Do Parent Perceptions Predict Continuity of Publicly Funded Care for Attention-Deficit/Hyperactivity Disorder?

abstract

OBJECTIVE: To examine whether parent perceptions about care (barriers, disorder knowledge, treatment willingness) vary among children who drop out of or stay in publicly funded care for attention-deficit/hyperactivity disorder (ADHD) and to explore whether parent perceptions are predictive of staying in care over time.

METHODS: A longitudinal cohort study of 529 children ages 5 to 11 years receiving care for ADHD in primary care or specialty mental health clinics in a large, countywide, managed-care Medicaid program. Multiple logistic regression analyses were performed to identify parent perceptions associated with the likelihood of staying in care across three 6-month time intervals, controlling for child and parent demographic characteristics, parental distress, clinical need, and recent special education use.

RESULTS: At least three-fourths of children had at least 1 contact for any mental health care during a 6-month time interval (75%, 85%, 76%). Parent-perceived barriers, ADHD knowledge, and counseling willingness did not predict staying in care, whereas willingness for medication treatment was predictive at baseline. Minority status, nonmarried parent, parental distress, clinical need, and special education use were predictive of staying in care, but mostly during only one 6-month time interval, and their influence varied over time.

CONCLUSIONS: Parent willingness for medication treatment along with several demographic and need factors predicted staying in care but not consistently over time. Future research is needed to develop practical tools for clinicians to elicit parent priorities about ADHD treatment and to integrate them into quality-improvement interventions targeted to improving shared decision-making for longer term ADHD care.

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KEY WORDS

attention deficit hyperactivity disorder; continuity of care, primary care, parent attitudes, parent-centered care

ABBREVIATION

ADHD—attention-deficit/hyperactivity disorder

Dr Zima was responsible for all phases of the research and preparation of this manuscript; Dr Bussing consulted on the study design and all methods and participated in writing early and final manuscript drafts; Dr Tang provided statistical consultation on the data analysis and interpretation and participated in writing early and final manuscript drafts; and Ms Zhang led the data management and programming and development of the data tables.

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Continuity of care is a core value of pediatric care. This cornerstone resonates with national recommendations to improve health care quality and the principles of the Medical Home and Systems of Care models. It is also related to improved parent-provider relationship, care coordination, adherence to treatment guidelines, and reduction in emergency department visits and hospitalizations. Nevertheless, for children with mental health problems, continuity of care is a target area for quality improvement in primary care and specialty mental health clinics. In primary care, the median number of follow-up visits for attention-deficit/hyperactivity disorder (ADHD) was found to be 1 visit within 6 months in 2 large community-based populations. Improving the continuity of care for ADHD is also of public health significance because it affects 3% to 9% of US children and is chronic, debilitating, and costly. Infrequent visits adversely affect treatment because behavioral interventions should be consistently used over time and stimulant medication requires regular monitoring for safety and efficacy. In addition, children enrolled in Medicaid may be at particularly high risk of poor continuity of care, because they are less likely to have a regular source of care or have a medical home and receive care that is perceived by parents as family-centered or coordinated.

Child, parent, and system-level factors are posited to influence access to and use of mental health services, yet whether parent perceptions about care are predictive of staying in longer term ADHD treatment is less established. Influential individual-level characteristics for mental health service use include child sociodemographic characteristics, clinical severity, and parental mental health. In addition, parent-perceived barriers to care and attitudes are hypothesized to affect access to and continuity of care, such as stigma, recognition of symptoms or a problem, and receptivity to stimulant medication treatment. On the system level, the considerable overlap in mental health and special education service use may increase the likelihood of staying in care through shared problem recognition and monitoring. However, across these studies, continuity of care is broadly and variably defined, ranging from accessing care to premature termination of long-term behavioral therapy, the outpatient setting is restricted to primary care, specialty mental health, or is unspecified. This study had 2 objectives. With the use of a longitudinal cohort of 529 children receiving care for ADHD in primary care or specialty mental health clinics in one of the nation’s largest managed-care Medicaid programs, this study (1) examined whether parent-perceived barriers to care, knowledge about ADHD, and treatment willingness vary between children who drop out of or stay in care and (2) explored whether parent perceptions are predictive of staying in care, after adjusting for more established factors that influence service use. The analysis was exploratory, because there are few empirical longitudinal data to support hypothesis testing.

