

A Pilot Study of Autism-Specific Care Plans During Hospital Admission

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abstract

BACKGROUND AND OBJECTIVE: Hospital admissions can be difficult for patients with autism spectrum disorder (ASD). We created an autism-specific care plan (ACP) to help improve the hospital experience for patients with ASD, and we tested feasibility and acceptability and compared the experience of care for children with and without an ACP.

METHODS: We performed a nonrandomized, retrospective chart review of all patients with ASD and a hospital admission from January 2013 to December 2013 ($n = 142$) to determine feasibility of the intervention. We then mailed surveys to all 142 families to measure experience with the ACP and to compare experience of care in those who did and did not have an ACP. Using multivariable linear regression we assessed the association of experience of care with ACP use while adjusting for covariates.

RESULTS: The ACP was well tolerated by parents and used frequently by staff. Compared with parents who did not use the ACP, parents who used the ACP reported a better experience relating to their general hospital experience ($B = 1.48, P < .001$) and staff attention to their child's ASD-specific needs ($B = 3.07, P < .001$).

CONCLUSIONS: According to this pilot study, care plans are feasible and hold promise to improve the experience of care for children with ASD and their families in the hospital setting.

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DOI: 10.1542/peds.2015-2851R

Accepted for publication Nov 9, 2015

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Supported by MassGeneral Hospital for Children; Nancy Lurie Marks Family Foundation to the Massachusetts General Hospital; and Cooperative Agreement (UA3 MC 11054) from the US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program, to the Massachusetts General Hospital.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

To cite: Broder-Fingert S, Shui A, Ferrone C, et al. A Pilot Study of Autism-Specific Care Plans During Hospital Admission. *Pediatrics*. 2016;137(s2):e20152851R

Hospital admissions for patients with autism spectrum disorder (ASD) are increasing,¹ yet little is known about these patients' experience with care in the hospital setting. Hospital care may be particularly challenging for children with ASD. These children have communication impairments that can prevent effective interaction with the hospital care team.²

Unfamiliar people and environments may cause stress or agitation. Hypersensitivity to auditory, visual, or other sensory stimuli may create difficulties tolerating equipment such as cardiac monitors, venipuncture, and blood pressure cuffs.^{3,4} Finally, the expression of pain and other physical symptoms may be difficult to interpret in children with ASD.^{5,6}

Another concern for patients with ASD is safety. Many children with ASD display disruptive or self-injurious behavior that could lead to significant safety problems when in the hospital.⁷ A recent survey found that half of parents of children with ASD reported safety concerns for their children while in the hospital.⁸

Physician comfort in caring for children with ASD may play a role in their difficulties with hospital care. Studies show that general pediatricians do not feel adequately prepared to care for children with ASD.^{9,10} In a survey of 539 pediatricians and family physicians, physicians reported significantly lower overall self-perceived competency in caring for children with ASD compared with children with other neurodevelopmental conditions.⁹ We suspect this lack of preparation is also a concern among pediatric hospitalists.

Care plans may be a way to address the needs of patients with ASD in the hospital. The use of care plans is not new. Care plans are commonly used in palliative care, cancer care, and emergency preparedness.¹¹⁻¹⁴ For example, the Institute of Medicine recommends that survivorship care plans be implemented for all cancer

survivors entering follow-up care.¹⁴ Patients with ASD are a logical next step in care plan use. They are highly complex, with a wide variety of symptoms relating to their ASD.¹⁵ Therefore, a personalized approach may be necessary to accommodate their needs.

As part of an ongoing initiative to improve hospital care for children with ASD, we developed an autism-specific care plan (ACP) to be used in the hospital setting. We then compared the experience of care in families who used the care plan with those who did not. We hypothesized that the ACP would be a well-tolerated approach to improving the experience of care for children with ASD and their families and that users of the ACP would have better outcomes than nonusers.

METHODS

Study Design

In 2011, we created and piloted an ACP as a quality improvement initiative for children with ASD at a single tertiary care hospital. Then, we conducted a nonrandomized retrospective cross-sectional study of children with ASD who had a hospital admission from January 1, 2013 to December 31, 2013 and their parents. The study consisted of two parts. First, a retrospective chart review was performed of patients who both did and did not use an ACP. For children with an ACP, we examined acceptability based on parent survey and used chart review to assess frequency of use. Second, we compared safety-reportable events, length of hospital stay, and (through parent survey) experience of care in those with and without an ACP. The study was approved by the institutional review board at MassGeneral Hospital.

