

The Birth of an Intersex Infant: Exploring the Options and Ethics Behind Decision-Making

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Abstract

While joyous and miraculous, the birth of a healthy infant is an event laden with eustress, fear of inadequacies, and permutating visions of the future. Add to this the diagnosis of an intersex infant, and the family is catapulted into an abyss of unfamiliar questions and unexpected decision-making. Immediate surgical intervention to alter genitalia is a common decision, but is not the only option. An ethical debate stems around the core question of whether choosing the sex of a child is the responsibility of the parent, or of the child, as he or she ages. The psychological repercussions of sexual incongruency resonates unabated throughout childhood and adolescence. The following paper explores the ethical considerations behind sex assignment surgery for intersex infants.

The Birth of an Intersex Infant: Exploring the Options and Ethics Behind Decision-Making

In 2002, Pulitzer Prize-winning Jeffrey Eugenides, published the book, *Middlesex*, that chronicles the life of a child born with ambiguous genitalia. While presence of ambiguous genitalia has been acknowledged since the late 14th century, this is one of the first novels that attempts to progress the discussion of ambiguous sexuality from a state of medical curiosity and societal stigmatism to one of open discussion and normalization.

In a field laden with power and rapid development, the four pillars of ethics have been constructed to guide medical professionals in making the most appropriate patient care decisions. In addition to the principles of nonmaleficence, beneficence, justice and autonomy, the American Nurses Association (ANA) has constructed nursing guidelines that help to unite the profession, identify shared values, delineate obligations and embody moral expectations (ANA, 2005). The University of Pennsylvania's Bioethicist, Connie Ulrich, PhD, defines an ethical issue as any situation that one believes has important moral challenges embedded within, that ultimately demands extrication and identification (Ulrich, 2009). An ethical issue is one that presents no obvious solution; one that may hold deep significance to those involved and unfortunately does not shout black or white. It is during these times of gray that nurses grapple for moral fortitude, employing the ethical guidelines prescribed to our profession, to seek and establish a solution that upholds these principles.

One situation, fraught with ethical challenges, is the assignment of sex, and subsequent gender, in an intersex infant. The umbrella term intersex refers to "a group of disorders in which phenotype appearance of external genitalia does not occur in conformity with genotypic sex" (Akhtar, 2004). When an infant is born with gonad or sex discordance, it has been traditional in Western societies to choose a sex for the child and perform immediate surgery analogous to a potential medical emergency. In a culture restricted by a binary sex paradigm, it is not uncommon for both parents and healthcare providers believe it beneficial to assign a child a sex as soon as possible (Thyen, Richter-Appelt, Wiesermann, Holterhus & Hiort, 2005). Unfortunately, despite paucity in longitudinal research studies, results indicate many children are unsatisfied with their sex assignment.

"Whereas I, even now, persist in believing that these black marks on white paper bear the greatest significance, that if I keep writing I might be able to catch the rainbow of consciousness in a jar." Jeffrey Eugenides, Middlesex

In a world of dual check boxes, sex and gender remain concepts easy to categorize into black and white.¹ The truth remains that the complex interplay of chemistry, genetics, biology and environment, ensures a colorful spectrum of possibilities, not surprising in a world of cobalt blue and crimson. But what happens when a parent is handed a tightly bundled child, and told by their provider that they must choose whether they will be leaving the hospital with a Daniel

or Danielle? Must they decide to cut, snip or sew? Some experts claim that surgery is mutilating to an infant and not necessarily an appropriate reflection of what the child would want. The intersex dilemma materializes as a question emerges—if experts do not agree, how is a new parent, burdened with fear and uncertainty, expected to make such a life-altering decision? The following three articles address three of the most pivotal ethical concerns weighing upon the minds of the family of an intersex infant: Is corrective surgery the only valid option? Does a child have a right to choose? And lastly, what is the role of the health care team?

Is Corrective Surgery the Only Valid Option?

"I was born twice: first, as a baby girl, on a remarkably smogless Detroit day in January of 1960; and then again, as a teenage boy, in an emergency room near Petoskey, Michigan, in August of 1974." Jeffrey Eugenides, Middlesex

A study conducted by Maharaj, Dhai, Wiersma and Moodley (2005), illuminates the trend for many health care providers formulate their gender reassignment recommendations based on the appearance of the external genitalia and the predicted outcome for the most successful surgery. The biological and psychological issues embedded within these individuals is still poorly understood and modern science has yet to validate whether sexual identity is determined by genes, society or culture (Maharaj et al., 2005). Surgery can, and often does, compromise sexual function but the absence of surgery can yield a confused youth inadequately prepared for adolescence. Assigning sex, however, does not guarantee that through puberty and adulthood the individual will conform to the gender identity assigned.

As an educator, the nurse's role includes assisting parents to understand that immediate surgery is not the only option. Sex assignment surgery does not ensure a congruent identity across the lifespan, nor does an intersex infant necessitate emergent action. Our technology is developing at a pace that supersedes our understanding of certain biological phenomena. In a culture accustomed to fixing problems, it might be helpful to reassure mothers that perhaps this is not a problem that requires immediate repair.

This article, by Maharaj et al. (2005), is unique, in that it is written by a team of physicians and lawyers, who explore the motivation behind this surgical trend.

While they value science and technology, the authors unite in recommending a non-directional counseling approach that provides awareness of non-surgical management while encouraging psychological support for mother and child.

