HHS Public Access

Author manuscript

J Autism Dev Disord. Author manuscript; available in PMC 2021 June 01.

Published in final edited form as:

J Autism Dev Disord. 2020 June ; 50(6): 2053–2063. doi:10.1007/s10803-019-03961-x.

Elopement Patterns and Caregiver Strategies

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Abstract

The Interactive Autism Network (IAN) administered a survey to caregivers of children with Autism Spectrum Disorder (ASD) on their interventions for elopement behavior (EB). Data from 526 respondents were analyzed. Most families reported multiple interventions for EB and rated interventions overall as effective but burdensome. Several interventions such as fencing and window locks had favorable effectiveness/burden profiles. Tracking devices were used infrequently and rated as having low effectiveness. Behavioral specialists were commonly used, rated as effective, and most often provided by insurance. Medications were rated as having low effectiveness for EB, whether taken off-label for EB or for other reasons. Further study is needed to identify EB interventions that are effective, affordable, and easy to implement are needed.

Keywords

Autism spectrum disorder; elopement; wandering; injury; mortality

Elopement behavior (EB), sometimes termed “wandering”, is defined as a dependent person leaving a supervised, safe space (National Autism Association, 2014). Recent epidemiologic studies have established that EB is common among individuals with Autism Spectrum Disorder (ASD), occurring in ¼ to ½ of those affected (Anderson et al., 2012; Kiely, Migdal, Vettam, & Adesman, 2016; Rice et al., 2016). In addition to being a significant source of stress for parents and caregivers, EB poses safety risks for individuals with ASD. In 2012, Anderson and colleagues reported that 65% of children with ASD who eloped and were missing long enough to cause concern had “close calls” with traffic injuries, while 25% were at risk of drowning (Anderson et al., 2012). Although the study did not report on deaths resulting from EB, numerous cases of drowning and deaths due to traffic accidents have

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There was no change in author affiliations during the study.

been reported by parent and community organizations (Lori McIlwain & Fournier, 2012). More recently, an epidemiologic study reported a 40-fold risk of drowning in individuals with ASD, lending further support to the potential link between EB and ASD-related mortality (Guan & Li, 2017).

Despite increasing awareness of the prevalence of EB and associated risks, little evidence is available to guide families and caregivers in dealing with the behavior (L McIlwain & Fournier, 2010). The majority of published research on EB to date has focused on behavioral treatments such as Applied Behavioral Analysis (ABA), in which a functional assessment of the behavior is conducted with the goal of identifying specific interventions targeted at reducing the behavior such as functional communication training, differential reinforcement of other behaviors, and noncontingent reinforcement (Boyle & Adamson, 2017). However, as reviewed by Lang and colleagues (Lang et al., 2009), the majority of studies on ABA as a treatment for EB have been of a small size and lacking in a clear experimental design. The review concluded that, although not “well-established” evidence-based practice, functional behavioral interventions were promising and might be effective.

In a more recent review of functional analysis and function-based treatments of EB by Boyle and colleagues (Boyle & Adamson, 2017), a total of only twelve studies totaling 20 subjects were found meeting criteria for review, and the authors concluded that “conclusions regarding effectiveness of treatments should be drawn tenuously.” The authors also noted that the nature of EB renders it difficult to study from a functional behavioral standpoint. Specifically, allowing elopement to occur in a clinical setting requires that the individual then be retrieved, potentially confounding the natural consequences of the behavior. Infrequently occurring EB may also preclude the ability to perform a functional assessment of the behavior during a time-limited outpatient visit.

Other interventions have also attracted interest in the treatment of EB. The advocacy organization, the National Autism Association has made available a comprehensive safety plan to prevent EB called the “Big Red Safety Toolkit” (National Autism Association, 2014), including a number of relatively inexpensive interventions such as door alarms, shoe ID tags, visual prompts and swimming lessons. However, evidence for these interventions is similarly limited. GPS tracking devices are portable and can rapidly alert caregivers when EB occurs. Cost may be a major barrier in the use of GPS devices, however, and there is limited data on their effectiveness and burden of use relative to other treatments (Hayward, Ransley, & Memery, 2016).

