

# Ethics & Medics

A CATHOLIC PERSPECTIVE ON MORAL ISSUES IN THE HEALTH AND LIFE SCIENCES

## Sex and Trisomy 21 - Part One

In the last decades, public perception of the person with Trisomy 21 (Down syndrome) has undergone a slow but substantial change. Whereas a majority of people once viewed a Down syndrome sufferer as either subhuman or an eternal child, now most people recognize that an individual with Down's syndrome is a *person* with all of the corresponding rights and dignity that personhood implies. Encouraged by this development, organizations like the Association for Retarded Citizens actively promote the optimum integration of mentally retarded persons into the larger society.

The 1977 International Symposium on Normalization and Integration describes the agenda of this process as applicable to every aspect of human existence, including the area of sexuality. In a public statement, the symposium asserted that the foundation for the sexual rights of the mentally handicapped is the entitlement to a normal life in our heterosexual society (see *Ethical Issues in Mental Retardation*, D. F. and V. S. Allen, Abingdon Press, 1979).

As more persons with Down syndrome begin to take their place in the community, changes in their sociosexual development are to be expected. Through sexually integrated group living and the process of "mainstreaming"—affording mentally handicapped persons greater educational and community opportunities—the Down syndrome adolescent and adult meet new responsibilities and require, consequently, the corresponding interpersonal social skills and moral training in order to act appropriately and responsibly.

This two-part article will discuss three practical questions in regard to a Down syndrome person's response to and exercise of sexuality. Each question is not only personally and parentally troublesome, but it also appears to be problematic in light of Catholic moral teaching. Before we take up the issues, however, a brief description of the etiology of Down syndrome as well as the relevant aspects of reproductive anatomy and physiology of a Down syndrome sufferer is a necessary preliminary.

### Etiology

Occurring in about 1 in 800 live births, Down syndrome or Trisomy 21 is the genetic birth defect most

frequently associated with mental retardation (cf. *Facts about Down syndrome*, U.S. Dept. of HHS, p. 1ff). It manifests itself in all races and has severe effects on the physical and mental development of the person afflicted with this birth defect. In 99% of the cases, a person born with Down's is mentally retarded (moderate to mild range, 40-70 IQ) and exhibits varying combinations of distinct physical abnormalities: slanting eyes, slightly protruding lips, low set ears, large tongue, and short hands, feet, and trunk. These physical and mental aberrations result from a chromosomal abnormality: extra chromosome 21 material. In 95% of the cases, chromosome 21 is represented by three rather than the normal pair of chromosomes (trisomy 21); in 4% of the cases, extra chromosome 21 material breaks off and attaches to another chromosome (translocation); in 1% of individuals with Down syndrome, cells differ as to chromosome count (mosaicism), e.g., some cells of the same individual have 47 chromosomes, some 46.

S. M. Pueschel and P. S. Scola provide some research data regarding sexual development as well as sexual feelings, thoughts, and desires of adolescents with Down syndrome (see "Parents' perception of social and sexual functions . . .," *J. of Mental Deficiency*, Vol. 32, 1988, 215-20). Previous reports in the literature (1929-1969) showed that men with Down syndrome can have a diminished sexual drive, smaller than average-size testes, decreased sperm counts, and they are sometimes sexually impotent. Since a mosaic male with Trisomy 21 can have a normal germ cell line, human reproduction is a possibility. The apparent infertility of males with Trisomy 21 not associated with mosaicism or translocation is

(continued on page 2)

### IN THIS ISSUE

#### Sex and Trisomy 21 - Part One

Moral evaluation of a hysterectomy to alleviate menses-related difficulties in a person with Down syndrome

#### Sperm Banks: A Catholic Perspective

Key ethical issues concerning donor sperm

attributed to their impotence and/or inability to produce sufficient gametes. Recently, however, *The Journal of Medical Genetics* (Vol. 26, 1989, pp. 294-98) presented the first fully documented case of a non-mosaic 29 year-old male with Trisomy 21 who fathered a pregnancy (subsequently terminated by a miscarriage).

Various studies have shown that females with Down's syndrome have ovaries that are small and developmentally immature with decreased activity of the germinal epithelium, many large follicular cysts, and absence of mature follicles. Delayed menarche and breast development as well as an absence of areolar glands also typify females with Trisomy 21. Although earlier studies concluded that 50% of Trisomy 21 females never menstruated (Biedelman, 1945), in a later study, Stearns and Tricomi (1960, 1964) reported that a majority of Down's syndrome women do menstruate regularly. Statistics vary about the percentage of babies (25-50%) born to Down syndrome females who are also afflicted with Trisomy 21 or other mental handicaps.

