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Specialized Inpatient Psychiatry for Serious Behavioral Disturbance in Autism and Intellectual Disability

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Abstract Psychiatric hospitalization of children with autism spectrum disorder and/or intellectual disability is common, however, the effectiveness of this intervention is largely unknown. Thirty-eight clinically-referred children 8–19 years old admitted to a specialized inpatient psychiatry unit were assessed by a consistent caregiver on the Aberrant Behavior Checklist-Irritability (ABC-I) subscale at admission, discharge and 2 months post discharge. There was a decrease in the mean ABC-I score from admission (27.3, SD 7.4) to discharge (11.9, SD 8.8), which was sustained at 2 months post discharge (14.8, SD 9.3) ($p < 0.001$). Seventy-eight percent of the subjects were rated as “Improved” on the clinician Clinical Global Impressions Improvement scale at discharge. The study is limited by lack of a control group, but offers preliminary evidence for specialized inpatient psychiatry as an intervention for serious behavioral disturbance in this population.

Keywords Autism · Psychiatric · Hospitalization · Intellectual disability

Introduction

Psychiatric hospital treatment of individuals with autism spectrum disorder (ASD) and intellectual disability (ID) has evolved from early twentieth century practices of long term institutionalization, through the movement for deinstitutionalization of the 1970's and 1980's, to the current era of short stay, acute hospital admissions. Psychiatric hospitalization of children with ASD is common. Eleven percent of children with ASD are psychiatrically hospitalized in the United States (U.S.) prior to age twenty-one, with a 1 year prevalence of 1.3–7 % (Croen et al. 2006; Mandell 2008). Children with ASD have been identified in increasing numbers by the Centers for Disease Control (2012), and utilization of psychiatric hospitalization by this population is therefore expected to increase. Children with ASD and/or ID are typically admitted to either *general* or *specialized* psychiatry units. Over the last decade the number of specialized child psychiatry units—those that exclusively serve children with ASD and ID, has doubled in the United States (Siegel et al. 2012). These specialized units are designed to target the unique needs and symptom presentation of this population. Despite the large public health implications of these trends, there are no prospective studies on the effectiveness of psychiatric hospitalization of children with ASD and/or ID.

A small body of literature has examined the effects of specialized psychiatric units on psychotic symptoms, mental illness severity, length of stay and readmission rates, though most of these studies have been retrospective designs focused on the adult ID population (Ballinger et al. 1991;

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Day 1995; Hurst et al. 1994; Reid et al. 1984; Palucka and Lunsky 2007; Lunsky et al. 2010). A prospective Finnish study of 31 adult patients with ID reported a reduction of psychotic symptoms during specialized hospitalization and at 6 month follow-up (Raitasuo et al. 1999). In the United Kingdom, a prospective study reported that adults with ID admitted to a specialized psychiatry unit had a longer average length of hospital stay than a similar group in a general psychiatric unit, but showed greater improvements in mental illness severity and were less likely to be discharged to a residential placement (Xenitidis et al. 2004).

Recently, a study by Gabriels et al. (2012) retrospectively compared outcomes for ASD and ID patients in a United States general child psychiatry unit with similar patients treated in a specialized child psychiatry unit specifically designed for children with ASD and ID. Children in the specialized unit had a shorter average length of stay (26 vs. 45 days), and a lower 1 year readmission rate (12 vs. 33 %). In addition, the study reported an improvement from admission to discharge on the Aberrant Behavior Checklist Irritability Subscale (ABC-I) (Aman et al. 1985), a measure of behavioral functioning, for children admitted to the specialized unit, though this measure was not available from the general inpatient unit group. Prior work has thus identified that specialized psychiatric unit treatment may impact co-morbid psychiatric symptoms, behavioral functioning, readmission rates and length of stay for the ASD and ID populations.

To build upon this preliminary work, we sought to examine whether children with ASD and/or ID admitted to a specialized child psychiatry unit would show improvement on a caregiver-rated ABC-I and a clinician-rated Clinical Global Impression (CGI) scale (Guy 1976). The purpose of this study was to examine the behavioral outcomes of a specialized inpatient unit and to identify possible factors that may contribute to treatment success and sustainability. Our primary objective was to measure behavioral change from admission to discharge and through 2 month follow-up. Our secondary objectives were to provide descriptive information regarding the occurrence of co-morbid psychiatric disorders in the population, and to explore the effects of caregiver attendance in a behavior management training program on the children's behavioral outcomes. To our knowledge, this is the first prospective study of specialized inpatient psychiatric care utilizing standardized outcome measures for children with autism and intellectual disability.

