

Unit One: Introducing Intersex

Objectives

To help students understand the basics of intersex, including how intersex conditions and people have been described in medical literature and treated according to sociomedical paradigms.

Recommended Readings

Dreger 1998

Dreger, Alice Domurat. "Doubtful Sex." *Hermaphrodites and the Medical Invention of Sex*. Harvard University Press, 1998: 15-45.

In this chapter, Dreger offers an introduction to the historical discussions surrounding hermaphrodites, touching on both social and medical texts that influenced how people called hermaphrodites were understood and treated.

Questions

- What questions does the public changing of Alexina Barbin's sex to male raise regarding people's rights to self-define?
- Dreger notes that sketches were made of Barbin's genitals but that no picture of her face exists. What might the effects of these sorts of practices and historical records be?
- Given the confusion doctors expressed about how to define male and female, what "evidence" of true sex was most convincing to you? Why?
- Dreger points to many difficulties when trying to assess the frequency rates for intersex conditions. How important are these statistics? When are they important? When are they not important?

Preves 2003

Preves, Sharon E. "Medical Sex Assignment." *Intersex and Identity: The Contested Self*. New Jersey: Rutgers University Press, 2003: 23-59.

In this chapter, Preves introduces readers to the contemporary practices surrounding the birth of intersex infants and highlights current controversies surrounding the medical treatments for children born with intersex conditions.

Questions

Preves includes excerpts from many people with intersex conditions who seem to have been harmed by the secrecy surrounding their conditions. What sorts of ethical issues do these interviews highlight for you?

- What do Preves' discussions of institutions such as church and religion and her cross-cultural comparison of ideas about intersex suggest about the cultural issues surrounding intersex conditions?
- Preves notes that there are several different problems with medicine as an authority and the medicalization of intersex bodies. Which of these problems do you see as most important? Why?
- Preves quotes Claude Migeon as saying that many of his fellow physicians believe that you can "make a hole [vagina] but you can't build a pole [penis]." What does this quote suggest about how some surgeons are thinking about intersex bodies? About intersex people? About male and female bodies and their purposes? About sexuality?

Wong 2001

Wong's *Essentials of Pediatric Nursing*, 6th edition (see sections on ambiguous genitalia and surgery).

The text suggests that caregivers and parents relay harmful messages to children with intersex conditions who have not undergone surgery because their bodies look “different.” Therefore, the text recommends performing surgeries as early as possible in the hopes of stopping these harmful messages.

Byne 2004

Byne, William and Christina Skaer. “The Question of Psychosexual Neutrality at Birth.” *Principles of Gender Specific Medicine*. ed. M. Legato. San Diego: Elsevier Science, 2004: 155-166.

In this chapter, Byne and Skaer explore both the general questions and concerns about intersex care and provide some commentary on care for specific conditions such as hypospadias. The chapter explores contemporary research that suggests that gender and sexual identity are not entirely plastic. While previous scholarship on intersex conditions often suggested that children would adhere to whatever gender they were assigned, Byne and Skaer review contemporary studies that suggest this often isn't the case. Instead, they suggest that psychosexual identity is influenced by myriad factors, including exposure to prenatal hormones. From these studies, they conclude that there are many questions that should be answered before healthcare providers rush to gender assignments, especially those that involve surgery.

Questions

- Are you surprised that there are such differing opinions about what is best for children with intersex conditions?
- What might these significant differences signal to us about medicine? About intersex care?
- How do Byne and Skaer's claims challenge constructions of gender and sexuality that are popular among scholars in the humanities? What might this mean for the groups involved?
- How might medical professionals and social activists having different ideas about gender and sexual identity create tension? How can those differences be negotiated?

Please see the exercise called “Finding the Standard of Care” if you'd like to give your students a chance to explore the medical literature on their own.

Groveman 1999

Groveman, Sherri Morris. “The Hannukah Bush: Ethical Implications in the Clinical Management of Intersex.” *Intersex in the Age of Ethics*. ed. Alice Domurat Dreger. Hagerstown, MD: University Publishing Group, 1999: 23-29.

Groveman writes about her own experiences with her intersex condition and discusses the stigma and shame that occurs around intersex, specifically when family and physicians choose to keep secrets from children with intersex conditions.

Questions

- What do you think about Groveman using a discussion of religious practices to open a discussion about medical practices surrounding children and adults with intersex conditions?
- Groveman claims that AIS was a blessing, which seems to contradict how many people would imagine a person with intersex would feel about his or her body. What do you make of her claim? Should this sort of testimony affect medical practices? Why or why not? If so, how?

