

Background

Elopement behavior (EB), sometimes termed “wandering”, is emerging as a significant contributor to morbidity and mortality among individuals with Autism Spectrum Disorder (ASD). Causes of death among individuals with ASD who elope include drowning and traffic accidents. Prior investigations have established a high rate of elopement among children with ASD, ranging from 26% to 49%. To prevent elopement-related injury and death, parents implement a wide variety of environmental, behavioral, electronic, and pharmacologic interventions. What is not known, however, are the relative costs, effectiveness, burdens and side effects of these interventions among children with ASD.

Objective

To assess caregiver responses to EB among children and adolescents with ASD and co-occurring disorders such as ID, ADHD, and Language Disorder, as well as their perceived costs, effectiveness, and burden of use.

Methods

During 2015, parent participants in the Interactive Autism Network (IAN) — a large, validated (Lee et al., 2010; Marvin et al., 2014) and verified (Daniels et al., 2012), internet-mediated, parent-report autism research registry — were invited to complete the Elopement Patterns and Caregiver Strategies Survey about their children with ASD ages 4 or older.

Survey items included past and current patterns of EB, consequences of the behavior, parental responses and interventions attempted to prevent the behavior (including medications) or harmful outcomes, their perceived effectiveness, burden of use, and estimated costs.

Inclusion criteria:

- Completion of Elopement Patterns and Caregiver Strategies Survey
- Professional diagnosis of ASD
- Confirmatory Social Communication Questionnaire (SCQ) score ≥ 12
- Completed Social Responsiveness Scale (SRS)
- Completed Birth and Autism Diagnosis History questionnaire

Results

Total surveys completed = 1127; 867 met analysis inclusion criteria.

Demographic characteristics: Mean Age (SD) in Years: 11.5 (3.8); 81% male; 88% non-Hispanics; 89% white; income – 66% >\$50K/year.

Clinical Characteristics: SRS Mean (SD): 87.4 (13.7); 16% Intellectual Disability 16%; 31% Language Disorder; 42% Attention-Deficit/Hyperactivity Disorder; 10% Mood Disorder (any); 38% Anxiety Disorder (any); 21% Aggressive Behavior: 21%; 24% Self-Injurious Behavior.

Table 1: Caregiver Strategies to Prevent EB

Intervention	Ever Used	Effective ¹	Burden ²	Cost (\$) ³
Dead bolts	51%	68%	13%	1-100
Latches on door	49%	57%	18%	1-100
Behavioral specialist	41%	76%	18%	NA
Social stories	40%	49%	3%	0
Behavioral aide or 1 to 1 aide	39%	87%	16%	NA
Baby gates or other type of gate	36%	32%	28%	1-100
Swimming lessons	35%	72%	11%	100-500
Additional locks/keys on doors	31%	69%	28%	1-100
Headphones or earplugs	30%	69%	7%	1-100
Door alarms	29%	73%	23%	1-100
Window locks	28%	74%	13%	1-100
Door chimes or bells	25%	70%	11%	1-100
ID bracelet or shoe tag	24%	40%	8%	1-100
Visual prompts (e.g. STOP signs)	21%	21%	0%	0
Physical fencing	21%	81%	12%	100-500
Increased exercise	20%	46%	19%	100-500
Changed sleep routine	15%	51%	9%	1-100
Security system	14%	88%	15%	100-500
Wireless camera	12%	68%	5%	100-500
Medic Alert bracelet	8%	51%	12%	1-100
Window bars	7%	81%	25%	1-100
Cell phone with GPS	7%	53%	5%	100-500
GPS Tracker	7%	43%	31%	100-500
Temporary tattoo with ID	6%	48%	6%	1-100
Project Lifesaver bracelet	5%	72%	14%	1-100
Service animal	3%	87%	40%	500-1000
LoJack SafetyNet bracelet	1%	100%	0%	100-500

¹ “Good” or “Very Good”;

² “High” or “Very High”;

³ Median Cost Range (\$ in past 2 years); NA indicates intervention provided through insurance, school, or local agency

Support and Acknowledgements

This study was funded by the Wendy Klag Center for Autism and Developmental Disabilities, Johns Hopkins Bloomberg School of Public Health. IAN is a partnership project of the Kennedy Krieger Institute and the Simons Foundation. IAN is also partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award for development of the National Patient-Centered Clinical Research Network, known as PCORnet. A special thank you to IAN Families for making this study possible.