Methods

Participants

Patients admitted to a specialized inpatient psychiatry unit from June, 2011 to August, 2012 were offered participation

in the study. Patients were clinically referred to the hospital by emergency rooms or the patient's primary provider (physician, nurse practitioner, etc.) Caregivers were offered participation in the study after the subject had been admitted by a research assistant with no role in clinical treatment, and no incentive for study participation was offered. Inclusion criteria were a score of 14 or greater on the caregiver-rated ABC-I and a clinician-rated CGI-Severity score ≥ 4 (at least moderately ill) at admission. The inclusion score of 14 or greater on the ABC-I is similar to that used in multiple other treatment studies in ASD performed with this age group (e.g. RUPP, 2002 (age range 5–17 years old); Owen et al. 2009 (age range 6–17 years old)). Subjects were excluded from the study if they had been admitted to the unit in the prior 2 years, as we sought to examine the effect of first-time admission on novel subjects.

A total of 51 unique admissions were assessed for eligibility. Twelve were excluded due to prior admission to the unit within the past 2 years, 1 declined participation, and 38 consented to participate, all of whom completed the discharge measures and 2 month follow up and were included in the analysis. The study protocol was approved by the Institutional Review Board of Maine Medical Center Institutional Review Board and written informed consent was obtained from the guardian(s) of all subjects.

Treatment Program

The specialized inpatient psychiatry program in this study performs assessment and treatment of co-morbid psychopathology and acute behavioral disturbance in children with ASD and/or ID. Specialized psychiatry units in the United States have been found to universally employ a combined pharmacologic and intensive behavioral therapy approach, utilize large multi-disciplinary treatment teams (average of 4.6 disciplines), and have an average length of stay of 42.3 days (Siegel et al. 2012). The specialized unit in the current study matches the average characteristics of other specialized units well, with a mean length of stay of 45 days, a multi-disciplinary team that includes 5 disciplines (child psychiatry, behavioral psychology, speech-language pathology, occupational therapy and social work), and combined use of pharmacology and behavioral treatment modalities.

Hospitalization in this specialized psychiatry unit consisted of an intensive diagnostic assessment, removal of psychotropic medications when possible, development of an individualized behavioral plan based upon principles of applied behavior analysis and positive behavioral supports, targeted psychopharmacology, treatment of medical issues, functional communication training, occupational therapy, milieu therapy, special education, and family therapy. As

most children present with acute or chronic crises, the program addressed both the acute symptomatology as well as the key underlying chronic factors that contributed to unsafe behavior. For example, identifying that an aggressive non-verbal child has no communication system might prompt treatment of the aggression with medication and implementation of functional communication strategies, such as choice boards, first-then prompts, “break please” cards, etc. (see Hutchins and Prelock 2014). Following principles of applied behavioral analysis, target behaviors such as aggression or self-injury were defined and operationalized for the direct care staff and recorded in 15 min increments to produce 24 h frequency counts. Response to intervention was monitored by daily analysis of target behavior data by the multi-disciplinary treatment team (see Siegel and Gabriels 2014 for a detailed review of specialized unit treatment processes).

Measures

At admission, discharge and 2 month follow-up, a consistent primary caregiver completed the ABC-I subscale. The ABC-I is a 15 item parent-rated subscale measuring the severity of challenging behaviors such as aggression, self-injury or emotional dysregulation on a scale of 0 (the behavior is not at all a problem) to 3 (the behavior is a severe problem), yielding a maximum score of 45. Higher scores indicate more challenging behavior. Only the irritability subscale of the ABC was administered because it is the subscale that most directly measures the primary behavioral challenges of children with autism admitted to specialized psychiatry units: aggression, self-injury and emotional dysregulation, and use of the single subscale reduced parent reporter burden for the repeated administrations. The ABC was developed and validated as a treatment-sensitive outcome measure in youth with developmental disabilities and has been reported to have high internal consistency and test-retest reliability (Aman et al. 1985). We found a high Cronbach's alpha reliability of 0.79, 0.93, and 0.92 for ABC-I scores at admission, discharge, and 2-month follow-up respectively. The ABC-I was completed in written form at admission and discharge, and by telephone at 2 month follow up. Characteristics of telephone administration of the ABC-I have been reported previously (Siegel et al. 2013).

