

Decision Making for Adolescents and Young Adults with Differences of Sex Development

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PURPOSE

- Adolescents and young adults (AYAs) with differences of sex development (DSD) face complex clinical management decisions (e.g., elective urogenital surgeries). Furthermore, decisions previously made by parents (together with the child’s provider) are increasingly being delayed to allow for AYA input.
- AYAs must balance the uncertain benefits and harms of a variety of treatment options for which high quality outcome data are scarce.
- To help AYAs make informed, values-sensitive decisions, it is critical to understand specific decision-making needs and experiences.

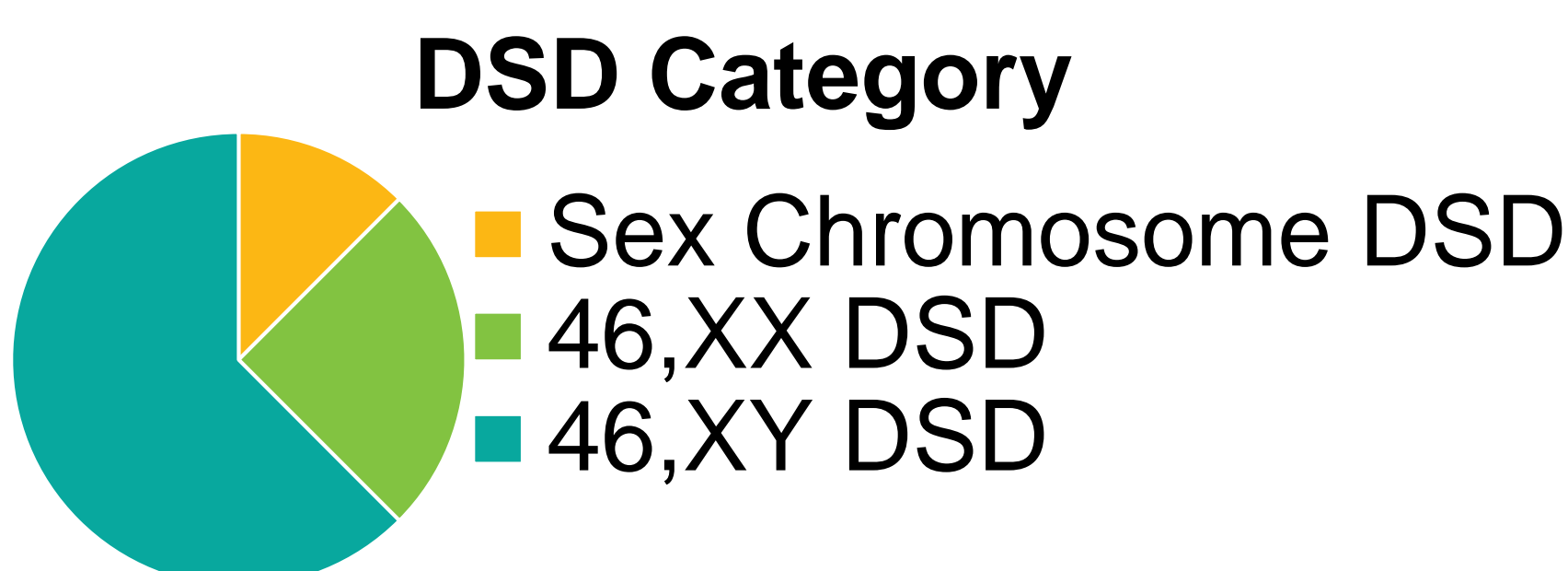
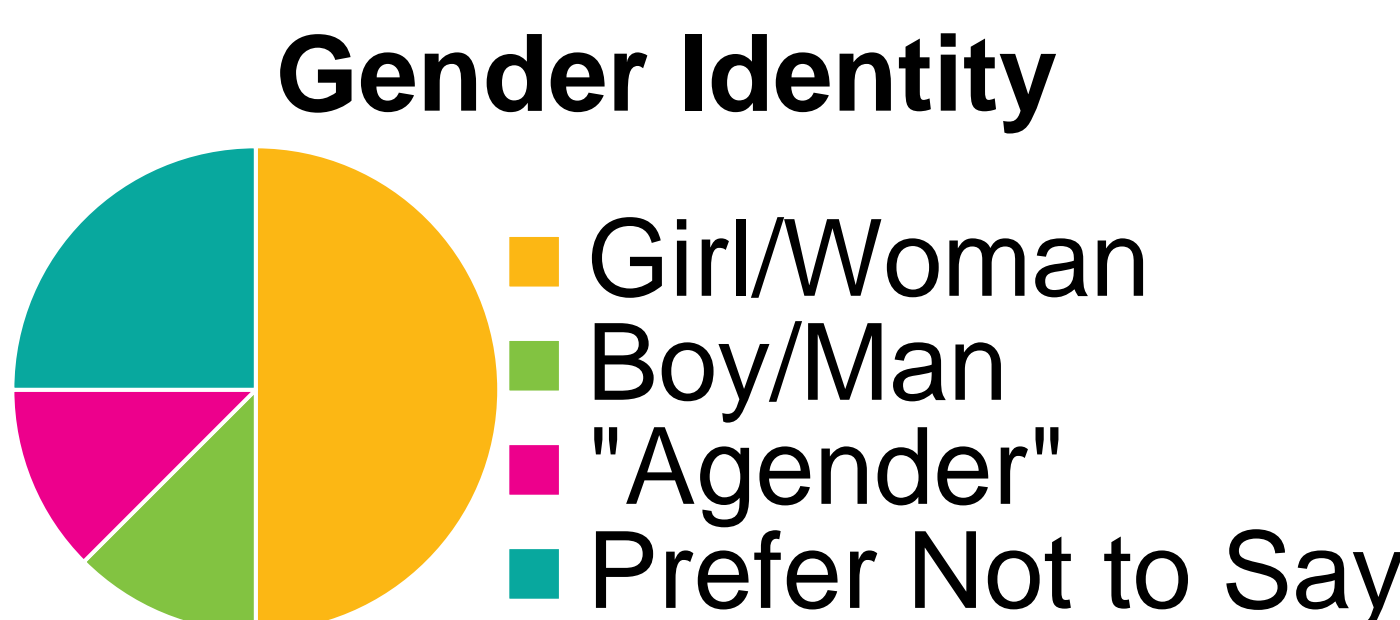
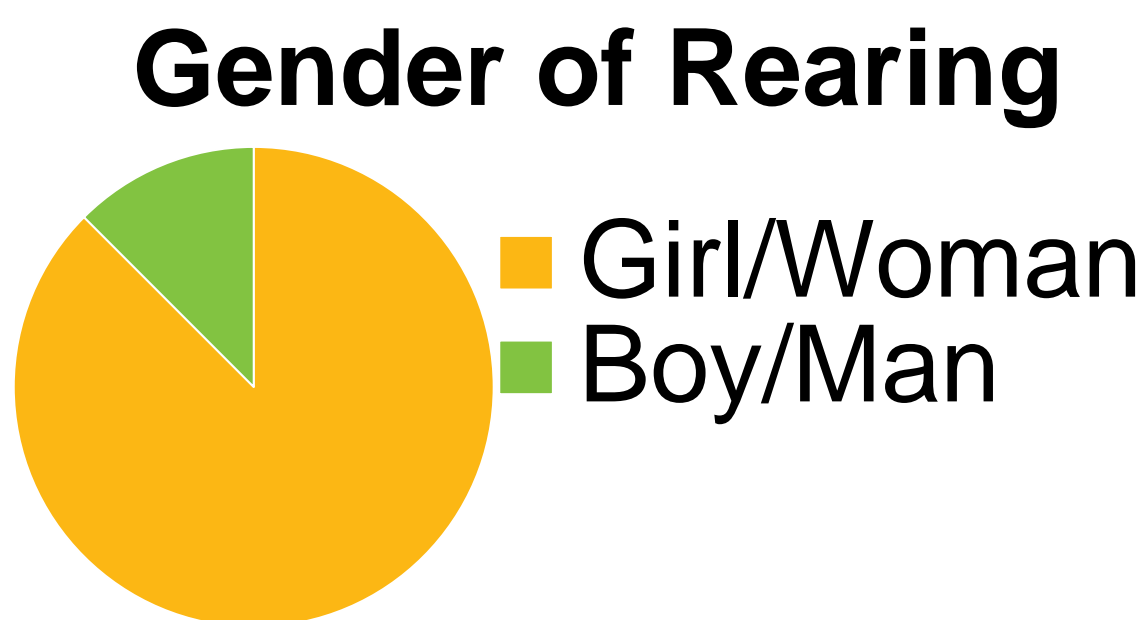
AIM