Finally, although there are no FDA-approved medications for EB and no professional body recommends the use of any medications for EB, it remains possible that in some cases, parents or caregivers, in consultation with healthcare providers, might use medications in an attempt to reduce the behavior. This could be due to viewing EB as a manifestation of an underlying disorder, such as impulsive behavior in a child with Attention-Deficit/ Hyperactivity Disorder (ADHD), or an attempt to leave a distressing situation in a child with elevated anxiety. Alternately, parents might have observed an improvement in EB after a child was started on a medication for another specific indication, and then view it as an effective treatment for EB despite not hypothesizing a reason for this improvement. To our

knowledge, no study to date has examined parent and caregiver attitudes and practices regarding the use of psychiatric medications for EB, despite the significant risks that many such medications carry.

Greater understanding of the relative effectiveness, cost, and burden of interventions being used by families and caregivers is essential so that healthcare professionals may provide preliminary guidance to families on ways to reduce their loved ones' risks in the absence of more definitive clinical trials. Although a variety of interventions for EB have been studied, as detailed above, studies have typically reported on only one intervention or variations on similar types of interventions, such as ABA therapies, and no studies to our knowledge have compared behavioral therapies and other kinds of interventions, such as environmental or electronic measures. The purpose of this study was to leverage IAN's unique ability to administer large-scale surveys to members of the ASD community in order to address this gap in our knowledge of comparative effectiveness, burden of use, and cost of the wide variety of interventions for EB being employed in the real world by families and caregivers.

Methods

Study Population

Participants in the Interactive Autism Network (IAN) research registry and database were invited to complete a questionnaire about their child/dependent's EB. IAN (https://iancommunity.org) is an internet-mediated research registry for individuals with ASD and members of their immediate family, including unaffected parents and siblings, with more than 55,000 individuals registered. Parents and children/dependents were consented into the IAN network registry and database on registration.

Sample

Families of children/dependents with ASD aged 4 and older were invited to complete the survey. Children/dependents under age 4 were excluded due the higher prevalence of EB among all children at younger ages (Anderson et al., 2012).

All IAN parent participants verify their child's prior receipt of a diagnosis of ASD made by a professional in the community and complete an online version of the Social Communication Questionnaire (SCQ) for verification of the diagnosis (Chandler et al., 2007; Daniels et al., 2012; Lee et al., 2010; Marvin et al., 2014). The SCQ is a validated screening instrument for ASD with scores ranging from 0 to 39; a cutoff of 12 is suggested for a child who is at risk for ASD (Rutter, Bailey, Lord, Cianchetti, & Fancello, 2007). Although ASD diagnoses are not independently confirmed, a prior IAN clinical validation study of 107 children who had community diagnoses of ASD and SCQ scores of 12 or higher demonstrated that 99% met criteria for ASD according to the Autism Diagnostic Interview – Revised (Lee et al., 2010). All IAN participants were required to have an SCQ lifetime score of 12 to be eligible for participation in the current study.

Measures

An elopement prevention questionnaire was developed in 2016 by the authors, and was active April 2016 through September 2016. The survey was assigned by email under the registry family profile to children ages 4-17 years and dependent adults >=18 years with ASD, totaling 13,508 families assigned. Of these, it is estimated that 72.79% were associated with currently active email addresses, based on IAN-wide participation statistics, for an estimated total of 9,832 assignments to active IAN participants.

Survey participants first completed screening questions asking if their child/dependent had either ongoing EB in the past 2 years, or, if not, whether the family was using any ongoing interventions to prevent EB in the past 2 years. Participants answering yes to either screening question were invited to complete the remainder of the survey on EB patterns and interventions.

EB Patterns

Participants were asked to select from one of seven options regarding the frequency that their child/dependent tried to leave safe spaces and/or the supervision of caregivers during the past year, with options ranging from less than once a month to many times daily. Participants were also asked to enter the number of times the child/dependent had succeeded in leaving safe spaces and/or the supervision of caregivers over the past year. Participants were next asked to select all that applied to from among a list of patterns associated with their child/dependent's EB, including 15 common locations (e.g. classroom, own home, stores), 15 perceived motivations for EB (e.g. too much energy, to gain attention, escape anxious situation), 11 types of environments (e.g. noisy, crowded, busy), and 5 observed styles of EB (e.g. sneaks, walks). For each set of EB associated patterns, participants could also select "other" or "none".

EB Interventions

They were then asked about a wide variety of interventions employed to deal with EB, totaling 35 in number. Interventions included several different categories: environmental modifications such as gates and locks, interventions to alert caregivers to an elopement in progress such as security cameras or alarms, IDs worn by the child/dependent to identify them in case of an elopement, tracking devices including GPS trackers. Interventions also included any behavioral specialist services (e.g. a psychologist employing ABA therapy) attempting to reduce the frequency of EB and individual behavioral aides to monitor the child/dependent and block elopement attempts, or the use of a service animal. Lastly, we asked about some interventions intended to reduce EB frequency (e.g. increased exercise, changes in sleep routine, social stories to help prepare individuals for transitions or other challenging situations, sensory interventions, STOP signs) or prevent adverse consequences of EB (e.g. swimming lessons to prevent drowning).