The CGI-I, our secondary outcome measure, is a clinician-rated measure of change in mental health status on a 7 point scale ranging from 1 (Very much improved) to 7 (Very much worse). The CGI-I score was independently generated by two of the study team clinicians (MS and DP) at discharge based upon daily observation of the subject. The CGI was not performed at the 2 month telephone follow-up, as the information available from a brief telephone call was not considered an equivalent comparator to

the rich observational information available to the rater at the end of the hospital stay.

Behavior Management Training

The primary caregivers of each subject were offered the opportunity to participate in a three step behavior management training program, where they were *taught* their child's individualized behavioral plan, *shadowed* the direct care staff running the plan, and ultimately *ran* the plan themselves with staff coaching. Primary caregiver attendance in the behavior management training was recorded daily by having caregivers document the purpose of their visit (learning the behavior plan, shadowing the plan or running the plan) each time they entered the unit, which was verified by a unit nurse.

Diagnoses

Discharge diagnoses of ASD, ID and co-morbid Axis I disorders were made using DSM-IV TR (American Psychiatric Association 2000) criteria through a consensus process at time of hospital discharge by a child psychiatrist, child psychologist and physician assistant. Each diagnostician had expertise in the ASD and ID populations and diagnosis was based on extensive review of records and an average of 45 days of inpatient observation of the subjects. Diagnoses of Generalized Anxiety Disorder and Attention Deficit/Hyperactivity Disorder were made, recognizing the impending removal in DSM-5 of the prohibition on concurrent diagnosis of these conditions in individuals with autism.

Analyses

Descriptive statistics comparing ASD versus non-ASD patients were performed using Student's *t* test for continuous variables and Chi square for categorical variables. The primary outcome measure was analyzed using Mixed-model Repeated Measures Analysis of Variance (RMANOVA) to assess differences between ASD and non-ASD patients' scores on the ABC-I across the three time points.

For analysis purposes, the CGI-I was truncated into two categories: “Improvement” (collapse of “very much improved” and “improved” scores) and “No Improvement” (collapse of the remaining 5 CGI-I scores). Agreement between the two CGI-I clinical raters was conducted using the kappa statistic (Fleiss and Cohen 1972). The sample for agreement analysis was smaller ($N = 27$) than the total sample due to subjects where only one clinician CGI-I score was received. Chi square analysis or Fisher's Exact test (for cells with $N \leq 5$) was conducted to examine for differences in proportion of patients who showed “Improvement” on the CGI score between ASD and non-ASD patients.

Table 1 Chi square and *t* test analyses comparing demographic and clinical variables between groups (ASD/Non-ASD)