Intervention

The ACP was developed in 2011 as a quality improvement project

through MassGeneral Hospital for Children (MGHfC), the Lurie Center for Autism, and Autism Speaks–Autism Treatment Network's Autism Intervention Research Network on Physical Health. To develop the tool, a single investigator conducted interviews with key informants (3 physicians and 2 parents) about hospital care for children with ASD. These were open-ended interviews to discuss general concerns and experiences regarding hospital care. Then, 6 working-group meetings of clinicians, nurses, occupational therapists, social workers, child life specialists, medical students, and parents were convened to discuss strategies for improving in-hospital care for children with ASD. The prominent concern identified was providers' lack of understanding of patients' individual ASD needs.

The group decided a care plan specifying a patient's autism-specific needs would be an effective means for improving care. A conceptual model was developed to represent the benefits of a care plan (Fig 1). Through multiple iterations a document was created and revised with questions to address 3 domains: expressive and receptive communication, social and pragmatic concerns, and safety. The final product (the ACP) is available online through a secure online portal for parents to complete before a hospital admission or in a downloadable paper version. Once completed, the form is uploaded into the patient's electronic medical record (EMR) and stored as a note titled "Acute Care Plan for Autism." There are no specific triggers for a provider to read the ACP; it is the responsibility of the provider to find (or the patient to inform them of) the note.

Medical physicians were informed of the program through hospital-based trainings and mailings sent to administrators. Psychiatrists were not involved with development of the instrument, nor were they targeted

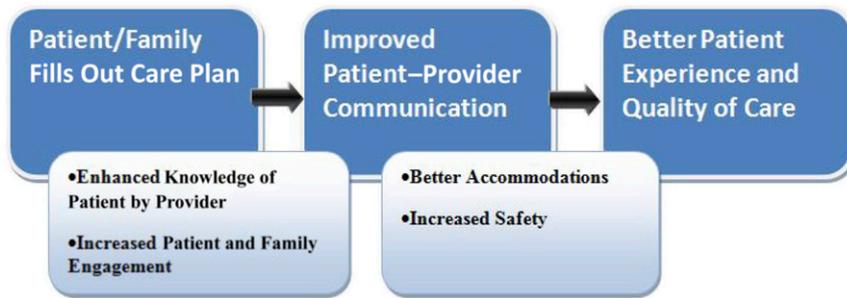


FIGURE 1
Conceptual model of care improvement through use of a care plan for patients with ASD.

for training. The ACP was intended for patients who are hospitalized for medical issues specifically.

Intervention Recruitment

Parents were recruited to complete an ACP via 3 methods. First, physicians within the outpatient autism clinic (the Lurie Center for Autism) were trained on how to complete an ACP for patients or to refer parents to the Web site to complete on their own. Physicians were asked to refer all patients with ASD to fill out an ACP, but these referrals were not tracked. Second, letters were sent to pediatric clinics at MGHFC (gastroenterology, neurology, and hospital-based primary care) with instructions on how to direct their patients to complete an ACP. Third, announcements were sent to local ASD parent groups.

Study Sample

Patients were identified through the Partners HealthCare System Research Patient Database Repository administrative database, which includes demographics (race and ethnicity, insurance type), diagnoses at each visit, location of visit (specific inpatient unit), dates of admission and discharge, and billing codes.¹⁶ We identified all patients ages 2 to 21 years who had a hospital admission at MGHFC between January 1, 2013 and December 31, 2013 with an International Classification of Diseases, Ninth Revision diagnosis of ASD (299.0, autistic disorder;

299.8, Asperger's disorder; or 299.9, Pervasive Developmental Disorder-Not Otherwise Specified). An International Classification of Diseases, Ninth Revision code of ASD listed in the chart at any time was the criterion for inclusion. Subjects were excluded if their hospital admission could not be confirmed by review of their EMR, if they did not speak English, or if their admission was to a nonmedical unit (eg, psychiatry).

A single investigator reviewed records to confirm eligibility. Of the 400 charts abstracted, 258 were ineligible because they did not have a qualifying hospital admission ($n = 255$) or they were not English speaking ($n = 3$). Two patients had >1 hospital admission during the study period, and their most recent admission was used for analysis.

