

Evaluation of Patient Support Resources in Multidisciplinary Clinic for Individuals with Differences of Sex Development

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Objectives: The international shift towards telemedicine and virtual interactions amidst the COVID-19 pandemic highlighted shortcomings of pre-existing virtual resources and infrastructure for medical support groups. This quality improvement project aimed to identify areas of strengths and improvement in the support resources currently given to patient and families within a pediatric multidisciplinary clinic (MDC) for individuals with a difference of sex development (DSD).

Methods: 99 patients and their families seen in the pediatric DSD MDC were invited to complete an online survey. Patients and/or parents received the survey link through a message in the electronic medical record portal or during an in-person clinic visit. The survey included 9 demographic questions, about whether families had utilized any of 12 available support resources, and their experience and perceived usefulness of these resources, as well as a free-text option. Descriptive statistics are presented here.

Results: 30/99 families responded (30%), and 21 completed the survey in its entirety. Patient ages ranged from 0 to >20 years and were predominantly white (67%) and non-Hispanic (76%). Gender identity of patients are 57% female, 38% male, and 1% another gender identity. Self-reported DSD diagnoses include 46,XY DSD (n=6), Congenital Adrenal Hyperplasia (n=7) and others. Quantitative results include the number and percentage of respondents that both used the resource and rated it as moderately or very useful [n(%), n(%)]. Of those assessed, the highest rated resources include the DSD MDC care team [25(96%), 24(96%)]; clinic-provided resource binder [17(68%), 15(88%)]; clinic volunteers [16(61%), 14(88%)]; DSD clinic website [10(40%), 8(80%)]; and clinic-hosted support groups [8(32%), 8(100%)]. Qualitatively, respondents reported desire in improving resources around information on supporting siblings of patients with DSDs, navigating adult life with a DSD, and organization of online resources by ages and interests. Respondents also reported a desire for more opportunities for patient-to-patient interactions, videos from adult volunteers with DSDs discussing their experiences, and diagnosis-specific counseling resources. Overall, patients described the assessed resources as critical in providing adequate guidance and support in navigating a DSD diagnosis.

Conclusions: Comprehensive and thoughtful support resources for patients with DSDs are vital for continuity of care in the pediatric DSD MDC setting. These findings highlight valued and utilized resources, as well as suggestions for areas for improvement and expansion of existing resources.