Research Days

May 5th, 11:30 AM - 1:30 PM

Barriers and Facilitators to Precision Medicine for Black Children with Autism Spectrum Disorder

Rachel Goodson

Barriers and Facilitators to Precision Medicine for Black Children with Autism Spectrum Disorder

Submitting/Presenting Author (must be a trainee): Rachel Goodson, DO
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☐ Medical Student
☐ **Resident/Psychology Intern (≤ 1 month of dedicated research time)**
☐ **Resident/Ph.D/post graduate (> 1 month of dedicated research time)**
xFellow

Primary Mentor (one name only): Cy Nadler, PhD
Other authors/contributors involved in project: July Jean-Cuevas, MD; Hanein Edrees, MD; Jennifer Wagner, MD; Tracy Sandritter, PharmD, BCPPS

IRB Number: STUDY00002097 (non-human interests study)

Describe role of Submitting/Presenting Trainee in this project (limit 150 words):
Submitting/presenting trainee is the primary investigator on this project. With the support of my mentors & collaborators, I have written the IRB, designed a patient survey, and have drafted and submitted a grant proposal to fund this proposed project.

Background, Objectives/Goal, Methods/Design, Results, Conclusions limited to 500 words

Background:
The field of pharmacogenomics (identification of biomarkers regarding drug metabolism and activity to inform precision prescribing) is rapidly advancing for individuals on the autism spectrum, but these advancements are not equitably benefiting all communities. Specifically, utilization data suggests that Black families may be less likely to have access to clinical precision medicine supports. Moreover, historic underrepresentation of African-descended populations in genetic reference samples means that emerging research on precision medicine will retain these biases and perpetuate disparities in downstream clinical benefit. These issues are especially relevant to the autism community, who are more likely to receive psychotropic medications that are metabolized through specific enzymes with known pharmacogenetic implications.

Objectives/Goal:
The goal of this project is to partner with clinical, research and community stakeholders to identify specific modifiable barriers and facilitators related to improving access to pharmacogenomic testing and research participation for the Black and African American autism community. Our overarching goals are to increase clinical accessibility of precision medicine, minority representation in pharmacogenomic research, and the clinical utility of precision medicine for this population.

Methods/Design:
The present project will survey the parents of children with autism from the Black and African American communities regarding their experiences, knowledge, and perception of precision medicine. Recruitment will occur via the SPARK Research Match, a national network of families in the autism community. We will survey 500 families that self-identify as Black or African American, with the possibility of expanding to

include other racial/ethnic minority communities. The survey was created with the assistance of a Patient and Family Advisory Council, covering family experience with medications and health systems, general health literacy, pharmacogenomic specific knowledge and perceptions, and barriers and facilitators to obtaining this clinical testing.

Results:

Local pilot data identified racial/ethnic disparities in the population of patients accessing our hospital's personalized medicine clinic in comparison to the autism clinic and overall hospital population (Table 1). This underrepresentation further emphasizes the need for evidence-based strategies to increase equitable access to these services. The planned survey will yield qualitative data about family experience, as well as quantitative responses supporting investigation of the associations between family/child characteristics and health care experiences/perspectives to identify and explore the prominent barriers and facilitators for accessing precision medicine and participating in pharmacogenetic research.

Conclusions:

This research serves to expand on previous studies to identify specific modifiable barriers for Black individuals on the autism spectrum accessing precision medication services and participating in pharmacogenomic research. Results will be utilized to pilot strategies for improving access to precision medicine services locally (data from Table 1 serving as a baseline). Development and dissemination of evidence-based strategies for increasing minority representation will then advance our overarching goals of increasing clinical access, research participation, and the equitable clinical utility of precision medicine.

	Black/Afr. Am.	**White**	**Latinx**	**Multiracial/Other**
Hospital (Overall)	16%	61%	12%	12%
Autism Clinic	14%	66%	12%	8%
Personalized Med. Clinic	9%	83%	2%	6%

Table 1. Demographics by clinic.