

Clinical Needs and Desires of Patients and Families Affected by Sex Chromosome Variations: Addressing Patient-Centered Care

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Conflict of Interest Disclosure

- Conflict of Interest:
 - None
 - Amy Blumling
 - Sharron Close; Kristy Martyn



Objectives

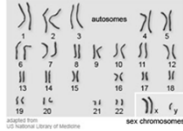
- Explore patient clinical needs, preferences, & desires using a patient-family point of view
- Report the findings of a patient survey conducted through a national advocacy association
- Discuss how to improve access & integration of care for patients
- Describe the role that pediatric endocrine nurses might play for improving care coordination for these patients

Putting Patients First!

Background

■ Sex chromosome variations (SCV) signs & symptoms:

- Physical
- Neurocognitive
- Psychosocial



■ Patients report:

- Providers do not know clinical needs & desires of patients and families affected by SCVs
- Result → left to navigate health care on their own

Method



- Cross-sectional descriptive study using online surveys
- Surveys sent to 6,000 members of National Advocacy Association = AXYS
- Descriptive statistics → analyze item data
- Descriptive content analysis → open-ended questions



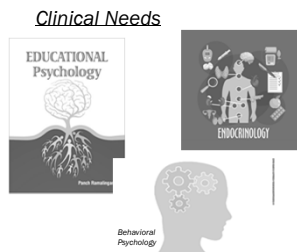
Results

Participants

- n = 230

■ 8 SCV diagnostic categories:

- XO
- XXY*
- XXX
- XYY
- XXXX
- XXYY
- XXXY
- XXXXY

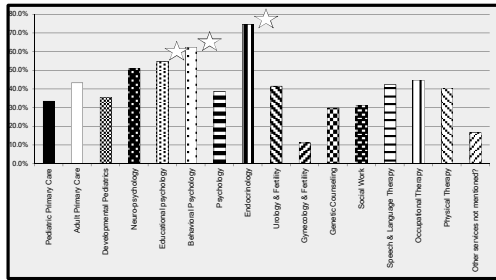


Results, continued

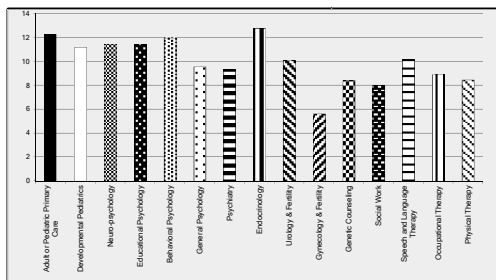
- Providers did not understand individual needs with SCVs
- Providers unlikely to make referrals that were important to patients
- Respondents' desires for: support, provider education, help navigating insurance, education, and legal concerns



“If you could have access to a Multidisciplinary Clinic for X & Y Variations, please select the specialties that you would like to serve you”



“Referring to the previous question, please rank those that are most important to you”



Discussion

- Current SCV care → disjointed & lacking clinical collaboration
- Need for improved access:
 - Multidisciplinary care
 - Integration of services via clinical collaboration
- Pediatric endocrine nurses are uniquely positioned to identify needs & assist in coordination of much-needed care
 - Understand scope of issues associated with X & Y chromosome variations
 - Anticipate complexity of needs
 - Be knowledgeable about resources to assist families in finding help

Acknowledgements - Thank you!

- Survey participants
- AXYS
- PENS



References

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Questions?