METHODS

Study Population

The study population consisted of children, ages 5 to 11 years, who were identified by the agency as receiving any ADHD care in one of the nation’s largest managed-care Medicaid programs in primary or specialty mental health care outpatient settings from November 2004 through September 2006. The health plan serves nearly 750,000 County of Los Angeles residents of all ages enrolled in managed-care Medicaid. Within this health plan, specialty mental health services are provided by the County of Los Angeles Department of Mental Health.

Sample

By using merged Medicaid service encounter and pharmacy claims data from the primary care and specialty mental health care agencies, a child was identified as receiving ADHD care if she or he had at least 1 visit with a primary diagnosis of ADHD (International Classification of Diseases, Ninth Revision: codes 314.00, 314.01, or 314.09) or at least 1 claim for a stimulant prescription during the sampling time period. The other eligibility criteria were aged 5 to 11 years, a primary language of Spanish or English, and Los Angeles County residence. We identified 3134 eligible children. All girls (n = 591) were included, and boys were randomly selected (1338 of 2543; 53%), yielding 1929 children. Of these, 56% were not reachable, with the most common reason being incorrect contact information (910 of 1084; 84%). Of the 845 parents or primary caregivers contacted (hereafter referred to as parents), 546 (65%) participated in the home interviews and, of these parents, almost all of the children (n = 542; 99%) completed depression and anxiety screening. Of the 546 parents enrolled, 530 children had Medicaid claims data that were available between January 2003 and December 2006. The selection of boys, reachable status, and participation varied by sector; therefore, enrollment weights were created to adjust for the probability of selection, reachability, and nonresponse. Details of the sampling procedure and enrollment weights are described elsewhere.

Procedures

Study and consent procedures were approved by the State of California...
Staying in Care
During the 6 months before the baseline interview, 75% of the children (395 of 529) identified by the agency as receiving ADHD care had at least 1 contact for mental health care. Of those in care, 27% had contact in primary care (n = 106), 57% had contact in specialty mental health (n = 226), and 16% had contact in both types of clinics (n = 63). During the following two 6-month time intervals, 85% (337 of 395) and 76% (301 of 395) of children, respectively, had at least 1 contact with a primary care or specialty mental health clinic for an emotional or behavioral problem. The distribution of contact by care sectors was similar over time (data available upon request to first author).

Child and Parent Characteristics at Baseline
Child and parent demographic characteristics, parent distress, child clinical characteristics, special education use, and parent perceptions, stratified by 4 care sector contact groups are summarized in Table 1. On average, child age was 10 years (SD: 1.8 years). Slightly more than 80% of the children were boys, and most (n = 457; 83%) were from racial/ethnic minority backgrounds. Among the parents, >60% (n = 315; 61%) had at least a high school education and almost 40% (n = 212; 39%) were currently married. Ten percent of the primary caregivers (n = 58) were a relative of the child, most frequently a grandmother or aunt, and few (n = 20; 3%) were foster parents. Almost one-quarter of the parents (n = 139; 24%) reported symptoms that corresponded to high psychological distress.
Parent/primary caregiver

Parent perception

Child clinical need

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Most of the children (n = 398; 77%) met criteria for past-year ADHD diagnosis, and 40% (n = 216) met criteria for past-year diagnosis and high functional impairment. Slightly more children (n = 226; 42.3%) had at least 1 common mental health problem and high functional impairment. In addition, 44% of children (n = 225) had ever received special education and, of these, most (179 of 225; 80%) had received this service in the past 3 months. Care sector contact varied by race/ethnicity, parent marital status, being a nonbiological parent, and lifetime special education service use.

Parent Perceptions of Care

Almost 60% of parents (n = 307; 58%) reported at least 1 intangible barrier to getting care for a child with an emotional or behavior problem, such as concerns about talking with their doctor (n = 102; 20%), stigma (n = 79; 15%), or fears about losing custody of their child (n = 98; 17%). In addition, almost one-half of parents (n = 239; 49%) reported at least 1 tangible barrier to care, such as a logistical problem (n = 224; 42%) (ie, lack of available services). Overall, more than one-half of the parents (n = 283; 53%) reported ≥2 barriers to care from a list of 15 items, but there was little overlap. On average, parents reported 1 intangible (SD: 1.3) and 1 tangible (SD: 1.4) barrier.

Parents, on average, had only a 53% pass rate on the ADHD knowledge scale. Some of the common misperceptions included the following: that ADHD did not often persist into adolescence or adulthood (50%), that special diets improve ADHD (45%), and that medication is of little benefit when the child reaches adolescence or adulthood (47%). On a 4-point Likert scale, parents reported, on average, a medication willingness score of 2.8 (SD: 0.6) and a counseling willingness score of 3.1 (SD: 0.6). The distribution frequencies of the parent responses to the individual survey items that comprise these composite perception variables are summarized in Supplemental Table 4.