Chart Review

Characteristics

The following data were abstracted from the medical record: medical record number, date of admission, date of discharge, date of birth, race and ethnicity, payer, admitting diagnosis, and number of previous admissions. Length of stay was calculated by subtracting date of discharge from date of admission and was measured as mean and SD for comparison of means and then coded dichotomously for regression analysis (≤ 2 days or > 2 days). Age was coded dichotomously (≤ 11 years or > 11 years). We categorized race or ethnicity as white or nonwhite. Our

database allows patients to report only 1 value for race or ethnicity. We used insurance at the time of visit and categorized it as either public or private.

For diagnosis at admission, we categorized the following as "psychiatric": 299.00 (Autistic disorder, current or active state), 298.9 (Unspecified psychosis), 314.01 (Attention deficit disorder with hyperactivity), 299.80 (Other specified pervasive developmental disorders, current or active state), 311.0 (Depressive disorder, not elsewhere classified), 295.70 (Schizoaffective disorder, unspecified), 296.24 (Major depressive affective disorder, single episode, severe, specified as with psychotic behavior), 296.23 (Major depressive affective disorder, single episode, severe, without mention of psychotic behavior), 296.32 (Major depressive affective disorder, recurrent episode, moderate), and 296.90 (Unspecified episodic mood disorder). All other codes were categorized as "medical."

Opening of the ACP

Each time the ACP is viewed in the EMR it is tracked by the electronic system with the unique identification of the user. We counted the number of times the ACP was opened in the EMR during a hospital visit and by whom. If the same person opened the note twice, we counted that as 2 separate events. We used the hospital employee directory to derive job title. We coded notes as being opened by 1 of the following: attending physician, fellow, resident, medical student, nurse, or "other." We did not count "other" in our analysis, because of the low frequency of use of this category ($n = 12$). We then counted the number of times the ACP was opened by each staff category on each day of hospital admission.

Safety Reports

We used MGHfC's safety reporting system to measure safety reports. This online form allows patients or staff to report patient safety-related events that occur at the hospital. The form includes patient's name, date, location of the incident, staff involved, and a description. We submitted a list of medical record numbers and date ranges (date of admission through date of discharge) to measure the number of safety reports that occurred relating to our population during the time of interest. We were not able to obtain details of safety reports, only a "yes/no" with the date.

Survey Instrument

We developed a 31-question survey instrument covering 4 domains. Multiple parents and clinicians reviewed the survey and discussed content and face validity with the research team. The first domain was the experience with the ACP (asked only of those who used it). We asked questions relating to ease of use and perceived utility. The second domain was experience of care. Seven items were adapted from the Pediatrics Hospital Communication Assessment of Healthcare Providers and Systems survey (S. Toomey, MD, MPH personal communication, 2013). These items included questions about staff's treatment of the patient and family ($n = 4$), likelihood of recommending the hospital ($n = 1$), and rating the overall experience on a scale of 0 to 10 ($n = 1$). For the third domain, we created 4 questions covering staff's attention to ASD-specific needs. These questions were based on our previous work looking at parent report of ASD-related needs during hospital visits and included questions about safety, staff communication, and sensory issues.⁸ Finally, we asked 5 questions about ASD-specific concerns during a hospital admission (eg, safety concerns, concerns about the

physical examination), which were also based on our previous work.⁸ Parents were asked to think only of their most recent hospital admission when responding. We determined reliability by using Cronbach's α . For questions relating to general hospital care (second domain), Cronbach's α was 0.65. For questions relating to autism-specific care (third and fourth domain), Cronbach's α was 0.55.

To rate a child's ASD severity, we convened a group of parents and ASD experts to create a severity score (SS) based on survey responses, specifically the 5 questions related to social communication, behavior, sensory processing, and safety. Each question had 5 to 10 options for accommodations that could be made, along with an open response option. The SS was determined to be "severe" if the family listed ≥ 2 accommodations and "mild" if the family reported < 2 accommodations. Examples of accommodations include avoiding bright lights, loud noises, or specific parts of the physical examination. We then created a severity variable for each patient, which was coded dichotomously.