Table 2: Medications to Prevent EB

Medication	Ever Taken	Taken for EB	Effective ¹	Side Effects ²
Melatonin	186	10%	12%	4%
Risperidone	129	23%	13%	64%
Diphenhydramine	123	3%	7%	13%
Aripiprazole	83	23%	14%	55%
Methylphenidate	82	13%	13%	70%
Supplements/Alternatives	77	10%	13%	3%
Sertraline	68	19%	2%	40%
Guanfacine	65	25%	7%	31%
Fluoxetine	64	14%	0%	38%
Mixed amphetamine salts	46	13%	21%	60%
Clonidine	39	13%	12%	29%
Lisdexamfetamine	32	19%	19%	63%
Atomoxetine	32	16%	27%	23%
Divalproex	32	9%	13%	58%
Quetiapine	31	16%	14%	64%
Dexmethylphenidate	30	10%	14%	52%
Lamotrigine	29	3%	4%	48%
Escitalopram	29	7%	17%	30%
Clonazepam	26	4%	5%	45%
Lorazepam	24	29%	33%	43%
Citalopram	21	14%	7%	27%
Olanzapine	15	20%	9%	64%
Lithium	13	8%	0%	64%
Oxcarbazepine	13	0%	0%	57%
Carbamazepine	10	0%	14%	57%
Diazepam	10	10%	25%	38%
Alprazolam	10	30%	0%	25%
Mirtazapine	8	0%	0%	33%
Ziprasidone	7	29%	33%	33%
Benzotropine	7	0%	0%	33%
Paroxetine	6	17%	0%	20%
Lurasidone	4	25%	25%	25%
Dextroamphetamine	3	0%	0%	50%
Haloperidol	3	33%	50%	50%
Duloxetine	3	0%	0%	100%
Paliperidone	2	50%	0%	0%
Venlafaxine	2	0%	0%	0%
lloperidone	1	0%	100%	100%
Asenapine	1	0%	0%	100%

Results (Continued)

Rate of EB or prevention strategies used per Elopement Patterns and Caregiver Strategies Survey:

- No EB or prevention strategies used in last year: 499 (57.6%)
- EB up to daily or 1 success in last year: 269 (31.0%)
- Daily EB or 5 or more successes in last year: 99 (11.4%)

Elopement Patterns, Resources, Responses, Guidance

- Areas for EB: home (70%), parks/outdoor spaces (48%), stores (47%), and the classroom (41%)
- Causes of EB: crowde situation (44%), demanding situation like school (42%), enjoy running or exploring (40%), stressful situation (38%) noisy situation (38%), uncomfortable sensory stimuli (33%)
- Resources mobilized: school personnel (39%), neighbors (38%), police (19%)
- Caregiver responses: increased supervision (99%), avoid going certain places (79%), avoiding child’s special interest (44%), changing transportation methods (29%), sleeping inside child’s room (28%)
- Sources of advice about EB: autism advocacy organization (25%), local agency (22%), physician (12%), psychologist (8%), no advice (44%)

Elopement Prevention Strategies

- Caregiver strategies to prevent EB and negative consequences included a variety of physical, electronic, and behavioral interventions (see Table 1).
- Many environmental interventions such as locks, door alarms, security systems, and fencing were rated as highly effective.
- Security systems were rated as highly effective but more expensive, while GPS trackers were similarly expensive but rated as less effective and more burdensome.
- Aide services were rated as highly effective but generally provided through insurance, school, or local agencies rather than being paid for out of pocket.
- A variety of medications administered specifically to reduce EB or for other disorders were generally ineffective in reducing EB and had significant rates of side effects (see Table 2).

Conclusions

- Caregivers use a variety of intervention strategies to prevent EB and related injuries and death in youth with ASD. Environmental and behavioral interventions are generally rated as much more effective than medications in reducing EB.
- Clinicians should screen for elopement behavior in children with ASD and advise the use of inexpensive, easy to implement interventions such as locks, door alarms and dead bolts for children who elope. GPS tracking devices may be effective in some patients but more expensive and burdensome. Caution is indicated when prescribing medications off-label to reduce EB given parental reports of their poor effectiveness and side effect burden.
- Further study of interventions to prevent EB including their associated costs, effectiveness, and burden of use is indicated.