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#### **Case 17:**

### An Intersex Infant and Decisions about "Normalization"

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The genesis of a new life into the world is a joyous occasion and the experience, although quite a travail for the the ends in entrance mother-to-be, momentous parenthood for both the mother and father. Imagine, however, that this happy milestone is immediately marred by the presence of a medical abnormality. This is what occurred in the case of Fred and Jenny D., the new parents of an otherwise healthy baby boy, save for his extremely small penis. Although the infant had been born with all of the correct male anatomy, including testicles, his penis was so small that it had created confusion as to the actual sex of the child. Fred and Jenny D., who are supposed to be celebrating the new life of their child, are suddenly faced with an incredibly difficult decision. Physicians have advised that in order for the infant to garner healthy psychosexual development that it must have a social assignment to one specific gender and have the according genital appearance. As the infant's penis is so small, it has been recommended by a team of physicians that the baby's testicles be removed and that additional surgery and hormonal therapy be given to the child so that it may be raised as a female. The parents are to consider the above proscribed treatment, as well as the option of letting the child be and raising it as a boy, providing psychological therapy as need be

and allowing the child to make decisions on his own concerning his sexuality when he is older.

What is the correct course of action for the new parents Fred and Jenny D. to take in this situation? That is, which decision would be most supplemental to the child's long-term interests and health? How can the team of physicians better aid the parents' decision making? These questions can only be answered through a discussion of the moral issues at stake with concern to the case and their application to the life of the intersex newborn. At the heart of the issue is concern towards the autonomy, paternalism, and beneficence of the infant. Secondary arguments revolve around the role of the abovenamed physicians, maleficence, and justice.

In order for one to be an acting agent in our society one must have autonomy, or self-determination. With all medical decisions, one is usually entitled to their determination with regard to treatment, yet in circumstance the newborn child cannot exercise his autonomy since he is not of a high enough cognitive mind. Thus, in effect, paternalism, the attitude that others must be taken care of or controlled for their own good, must be applied by the infant's parents. Enforcement of paternalism will maintain a determination as to what medical measures must be taken so that the best interests of the child are represented by reciprocal medical treatment. Only one of the two options detailed by the physicians allows the newborn to delineate its own path in life with special concern to his ambiguous genitalia, while the other places the burden of the medical decision entirely upon the newborn's parents. Here, the infant's parents are faced with the task of "forcing" a gender assignment upon their child, or allowing their child to develop into his adolescence as is, allowing him to make the choice later in life on his own accord.

Following this discussion comes the introduction of bene-ficence, defined as the ethical principle that requires that medical providers and parents do what is in the patient's best interest. This is a particularly difficult area with concern to intersex infant situation as one can argue beneficence for either course of action, either autonomy for the child later on in life, or paternalism by the parents in "normalizing" the infant. Until recently, the standard medical approach would be to perform a "normalizing" surgery with a plan of shielding the maturing child from the truth about their true condition. This method is seen as being in the overall best interest for the patient's psychological benefit and future social acceptance. Corrective surgery to turn a genotypic boy into a phenotypic girl is generally not necessary for protection of life or health, but rather purely for aesthetic and social purposes. Defenders of this view argue that it is necessary for an individual's own good to be clearly identified as male or female in order for to function socially and not have long term psychological affects concerning their ambiguity. However, although "normalization" seems to be a good option, there have been many intersex individuals who have recently decided to publicly speak out as to their resentment of the sexual reassignment surgeries performed on them when they were infants. In these cases what was at first deemed as a beneficent act has, in the end, actually turned out to be a maleficent act. The paternalistic decision made for sexual assignment and the at-tempted shielding of the patient will, in the end, hurt the individual more.

As is obvious, having a child with an ambiguous sex is an inextricably confusing situation for parents. In previous discussion it was observed that many older adults, who have experienced "normalization" or sexual reassignment surgery, have come to resent the medical decisions that were made for

them without their explicit consent. It can be argued from this viewpoint that sexual reassignment surgery would become a maleficent act in the eyes of the previously gender-ambiguous individual. If surgery is the preferred method of "treatment" for this issue and the outcome of it is not what the affected adult would have wished for, then the pain and suffering of the gender reassignment surgery and hormonal treatment will have been for naught. The potential emotional scarring from such an act could run deep- it is impossible to predict how the affected individual will react to this sort of medical treatment when they have grown old enough to fully comprehend the choices made for them. It is also possible that the parents of such an affected infant may withhold the information concerning the sexual reassignment from the child in order to "protect" him from the truth of the situation, which although prima facie seems to be a benevolent act, in the child's majority, it will become a malevolent one which may spark feelings of hurt and betrayal in the affected individual.

Another ethical issue that must be considered in the analyzation of the intersex infant case is justice, that is, the proper distribution of medical resources. In the case of gender reassignment surgery, it is clear that more medical resources will be used if the male infant is changed to a female. Multiple surgeries, hormonal therapy treatment, and psychiatric treatment on the whole will cost more than a problem that could potentially be alleviated with solely psychiatric treatment. Such extensive medical treatment should be reserved for those in greater need of therapy, and not on individuals whose problems may be treated with simple psychiatric services alone. Regardless of whether or not the gender-ambiguous infant is given the surgery, the child will require mental health care. With this sort of a prognosis, it can be surmised by opponents to the surgery that more good will

be done for a greater number if the child is left as a boy, freeing up medical assets to use in more urgent medical situations than that of an intersex infant.

