

Caregivers' Preference for Antipsychotic Medication for Youth Less Than 18 Years-Old: A Discrete Choice Experiment Pilot

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Background: Antipsychotics are often prescribed for youth with complex mental health conditions but carry risks of metabolic adverse effects. Caregivers play a key role in weighing the potential benefit of treating the underlying mental health condition with the potential risk of side effects.

Objective: To evaluate caregivers' preferences for the benefits and risks of antipsychotic medication for their child and to assess how these preferences relate to treatment acceptability.

Methods: We recruited 26 caregivers of youth <18 years-old across the greater Baltimore region to pilot test a discrete choice experiment (DCE). The DCE included nine choice tasks, each with three profiles and six attributes per profile, with three for the risks (weight gain, diabetes, cholesterol) and three for the benefits (self-harm episodes, aggressive behavior, hospitalizations) of antipsychotics. For each choice task, participants first selected the most acceptable profile; second, indicated if they would use their chosen profile. Conditional logit models estimated part-worth utilities. We calculated the relative attribute importance and assessed trade-offs between attributes. Summing the part-worth utilities for attributes within each DCE profile, we identified profiles with the largest utility and assessed the acceptance of the profile chosen.

Results: Participants were, on average, 44 years-old; 76% were biological mothers. Nearly half of the youth (46%) had prior psychiatric hospitalization, 70% had aggression towards property, and 90% had aggression towards others. Reduction in hospitalizations (34%), days with aggressive behavior (22%), and self-harm episodes (15%) achieved greater relative importance than diabetes risk (14%), weight gain (11%), and high cholesterol (4%). Participants accepted 2.21 hospitalizations per year to reduce diabetes risk from four-fold to two-fold. Sixty-five percent of the profiles selected were those participants would use.

Conclusion: Prioritizing outcomes over the antipsychotic metabolic adverse effects underscores the importance of eliciting caregiver preferences for the benefits and risks of medication.

Plain Language Summary: This preference survey study asked caregivers of a child who may have been treated with an antipsychotic medication to consider the benefits and risks of the medication. Six attributes of the medication that caregivers considered included the benefits of reductions in hospitalizations, aggressive behavior, and self-harm along with the risks of weight gain, diabetes, and high cholesterol. The most important attributes when choosing an antipsychotic medication for their child were hospitalizations and the number of days without aggressive behavior, suggesting caregivers are willing to accept the adverse effects of antipsychotic medications to achieve these outcomes.

Keywords: antipsychotic, child mental health, discrete choice experiment, caregiver preference, benefit-risk

Introduction

Mental and developmental disorders affected an estimated 27.7% of children aged 3 to 17 in the United States in 2021 and the past decade has witnessed a steady increase in their incidence and prevalence.¹⁻³ These conditions are linked to

poor short- and long- term health and social outcomes, including poor overall physical health, more chronic diseases, lower educational attainment, reduced economic stability, and challenges transitioning into adulthood.⁴ Psychotropic medications are frequently considered first-line treatments for managing many of these disorders.⁵

Aggressive behavior among youth with mental and developmental disorders often requires pharmacologic intervention.^{6,7} Antipsychotic medications are commonly used to manage aggression in youth, but they are associated with metabolic adverse events. Youth can gain 7% or more of their body weight in the first six weeks of treatment.⁸ Other studies have reported a twofold increase in obesity, a threefold increase in type 2 diabetes, and nearly threefold higher odds of developing cardiovascular conditions among youth prescribed antipsychotics compared with those not treated with psychotropic medications.^{9–11}

Decisions to initiate an antipsychotic medication for a youth require caregivers to weigh the potential benefits against the potential adverse effects. Understanding trade-offs among the benefits and risks is crucial for supporting patient-centered informed decision-making and enhancing treatment satisfaction, which can ultimately lead to better adherence and the promotion of safe and effective antipsychotic use in pediatric mental health care.^{12,13} Studies in adult samples have shown that caregiver preferences and tolerability for antipsychotic side effects affect willingness to initiate treatment.¹⁴ Among caregivers of adult patients, hospitalization and symptom improvement are important factors in initiating antipsychotic treatment.¹⁵ To date, there have been no investigations into caregiver preferences for initiating an antipsychotic medication for their child.