Survey Sample Recruitment

In April 2014, parents of patients age 2 to 21 years with ASD who had a hospital admission from January 1, 2013 to December 31, 2013 were mailed a survey ($n = 142$). Three weeks after the initial mailing, nonrespondents received a follow-up phone call. A second mailing to nonrespondents was sent 1 month later.

Analysis

Provider Use of Care Plan in Patients With an ACP

Provider use of the ACP is presented as mean and SEM.

Comparison of Length of Stay and Safety Reports Between Subjects With and Without an ACP

A t test was used to compare length of stay in the 33 patients with an

ACP compared with the 109 patients without an ACP. Means and P values are reported. χ^2 analysis was used to test whether the percentage of patients with a safety report differed by ACP status.

Potential Covariates

Fisher's exact tests were performed to test the association between ACP status and potential covariates. Covariates with $P < .05$, along with the number of previous hospital admissions, were included in subsequent models.

Experience of Care

χ^2 analysis was used to compare both response rates and survey responses between all possible covariates and ACP and non-ACP groups. For purpose of analysis, questions were grouped into 4 domains as follows: general hospital experience (4 questions each on the 3-point scale of *yes, definitely, yes, somewhat, or no*), autism-specific experience (4 questions each on a 3-point scale of *yes, definitely, yes, somewhat, or no*), likelihood of recommending the hospital (1 question on a 7-point scale from *extremely likely to extremely unlikely*) and rating of the hospital from 0 to 10. Items in domains with > 1 item were summed. Multivariable linear regression was used to determine the associations of each experience of care domain score with ACP use while adjusting for covariates. B coefficients and P values are reported. Missing data were handled via listwise deletion. Regression analysis was done with SAS version 9.4 (SAS Institute, Inc, Cary, NC).

RESULTS

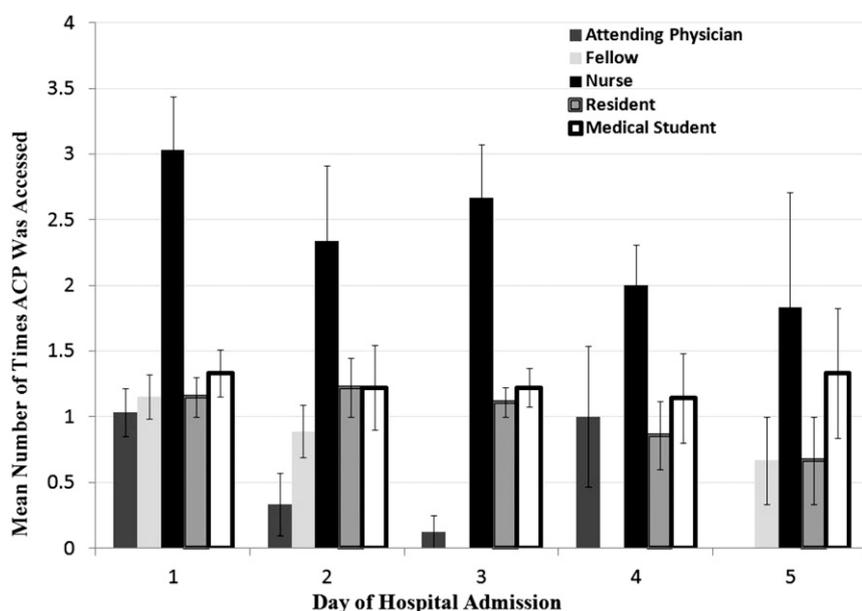
Subject Demographics

Of the 142 parents mailed a survey, 92 responded (65%). Most patients were white ($n = 77$), male ($n = 68$), and < 12 years of age ($n = 51$; Table 1). Response rates were similar between ACP and non-ACP groups (64.2% and

TABLE 1 Demographics of Survey Respondents

Characteristic	No ACP (n, %)	ACP (n, %)	P
Total	70	22	
Patient age			
2–11 y	36 (51.4)	15 (68.2)	.22
12–21 y	34 (48.6)	7 (31.8)	
Gender			
Male	51 (72.9)	17 (77.3)	.79
Female	19 (27.1)	5 (22.7)	
Race or ethnicity			
White non-Hispanic	59 (84.3)	18 (81.8)	.75
Nonwhite	11 (15.7)	4 (18.2)	
Insurance			
Private	28 (40.0)	8 (36.4)	.81
Public	42 (60.0)	14 (63.6)	
Admission diagnosis*			
Medical	32 (50.8)	21 (95.5)	<.001
Psychiatric	31 (49.2)	1 (4.5)	
Length of stay			
≤2 d	60 (85.7)	18 (81.8)	0.74
>2 d	10 (14.3)	4 (18.2)	
Autism severity*			
<2	50 (71.4)	10 (45.5)	0.039
≥2	20 (28.6)	12 (54.5)	
Previous admissions			0.13
<1	46 (65.7)	10 (45.5)	
≥1	24 (34.3)	12 (54.5)	

* $P < .05$ via Fisher's exact analysis for difference between no-ACP and ACP group.