With these facts in mind, the question arises as to the specific role of the physicians involved in this case. The physicians in particular invoke several of the considerations already discussed, including paternalism and beneficence. Also to be mentioned are the roles the physicians play with regard to maleficence, justice, and most importantly, informed consent. Without informed consent, the infant may be unintentionally harmed and maleficence will occur on the whole as a result. Informed consent arguments come into play in the case of the intersex infant as regardless of what route of treatment the parent's of the infant decide to traverse. physicians must fully inform the parents of the details, benefits, and disadvantages of each choice to fulfill consent. Physicians are morally and legally bound to inform patients, specifically the parents of the intersex newborn, of all possible medical options so that the best decision, medically and ethically, can be made for the patient keeping their best interest at the forefront of the determination. In addition, in these intersex situations the medical team is not only treating the patient, but the patient's parents and family too. In these circumstances parents need emotional support and unbiased help in making an informed decision. To make an informed decision they should be provided with a plethora of resources detailing the intersex condition. They should also, perhaps, be provided the opportunity to speak with intersex individuals who have both had and not had the initial "normalizing" surgery. In the end they should have the freedom to make a medical decision on their child's behalf in the absence of outside pressure, while fully having a clear understanding of their options.

On the whole, with the given facts, it could be easy to sway either way on the course of medical treatment that should be given to the intersex infant in question. Should the infant undergo sexual reassignment surgery and be raised as a female? Or should the infant be raised as a male and be allowed to make his own choice concerning his sexuality when he has reached his majority? Which of these decisions would be of most benefit to the child and which would be the most malevolent? Is justice served in either case of treatment? Even armed with unbiased information as to both sides of the argument, it is a daunting task to attempt to solve this inarguably complex problem.

#### Our Decision

In an unwavering unanimous judgment, it was decided that the intersex infant should be raised as a boy, receiving psychiatric counseling if and when needed, and be allowed to make any major decisions about his sexuality when he is older given the evidences provided for this case in point. This was considered the most morally sound option of treatment as it affords the intersex infant with optimal opportunity for both happiness and a normal, healthy lifestyle. In such a complex case, the court must often act as the parent's patriae, acting in the best interest of the affected individual. In this unanimous decision, the best interest of the intersex infant has been represented fairly and adequately, with all other options given equal consideration. The rationale for this decision was based upon arguments which stemmed from discussions of autonomy, beneficence, and maleficence.

With respect to the autonomy of the intersex infant, by choosing to avoid unnecessary surgery and hormonal treatment, the new parents will be employing the best interests of the boy. Such a choice allows for the securing of future autonomy for the intersex infant, allowing him to make all major decisions concerning his sexuality when he is older, being that his interests in that regard are currently unknown given his status as an infant. By taking this course of action, the boy's liberties are in no way infringed upon and he may make this important decision on his own as he develops into a mature and responsible adult with his own views and opinions about himself, the world, and society at large. This being the case, it would be unethical for the parents of this intersex infant to force a conflicting sexual assignment onto him as it would not be in his best interest.

With special attention to beneficence, the fact of the matter is that sexual and gender identifications are more complicated than a surgical decision that claims to split the human experience of it into two neat, simple classifications. Many intersex people later suffer, rather than benefit, from a surgical sexual reassignment which they did not consent to because of a strong identification with the "excised" sex, decreased sensitivity of their modified organs, or problems resulting from the initial surgery. What is truly in the intersex infant's best interest is for the parents and medical practitioners is to accept the affected infant's condition and throughout the years, as they come into competent mind, divulge the truth to the infant's about their ambiguous sexuality. The intersex patient should then be provided with ample counseling and information about the condition. No more surgery should be performed before the infant has reached the age of consent than is necessary for his physical health. Once the infant reaches a competent age he can make his own informed decision about what will truly be the best option for him personally. In addition to the beneficence garnered by the intersex individual, many other patients in need of treatment, be it surgical or hormonal, may receive it if

the intersex baby does not use up resources that are unnecessary to him. The freedom of medical services incurred from the intersex individual foregoing surgery is not only beneficent to others, but serves the purpose of medical justice as well.

As was previously discussed, the premise of maleficence plays a large role in the decision that was made in this case. Of specific note is the fact that perhaps the parents of an intersex infant that has undergone a sexual reassignment surgery may hide the truth from their child in order to "protect" them. If, in fact, the truth of the matter at hand must he hidden from the child for his "protection," can the parents truly believe that they have made the correct decision in having a surgical sexual reassignment performed upon their newborn child? The very word "protection" invokes imagery of solace from inordinately horrible or fearful things- is sexual reassignment surgery something that warrants protection from knowing the truth of it? If so, then a decision to go through with such a surgery would surely render that decision unacceptable. If the truth in such a case were initially withheld from the intersex individual and discovered at a later time, it would not only be devastating for the intersex individual, but it would also truly hamper the former trusting relationship between the intersex patient, his parents, and perhaps even future physicians for fear of other truths being withheld.

The choice to allow the intersex infant to be raised as a male and to make its own decisions concerning his sexuality raises no questions as to the autonomy of the infant; it harbors no ill feelings of fear as such a decision would never be a skeleton in the family's closet; it allows for the full utility of the infant and keeps the best interest of the infant in mind at all times. With the provision of psychiatric counseling and only as much surgery as is needed to keep the child healthy,

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the decision to allow the intersex infant to be raised as a genotypic male, as it was born, is the best decision possible in such a case as described because it is the most reasonable and the most ethically sound.