To address this gap, we developed a discrete choice experiment (DCE) to examine how caregivers navigate these complex decisions. While the origin of DCEs emerged from health economics,¹⁶ this method is applicable for healthcare decision making.¹⁷ Importantly, stakeholder engagement in DCEs is also growing as a method to enhance implementation of effective healthcare interventions.¹⁸ We implemented a stakeholder-engaged approach to identify the key attributes of antipsychotics that caregivers consider when making decisions to use this medication for their child with mental and developmental disabilities. We sought to answer the question, “Do caregivers prioritize the medication benefits over the risks associated with antipsychotic use?” The goals of this pilot study were to assess the relative importance of the attributes of antipsychotic benefits and risks among caregivers who were considering treatment for a youth and to identify trade-offs among these attributes. The findings are intended to enable broader application of our DCE to inform patient-centered decision-making for antipsychotic medication treatment in youth.

Methods

Attribute Selection

The attributes and corresponding levels were identified through a structured and iterative process that integrated data from qualitative interviews, a targeted literature review, and stakeholder-engaged feedback via focus groups. We conducted a secondary analysis of transcribed 1:1 in-depth interviews with caregivers of a child who had a mental health condition and a developmental disability, which were part of a grant funded by the Patient Centered Outcomes Research Institute.¹⁹ The qualitative interviews were analyzed for caregiver-identified outcomes that they hoped to achieve by using an antipsychotic medication for their child. Three domains emerged from the qualitative interviews: efficacy of managing aggressive behavior towards self, others, and property; the impact of residential placement on medication complexity; distance to a provider for medication management. We reviewed the literature to identify the key side effects of weight gain, risk of type 2 diabetes, and risk of high cholesterol. The authors (BB and SDR) synthesized the data from the qualitative interviews with the information from the literature review to identify nine attributes: weight gain, diabetes risk, high cholesterol risk, aggression towards self, aggression towards others, verbal aggression, impact of residential placement on medication use, number of hospitalizations per year, and distance to a provider. To refine the attributes and levels, two authors (BB and SDR) conducted a focus group with eight caregivers of a child who had been prescribed an antipsychotic. Based on their feedback, we omitted two attributes (i.e., impact of residential placement on medication use, and distance to provider) and we retained levels that were deemed important. Aggression towards self was framed as self-harm. Aggression towards others and verbal aggression were combined as these were seen as general aggressive behavior towards others.

