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

Amy A. Blumling, BSN, RN, Doctoral & PNP student
Kristy Martin, PhD, CPNP-PC, FAAN
Sharron Close, PhD, MS, CPNP-PC, FAAN

Emory University School of Nursing

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 to analyze item data
- Descriptive content analysis to open-ended questions

Results

Participants

- n = 230

8 SCV diagnostic categories:
- XO
- XXX
- XXX
- XXX
- XXX
- XXX
- XXX
- XXX

Clinical Needs:

- Behavioral Psychology
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”
Please select from below as many issues that apply that lead to barriers for you or your family member receiving the care you need*.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Response %</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1: Local clinicians not understanding the health care needs of X &amp; Y variations</td>
<td>71.2</td>
</tr>
<tr>
<td>No access to a multidisciplinary clinic</td>
<td>67.1</td>
</tr>
<tr>
<td>Restrictions due to insurance coverage</td>
<td>66.2</td>
</tr>
<tr>
<td>Financial constraints associated with out-of-network or out-of-pocket expenses</td>
<td>56.6</td>
</tr>
<tr>
<td>Financial constraints associated with travel</td>
<td>50.2</td>
</tr>
<tr>
<td>Constraints due to family responsibilities</td>
<td>45.7</td>
</tr>
<tr>
<td>Telehealth</td>
<td>40.0</td>
</tr>
<tr>
<td>Travel Clinics</td>
<td>30.0</td>
</tr>
<tr>
<td>Small Group Care</td>
<td>20.0</td>
</tr>
<tr>
<td>Clinical Tele-training</td>
<td>10.0</td>
</tr>
<tr>
<td>Legal Consult</td>
<td>0.0</td>
</tr>
<tr>
<td>Concierge Clinic Services</td>
<td>0.0</td>
</tr>
<tr>
<td>Other</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Please explain any clinical need or other supportive need that you feel would benefit the person with X & Y variations and his or her family.
Discussion

- Current SCV care is 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