For each intervention, if participants reported ever having used it (yes or no), they were asked "how would you rate the effectiveness of [intervention]" and select an answer ranging from "Useless" to "Very Good", with responses then coded as an integer from 0 to 4. Similarly they were asked to rate burden of using the intervention, selecting an answer from

"No burden/hassle" to "Very High" burden, with responses coded as an integer from 0 to 5. Next, for each intervention used, participants were asked to estimate their out of pocket spending on that intervention over the last 2 years, selecting from one of 6 options ranging from 0 to $5000 or more, or select "Not applicable". Participants were asked to indicate whether there was a primary source of funding for the intervention other than out of pocket spending, selecting from "health insurance", "school", "grant funding", "local agencies", or "other". Finally, after rating each intervention individually, participants were asked to rate the overall effectiveness of their EB interventions as well as their overall burden of use according to the same scales above.

Medications

We inquired about the use of a total of 43 different medications, including medications for ADHD, antidepressants, antipsychotics, mood stabilizers, benzodiazepines, and over the counter medications. First, parents were asked if their child had ever taken any psychiatric medications or other medications intended to address problems with mood or behavior. If so, they were next asked to select from a list of the 43 medications any that the child had ever taken. Next, for each medication ever taken, they were asked whether it had ever taken specifically or partially to reduce EB. They were then asked to rate the medication's effectiveness for EB by selecting an option ranging from no observable effect up to a "very good" effect, with answers then coded as integers ranging from 0 to 5. Lastly, they were asked to rate the level of side effects by selecting an option ranging from no observable side effects up to a "very high" level of side effects, with answers coded as integers ranging from 0 to 5. Analyses were restricted to interventions ever used by 10 or more children/dependents.

Elopement Behavior

Frequency of elopement was coded as a variable for secondary analysis of the parent-reported effectiveness and burden or side effects of interventions and medications. Children/dependents with no EB but ongoing EB interventions were classified as having "no" EB, those with EB occurring less than once a week were classified as having "low" EB, and those with EB occurring once a week or more were classified as having "high" EB.

Sociodemographic and Clinical Characteristics

Child/dependent variables including age, gender, race, ethnicity, and household income were obtained from the IAN Research database. Social Responsiveness Scale (SRS) total raw scores were included as covariates in some analyses. The SRS is a validated rating scale for individuals with ASD aged 4 and older that measures the severity of ASD severity, with higher scores reflecting greater severity. (J. N. Constantino et al., 2003; John N Constantino & Gruber, 2007).

Parents were then asked to select any that applied to their child/dependent from a list of DSM-IV-TR (American Psychiatric Association, 2000) psychiatric diagnoses (Attention-Deficit/Hyperactivity Disorder, Oppositional-Defiant Disorder, Disruptive Behavior Disorder, NOS, Mood Disorder, NOS, Depressive Disorder, NOS, Major Depressive Disorder, Bipolar Disorder, Anxiety Disorder, NOS, Social Anxiety Disorder, Separation

Anxiety Disorder, Generalized Anxiety Disorder, Obsessive Compulsive Disorder, Intellectual Disability, Language Disorder) and challenging behaviors (self-injury, aggression, disruptive behavior). Lastly, parents were also asked whether their child/dependent's general knowledge, ability to understand concepts, and problem solving skills were at or above age level, below age level, or significantly below age level as descriptive measure of functional ability in the domain of cognition. They were similarly asked how often they were able to communicate their name and address as a descriptive measure of functional ability in the domain of communication, given the relevance of communication ability to safety during elopement attempts.

Statistical Analysis

Frequency of use and mean ratings of parent-reported effectiveness and burden for interventions and medications were calculated according to the ratings selected by parents. We then tested whether there were differences in the frequency of use, parent-reported effectiveness, and burden (or rate of side effects for medications) of interventions by the level of EB frequency and presence of parent-reported ADHD, Anxiety Disorder, NOS, or Language Disorder (LD). For these analyses, EB frequency was coded as none, low, or high. For secondary analyses, co-occurring psychiatric diagnoses were coded as present or absent. Chi-square tests, Welch's t-tests, and Goodman-Kruskal gamma statistics were calculated, as appropriate, for the comparison of proportions and means. Analyses were restricted to interventions ever used by 10 or more children/dependents to be adequately powered ($1 - B = 80\%$, $a = 0.05$) to detect a 2 SD difference in intervention ratings between two groups under Welch's two-sided t-test.