**FIGURE 2**

Average number of times the ACP was accessed per patient per day by provider type according to hospital day ($n = 33$), mean and SEM.

69.7%, $P = .61$; data not shown) and did not differ by any demographic measured (patient age, gender, race or ethnicity, insurance type, admission diagnosis, length of stay, SS, or number of previous admissions).

Characteristics of ACP Group and Non-ACP Group

The ACP versus non-ACP group differed significantly by admitting diagnosis and SS by Fisher's exact

TABLE 2 Length of Stay and Safety Reports in Patients With and Without an ACP ($n = 142$)

	No ACP	ACP	P
Length of stay, mean d (SD)	1.8 (2.1)	1.6 (2.6)	.69
Safety reports (percentage of patients)	15.1%	13.8%	.84

$P < .05$ via t test analysis for difference between mean length of stay in control and intervention group and via χ^2 analysis for difference between safety reports in control and intervention group.

test (Table 1). Groups did not differ by patient age, gender, race or ethnicity, insurance type, length of stay, or previous admission.

Provider Use of ACP

All patients who had an ACP in their EMR had it accessed during their hospital admission (Fig 2). ACPs were most commonly accessed on hospital day 1. Accessing the ACP varied across patients and providers. Nurses were the most frequent users (mean 2.08 times per day, SEM 0.64), and attending physicians were least likely to use the ACP (mean 0.33, 0.48). The number of times an ACP was accessed in a single patient ranged from 1 to 49 times during a hospital stay.

Length of Stay and Safety Reports

No differences were seen in length of stay (ACP mean 1.6 days, SD 2.6 days; non-ACP mean 1.8 days, SD 2.1 days, $P = .69$; Table 2) or percentage of patients with a safety report between groups (ACP 15.1%, non-ACP 13.8%, $P = .84$).

Experience With ACP

All respondents reported that the ACP was easy to use and took <10 minutes to complete (data not shown). ACPs were completed by providers in 5 cases and parents in 17 cases. The majority of parents (88%) reported that the ACP "definitely" improved their hospital

experience compared with not having an ACP. Only 1 parent reported no improvement in their experience (data not shown). For respondents who did not have an ACP, the most common reason listed was that they “did not know it existed” (data not shown).

Comparison of Experience of Care

Parents with an ACP were more likely to report that staff “explained things in a way that was easy to understand” (ACP 100% *yes, definitely* vs non-ACP 80%, $P = .03$), “listened carefully” (ACP 91% *yes, definitely* vs non-ACP 69%, $P = .02$), and “helped your child deal with the fear or stress of being in the hospital” (ACP 68% *yes, definitely* vs non-ACP 37%, $P = .002$; Fig 3). When asked about autism-related care, parents with an ACP were more likely to report that staff asked “if there was a part of the physical exam that was not tolerable to your child” (ACP 77.3% vs non-ACP 44.3%, $P = .003$), “how your child expresses their needs/desires” (ACP 86.4% vs non-ACP 24.3%, $P \leq .001$), “if there was any sensory stimuli that is not tolerable to your child” (ACP 45.5% vs non-ACP 17.1%, $P \leq .001$), or “if your child had behaviors that might require staff assistance” (ACP 63.6% vs non-ACP 22.9%, $P = .003$; Fig 3). Experience of care did not differ by any other variables measured (including SS or admitting diagnosis, data not shown). In a multivariable linear regression model, parents who used the ACP reported better experience of care relating to their general hospital experience ($B = 1.48$, $P < .001$) and staff attention to the child’s ASD specific needs ($B = 3.07$, $P < .001$) compared with those without an ACP (Table 3). No differences were seen in rating of the hospital ($B = 0.64$, $P = .284$) or likelihood to recommend the hospital ($B = 0.15$, $P = .598$).