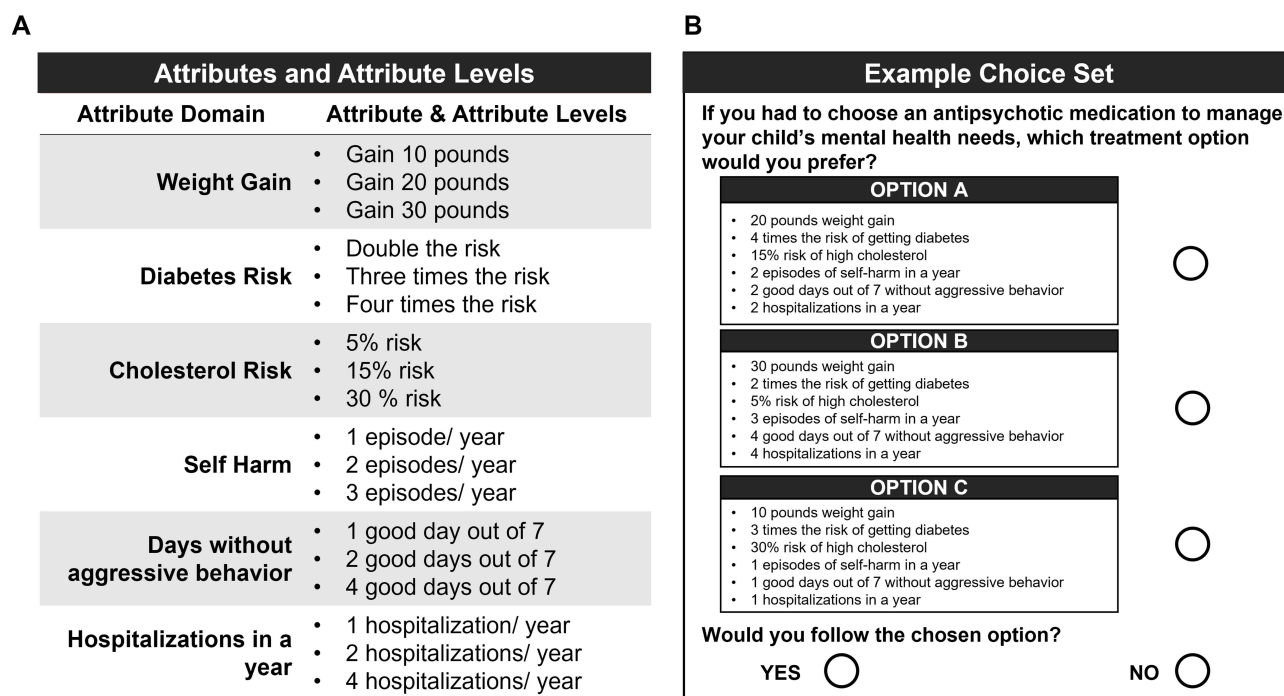


Figure 1 Discrete choice experiment framework and example choice task. **(A)** presents the full list of attribute domains and corresponding attribute levels. **(B)** provides an example of a discrete choice experiment choice set, followed by a question asking whether the caregiver participant would use the option they selected.

The final framework included six attributes, each with three levels (i.e., distinct categories representing varying magnitudes or severity of an outcome; see Figure 1A). Three attributes of the caregiver-defined benefits of the medication included the extent to which the antipsychotic reduced the number of self-harm episodes, the number of days the youth exhibited aggressive behavior, and the number of mental health-related hospitalizations. Three attributes of the risk of antipsychotic medication included weight gain, the risk of diabetes, and the risk of elevated cholesterol.^{8–10,20} Each attribute had three mutually exclusive levels, with lower levels reflecting a reduction in the magnitude or severity.

Discrete Choice Experiment (DCE) Design

The DCE was developed as an orthogonal array using SAS[®] macros to establish the experimental design for the choice tasks.²¹ We selected a full factorial, orthogonal array with 96% D-efficiency for the DCE design. There were nine choice tasks, each displayed three profiles with six attributes per profile. One level from each attribute was displayed in each profile, which resulted in all attribute levels being displayed the same number of times across all choice tasks.

In each choice task, participants were asked to review each of the three profiles and select the one that was most acceptable to them. A follow-up question after each choice task required participants to indicate whether they would use the selected option. This enabled distinguishing selections that were acceptable.

Study Sample

Participants were recruited with the assistance of one of the authors (BB) who worked with families in community clinics and organized support groups in the greater Baltimore Metropolitan Area. Eligible participants were caregivers of youth aged ≤18 years-old who had been offered or had taken an antipsychotic medication within the past 12 months. A brief telephone screen was conducted to determine eligibility for the study.

Our target sample was caregivers of youth for whom antipsychotic medication is prescribed for the management of aggression, severe mood disorders, or the irritability associated with autism. This is the population to whom our sample of youth less than 18 years old generalizes.

Survey Administration

We piloted the DCE in an online survey using the Qualtrics web-based platform. All participants provided informed consent prior to completing the online survey. After completing the survey, participants received a \$20 gift card. The targeted sample size for this pilot was 30, of which 26 were enrolled, yielding a response rate of 87%.

