

Supporting Transgender Patients with Neurodevelopmental Disabilities

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Background & Aims of Project

- Higher rates of autism spectrum disorder have been found in pediatric gender clinic patients (Strang et al., 2014).
- Higher rates of gender diversity have been found in youth with autism spectrum disorder (Janssen, Huang, & Duncan, 2016).
- Invisibility of transgender patients with neurodevelopmental disabilities is a concern in health care (Moreno, Laoch, & Zasler, 2017).
- Transgender youth face certain risks, including suicide attempts (Toomey, Syvertsen, & Shramko, 2018).
- Patients face barriers, but mental health improves with affirming health care (Safer et al., 2017).
- Transgender patients want to be asked about their gender identity when receiving care in medical settings (Cahill et al., 2014).
- Documentation of gender identity in the medical record is important for providing quality health care.
- Professionals are mixed in their willingness and comfort to provide health care for transgender patients (Unger, 2015).
- Questions:
 1. Do professionals feel comfortable treating transgender patients and patients with disabilities?
 2. Do professionals understand different aspects of care?
 3. How are professionals supporting patient needs?
 4. What information is collected in the medical record?
 5. What is the percentage of patients of gender diversity in patients with neurodevelopmental disabilities?

Procedures

- Created 20-item survey for medical/mental health professionals:
 - Demographics: "What is your gender?"
 - Comfort: "How comfortable are you treating patients who are transgender and also have a developmental disability (i.e., autism spectrum disorder)?"
 - Medical record: How do you document information in the electronic medical record regarding the gender identity of patients you treat?"
- Performed medical records search in HERON (Healthcare Enterprise Repository for Ontological Narration)
 - Patients with intellectual disability, autism spectrum disorder, and related diagnoses
 - Patients with gender dysphoria and related diagnoses
- Completed analyses in HERON and Excel to identify total patients with overlapping diagnoses.

Age in Years

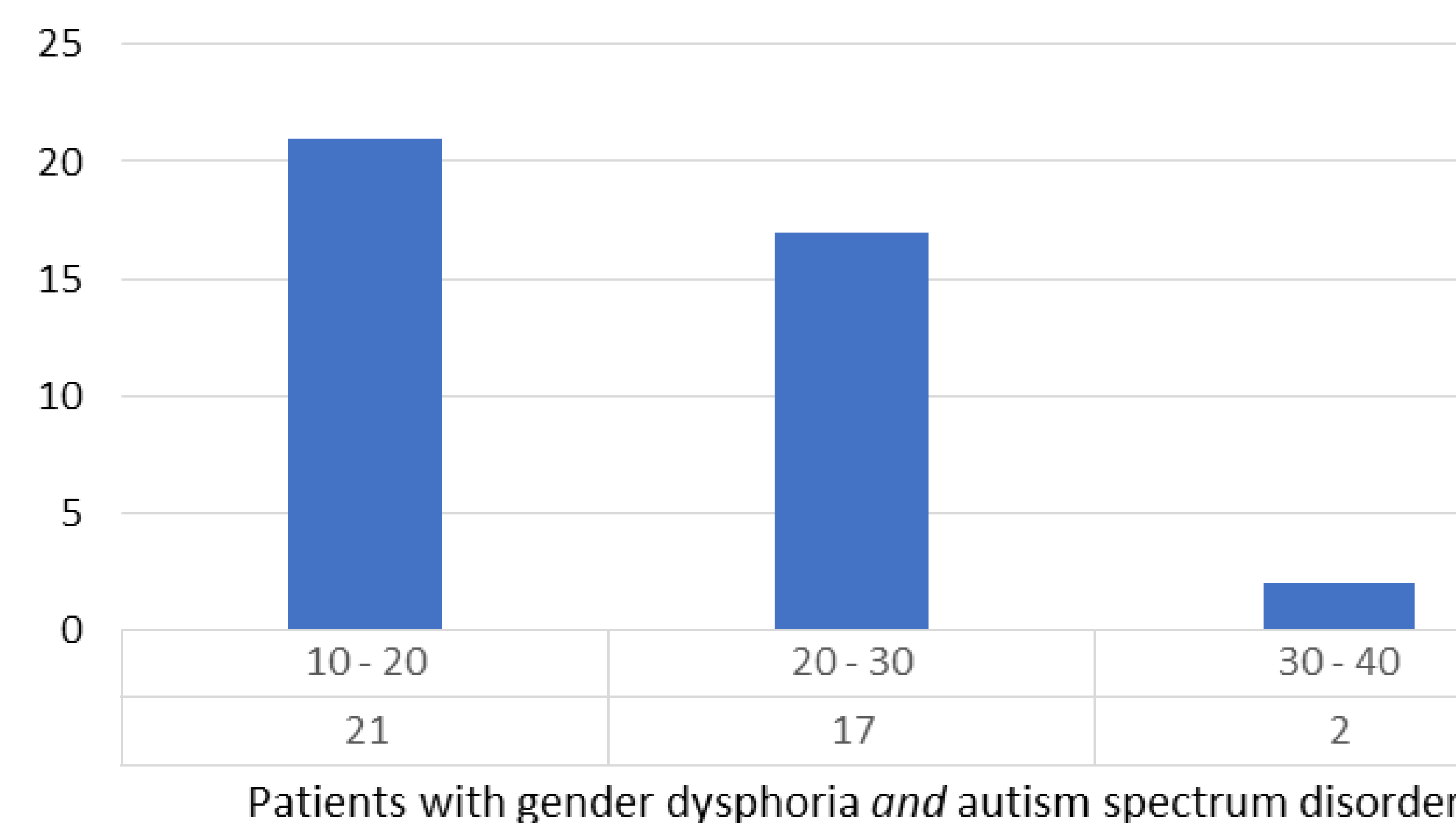


Figure 1 is a bar graph that measured the age in years of patients with gender dysphoria and autism spectrum disorder.