Parent perceptions of care did not vary by care sector contact group, with the exception of medication willingness. For the 2 follow-up time intervals, findings from the bivariate analyses examining how the independent variables varied by no care versus in care and by staying in primary care versus any specialty mental health care are summarized in Supplemental Tables 5 and 6.
**Predictors of Staying in Care**

Findings from the multiple logistic regression models are presented in Table 2. Of the parent perception variables, only medication willingness was associated with staying in care during the first 6-month time interval. Children of parents with higher medication willingness scores had a 11% greater probability of staying in care compared with children of parents with lower scores (at 1 SD above mean versus at mean).

Of the covariates, minority race/ethnicity, having a single parent, parent high psychological distress, and child clinical need (ie, current ADHD symptoms and high impairment, recent special education use) were associated with staying in care but only during one 6-month follow-up period, with the exception of marital status. Children from minority races or ethnicities had a 23% greater probability of staying in care than did white children between the baseline and 6-month follow-up interviews. During the first and third time intervals, children of single mothers had a 24% and 19% greater probability of staying in care compared with children of married parents. Children of parents with high distress had an 18% greater probability of staying in care compared with children of parents without distress between the baseline and 6-month interviews. Compared with less symptomatic children, those who met diagnostic criteria for ADHD and high functional impairment had a 25% greater probability of staying in care between the 6- and 12-month follow-up time intervals. In addition, children with a history of recent special education use had a 13% greater probability of leaving care.

**TABLE 2 Logistic Regression Analyses for Predicting in Care at Baseline and Staying in Care Over Time**

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>In Care at Baselinea</th>
<th>Among Children Who Were in Care at Baseline</th>
<th>In Care Between Baseline and 6 Monthsb</th>
<th>In Care Between 6 and 12 Monthsc</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AOR (95% CI)</td>
<td>ARR (SE)</td>
<td>AOR (95% CI)</td>
<td>ARR (SE)</td>
</tr>
<tr>
<td>Child</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (y)</td>
<td>1.22 (0.96, 1.55)</td>
<td>1.04 (0.03)</td>
<td>1.08 (0.70, 1.66)</td>
<td>1.01 (0.03)</td>
</tr>
<tr>
<td>Male (versus female)</td>
<td>1.16 (0.75, 1.79)</td>
<td>1.04 (0.06)</td>
<td>1.26 (0.56, 2.85)</td>
<td>1.03 (0.06)</td>
</tr>
<tr>
<td>Nonwhite (versus white)</td>
<td>0.98 (0.24, 1.40)</td>
<td>0.89 (0.07)</td>
<td>3.35 (1.12, 9.92)*</td>
<td>1.25 (0.15)</td>
</tr>
<tr>
<td>Parent/primary caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school education or above (versus less education)</td>
<td>1.24 (0.76, 2.03)</td>
<td>1.05 (0.06)</td>
<td>1.32 (0.60, 2.69)</td>
<td>1.04 (0.06)</td>
</tr>
<tr>
<td>Currently not married (versus married)</td>
<td>2.34 (1.43, 3.86)**</td>
<td>1.24 (0.08)</td>
<td>0.69 (0.28, 1.71)</td>
<td>0.95 (0.06)</td>
</tr>
<tr>
<td>High psychological distress, MHI-5 &lt;56 (versus none)</td>
<td>0.79 (0.46, 1.35)</td>
<td>0.94 (0.06)</td>
<td>8.04 (1.82, 35.51)**</td>
<td>1.18 (0.05)</td>
</tr>
<tr>
<td>Child clinical need</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any ADHD + high impairment, current (versus none)</td>
<td>1.12 (0.66, 1.91)</td>
<td>1.03 (0.06)</td>
<td>1.50 (0.57, 3.98)</td>
<td>1.06 (0.07)</td>
</tr>
<tr>
<td>Any special education (versus none)</td>
<td>1.33 (0.81, 2.20)</td>
<td>1.07 (0.06)</td>
<td>2.61 (1.08, 6.31)*</td>
<td>1.13 (0.06)</td>
</tr>
<tr>
<td>Parent perception</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 or 0 barriers to service use (versus ≥2)</td>
<td>1.16 (0.71, 1.88)</td>
<td>1.03 (0.06)</td>
<td>0.64 (0.28, 1.46)</td>
<td>0.94 (0.05)</td>
</tr>
<tr>
<td>ADHD knowledge</td>
<td>0.88 (0.71, 1.09)</td>
<td>0.97 (0.03)</td>
<td>0.90 (0.64, 1.26)</td>
<td>0.98 (0.02)</td>
</tr>
<tr>
<td>ADHD medication willingness</td>
<td>1.75 (1.33, 2.30)***</td>
<td>1.11 (0.03)</td>
<td>1.24 (0.84, 1.84)</td>
<td>1.03 (0.02)</td>
</tr>
<tr>
<td>ADHD counseling willingness</td>
<td>0.98 (0.73, 1.30)</td>
<td>0.99 (0.03)</td>
<td>1.31 (0.84, 2.03)</td>
<td>1.03 (0.03)</td>
</tr>
</tbody>
</table>