Survey Instrument

The final survey included 60 multiple-choice questions across three sections: (1) demographic information about the caregiver (ie., age, sex, race/ethnicity, relation to the child, marital status, education, household size and income, employment status and residential community) and the child (ie, sex, race/ethnicity, school grade), (2) current care management for the child, (3) clinical characteristics (i.e., speech impairment, aggressive behaviors, mental health diagnoses, psychotropic medication, and mental health or behavior care), and (4) the DCE. An example of the DCE choice task is shown in [Figure 1B](#). We followed the established checklist for reporting DCE in health ([Supplementary Material 1](#)).²² A copy of the survey is available in [Supplementary Material 2](#).

Statistical Analysis

Completed surveys were downloaded as an Excel file and converted to a SAS[®] dataset. Descriptive statistics were used to summarize demographic characteristics of the participants and their children. A conditional logit regression estimated the part-worth utilities and 95% confidence intervals (CI) from the DCE responses. Part-worth utilities with positive values above zero reflect desirable attributes and negative values below zero reflect undesirable attributes. We used established methods to quantify the relative attribute importance using the min-max difference and to estimate the benefit-risk trade-offs.^{23–25} Responses to the follow-up question were analyzed to identify the selected profiles that participants indicated they would use. We summed the part-worth utilities across all attributes in the profile and ranked the profiles from the highest to the lowest.²⁶ We evaluated the attribute levels and total utility in the profiles selected as acceptable. All data were analyzed using SAS[®] 9.4 (Carey, NC) and STATA 14.

Results

Characteristics of Participants and Their Child

The demographic characteristics of the 26 participants and their child are presented in [Table 1](#). Participants had a mean age of 44 years, were predominantly biological mothers (77.0%), and 38.4% of the sample comprised single-parent households. The majority was employed (73.1%), had a college degree (77.0%), and resided in a suburban community (84.6%).

Nearly 80% of the children were male and 69.2% were in grades K through 8. The most common diagnosis was attention-deficit/hyperactivity disorder (ADHD; 84.6%) and 46.2% had an autism spectrum disorder. Most of the children exhibited aggressive behavior.

The most reported mental health or behavioral therapy was individual psychotherapy (57.7%), followed by family therapy (42.3%) and cognitive behavioral therapy (42.3%). Most youth (84.6%) were currently taking an antipsychotic, and 11.5% had used the medication in the past year ([Table 1](#)). All caregivers indicated that their child was taking other psychotropic medications. Specifically, most youth also were taking stimulants (88.5%) and mood stabilizers (80.8%). There were 69.2% of participants who reported weight gain in their child following antipsychotic use, and 61.5% noted mood changes. Many (73.1%) indicated that targeted symptoms were only partially reduced, while 15.4% observed no improvement at all.

Preferences for Attributes of Antipsychotic Medication

The part-worth utilities, also referred to as preference weights, for each level across attributes are displayed in [Figure 2](#). The utility values decreased as weight gain, diabetes risk, self-harm episodes, and hospitalizations increased. Negative preferences for weight gain of 20 pounds or more plateaued with little change in the part-worth utility. Cholesterol risk had little impact on preferences with part-worth utilities around zero.