Eugenides 2002

Eugenides, Jeffrey. “The Oracular Vulva” and “Looking Myself Up in Webster's.” *Middlesex*. New York: Picador, 2002.

In these two chapters, Eugenides offers readers a look at the experiences of his main character, Calliope, as she visits a gender and sexual identity clinic and is subjected to numerous exams without ever being told the truth about her own diagnosis.

Questions

- What did you find most shocking about Calliope's visits to the gender clinic? How are this character's experiences similar to or different from the practices discussed by other authors?
- What factors do you think the doctor relies most heavily on when making his determination that Calliope is female? Do you agree with this diagnosis? Why or why not?
- Calliope's response to her assignment as "female" is drastic. Why do you think she takes such drastic measures? What does her response suggest about how traditional treatment paradigms affect patients and families?

Recommended Videos

Discovery 2000

Is it a Boy or a Girl?: (45 minutes, 2000)

This Discovery Channel documentary features adults with intersex conditions, scientists, and medical professionals discussing their experiences with intersex and their thoughts about the treatment of intersex as a social and medical emergency. The video also provides an opening segment that explains the physiological development of sexual anatomy in utero and how intersex conditions sometimes result.

Questions

- The surgeon featured in the documentary states that it's best to operate on children's genitals before 15 months of age, even when no medical necessity exists. He says this is important, in part, so that parents can accept the child's gender assignment. Who's interests are more important here, that of the parents or the child? How do you justify your decision?
- Cheryl Chase says that she learned about her intersex condition at the age of eighteen and had the opportunity to read her own medical records. She then was unable to speak about her condition and these events until she was 35. What, if anything, do so many years of silence suggest to us about the consequences of not being open with children about intersex conditions?

Unit Two: Changing Practices and Becoming Authorities

Objectives

To help students understand more about intersex activism, how people with intersex conditions understand themselves, and what the goals of intersex activism are.

Recommended Readings

ISNA “Agenda”

“What Is the Agenda of the Intersex Patient Advocacy Movement?” located at <http://www.isna.org/agenda>

In this brief piece, ISNA defines the basic principles guiding the movement for intersex rights. The piece includes explanations of ISNA’s basic policies that aim to end shame, stigma and unwanted genital surgeries.

Questions

- What parallels do you see among ISNA’s mission and that of other rights-based groups? Differences? Why might these similarities and differences be important for ISNA’s mission?

Walcutt 1999

Walcutt, Heidi. “Time for a Change.” *Intersex in the Age of Ethics*. ed. Alice Domurat Dreger. Hagerstown, MD: University Publishing Group, 1999: 197-200.

In this personal story about her experience with intersex, Walcutt frankly discusses her family history, medical history, and current struggles to understand her early childhood surgery and treatment. Walcutt also writes about her experiences with finding ISNA and other adults with intersex conditions and how these interactions have shaped her current understanding of intersex issues and her own identity as lesbian-identified.

Questions

- Walcutt is told that she will have to have a vaginoplasty if she ever wants to have “normal sex with her husband” (198). What sorts of assumptions inhere in such a claim? Does such a belief help construct a certain kind of sexuality or appropriate sexual expression? What might this tell us about why people are so concerned about intersex bodies?
- Many times in this piece Walcutt “talks back” to Dr. David Sandberg, a physician who works at Buffalo Children’s Hospital (where she was treated). Looking back closely at Walcutt’s mentions of Dr. Sandberg, how might you feel if you were Dr. Sandberg? Would you be surprised? Upset? How might the emotions on both sides of this issue affect the discussion of what, if any, treatments are best for children with intersex conditions?

Nicholson 1999

Nicholson, Sven. “Take Charge! A Guide to Home Auto-Catheterization.” *Intersex in the Age of Ethics*. ed. Alice Domurat Dreger. Hagerstown, MD: University Publishing Group, 1999: 201-210.

Sven Nicholson’s account of his experiences with his intersex condition, the surgeries to “correct” his hypospadias, and his refusal to be medicalized any more than necessary are discussed in this short piece. Specifically, Nicholson describes, in some detail, how he now catheterizes himself rather than visiting a physician.

Questions

- Why do you think it’s so important to Nicholson that he “take charge” of his own catheterization?
- What positive social effects might come from diminishing or eliminating the unnecessary medicalization of intersex bodies?

- How does Nicholson's experience question what is and isn't a medical issue?

Howe 1999

Howe, Edmund G. "Intersexuality: What Should Care Providers Do Now?" ed. Alice Domurat Dreger. Hagerstown, MD: University Publishing Group, 1999: 211-224.