Odds ratios for continuous variables reflect a 1-SD increase; risk ratios for continuous variables reflect a 1-SD increase from the mean. *P < .05, **P < .01, ***P < .001, ****P < .10. AOR, adjusted odds ratio; ARR, adjusted risk ratio; CI, confidence interval; MHI-5, 5-item Mental Health Inventory.

a Logistic regression for in care at baseline with predictors listed in the table, N = 524.
b Logistic regression for staying in care between baseline and 6 months among those who were in care at baseline, N = 268.
c Logistic regression for staying in care between 6 and 12 months among those who were in care at baseline, N = 238.

**FIGURE 1** Percentage of children in care by parents’ medication willingness.
staying in care compared with children not receiving special education services during the second 6-month time interval. The adjusted percentages of medication willingness, parent high distress, and clinical need among children staying in care during the 3 study time intervals are also graphically depicted in Figs 1, 2, 3, and 4. A similar trend across the 3 time intervals was seen for medication willingness and clinical need variables but not for parent distress status.

DISCUSSION

Findings from this study suggest that parental perceptions were not predictive of staying in care for ADHD treatment over time, with the exception of medication willingness during the 6 months before the baseline interview. Although the direction of the finding on medication receptivity is similar to earlier studies that focused on access to care or early phases of mental health care, the conclusion that parent perceptions are not influential to staying in care would be premature. Given this study’s sampling strategy, the baseline assessment of parent perceptions did not align with initial ADHD treatment because children entered the study with variable episodes of care. Nevertheless, the potential relevance of eliciting parental medication willingness during ADHD care supports efforts to identify treatment preferences that can be reliably elicited by frontline clinicians. Placing priority on parent attitudes toward stimulant medication treatment also aligns with the core values that child health care be family-centered and the decision-making process be equally shared by parents and providers.

Parent distress and clinical need were inconsistently predictive of staying in care during the 6- and 12-month follow-up time intervals, but the direction of these relationships was consistent with earlier studies. Together, the variation in predictors of staying in care over time may reflect the more dynamic decision-making process of parents continually “revisiting decisions about treatment” during the course of ADHD care. Attitudes about medication treatment may be more influential during an earlier phase of treatment, whereas parent-perceived need for continued care may be more influential during more long-term ADHD care.

Contrary to studies that hypothesized that parent-perceived barriers are related to reduced access to child mental health services, fewer barriers did not improve the likelihood of staying in care. The relatively low number...
of perceived barriers may reflect a selection effect, such that parents who overcame barriers were more likely to be entered into the sampling pool. In addition, parent knowledge about ADHD did not relate to staying in care, but a considerable proportion of parents reported misperceptions related to the chronicity of ADHD and benefits of more long-term treatment. These findings are in step with ADHD treatment guidelines that emphasize parent education and linkage to child mental health advocacy groups to enhance health literacy.82,83

Conclusions about the continuity of publicly funded care for ADHD should be tempered by the study’s limitations. The estimates of follow-up care are likely inflated because staying in care was broadly defined as at least 1 contact for any mental health problem using agency data or parent report. Therefore, children identified as staying in care include children receiving a frequency of care that is lower than that recommended in treatment guidelines.42 Criteria for staying in care also do not meet the traditional definition of continuity of care that requires that care be delivered by the same provider over time.1 In addition, findings are not generalizable to other Medicaid child populations.

CONCLUSIONS

Despite these limitations, this study is the first to examine whether parent perceptions about barriers to care, disorder knowledge, and attitudes about treatment influence staying in care over time among children receiving care for ADHD in primary care or specialty mental health clinics within a large managed-care Medicaid program. Our findings support the need for future research to develop practical tools for clinicians that can elicit parent priorities about ADHD treatment76 and to integrate these into quality-improvement interventions targeted to improving shared decision-making for longer term ADHD care.

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