Table 1 Characteristics of Study Sample of Caregivers and Their Child

Characteristics		
Caregiver		
Relation to child, n (%)	Mother Grandparent Uncle/ aunt/ foster parent	20 (77.0) 3 (11.5) 3 (11.5)
Age, mean (SD)		43.6 (11.1)
Sex, n (%)	Female Male	23 (11.5) 3 (88.5)
Race, n (%)	White Black	17 (65.4) 9 (34.6)
Ethnicity, n (%)	Hispanic	2 (7.7)
Marital status, n (%)	Married/ cohabitation Divorced/ separated/ widowed Never married Missing	15 (57.8) 9 (34.6) 1 (3.8) 1 (3.8)
Education, n (%)	High school or less College Post-graduate	6 (23.1) 9 (34.6) 11 (42.3)
Employment, n (%)	Working Unemployed	19 (73.1) 7 (26.9)
Household size, mean (SD)		3 (1)
Annual household income, n (%)	≤\$25,000 \$25,000-\$50,000 >\$50,000	5 (19.2) 3 (11.5) 17 (65.4)
Living community, n (%)	Urban Suburban Rural	2 (7.7) 22 (84.6) 2 (7.7)
Child		
Sex, n (%)	Female Male	6 (23.1) 20 (76.9)
Race, n (%)	White Black Mixed	12 (46.2) 12 (46.2) 2 (7.7)
Ethnicity, n (%)	Hispanic	2 (7.7)
School grade, n (%)	K-5 6-8 9-12	10 (38.4) 8 (30.8) 8 (30.8)
Speech impairment, n (%)	Verbal Non-verbal	24 (92.3) 2 (7.7)
Aggressive behavior, n (%)	Towards self Towards others Towards property	14 (53.8) 24 (92.3) 19 (73.1)

(Continued)

Table 1 (Continued).

Characteristics		
Mental health conditions, n (%)	Autism ADHD Depression Bipolar Conduct/oppositional defiant disorder	12 (46.2) 22 (84.6) 8 (30.8) 7 (26.9) 13 (50.0)
Ever hospitalization for mental health disorder, n (%)		12 (46.2)
Current mental health or behavior care, n (%)	Cognitive behavioral therapy Other behavioral therapy Individual psychotherapy Family therapy Group therapy Occupational therapy Physical therapy Speech and language therapy Other therapy None of the above	11 (42.3) 8 (30.8) 15 (57.7) 11 (42.3) 8 (30.8) 3 (11.5) 0 (0) 7 (26.9) 3 (11.5) 1 (3.9)
Antipsychotic use, n (%)*	Current user Past user in the prior 12 months	22 (84.6) 3 (11.5)
Current medication use, n (%)	Stimulant Antidepressant Mood stabilizer Anxiolytic Sleep medication	23 (88.5) 6 (23.1) 21 (80.8) 14 (53.8) 6 (23.1)
Antipsychotic medicine effect on target symptoms	No change Partly reduced targeted symptoms Reduced all target symptoms	4 (15.4) 19 (73.1) 3 (11.5)
Adverse events of antipsychotic medication experienced, n (%)	Weight change Mood change Personality change Other Not experienced any adverse events	18 (69.2) 16 (61.5) 5 (19.2) 1 (3.9) 2 (7.7)

Note: *Antipsychotic medication status was not documented for one participant.

Abbreviations: ADHD, attention deficit hyperactivity disorder; SD, standard deviation.

The relative attribute importance is shown in [Figure 3](#). Participants prioritized the potential benefits of antipsychotics (i.e., hospitalizations (34%), days without aggressive behaviors (22%), and self-harm episodes (15%)) over the potential risks (i.e., diabetes risk (14%), weight gain (11%), and high cholesterol (4%)). Estimating trade-offs between attributes, participants would accept 2.21 hospitalizations per year in exchange for a decrease from four-fold to double the risk of diabetes.

Acceptance of Selected Antipsychotic Profiles

We summed the part-worth utilities for all attributes in the profile to obtain the total profile utility. [Table 2](#) summarizes the nine top-ranked choice task profiles from the DCE based on the total utility. The acceptance percentage reflects the proportion of participants who selected the profile that indicated they would use the profile. The most acceptable profile (65.4%) included the lowest risk of weight gain, diabetes, self-harm, and hospitalizations and the most days without aggressive behavior. Profiles that participants indicated they would follow included the maximum days without aggressive behavior, but variable weight gain

