Clinical Decision-Making in Disorders of Sex Development: Physician Recommendations Pre- & Post-Consensus Statement

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Background

Despite advances in genetic diagnosis and surgical technique, and guidance from the Consensus Statement on Intersex Disorders, aspects of clinical management in disorders/differences of sex development (DSD) remain unsettled.

Actively debated decision points include:
- Gender of rearing in specific syndromes
- Genital surgery prior to the patient developing the capacity to provide assent
- Uncertainty over how and when to best educate young patients about diagnostic and medical management history details

Objective

- Survey expert opinion & treatment recommendations on clinical management of children born with varying DSD at 2 points in time: before and after the Consensus Statement
- Examine how physician characteristics and time (pre vs post consensus) predict recommendations

Methods

Web-based Survey

5 Case vignettes:
- XX “Mild” CAH
- XX “Severe” CAH
- Microphallus
- partial AIS
- Penile Amputation

Physician Recommendations Pre- & Post-Consensus Statement

2003-2004 (T1) 2010-2011 (T2)

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<th>participation rate %</th>
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Results & Conclusions

Gender of Rearing Recommendations: Pre- vs Post Consensus

- Variability existed in gender of rearing recommendations
- Similar variability was observed for surgical and disclosure decisions (not shown here)
- Differences by physician characteristics emerged, but did not form a systematic pattern across vignettes

Surgical Decision-Making: Endocrinology vs Urology

- Variability in clinical management recommendations, independent of case characteristics, is a cause for concern
  - particularly for parents faced with contrasting recommendations
- There is an acute need to account for variability in provider recommendations which may be untethered to evidence

Discussion

- Specialty was inconsistently associated with recommendations.