### Moral Considerations

**Question #1:** Is it morally permissible to perform a hysterectomy on a Down syndrome female who suffers major physical and psychoemotional upset by menstruation?

This question received public discussion in 1976 when Ruth Whitney, a registered nurse and mother of a Down syndrome child, recounted her efforts to procure a hysterectomy for her 12 year-old daughter, Camille (cf. "I Dared to Seek Surgery for My Retarded Daughter," *RN Magazine*, Vol. 39, 1976). Although the doctors she approached were opposed to or reluctant about performing the operation, Whitney persisted. She saw the hysterectomy as the only solution to her daughter's extreme emotional, psychological, and physical maladjustment to menstruation. With each menses, Camille became depressed, refused to go to school, and was unable to manage the hygienic requirements of her period. Furthermore, Camille, with an IQ of 44, could not understand why the pain and distress were recurrent. Whitney did eventually find a doctor to perform the hysterectomy and reported that once again Camille exhibited her pre-menses well-adjusted relationship to people and circumstances. The question we raise is this: Is the hysterectomy just described an example of direct sterilization, that is, a procedure deliberately destructive of a basic human good and, therefore, prohibited by the Church?

**Reflection:** A way to answer this question is to ask two things of the parent or guardian of the person with Down syndrome who is contemplating the hys-

terectomy for his child. First, what are you proposing to do? In the case above and in similar cases, the parent or guardian should respond, "I am asking the doctor to remove my daughter's uterus." Second, why are you doing it? In this and similar cases: "To save my daughter from the physical and psychological upset which accompanies her period." Both answers reveal that the action is not done with a contraceptive intent. What is intended is the removal of an organ whose normal functioning under hormonal influences causes a psychopathological condition in the person. It follows, then, that this type of hysterectomy does not fall within the purview of the type of action prohibited by the Congregation for the Doctrine of the Faith: ". . . actions which are in themselves, that is, by their nature and condition, directed to a *contraceptive end*, namely, that the natural effects of sexual actions deliberately performed by the sterilized subject be impeded, . . ." (Reply of CDF on Sterilization, NCCB, p. 6, emphasis added) Furthermore, in the case of Camille and others like her, there is no question of "sexual actions deliberately performed" because they lack the intellectual, emotional, and psychological development that is commensurate with knowledge of and desire for sexual activity.

We could arrive at a similar moral conclusion if we approach the question of a therapeutic sterilization via the joint application of the principles of totality and double effect. The removal of a uterus, even though it is not pathologically diseased, is morally justifiable in certain circumstances for the sake of the overall or greater good of the person. In a similar vein, Pius XII approved an orchidectomy for the treatment of carcinoma even though the seminal glands themselves were not diseased. His rationale is clear from the following:

The decisive point rests not in the fact that the organ which is amputated or paralyzed be itself infected, but that its continued presence or functioning cause either directly or indirectly a serious menace for the whole body (*Allocution to Delegates at the 26th Congress of Urology, 1953, The Human Body*, p. 278).

Having invoked the principle of totality as a justification for Camille's hysterectomy, it is important to note that it cannot be invoked to justify a sterilization which is performed in order to prevent a physical or mental illness which most probably will occur as a result of a future pregnancy. In the latter, the future pregnancy, not the functioning of the uterus, is the menace to the overall good of the individual. Sterilization in this instance would have a contraceptive end. In the case involving a Down syndrome person suffering from menses, however, prevention of a future pregnancy is not at issue but, rather, the ame-

(continued from page 2)

lioration of a psychophysical maladjustment which is directly exacerbated by the functioning of the uterus, namely menstruation.

At a later date (Sept. 12, 1958), Pius XII pointed out that his decision in the orchidectomy case was also reached on the basis of the principle of double effect. An application of that principle to the sterilization case at hand results in a similar resolution. What is directly intended is the removal of a uterus which causes serious disturbance to the woman's psychoemotional well-being, what is foreseen but only permitted is the sterilization of the procreative dimension of sexual activity. The good effect is not brought about about by the evil effect—the sterilization—but by the removal of an organ whose continued functioning is a

threat to overall personal well-being. And, finally, a proportionately grave reason (the restoration of the emotional/physical equilibrium of the person) warrants a procedure which results in the evil effect of sterilization.

In sum, then, a correct application of the principle of totality to the hysterectomy under consideration assures that it is a therapeutic and not contraceptive sterilization, and a correct application of the principle of double effect assures that it is an indirect not direct sterilization.

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