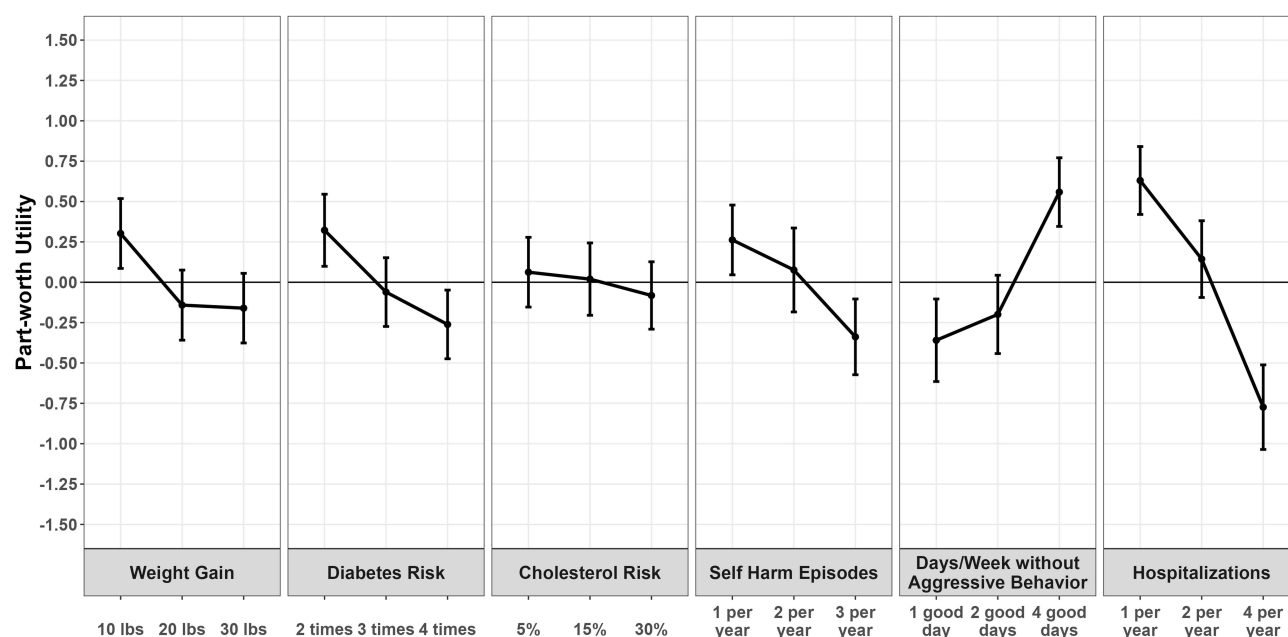


Figure 2 Part-worth utilities and 95% confidence intervals for attribute levels by attribute.

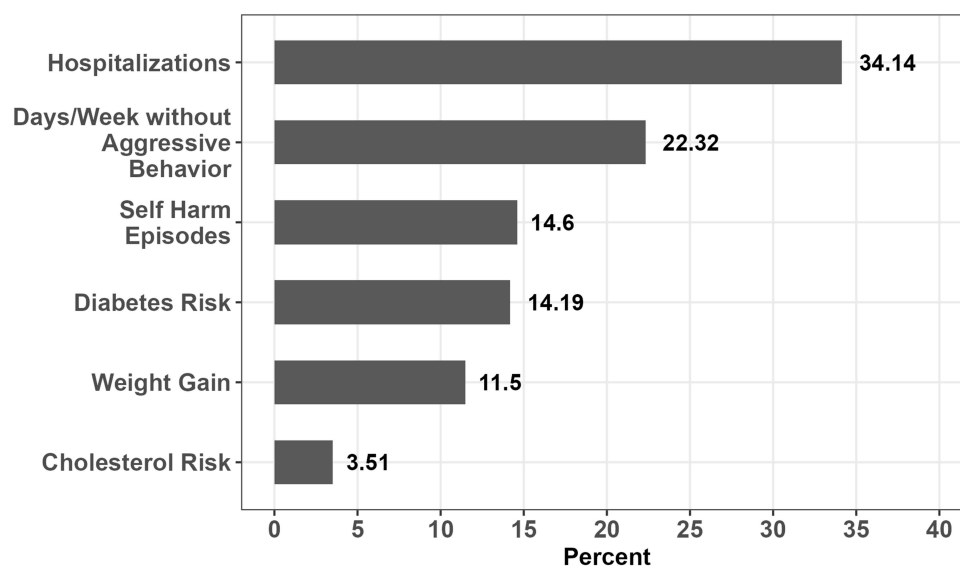


Figure 3 Relative attribute importance of antipsychotic medication in caregiver decision-making for their child (n=26).

