



Poster Presentation

Parent Decision-Making in the Use of Psychotropic Medications With Their Child With CHARGE

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Presenter Information

Emily Hanlon is a recent graduate of the Honors undergraduate program at Central Michigan University. Her degree is a Bachelors of Science in Psychology with a minor in Science. Emily aspires to become a physician one day, and hopes to begin medical school in the Summer of 2020. Emily joined Dr. Hartshorne's lab during her junior year of undergraduate after she was a student in one of his classes, and she has been a member of the lab for 2 years now. She is interested in both the medical and behavioral dimensions of CHARGE syndrome. Emily has also completed a research project that explores the decision-making process parents of children with CHARGE undergo when deciding whether to use psychotropic medications as a behavioral intervention for their child.

Natalie Noble recently graduated from Michigan State University with a primary major in Psychology and an additional major in World Politics. She was a research assistant in MSU's Autism Lab for a year and a half. Since graduation, she has joined the CHARGE Lab at Central Michigan University.

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. His doctoral degree is from the University of Texas at Austin. He also has a master's degree in counseling and is a licensed professional counselor. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Presentation Abstract

Past research on CHARGE syndrome has looked at the use of psychotropic medications, such as which are most commonly prescribed. Many children with CHARGE syndrome have been prescribed psychotropic drugs for challenging behavior. The use of these medications is a frequent topic of conversation on social media, particularly the CHARGE FaceBook page. However, research has not examined the decision-making process that parents of children with CHARGE undergo when deciding whether to use psychotropic medication. It is important to know why parents of children with CHARGE decide to use psychotropic drugs as a behavioral intervention. The purpose of this study was to understand if parents of children with CHARGE are given adequate resources and support to make these choices, if these medications are a last resort option, which factors influence parents to utilize psychotropic drugs, and to understand who or what parents consult in making this decision. In our sample, 37% of parents of children with CHARGE felt they had adequate resources and support to decide whether to use psychotropic medications or not, and physically aggressive behavior was a factor that influenced the decision to use psychotropic drugs



Psychotropic Decision Making in CHARGE

Emily Hanlon, Natalie Noble, & Timothy Hartshorne, Ph.D • Department of Psychology • Central Michigan University

Introduction

Many children with CHARGE syndrome have been prescribed psychotropic drugs for challenging behavior. As these medications can sometimes result in harmful side effects, it is important to understand the factors that contribute to the decision to use psychotropic medication as a behavioral intervention. The following questions guided this study:

1. What factors influence parents to use psychotropic drugs as a behavioral intervention?
2. Do parents feel like they have adequate resources and support?
3. Who or what do parents consult?
4. Is medication a last resort option?

Method

Participant (parents) completed a Qualtrics survey that included questions about:

- Demographics
- Their children's CHARGE diagnoses
- How well informed parents felt about psychotropic medications
- Who and what they consulted for information about these medications
- The factors that influenced parents to medicate their children

Findings

Demographics

- 60 children
- 48% Males, 52% Females
- Ages 1 to 17 (M=10)
- 37% prescribed, 5% suggested
- 67% positive, 8% negative, and 25% unsure of presence of CHD7 gene
- Mean age of walking = 3.15 years
- Mean number of surgeries = 3.86

Question 1

- **Behaviors:** physical aggression, verbal behaviors, and nonverbal behaviors.
- **Events:** physical aggression, anxiety, verbal abuse, and hallucinations

Question 3

- **Consulted:** pediatricians, psychiatrists, and behavioral specialists, as well as other parents of children with CHARGE, their families, and the internet
- **Prescribed:** psychiatrists, family medical providers, neurologists, and nurse practitioners

Question 4

- **Prescribed Group:** 91% of parents had attempted other strategies before medicating their children.
- **Suggested Group:** 100% of parents were using other strategies

Question 2

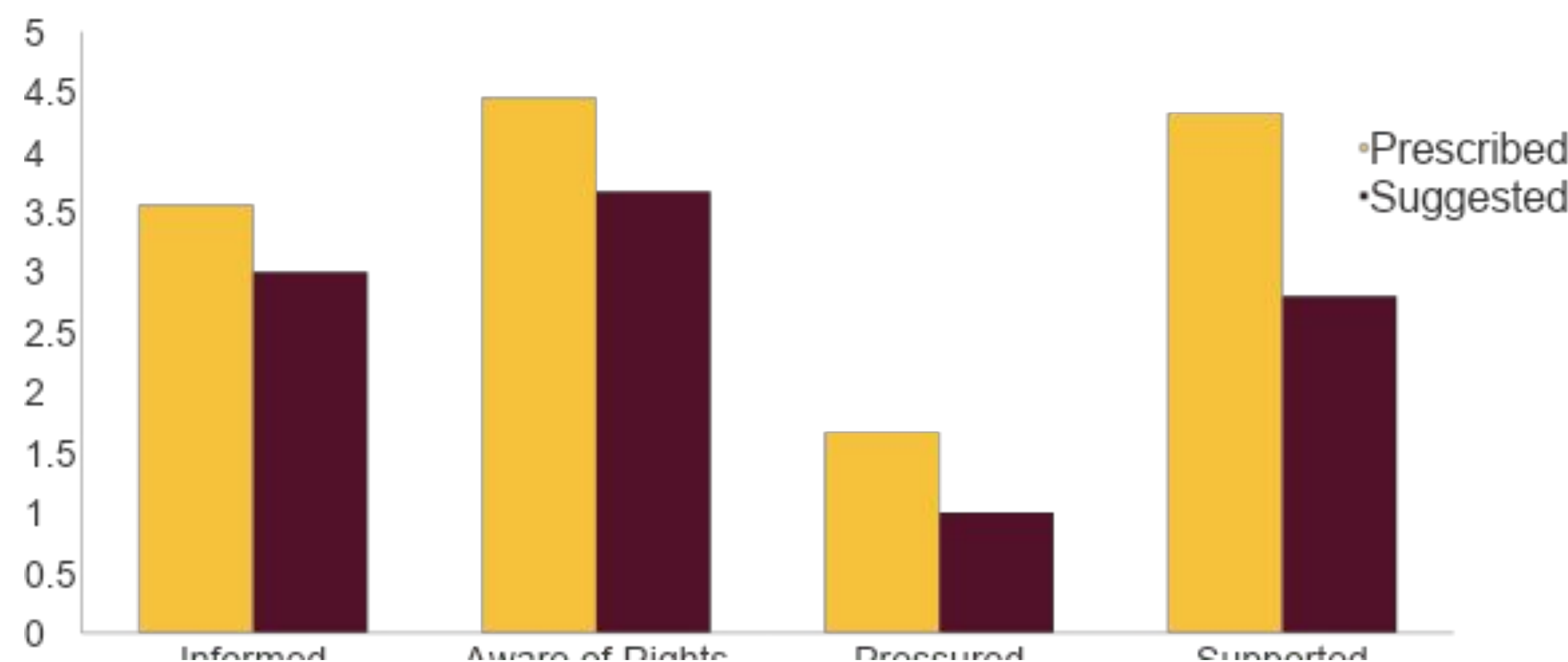


Fig. 1 Mean Parent Ratings

Conclusions

- **Question 1:** The presence of physically aggressive behavior was the greatest factor for parents in using medications.
- **Question 2:** It appears that when making important decisions regarding their children, parents within the CHARGE population go to their families and communities to decide.
- **Question 3:** Psychiatrists play the largest role in prescribing medications. Thus, psychiatrists are a target population for education on the complexity and behavior of CHARGE syndrome.
- **Question 4:** It would benefit the CHARGE community for professionals to continue working on new behavioral

References

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