Howe explores the underlying causes of the controversy surrounding intersex treatments and suggests that there is common ground among all groups involved: a desire to do what's best for children born with intersex conditions. From there, Howe carefully lays out a plan of action that will enable care providers and parents to put the children first and work together to provide the best possible medical and social care for children with intersex conditions and their families.

Questions

- Howe claims that it might be ethical and appropriate to recommend that parents who cannot bond with an intersex infant unless their child is given cosmetic surgery to make the genitals appear more "standard" receive therapy. In fact, he says that having such a reaction to their child could be called "phobic" (216). How is Howe's approach to treatment radically different from traditional paradigms? Do you agree with this shift? Why or why not?
- Howe notes that many cultures at many different times, have seen intersexed individuals as somehow "special." He himself believes that people with intersex conditions might have some special insight. Thinking back to all you've learned, what might an intersex person know (about medicine, bodies, families, etc.) that someone who isn't intersexed might not? Should we value this knowledge? If so, how?

Kipnis 1999

Kipnis, Kenneth and Milton Diamond. "Pediatric Ethics and the Surgical Assignment of Sex." ed. Alice Domurat Dreger. Hagerstown, MD: University Publishing Group, 1999: 173-194.

Kipnis and Diamond review the infamous John/Joan case (note that the young man's name is actually David Reimer, and we think it's important to emphasize that fact) and discuss the problematic assumptions made about genital appearance and concordance with gender identity. They review current medical literature, and specifically outcome studies, in order to discuss what an ethical response to children with intersex conditions would be.

Questions

- Kipnis and Diamond ask for a moratorium on surgeries on children's genitals, at least until those children are of proper age to consent. Further, they claim that parents also cannot offer informed consent on behalf of their children because physicians cannot fully inform parents of long term consequences and benefits due to lack of outcome studies. How do you feel about restricting parents' choice to have surgeries performed on their children? Is this ethical? Justify your answer.
- Kipnis and Diamond note that both children in countries where clitorectomies are practiced and intersex children in the United States who are subjected to cosmetic surgeries on their genitals are both subjected to these procedures in order to fulfill cultural expectations. Do you agree with this comparison? Why or why not? What are the useful similarities? Are there any key differences between these two practices that we should keep in mind?

Recommended Videos

Total Patient Care 2002

Total Patient Care: The Child with an Intersex Condition (20 minutes, 2002) Produced by ISNA, with a professional crew, Total Patient Care brings together an adult with an intersex condition, the parent of an intersex child, healthcare providers and ethicists in a conversation about traditional models of caring for patients with intersex conditions and how those models might be improved using ISNA's recommendations for patient-centered care. The video features Cheryl Chase, ISNA's founder and Executive Director, and members of ISNA's Medical Advisory Board.

Questions

- Debbie Rode Hartman, the parent of the child with an intersex condition, says that she was totally unprepared for having a child with an intersex condition. Do you imagine that parents' reactions to children with intersex conditions might be different if they knew it was a possibility, in the same way parents know that Down's Syndrome or cystic fibrosis are possible?
- Bill Reiner, the pediatric urologist and psychologist, states that during his medical training he was taught "facts" about intersex conditions that he now knows are not born out through research. In other words, he was misled by his medical training. What does this tell us about how some institutions teach about intersex conditions? Why do you think this happens?
- Sallie Foley, the social worker featured in the video, says that she was once called to consult on a case that involved a child with an intersex condition. When she arrived, she saw that a little girl with an intersex condition was being held down, apparently against her will, so that her genitals could be examined. What do you think about such a practice? Does it seem harmful to you? Ethically problematic?
- Bill Reiner says that if we want to know who children are, especially in terms of their gender identity, we must ask them. How might such a claim change current medical practices? Do you agree that this change should occur? Why or why not?
- Cheryl Chase, an adult with an intersex condition and the founder of the ISNA, says that doctors and parents ruined her sexual function, which was incredibly painful, but that they also thought that her very existence was painful and needed to be changed. How do you feel these medical practices might affect families?
- *How often do you think doctors take the opportunity to speak with their patients and learn from them? How does ISNA's approach change the very idea of doctor and patient relationships? What do you think about this change?

Hermaphrodites Speak 1997

Hermaphrodites Speak! (33 minutes, 1997) This film documents one of the first gatherings of intersex adults arranged by Cheryl Chase. Featuring ISNA Board Member Angela Moreno Lippert, Mani Mitchell (of *Yellow for Hermaphrodites*), and other adults with intersex conditions, *Hermaphrodites Speak!* sets the experiences of intersex adults at center-stage. Seated on a blanket, and with a handheld microphone, these intersex adults at center-stage. Seated on a blanket, and with a handheld microphone, these intersex adults frankly and openly discuss topics such as how they feel about their bodies, how they found out about their own medical histories, their experiences with medical professionals, and their relationships with their families and loved ones.