(10–20 pounds) and diabetes risk. A considerable proportion (42.3%) would use a profile with 30-pound weight gain, three-fold risk of diabetes, and 15% risk of elevated cholesterol in exchange for four days per week without aggressive behavior.

Discussion

This pilot study assessed caregivers' preferences for using an antipsychotic medication for their child, providing valuable insight into caregivers' consideration of the benefits and risks when making treatment decisions. We aimed to determine if caregivers prioritize the benefits of antipsychotic medication over the risks when considering antipsychotic treatment for their youth with mental and behavioral disorders. Our study found that the patient-informed benefits of antipsychotic

Table 2 Total Utility and Attributes for the Nine Most Acceptable Profiles

Acceptance Percent	Profile Total Utility ^a	Weight Gain	Diabetes Risk	Cholesterol Risk	Self-Harm Episode(s) per Year	Days/Week without Aggressive Behavior	Hospitalizations per Year
65.38	1.91	10 lbs	2X	15%	2	4	1
61.54	1.12	20 lbs	3X	5%	2	4	1
57.69	1.07	20 lbs	2X	30%	1	4	2
53.85	1.06	10 lbs	4X	5%	1	4	2
42.31	0.76	30 lbs	3X	15%	1	4	2
38.46	0.76	30 lbs	2X	5%	1	1	1
34.62	0.69	10 lbs	3X	30%	1	1	1
34.62	0.20	30 lbs	4X	30%	2	4	1
26.92	0.19	20 lbs	4X	15%	1	1	1

Note: ^aProfile total utility values were calculated summing the part-worth utility value of each attribute level in the profile.

Abbreviation: lbs, pounds.

medications had a higher relative importance than the risks of these medications. Specifically, the most important attributes when choosing an antipsychotic medication for their child were hospitalizations and the number of days without aggressive behavior. Preference for one hospitalization and four days per week without aggressive behavior were consistent across all analyses, with strong part-worth utility, high relative importance, and contribution to the most acceptable profiles. This suggests that caregivers are willing to accept the adverse metabolic effects of antipsychotic medications to achieve these outcomes.

The findings can be considered in the context of the intersection of many factors that affect adherence to antipsychotic medications. We found that reducing hospitalizations was an important factor influencing caregivers' preference for antipsychotic medication for their child. Zhang et al similarly reported the importance of reducing hospitalizations in an adult sample.¹⁵ The effectiveness of antipsychotics in reducing hospitalizations could ultimately promote adherence. A noted barrier to treatment adherence is antipsychotic side effects,²⁷ and we found that weight gain was tolerable to a certain extent. These findings highlight the importance of ongoing shared decision-making to ensure personalized care that can promote treatment adherence.²⁸

It is important to acknowledge youth's preferences and experiences with antipsychotic medication. Several qualitative studies of youth experiences with antipsychotic use found the benefits of symptom relief were countered by adverse effects on their mental and physical well-being.^{29,30} These findings are in contrast with our study, where caregivers prioritized the benefits over the potential risks.