- Utilize qualitative methods to examine the experiences of AYAs making important decisions about their DSD.

METHODS

- AYAs with DSD (n = 8; Mean age = 15.6 years, range 12-21) from one US children’s hospital were recruited to complete an hour-long interview focused on their involvement and experiences related to decision making for their DSD. Interviews were recorded, transcribed, and emerging themes identified.

PARTICIPANT CHARACTERISTICS



RESULTS

DECISIONS

- Surgical removal of the gonads
- Phalloplasty
- Hormone replacement therapy delivery method
- Puberty blockers
- Gender
- Wearing a medical alert bracelet
- Obtaining peer support
- Sharing information with family members, friends, or romantic partners

FACTORS IMPACTING DECISION-MAKING

Internalized and enacted stigma can impact medical decision-making:

“When I first found out [my condition] my immediate reaction, and I really regret this now, was like I did not wanna know anything about it. I was completely ashamed. [...] And when I first heard that I had the option to have surgery performed to remove my undescended gonads. I was like I'm gonna do that. I didn't even think about it.” – 17-year-old

“It scares me to think about what [my friends] would think if I told them [about my condition]. [...] They may think that I'm not normal or that like... I don't know.” – 14-year-old

Wanting more support or guidance from caregivers and providers:

“I wish [my] mom [and my doctor] had most of the decision to make [about starting testosterone]. [...] I don't really like putting a spotlight on myself as like having to make these really big decisions that will change my future and then the way I'm going. I should have more of a part in decisions, but I'm not sure if I want to or not.” – 13-year-old

Difficulty understanding medical information or decision options:

“[It would be helpful to] have the doctor explain [the options] more than he did. He explained it to my mom and my mom simplified it. Because, you know, I don't understand half the things doctors say.” – 13-year-old

Fear of surgery:

“I was terrified. I don't know. I always get worried about surgery. [...] Every time you get put under, there's the risk.” – 17-year-old

CONCLUSIONS

- AYAs with DSD noted involvement in a range of decisions related to their condition and identified numerous challenges.
- Fear of stigmatization can influence medical decision-making.
- The use of decision aids is one evidence-based approach to support decision making, but their effectiveness with AYAs is unclear.
- Future directions:** develop interventions (i.e., decision aids) to address the decisional needs of AYAs with DSD.

Conflicts of Interest: None to disclose.

Funding: This research is supported by the Primary Children’s Hospital Foundation Early Career Development Award and the Utah Center for Excellence in ELSI Research (UCEER). UCEER is supported by the National Human Genome Research Institute of the National Institutes of Health (RM1HG009037)