. Life expectancy may also be reduced among individuals with severe and multiple disabilities. Nevertheless, the probability of a six-year-old girl with severe and multiple disabilities living long enough to experience menstruation is nearly 100%, but the probability of experiencing significant pain is lower. For example, 23% of women 404 women surveyed reported no discomfort from menstrual cramps and another 51% reported mild discomfort ("somewhat uncomfortable"), 22% reported that they were "quite uncomfortable," and 4% reported severe pain. In a follow-up survey of the same women after six years, 25% of women reported no menstrual discomfort and 53% reported mild discomfort, 20% reported that they were "quite uncomfortable," and 2% reported severe pain (Weissman, Hartz, Hansen, & Johnson, 2004). After hysterectomy, it is virtually certain that she will experience postsurgical pain, and there is strong possibility that she will experience one or more post-surgical complications resulting in additional pain. In another survey, 50% of adolescent girls indicated that they regularly experienced at least some degree of pain during menstruation (Farquhar, Roberts, Okonkwo, & Stewart, 2009).

In addition, menstruation can aggravate other health conditions. Approximately half of women who experience migraine headaches indicate that they occur more frequently during menstruation (Martin & Lipton, 2008), and about one-third of women with seizure disorders report increased seizure activity related to menstruation (Foldvary-

Schaefer, & Falcone, 2003),

Considering these factors, the probability that Ashley X would experience menstrual pain that could be eliminated by surgery needs to be weighed against the certainty that she would experience post-surgical pain and a significant possibility that she would experience chronic pain syndrome or other complications of surgery resulting in additional pain. Presenting either side of this dilemma without presenting the other does not properly consider the risks. Table 3 illustrates some of the potential risks and benefits of hysterectomy in a six-year-old girl with severe disabilities.

*Table 3. Comparison of risks with and without hysterectomy.*

	<b>Risks of Hysterectomy</b>	<b>Risks of No Hysterectomy</b>
<b>Mortality</b>	0.19 % chance of death resulting from surgery	0.47% chance of death from uterine cancer
<b>Life Years</b>	140 life-years lost per 1000 procedures	66 life-years lost to cancer among 1000 girls without hysterectomy
<b>Pain</b>	100% chance of post-surgical pain 15% chance of post-hysterectomy chronic pain syndrome 5% chance of Residual Ovary Syndrome	24% chance of no significant menstrual discomfort 52% chance of mild menstrual discomfort 21% chance of moderate menstrual pain 3% chance of severe menstrual pain
<b>Complications</b>	25% chance of at least one surgical complication 5% chance of complication requiring hospital readmission	Menstruation increases the risk of headache in about half of migraine sufferers. Menstruation increases seizure activity in about one-third of women with epilepsy

Clearly, there are risks and potential benefits associated with either course of action, and it would go beyond the scope of this article to conclude exactly where the balance lies. The relevant point here is that there are significant considerations on both sides of this issue, and that by placing strong emphasis on one while ignoring the other, various individuals identify themselves as advocates or adversaries of the Ashley procedures. Proponents of the Ashley X procedures describe hysterectomy as benign procedure with minimal risk that is likely to reduce future health risks and prevent future pain. Opponents of the procedures describe hysterectomy as a painful, invasive, and risky procedure that is likely to do more harm than good.

Gunther and Diekema (2006) describe the benefits of hysterectomy and its potential to spare the child pain associated with menstruation and pain that might be associated with hormone injections used to control menstruation. They say little about the risks associated with the procedure. They simply state:

The risks of this surgical procedure in prepubertal girls, and the risks of long-term complications, are minimal—certainly they do not exceed the risk of similar procedures many of these children will experience as part of their medical care. (p. 1015)

This not only trivializes the significant risk of surgery but also includes a simple but dangerous flaw in logic. The fact that an individual may be exposed to a necessary risk has no bearing on whether some other unrelated risk is more or less acceptable. Some children with multiple disabilities may require brain or heart surgeries, which carry substantial risk, but their exposure to additional procedures only adds to their cumulative risk. It cannot justify another risk and it cannot be justified by another risk. Clearly, if it is worth mentioning that surgery can prevent potential future pain, it is equally worth mentioning that surgery causes pain.

#### *Pain and Estrogen Treatment*

Gunther and Diekema (2006) did not suggest that estrogen treatment might actually reduce pain or discomfort for Ashley X. Diekema and Fost (2010) do, however, suggest that a smaller, lighter person can be lifted and transferred with less discomfort and less risk of injury. Both Gunther and Diekema (2006) and Diekema and Fost (2010) acknowledge that high-dose estrogen treatment carries some risk of thrombosis, which can be painful as well as dangerous, but dismiss this potential risk as being too remote to cause real concern.