Demographic	Total sample N = 38	ASD group N = 19	Non-ASD group N = 19	Statistic	DF	<i>p</i> value
Age (years) (mean/standard deviation)	12.6 (2.9)	13.3 (3.2)	11.8 (2.5)	<i>t</i> = -1.58	36	0.12
<i>Age groups</i>						
5–12 years	22 (58 %)	9 (47.4 %)	13 (68.4 %)	$\chi^2 = 0.97$	1	0.32
13–21 years	16 (42 %)	10 (52.6 %)	6 (31.6 %)			
Gender (male)	32(84 %)	16 (84.2 %)	16 (84.2)	$\chi^2 = 0.00$	1	1.00
Race (Caucasian)	35 (92 %)	16 (84.2 %)	19 (100 %)	$\chi^2 = 3.26$	2	0.20
Ethnicity (non-Hispanic)	37 (97 %)	18 (94.7 %)	19 (100 %)	$\chi^2 = 0.00$	1	1.00
Intellectual disability	21 (55 %)	8 (42.1 %)	13 (68 %)	$\chi^2 = 0.00$	1	1.00
Unspecified	8 (21.1 %)					
Moderate	6 (15.8 %)					
Mild	2 (5.3 %)					
Borderline	5 (13.2 %)					
<i>Chief complaint</i>						
Aggression	34 (89 %)	16 (84.2 %)	18 (94.7 %)	$\chi^2 = 4.12$	2	0.13
Self Injury	1 (2.6 %)	0 (0 %)	1 (5.3 %)			
Functional decline	3 (7.9 %)	3 (15.8 %)	0 (0 %)			
Length of stay (mean days)	45.0 (SD 14.4)	45.0 (SD 17.4)	44.9 (SD 11.1)	<i>t</i> = -0.03	36	0.97
<i>Psychiatric co-morbidity</i>						
ADHD	13	3	10	$\chi^2 = 5.73$	1	0.02*
Disrupt beh. DO NOS	4	0	4	$\chi^2 = 4.47$	1	0.03*
Impulse control disorder	1	0	1	$\chi^2 = 1.03$	1	0.31
Oppositional defiant DO	4	0	4	$\chi^2 = 4.47$	1	0.03*
Conduct disorder	0	0	0	$\chi^2 = 0.00$	1	1.00
Any disrupt. behav. DO	22 (58 %)	3 (16 %)	19 (100 %)	$\chi^2 = 15.16$	1	0.001*
Anxiety disorder NOS	17	8	9	$\chi^2 = 0.11$	1	0.74
Generalized anxiety DO	3	2	1	$\chi^2 = 0.36$	1	0.55
Social phobia	1	1	0	$\chi^2 = 1.03$	1	0.31
Specific phobia	0	0	0	$\chi^2 = 0.00$	1	1.00
Post traumatic stress DO	0	0	3	$\chi^2 = 3.26$	1	0.07
Obsessive compulsive DO	2	2	0	$\chi^2 = 2.11$	1	0.15
Any anxiety disorder	25 (66 %)	12 (63 %)	13 (68 %)	$\chi^2 = 0.11$	1	0.73
Depressive disorder NOS	4	1	3	$\chi^2 = 1.11$	1	0.29
Mood disorder NOS	1	0	1	$\chi^2 = 1.03$	1	0.31
Major depressive disorder	0	0	0	$\chi^2 = 0.00$	1	1.00
Bipolar disorder	1	1	0	$\chi^2 = 1.03$	1	0.31
Any mood disorder	6 (16 %)	2 (10 %)	4 (21 %)	$\chi^2 = 0.79$	1	0.37
Reactive attachment DO	1	0	0			
Pica	1	1	0	$\chi^2 = 1.03$	1	0.31
Tic disorder NOS	3	2	1	$\chi^2 = 0.36$	1	0.55
Tourette's syndrome	4	1	3	$\chi^2 = 1.11$	1	0.29
Any DO of infancy/EC	9 (24 %)	4 (21 %)	4 (21 %)	$\chi^2 = 0.00$	1	1.00

* Significant at *p* < 0.05

A priori power analysis showed a 90 % power to detect a change of 6 or more points in the ABC-I score, at an alpha of 0.05 with a standard deviation of 7, and 16 subjects in each group.

Results

The patient population was primarily male, Caucasian and non-Hispanic (see Table 1). Demographic features did not

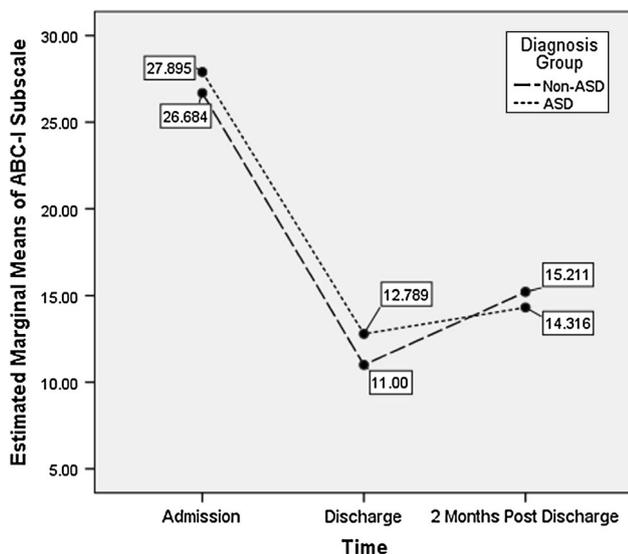


Fig. 1 Estimated marginal means of Aberrant Behavior Checklist Irritability (ABC-I) subscale of children with and without autism spectrum disorder (ASD) over time