Questions

- Mani Mitchell, from New Zealand, recounts her memory of being taken into an operating theater (without sedation) and hearing doctors explain her condition to onlookers. What do you think about the politics of this sort of display? Is it really necessary?
- Angela Moreno Lippert says that before her genital surgery she loved her clitoris and that although she still has sexual sensation she thinks of the time before her clitoral reduction as her time "in the garden." Why do you think these surgeries have persisted despite obvious consequences to sexual function? Do you think it's more important to have an genitals that look like standard male or female genitals or genitals that provide basic function and pleasure? Why?
- Many people seem shocked at the anger expressed by Heidi Walcutt, who says that she'd like to take a rusty knife and cut off doctors' penises and then ask them how they feel. Why is this anger shocking given what's been done to her and other intersex people? What does this anger suggest about traditional treatments for intersex?

Yellow for Hermaphrodites 2004

Yellow for Hermaphrodites: Mani's Story (1 hour, 2004) This documentary (winner of the prestigious Quantas Best Documentary Award) allows Mani Bruce Mitchell, an adult with an intersex condition, to tell her poignant story of growing up in rural New Zealand. Subjected to genital surgeries at an early age, Mani takes viewers through her

life, discussing both the difficult times she considered suicide and her path to healing, reconciliation, and service. By making the choice to own her identity as an adult with an intersex condition and her sense of herself as neither male nor female, Mani takes joy in her life and inspires family and friends with her strength. Mani reaches out to other individuals with intersex conditions, and through these relationships viewers also have the chance to hear the stories of other intersex adults.

Questions

- Mani says it took her over 40 years to give herself permission to be who she is. What does this extraordinary amount of time and struggle tell us about how the shame and stigma around intersex conditions affect people's sense of themselves?
- David Vandertie says that he grew up believing he was the only person in the world with "different" genitalia, as did Mani. The two of them note that knowing there are others like them is incredibly important? Why do you think this is the case?
- Mani says that there was a community meeting when her sex assignment was changed from male to female. What does such public involvement suggest about the importance of intersex bodies? She also says they decide to keep it a secret so that everyone else in the town knew but Mani didn't. What do you think about this decision?
- Both Mani and David are survivors of sexual abuse and say that one of the things that made them easy victims was that they were told never to speak about their genitals. What other consequences might children face due the silence and shame surrounding intersex?
- What do you think is the main cause of Mani's fractured relationship with her mother?
- Are you surprised that someone would celebrate a difference like intersex, as Mani does? Why or why not?

Exercise: Finding the Standard of Care

This learning activity can be included with the section on medical literature and offers students a chance to do their own research on intersex conditions and to better understand the challenges of changing medical practices.

One of the most challenging tasks ISNA faced in the movement for intersex rights and better medical care was to understand and evaluate current medical practices surrounding intersex patients. The task was so challenging, in part, because so many of the practices either weren't codified and sometimes those that were more clearly codified in medical literature weren't practiced uniformly. Our work toward understanding medical practices was greatly aided by scholars such as Suzanne Kessler, who digested and synthesized the volumes of literature about intersex care in her text *Lessons from the Intersexed*. From all those seemingly disconnected texts, Kessler constructed a cohesive overview of the state of intersex care and in doing so helped ISNA and others working toward better care understand current medical practices. Still, many of the standards of care are not codified and disparate recommendations abound; the lack of consensus in published literature continues to be a challenge for those working for better intersex care. Adults with intersex conditions and parents of intersex children trying to understand intersex conditions and treatment options have also been challenged by the lack of consensus.

To help students understand this challenge, have them do their own research on intersex care and ask them to construct the current standard of care. Here are a few suggestions for how you structure such an activity:

- Have students research intersex conditions in an online database such as PubMed and write a narrative about their experience with the search. What did they discover? What were their challenges during the research? If they overcame those challenges, how did they do so? How do they think these challenges might affect organizations and individuals working toward understanding and/or change?
- Have students research intersex conditions on an online database such as PubMed and then ask them to, using what they found, construct a "standard of care." In other words, ask them to attempt (either in narrative or chart form) to construct the current standards for intersex care.
- Ask students to imagine that they want to change current medical practices surrounding intersex. Given their experience researching, where would they start? What do they think would be their biggest obstacles to change?