Gunther and Diekema (2006) do not mention other more frequent side effects of high-dose estrogen treatment that can cause significant pain or discomfort. For example, in a study cited by Gunther and Diekema (2006) to demonstrate that high-dose estrogen is still an acceptable treatment modality to suppress the growth of tall girls, Barnard, Scialli, and Bobela (2002) found “[c]ommonly reported side effects include weight gain, headache, nausea, night leg cramps...” (p. 25). In a later article, Allen, Kappy, Diekema, and Fost (2009) do mention the high-dose-estrogen side effects mentioned in this study, suggesting that they are mild and transient, but appear to systematically exclude those associated with pain (i.e., “leg cramps” and “headache/migraine”) and including less troubling symptoms (i.e., areolar hyperpigmentation) and those obviated by the surgical procedures (i.e., irregular menses).

Shannon (2007) also minimizes the risk of side effects, indicating the “risks appear similar to those for birth control pills” (p. 176) without mentioning that the dosage given to a six -year old child is approximately 20 -30 times higher than the dosage taken by a grown women using birth control pills.

## Discussion

Proponents and opponents of the Ashley-X procedures have constructed two very different accounts of pain and surgery. Proponents portray surgical intervention along with medical treatment primarily as a means of preventing potential pain. Postsurgical pain and the potential pain from surgical complications are dismissed as insignificant.

Opponents portray the same surgical procedures and medical treatment as sources of inevitable pain or risks for possible additional pain and suffering. They dismiss the proposed benefits of surgery as speculative or trivial, while emphasizing the pain and risks of surgery, as well as the medical treatment.

Very little written or publicly discussed about the procedures can be realistically categorized as to be neutral or balanced. Perhaps the closest to a balanced view are the Terry and Campbell (2008) paper published in *Paediatric Nursing*, Liao, Savulescu, and Sheehan (2007) paper that appeared in the *Hastings Center Report*, and the Tan and Brassington (2009) article in the *Journal of Medical Ethics*. Terry and Campbell attempt to use the arguments raised by others on both sides of the issue to determine the essential questions to be debated without presenting any clear conclusion on one or the other side of the discussion.

Liao, Savulescu, and Sheehan (2007) provide arguments that are more favorable toward using medication to attenuate growth, but much more highly critical of the use of the surgical procedures. This split decision creates a kind of balance, although the practical application of this split is unclear since the growth attenuation with high-dose estrogen would likely be unacceptable without the surgery to reduce the impact of side effects.

Tan and Brassington (2009) point out that some aspects of the Ashley treatment may be much more problematic than others. While there is a risk of suffering associated with the medical treatment, some suffering appears to be virtually inevitable as a result of the surgical procedures. They also correctly point out that, since the surgery is justified in part as a means of addressing side effects of the medical treatment, it is of little practical value to endorse the medical treatment while prohibiting the surgery that it makes necessary. These authors question whether children like Ashley X can be considered to possess moral agency or moral worth, but voice concern that she will experience unnecessary pain and suffering as a result of the medical and surgical procedures.

Granted this, Ashley's putatively low inherent moral worth will not alter our obligations we have in respect to her. If we have obligations in

respect of non-agents, questions concerning whether or to what extent she is an agent and her place in hierarchy vis-à-vis others drop somewhat out of the frame. In treating a non-agent—an animal, or Ashley, as the case may be—merely as a thing or a problem to be solved, we may have wronged her, but we may be in danger of violating our duties to ourselves. (Tan & Brassington, 2009, p. 661)

They consider the notion the duty to Ashley might be much lower than it would be to a child without disabilities (a notion that advocates for people with disabilities or for universal human rights abhor and resist vigorously), but they also argue that there is a moral duty to avoid unnecessary suffering of children with disabilities.

As a strong believer in universal human rights and in equal rights of people with disabilities, I certainly disagree with their premises and would argue that our duties to all living humans in regard to rights and freedoms are equal. Regardless of my strong disagreement with their premises, however, I must recognize that these authors present one of the rare perspectives that considers both sides of the issue.

Polarized positions on the Ashley-X treatment have been of little value to a useful discussion of the issue. Diekema and Fost (2010) complain of inflammatory rhetoric and distortions presented by opponents while seemingly unaware of their own biases and distortions. This extreme polarization is a genuine lack of relevant information to guide decisions. How painful and risky are hysterectomy, mastectomy, and high-dose estrogen when applied to a six-year-old girl? The simple truth is that there is very little direct evidence available to answer this question, and Ashley X and other children like her cannot tell us what they think. An additional factor, contributing to the polarization may have been the original Gunther and Diekema (2006) publication, that purported to present both sides of “the ethical debate” (p. 1016) while clearly advocating for the procedures. In reaction, many wrote what were essentially counter-arguments in response to what they believed was only one side of the debate. Perhaps the courts ultimately will be the appropriate arena for arbitrating these differences of opinion since an adversarial process may be best suited to addressing the radically

opposing positions already in play and to ensuring that the child most directly affected has independent representation.

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