significantly vary across ASD and non-ASD diagnostic groups, and the average length of stay was 45 days ($SD = 14.4$, Range 14–84 days) with no difference in average length of stay between the ASD and non-ASD groups ($p = 0.97$). Length of stay was found to be normally distributed. RMANOVA analysis examining length of stay as a covariate of change in mean ABC-I scores from admission to discharge to 2 month follow-up revealed no significant effect of length of stay on patient ABC-I scores over time, $F(2, 34) = 2.26$, $p = 0.12$.

ABC-I scores decreased for the total sample and both sub-groups from admission to discharge with a slight increase at 2 month follow up. RMANOVA revealed a substantial main effect for time, $F(2, 36) = 52.57$, $p < 0.001$, demonstrating a significant reduction in ABC-I scores for the total sample (see Fig. 1). The main effect comparing the two groups was not significant, $F(2, 36) = 0.11$, $p = 0.74$. There was no significant time by group interaction, $F(2, 36) = 0.39$, $p = 0.68$, indicating that the time effect was similar in the two groups.

On our secondary outcome measure, the CGI-Improvement (CGI-I) scale, 84 % of the ASD group and 73 % of the non-ASD group were rated as “Improved” (CGI-I score of 1 or 2) at discharge. Fisher’s exact test revealed no significant difference in the percentage “Improved” at discharge between ASD and non-ASD groups (Fishers = 0.69, $p = 0.35$). The average agreement between the two clinician CGI-I raters was substantial, kappa = 0.69 (Viera and Garrett 2005), and the exact agreement was moderate, kappa = 0.52, both of which were significant at $p = .002$.

Half the sample ($N = 19$) were diagnosed with ASD and half were not. In the non-ASD group 68 % were diagnosed with ID ($IQ < 75$), and most of the remainder had Borderline Intellectual Functioning ($IQ 75–84$). Forty-two percent of those with ASD were also diagnosed with co-morbid ID. The sample showed a range of co-morbid Axis I psychiatric disorders and most participants were diagnosed with at least one co-morbid disorder (see Table 1). Among the ASD group, 89 % were diagnosed with a co-morbid Axis I disorder, most frequently an anxiety disorder (68 % of the sample). Of the non-ASD group, 100 % were diagnosed with a disruptive behavior disorder, primarily ADHD (53 %).

Increasing caregiver attendance in the three step hospital behavioral training program was not associated with greater improvement in behavioral outcome at 2 month follow up. We subsequently compared subjects whose caregiver did not implement the behavioral plan during the hospitalization ($N = 13$, 34.2 %), with those who implemented the plan only once ($N = 10$, 26.3 %) and those who implemented the plan more than once ($N = 15$, 39.5 %). A one-way ANOVA of the 2 month follow-up ABC-I scores was associated with increasing implementation of the behavioral plan, but did not reach significance and may not have been powered to detect a moderate effect size ($F = 2.19$, $p = 0.128$).

Discussion

Our results indicated that specialized inpatient psychiatric treatment was associated with a statistically significant and clinically relevant reduction in aggressive, self-injurious and tantrum behavior in children with ASD and/or ID, which was sustained at 2 months post discharge. Though we cannot suggest causality due to the absence of an untreated control group, the improvements seen across both the parent-rated ABC-I and clinician-rated CGI-I provide preliminary support for a treatment association.

On average, this was a population with serious behavioral disturbance, with a mean admission ABC-I score of 27.3, which is greater than or equal to most samples in outpatient psychotropic medication trials for children with ASD (RUPP Autism Network 2002; Owen et al. 2009; Marcus et al. 2009). The study ASD population also had significant cognitive impairment, with 42 % diagnosed with co-morbid ID.