All statistical analyses were performed in R version 3.3.2 with base packages (R Core Team, 2016) and the package MESS version 0.5.2 for Goodman-Kruskal gamma statistics (Ekstrøm, 2018).

Results

Demographics and Clinical Characteristics

A total of 906 registrants out of approximately 10,000 active IAN participants assigned the survey responded, for an estimated response rate of approximately 9%, similar a recent IAN survey (Mazefsky, Yu, White, Siegel, & Pilkonis, 2018). Following removal of participants lacking a confirmatory SCQ, duplicate entries, and participants who did not complete the entire survey, a total of 867 respondents remained. Of the 867 respondents, 341 (39%) did not report any EB in the last 2 years or any EB interventions in the last 2 years, and were therefore ineligible to complete the remainder of the survey. Among the remaining 526 respondents who completed the survey and were included in the analysis, 386 (45%) reported ongoing EB in their child/dependent in the last two years with or without interventions, while 140 (16%) reported no EB but did report ongoing EB interventions.

There were no significant group differences in gender, race, or ethnicity between the 526 participants who were included in the analysis and the 341 who were excluded from the full survey; however, those included in the analysis had a significantly younger mean age

compared those excluded [included: $M = 10.9$, $SD = 3.5$ vs. excluded: $M = 12.5$, $SD = 3.8$; $t(755.82) = -6.25$, $p < 0.001$]. Severity of ASD symptoms, as measured by the SRS score was also significantly higher among those included in the analysis compared to those excluded [included: $M = 114.3$, $SD = 26.0$ vs. excluded: $M = 99.3$, $SD = 25.8$, $t(685.12) = 8.01$, $p < 0.001$].

Sociodemographic and clinical characteristics of the children/dependents with ASD who reported EB interventions are given in Table 1. The mean age of the children/dependents was 10.9 years, with 10 over the age of 17. They were predominantly male, white, and from households above the poverty line. SRS scores were available for all but 56 children/dependents. Overall severity of ASD symptoms was fairly high, as indicated by a mean SRS score of $M = 114.4$ ($SD = 25.6$), indicating a "severe" level of ASD symptomatology. Males ($M = 114.1$, $SD = 25.3$) and females ($M = 116.1$, $SD = 27.4$), were nearly 4 and 5 standard deviations from the SRS population mean, respectively (John N Constantino & Gruber, 2007). The majority of children/dependents were reported by parents to have some degree of intellectual impairment and nearly half were rarely or never able to communicate their name and address. The most common co-occurring diagnoses included ADHD (42%), LD (31%), and Anxiety Disorder, NOS (18%).

In terms of EB frequency, 118 survey children/dependents (22%) were coded as having "no" EB, 258 (49%) were coded as having "low" EB, and 150 (29%) were coded as having "high" EB. Greater EB frequency was strongly associated with the number of successful elopement attempts ($p < 0.001$) in the last year. For those with "no" EB, the median number of successful elopement attempts was 0 (range 0 to 2), while those with "low" EB had a median of 1 (range 0 to 200), and those with "high" EB had a median of 2 (range 0 to 500).

As shown in Table 1, those with more frequent EB tended to be younger ($p < 0.001$), have higher SRS scores ($p < 0.001$), were less able to communicate their name or address ($p < 0.001$), and had higher rates of diagnoses of Intellectual Disability ($p < 0.05$), LD ($p < 0.01$), and higher rates of challenging behaviors including aggression ($p < 0.001$), self-injury ($p < 0.001$), and disruptive behavior ($p < 0.001$). The relationship between EB and ADHD became significant, X^2 (1, N=526) = 4.36, $p < 0.05$) when those with low EB and high EB were combined and compared to those with no EB. Interestingly, the rate of Anxiety Disorder was significantly higher among those with low EB (24%) as opposed to no EB (12%) and high EB (13%), X^2 (2, N=526) =10.76, $p < 0.01$), and the same group was significantly more likely to have ever been prescribed benzodiazepines, X^2 (2, N=526) =11.61, $p < 0.01$). There was no difference in the likelihood of having taken medication for mood or behavior with increasing EB frequency.