Results

- 12,475 patients with a neurodevelopmental disability (68% White)
- 1,066 with gender dysphoria (23% age 20 or younger; 79.6% White)
- 45 with a disability *and* gender dysphoria (51% ages 10-20; 84% White)
- 40 with autism spectrum disorder *and* gender dysphoria
 - 52.5% ages 10-20; 87.5% White
- Less than 1% of patients with a disability also had gender dysphoria
- 4.2% with gender dysphoria also had a disability
- 3.8% with gender dysphoria also had autism spectrum disorder; de Vries et al. (2010) found ASD in 7.8% of pediatric gender clinic patients
- Limitation: HERON search only able to identify patients with ICD-9 and ICD-10 codes, not gender identity or sex assigned at birth

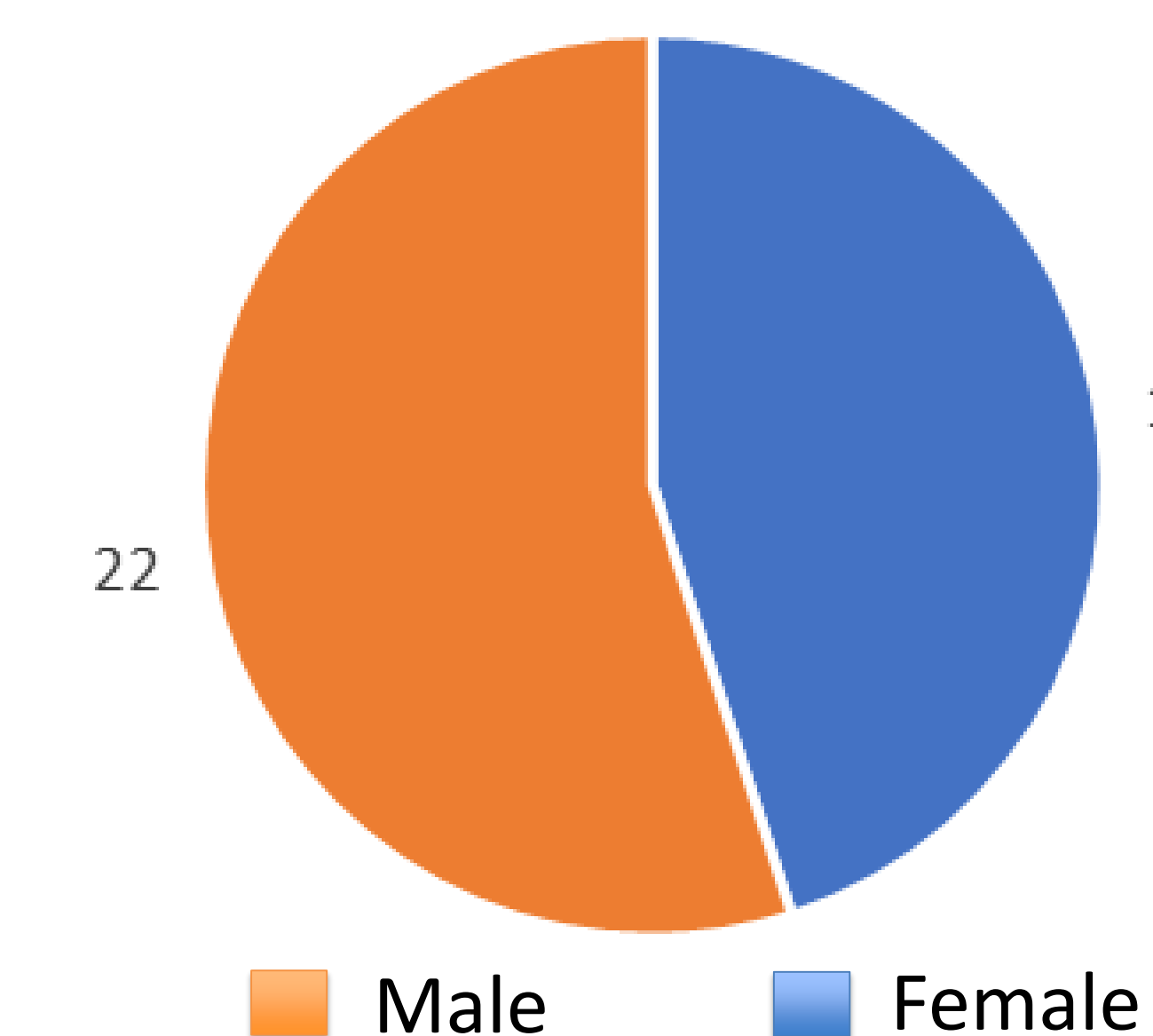


Figure 2 is a pie graph that measured the number of males and females with autism spectrum disorder and gender dysphoria.

Limitation: It is unknown if male or female in the medical records referred to legal sex, gender identity, or sex assigned at birth.

Conclusions

- Information still needed from professionals – survey in progress!
- Limited information on sex & gender identity complicate analyses; accurate documentation in medical record is key
- Recommend asking and documenting chosen name, pronouns, sex assigned at birth, gender identity – efforts help provide quality care!