The change in behavioral functioning was large (mean decrease of 15.4 points on the 45 point ABC-I), and showed only slight regression at 2 month follow up (mean increase of 2.9 points, n.s.). These results may be particularly notable given that this was a population typically refractory to multiple prior interventions (medications,

behavioral treatment, day treatment, in-home support and/or general psychiatric inpatient unit treatment). It is also possible that the sustained improvement at 2 month follow-up may represent a regression to a mean or baseline behavioral state that existed prior to the hospitalization.

Our findings revealed ASD and non-ASD groups performed equally well on the primary and secondary outcome measures. As some of the non-ASD children presented with borderline intellectual functioning and long standing disruptive behavior disorders, we had hypothesized that this group could show less improvement than the children with ASD. The non-ASD group's equivalent improvement, however, may be due to the high rate of identification of psychiatric co-morbidity (100 % of non-ASD subjects with at least one co-morbid axis I disorder).

A tenet of child psychiatric treatment of the ASD and ID populations is that the accurate identification of co-morbid psychiatric disorders will lead to more targeted treatments and better outcomes. As there is no widely accepted, validated measure available to reliably diagnose co-morbid psychiatric disorders in children with ASD or ID, we utilized an expert consensus process based upon extended inpatient observation and record review to assign discharge diagnoses. Our identification of high rates of anxiety disorders in the hospitalized ASD population, which was consistent with outpatient reports of anxiety disorders as most frequently co-morbid with ASD (Leyfer et al. 2006), highlights the importance of considering this dimension in children with ASD presenting with serious behavioral disturbance.

Other investigators have shown improved behavioral outcomes on the ABC-I with a combination of parent training and pharmacologic treatment (Scahill et al. 2009). We found no association with increasing caregiver attendance in our behavioral management training program. This result can be interpreted in several ways. It may be that the behavioral training program is ineffective. It is more likely that caregiver *attendance* at behavioral training sessions is a less sensitive variable than other possible variables, such as implementation, competence, engagement and self-efficacy. It also may be that families who had more exposure to trained hospital staff managing their child systematically offered a more negative appraisal of their child's behavior at 2 month follow up. Further exploration examining parent-child dyads within this patient population is needed.

Finally, both ASD and non-ASD groups showed slight regression in their ABC-I scores at 2 month follow up, though this was not statistically significant. This finding raises the important question of long term durability of treatment effects, which will be critical to assess to inform the public health discussion on the merits of this relatively intensive treatment. Similarly, our results warrant further

investigation of specialized inpatient treatment of children with ASD and ID to identify key treatment components that could potentially be exported to other settings. As 11 % of children with ASD are psychiatrically hospitalized by the age of 21 (Mandell 2008), primarily in general psychiatry units, it is equally urgent to evaluate the comparative effectiveness of general and specialized units.

The primary limitation in this study was the absence of a control group, which restricts the ability to establish causality between the intervention and the reported outcomes. Though establishing an untreated control group for acute psychiatric hospitalization is nearly impossible, future studies could build upon these preliminary findings by examining the comparative effectiveness of specialized and general psychiatric hospitalization. We excluded subjects who had been admitted in the prior 2 years, which may limit the generalizability of the results to those with first-time admissions. Other potential limitations of this study included the lack of ethnic and racial variability in the sample, reliance on clinical observation and record review to establish ASD and ID diagnoses, and the lack of a standardized measure to diagnose co-morbid psychiatric disorders. Diagnosis of ASD in outpatient research studies is often supplemented by use of a standardized observational measure. We would argue, however, that this is necessitated by the typically minimal exposure of outpatient study investigators to their study populations. In this study, we used an expert consensus process of three experienced clinicians who had an average of 45 days each of close observation of the subjects. Similarly, we utilized expert consensus diagnosis to establish co-morbid psychiatric diagnoses based on the extended inpatient observation period.

Conclusions

Children with ASD and/or ID show a significant decrease in aggression, self-injury and tantrum behavior upon discharge from a specialized inpatient psychiatry unit. These improvements are sustained at 2 months post-discharge. This preliminary finding of potential effectiveness in a population with serious behavioral disturbance should be followed up with further controlled study to establish efficacy of the treatment model and compare its effectiveness with standard hospital treatment. Psychiatric hospitalization of children with ASD and/or ID is common and will place increasing demands on the health care system to find effective treatments at all levels of care in the coming decades.

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Conflict of interest The authors declare they have no conflict of interest.

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