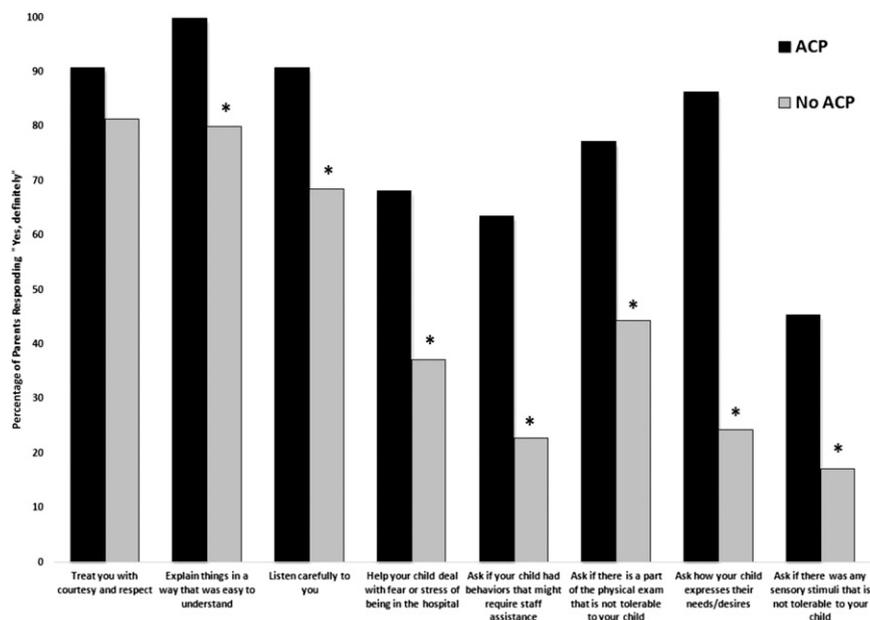


FIGURE 3 Survey responses by parents of children with and without an ACP ($n = 92$). * $P < .01$ by χ^2 analysis.

TABLE 3 Multivariable Models of Parental Experience With Hospital Stay in Patients With an ACP Compared With Those Without an ACP ($n = 92$)

	Univariate		Multivariable ^a	
	B Coefficient	P	B Coefficient	P
Overall rating of the hospital	0.36	.472	0.64	.284
Staff communication and responsiveness	1.04 ^b	.004*	1.48 ^b	<.001*
Attention to child’s individual needs	3.20 ^b	<.001*	3.07 ^b	<.001*
Likelihood of recommending hospital	0.39	.115	0.15	.598

^a Linear regression model adjusting for diagnosis at time of admission, autism severity, and number of previous hospital admissions.

^b Positive coefficient indicates better outcomes for ACP versus non-ACP.

* $P < .01$.

DISCUSSION

We hypothesized that an ACP would be feasible and acceptable to parents and that those who used the ACP would have a better experience of care than those who did not. We found that the ACP was used by multiple providers and received positive reviews from parents. In addition, parents with an ACP reported a better experience of care than those without an ACP. These findings suggest that care plans hold promise to improve the experience of care during hospital admission for patients with ASD and their families.

Although multiple studies document difficulty accessing medical

services for children with ASD,^{17–19} little work addresses hospital admissions specifically. To date, most interventions aimed at improving medical care for patients with ASD have focused on provider education. These interventions tend to be untested for effectiveness.^{20–22} Our intervention is novel in that it both increases physician knowledge and is personalized to each patient.

Our first aim of this pilot was to demonstrate feasibility. We found that when a patient had an ACP it was used frequently and in a timely manner, did not increase length of stay or safety events, and was well tolerated by parents who responded to our survey. One limitation is

that only 33 of the 142 patients admitted had an ACP (with only 22 responding to our survey). The most common reason listed by parents for not having an ACP was that they “did not know it existed.” Our primary recruitment approach was to train physicians to complete care plans in the office with patients. Contrary to this strategy, we found that the majority of ACPs were completed by parents online. A better implementation strategy may be direct-to-consumer marketing. In addition, we focused our staff training on physicians but found that nurses were more likely than physicians to open the ACP in the medical record. Therefore, a focus on training nurses may be more valuable.

