Commentary to 'Evidence regarding cosmetic and medically unnecessary surgery on infants'

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The accompanying review [1] continues to call for a moratorium on all genital surgery among children with disorders of sex development who have significant genital differentiation problems citing publications from the DSD Working Group [2]. Those not familiar with the long-term position of the author [3] should realize that this call for a moratorium was first made decades ago. This type of position is inherently polarizing and, if adopted, would simply introduce a different type dogma in place of the earlier employed optimal gender approach and ignores the data showing improvements in the care of DSD patients since the optimal gender approach was abandoned.

Further, it does not recognize the recent fundamental therapeutic changes in both sex assignment and genital surgery. The preliminary results from current outcome data, showing better outcomes than historical data have shown, were not mentioned. In fact, many of these recent therapeutic changes resulted from the impetus of prior poor outcomes. Genital surgery, particularly clitoral, is being done much less frequently, and with greater understanding of the importance of the neurovascular bundle in sexual responsiveness and function.

Seldom in medicine, as is life, is a universal moratorium appropriate. In this instance, leaving all DSD children with genitalia that are neither primarily male nor female, to later decide on gender and sexuality seems to represent an inappropriate form of social experimentation. Such a moratorium also denies basic parental rights and responsibilities to act as surrogate decision-makers for their children. In this complex situation, timely decisions, parental input, diagnosis, availability of surgical expertise and other factors are important. Hence, decisions are unique to each patient and circumstance.

The Annecy Working Party provided background for a reasonable approach for future evaluations and current care of children born with DSD and genital ambiguity. Although much is yet to be learned, current outcome information suggest significant progress within an ethical perspective. For example, sexual satisfaction may not relate to prior genital surgery as females are often satisfied with their surgical outcome and may not differ from age peers regarding general quality of life issues and sexuality with the caveat that degree of prenatal androgen exposure is likely related to negative outcomes. There is also a strong international trend toward not recommending female assignment for 46XY individuals with evidence of testicular function.

Thus, in considering the many factors involved in the care for DSD individuals, numerous changes in recent years were driven in part by the focus upon negative outcomes in the past. Although Dr. Diamond played a significant role in this focus, we would hope that at this point he would seek collaboration with those faced with helping care for DSD patients rather than continuing to trumpet an inflexible and polarizing stance. The authors strongly feel that the process of actively and openly seeking answers using the scientific approach remains the best hope for improving care in DSD patients.

References

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