A Child's Autonomy

"But in the end it wasn't up to me. The big things never are. Birth, I mean, and death. And love. And what love bequeaths to us before we're born."
Jeffrey Eugenides, Middlesex

Thyen et al. (2005) explore sex assignment by comparing the original "optimal gender policy" with the more progressive "full consent policy." The original policy was designed utilizing the premise that "gender identity is predominantly determined by psychosocial influence, and accordingly that expedited gender assignment in the newborn period was warranted to avoid prolonged parental insecurity" (Thyen et al., 2005, p.3). The authors note that mothers harbor feelings of shame, guilt and secrecy when they receive their infant's diagnosis, and underscore that the first policy was established to alleviate parental concerns. The new policy suggests that genital operations in infants should only be carried out if malignancy is suspected. Otherwise the operations should only be performed under the child's consent and that child has the right to choose his or her sex to match his or hers experienced gender.

The authors of this article honor the moral principle of autonomy, giving providers an opportunity to return some control to the child. By offering developmentally-appropriate information early, the nurse can help encourage the child to take an active role in questioning and decision-making (Thyen et al., 2005). The nursing code of ethics states that the nurse's primary responsibility is to the patient, whether an individual or family (ANA, 2005). As a nurse of the childbearing family, we embody a unique role, in that our patient is the family unit, encompassing infant and parents alike. The challenge formulizes as we make a suggestion that might create a divergence between the interest of parent and child. While immediate action might console a confused parent, the authors indicate the ethical option includes appreciating the voice of the child.

The authors acknowledge that very few studies have been dedicated to understanding the mental health of these individuals nor has patient satisfaction

been used as an outcome. They boldly suggest that repeated medical examinations on the genitals can result in feelings of shame, fear, pain, and isolation, that mirror those feelings experienced by victims of sexual abuse. There is a need for future research to address how parents determine when their child is cognitively mature enough to make such a decision, and with whose help, as well as discuss whether healthcare providers, who support a child's autonomy, are infringing upon the parent's rights?

The Role of the Health Care Team

“Plato said that the original human being was a hermaphrodite. Did you know that? The original person was two halves, one male, one female. Then these got separated. That’s why everybody’s always searching for their other half. Except for us. We’ve got both halves already.”

Jeffrey Eugenides, Middlesex

The third article is a composition piece of 50 international experts in the field, who congregated to review evidenced-based literature with the purpose of producing a consensus document. The authors attempt to tease apart the complex psychosocial aspects of sex and gender by distinguishing the differences among “gender identity,” “gender role,” and “sexual orientation.” They noted that although gender development initiates before age 3, it remains unclear at which age it can be accurately assessed. Additionally, the article details medical management, surgical outcomes, legal issues and role of the collaborative health care team (Lee et al., 2006).

In order to best advise and inform parents, the authors stress unified collaboration amongst the members of the healthcare team, despite knowing the best course of action might not be initially evident. They purport that an ideal multidisciplinary team should include endocrinologists, gynecologists, neonatologists, social workers, nurses, and a representative from medical ethics (Lee et al., 2006). Nurses can contribute to this team by offering developmentally appropriate education, disclosure, emotional support, empathy and cultural sensitivity to the family unit. Understanding the risk for psychological duress stemming from discrepancy between assigned sex and felt gender, as the child develops, the nurse should maintain a role as the child's advocate, facilitating confidential conversations or family meetings (Lee, Houk, Ahmed, & Hughs, 2006).

The article's strength is the suggestion of a collaborative approach and a belief that ongoing education and action requires a flexible individual-based approach. The research highlights the fact that each case is unique and that tailored communication strategies should be initiated with the parents from the time of diagnosis (Lee et al., 2006). Surprisingly, the authors agree upon several actions that are morally equivalent, without exploring the controversial nature of the issue. For example, they believe that all individuals should be assigned a sex (Lee et al., 2006), and relinquish any possibility that the child may choose for herself under the full consent policy. In a similar disregard for a child's autonomy, they suggest in order to avoid further shame upon the child, medical photography should be taken whenever a child is already under anesthesia (Lee et al., 2006).

As members of the health care team who will interact with parents during this potential crisis, we have the responsibility to encourage them to really take the time to think about their decisions. We have the ethical duty to keep parents informed through clarification, research, options and counseling, and help them understand that many surgical interventions are irreversible and life-altering. As nurses for the childbearing family, we have the ethical responsibility to be educated in the initial management of newborns, their families, and their options (Lee et al., 2006). We need to take it upon ourselves to understand that gender is culturally constructed and may be viewed differently from people of a different culture. It is suggested that “in most cases the birth of an infant with intersexuality is not a medical emergency. All efforts should be directed to reduce anxiety and support parent-infant bonding to allow time for adaptation and informed consent” (Thyne et al., 2005, p. 5). We must facilitate a transition that allows parents to understand that the most important decision that they can make for their child is the promise of love, acceptance, open communication and support. Assigning sex to a child is an ethical issue; accordingly, the concept of gender is not black and white, therefore it is okay to let our children live somewhere in the gray.

Future Directions

Within the medical field, we are a culture defined by science and technology, and then trend of today is to employ multimodal examinations to formulate a more educated assessment of an intersex infant. Current guidelines suggest that physical examination can be followed by chromosomal evaluation, biochem-

ical testing, radiographic imaging, diagnostic laparotomies, and finally, sex assignment. This diagnostic approach is married with warning label, however, that does stress that a cautious approach, with the consideration of reversible interventions (Baskin, 2008). As medical experts, by embracing a more accepting approach, we are moving in the right direction, however as a society at whole, candid discussion is the only way to rescue a topic deeply submerged, and allow some light to illuminate.

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Footnote

1 For the scope of this paper, sex is defined as "the biological character or quality that distinguished male and female from one another as expressed by... gonadal, morphologic, chromosomal, and hormonal characteristics" (Piper, 2008, p. 1421). Not just determined by chromosomes or genitals, gender identity involves the interaction of hormonal influences, role behaviour, sexual orientation, and is "considerably modified by psychological, social and cultural factors" (Thyen et al., 2005 p. 1).