Pediatric Caregiver Research Perspectives Survey: A Discussion on the Importance of Pediatric Clinical Research in Addressing Adolescent Mental Health Trends

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INTRODUCTION

The incidence of concerning mental health behaviors in adolescents in the United States is on the rise and is further compounded by the recent COVID-19 pandemic.1 These trends suggest there may be a greater need for additional mental health support in this population, including appropriate medication options.

Despite the US Food and Drug Administration implementing measures to encourage pediatric clinical research, a relative lack of therapeutic data compared with adults still exists.

To better understand caregiver considerations around clinical research, we developed a survey for parents and caregivers of children with serious mental illness centered around clinical research awareness, patient and caregiver burden, and barriers to their participation in a clinical research study.

RESULTS

Q: Do you feel you are well informed about all medication options that are available to treat your child’s illness?

63% Of respondents do not feel well informed about medication options that are available to treat their child’s illness.

Q: In your opinion, is there enough awareness about clinical research opportunities within your community and/or support groups?

82% Of respondents do not think there is enough awareness about clinical research opportunities within their community.

Q: What are some of the biggest barriers or concerns you might have about your child participating in a clinical research study?

Potential side effects accounted for the biggest concern for parents who were considering their child for clinical research study participation.

Q: What information would you want to have before making a decision about participation in a clinical research study?

Caregivers want to trust the study medication and have an understanding of the study medication’s role in their child’s treatment.

METHODS

The anonymous survey was distributed by the National Federation of Families, a national, family-run organization that links more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs or substance use challenges and their families.

73 survey responses were received across 24 different states.

LIMITATIONS

The sample of survey respondents involved with the National Federation of Families might not be representative of the entire population. Survey respondents may be more informed about clinical research and their child’s mental health care treatment options because of their involvement with the organization.

The small number of survey respondents limits conclusions that may be drawn from the data.

Clinical Research Awareness

The survey responses indicate that parents and caregivers of children with serious mental illness lack awareness regarding clinical trial research, medications, and clinical research participation as potential treatment options for their child.

Patient/Caregiver Burden and Barriers

Many caregivers felt that having greater flexibility and accommodations (eg, travel reimbursement, after-hour visits, etc) along with various forms of information, not only prior to but during consent but also throughout a trial, would better facilitate participation in a clinical research study.

REFERENCES


AUTHOR DISCLOSURES

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