Our second aim was to compare the experience of care for those who used the ACP with those who did not. We were surprised to find statistically significant differences given the small study population. One reason for unexpected significance may be the poor scores reported by the nonintervention group. To date, no studies documenting the patient experience during hospital admission specifically for people with ASD exist. Our data suggest that at baseline, parents may be having a poor experience of care in certain domains. For example, <50% of non-ACP parents responded “yes, definitely” to the question, “Did hospital staff help your child deal with the fear or stress of being in the hospital?” Studies show that some patients with a disability report worse experiences in the medical setting than patients without a disability.^{23,24} It is possible that patients with ASD, like those with a disability, are having a worse hospital experience than those without ASD. Therefore, our intervention to improve care could be creating a larger effect than initially anticipated.

Despite the differences in specific domains, overall rating of the

hospital was not different. This finding was also surprising given the large differences in individual domains. It seems that despite difficulties with autism-related care, patients still have an overall positive impression of the hospital. This finding may relate to parental expectations. If families do not expect hospital staff to address ASD-related needs, they may still give the hospital high ratings even if these concerns are not addressed.

The mechanism of effect of our intervention is probably multifactorial. Our intervention aims to increase both physician knowledge and patient engagement. First, increasing staff’s knowledge of a patient’s specific needs may allow the medical team to accommodate those needs, thereby improving the experience.²⁵ We did not measure whether specific accommodations were made based on the ACP’s recommendation. Second, filling out the ACP may help families prepare for a hospital visit (ie, increased patient engagement). This increased preparation may also improve their experience of care. Again, we did not measure patient engagement in this study. Third, reading the ACP may increase provider’s self-perceived competence in caring for patients with ASD. Studies show that low self-perceived competence is identified as a major barrier to providing care for children with ASD by medical providers.^{9,10} Increasing knowledge of a patient’s ASD may alleviate some of the providers’ concerns over competence and lead to better patient–provider interactions.

We also found that patients with more severe ASD by autism SS or who had a medical admitting diagnosis were more likely to have an ACP, although neither was associated with a difference in experience of care ($P = .56$ and $P = .34$, respectively; data not shown). One might expect that the reason for admission or autism severity correlates with the patient

experience, but we did not find this result in our data. We did not have a large enough intervention population to stratify into low and high SS for purpose of analysis. In future studies with a larger sample size, it would be important to determine whether autism severity influences the impact of the ACP.

There are several limitations to this study. Participants were not randomly assigned, and those who had an ACP were self-selected. The sample size was also small. Small size may be particularly limiting for our more rare outcomes, such as safety events. The population was not very diverse, and it is unclear what effect this intervention might have on a different demographic population. It is also important to note that a single investigator reviewed charts to determine eligibility and abstract data. We did not have sufficient staff to perform a validity check. The time lag between experience of a hospitalization and filling out the survey (range 3–15 months) is a significant limitation, and the survey was not previously validated and may need refinement. The SS is a novel measure, and no psychometric data are available. Finally, we did not work with psychiatrists or psychiatric units, which could help improve both the ACP and staff training.

CONCLUSIONS

ACPs show promise for improving the experience of patients with ASD and their families in the hospital setting. More rigorously designed trials are needed to determine whether these findings persist. Future work should include strategies for increasing use of the ACP. In addition, our team plans to conduct follow-up qualitative analyses of interviews with providers, patients, and caregivers to enrich our understand of the impact of the ACP on

medical decision making, quality of care, and patient and caregiver satisfaction.

ACKNOWLEDGMENTS

We acknowledge the MGHfC Quality and Safety Team, the Lurie Center for Autism, and the Autism Care Plan working group for their support. We also acknowledge Victoria Peake, MS, OTRL, Kimberly Kopecky, MD, Cindy Broder, OTRL, Katie Morris, SLP, Pamela Wrigley, RN, Pamela Bowers, MSW, LICSW, Jamie L. Rossi, CCLS, Clorinda Cottrell, MSW, Peter Greenspan, MD, John P. Co, MD, MPH, Kristen Solemina, MPH, Michael Silverstein, MD, MPH, and Eve Megargel for their contributions to this project.

ABBREVIATIONS

ACP: autism care plan
ASD: autism spectrum disorder
EMR: electronic medical record
MGHfC: MassGeneral Hospital for Children
SS: severity score

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DOI: 10.1542/peds.2015-2851R

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