The DCE was developed using a patient-engaged process to elicit outcomes that were meaningful to caregivers who considered antipsychotic medication for their child. We piloted the DCE to evaluate the sensitivity of preferences to changes in the attribute levels. Caregivers would not accept more than two hospitalizations per year or less than four days without aggressive behavior. Aggressive behaviors in youth may lead to residential or other institutional placement.³¹ Antipsychotic medication can minimize aggression and thereby allow youth to remain at home with their families. Thus, the importance of days without aggressive behavior relates to safety concerns and can keep families intact and youth in the community. Weight gain of more than 20 pounds was not acceptable, which suggests this was a ceiling regardless of gains in other outcomes. Despite the potential for elevated cholesterol following antipsychotic use, caregivers' preferences were not impacted by changes in this risk. It is possibly due to the limited research showing a consistent finding on cholesterol risk.^{10,20}

Research Implications

This pilot revealed that 65% of the sample would accept the profile with the highest overall utility. The fact that not all participants would accept this profile suggests that caregivers may be highly risk-averse or that the benefits were not sufficient to outweigh the risks. Aggressive behavior affects all family members and society across all settings,^{32–35} so it is possible that one hospitalization and four days without aggressive behavior was not enough to alleviate the disruption to others. Prior research has shown that antipsychotics have a moderate effect on reducing aggression.⁶ While we

generated profiles using existing literature and caregiver input, the low favorability of the hypothetical profiles points to dissatisfaction with current treatment options, which could hinder long-term medication adherence.³⁶

The predominance of males and history of aggressive behavior in the child sample align with existing literature showing that behavioral disorders are more common in boys.³⁷ The high prevalence of aggressive behaviors and polypharmacy in this study sample highlights the complexity of managing these conditions.^{38,39} Given the challenges in managing complex mental health conditions, understanding caregiver preferences is critical to supporting shared decision-making and promoting long-term treatment adherence.^{12,40} The study findings underscore the importance of integrating caregiver preferences into treatment planning. Future research should refine DCE attribute levels to better capture benefit-risk trade-offs and align more closely with what caregivers' value most.

Strengths and Limitations

Our study has several notable strengths. We implemented continuous stakeholder engagement through the development and piloting of the DCE. This is among the first studies to implement a DCE to quantify caregiver preferences for antipsychotic medications for their child. The two-part choice task question enabled a better understanding of the acceptance of the profiles presented. This offers a more holistic view of preferences and attempts to minimize bias in the inferences from the findings.⁴¹

This pilot study is not without limitations. Despite the focus group input on the adequacy of the level ranges, it is possible that they did not vary enough to influence choices. This was a small pilot study conducted in a single geographic location, and so the findings may not generalize to other regions. We aimed to enroll participants with lived experience in managing youth with serious mental health and developmental disabilities, as this is the target population who receives antipsychotic medication. However, we did not enroll adolescents, which is an important perspective to capture in future studies. Research in cancer and dementia show that disease severity can influence preferences;^{42,43} however, we were unable to measure disease severity and thus cannot evaluate whether this affected preferences. Lastly, we did not measure preferences at initiation of the antipsychotic medication; thus, participants past experiences may have affected their preferences for the choice task selections.

Conclusions

This study offers important insights into how adult caregivers evaluate the benefits and risks of an antipsychotic when deciding to initiate this medication for their child. Our findings generalize to youth with a mental health-related disorder or disability and for whom an antipsychotic medication may be indicated. Prioritization of minimizing hospitalizations and maximizing days without aggressive behavior indicated a strong emphasis on immediate and observable beneficial outcomes. The relatively low acceptance rate for profiles with the most favorable options suggests that available treatment options are not achieving the outcomes most important to caregivers. A deeper understanding of caregiver preferences can help align treatment plans with family values. Future research can build upon this work by including larger and more diverse populations and by exploring strategies to better tailor treatment options to caregiver needs and expectations.

Abbreviations

CI, confidence interval; DCE, discrete-choice experiment.

Data Sharing Statement

The survey instrument is available in [Supplementary Materials](#), but participant-level responses cannot be released due to privacy protections.

Ethics Approval

The University of Maryland Institutional Review Board reviewed and approved this study (HP-00080094). Participants provided informed consent prior to completing the survey. This study complies with the Declaration of Helsinki.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

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