We hypothesized that those with more frequent ASD might come to clinical attention at a younger age, and that this might confound our observed association between age and EB frequency. Therefore, we performed a post-hoc analysis to examine the potential for confounding between age and ASD severity as they related to EB frequency. In a multiple linear regression model, age was a significant predictor of EB frequency before ($B = -0.054$, $SE = 0.0079$, $p < 0.001$) and after ($B = -0.053$, $SE = 0.0083$, $p < 0.001$) adjustment for the SRS score, which was also a significant predictor ($B = 0.0057$, $SE = 0.0012$, $p < 0.001$).

EB Patterns

Across the entire sample, the most common areas reported to be associated with EB included the home (71%), parks or outdoor spaces (49%), stores or banks (47%), and the classroom (41%), while the least common were work settings (0.3%), day program (3%), summer camp (6%), and school grounds (6%). The most common motivations for the EB attributed by parents were trying to escape an anxious situation (43%), simply enjoying running or exploring (41%), escape from uncomfortable sensory stimuli (34%), times of transition (28%), and pursuing special interest (27%), while the least common were access to favorite foods (11%), a favored person (15%) or to gain attention (15%). The most common types of types of environments associated with EB included crowded (44%), stressful situations (39%), and noisy situations (38%), while the last common were dark (3%) and quiet (9%). The most common descriptions of the manner or way of EB included “bolts” (49%), “walks” (46%), “runs” (46%), and “sneaks” (31%), while the least common was “tiptoes” (3%). The number of patterns endorsed ranged from zero to 37, with a median of 11. The most strongly correlated patterns included escape from an anxious situation and stressful situations (0.52) and noisy situations and escape from uncomfortable sensory stimuli (0.49), and boring situations and feeling understimulated (0.43). Complete information on the frequency of endorsement of each EB pattern and their correlations are available as Online Resource 1.

Interventions for EB

Among all 526 respondents, 96% had ever used one of the listed interventions to prevent EB, and 94% had found at least one rated as “good” or “very good” in terms of parent-reported effectiveness. Parents rated the overall effectiveness of their EB interventions as “good” or “very good” 75% of the time, and 68% of parents rated the overall burden or hassle of implementing EB interventions as “high” or “very high”. The mean number of interventions ever used was 6.1 (SD 3.9), with an average of 3.7 rated as either “good” or “very good” in terms of parent-reported effectiveness. Median out of pocket expenditures for all interventions over the past two years was estimated by parents as between $500 and $999.

As shown in Supplemental Table 1, the most commonly used interventions were dead bolts (51%) and door latches (49%), followed by behavioral specialist services (41%), social stories (40%), and the use of an individual behavioral aide (39%). Among the least commonly used interventions used by 10 or more children/dependents were service animals (3%), Project Lifesaver bracelets (5%), GPS trackers (6%), and temporary tattoo IDs (6%).

The comparative parent-reported effectiveness and burden of use for EB interventions is depicted in Table 2. Excepting visual prompts, all interventions ever used by 10 or more children/dependents were rated as “adequate” or better, and none were rated as having a “high” or “very high” level of burden. Those with the best parent-reported effectiveness (“good” or “very good”) and low levels of burden included window locks, physical fencing, and individual behavioral aides. Of note, individual behavioral aides and behavioral specialists were both rated as “good” or “very good” but the most common source of funding for these was through the school district and insurance, respectively. Service

animals were rated as in the “good” to “very good” range of parent-reported effectiveness and had a “low” to “moderate” burden rating, but were the most expensive intervention, with an average out of pocket expense of $500 or more over the past 2 years. Interestingly, GPS trackers were rated as moderately expensive, with an average out of pocket cost of $100-499 over the past two years, but were only rated as “adequate” in terms of parent-reported effectiveness and were among the more burdensome interventions reported by parents.

Medications for EB

Forty-eight percent of all children/dependents had ever taken psychiatric medications. The median number of medications ever taken was five, and the median number of medications currently being taken was two. Overall, antipsychotics (29%) were the most common class of medication that children/dependents had ever taken for any reason, followed by antidepressants (25%) and ADHD medications (25%). Sixteen percent of all children/dependents had ever taken a medication specifically or in part to reduce EB. The most common medications ever taken specifically or in part to reduce EB were antipsychotics (27%), followed by ADHD medications (22%), and benzodiazepines (21%).

The parent-reported effectiveness of individual medications in reducing EB was universally low as shown in Supplemental Table 2. No medication was rated as better than “poor” on average in reducing EB. Side effects from medications were very common. Only melatonin, diphenhydramine, and the category “alternatives or supplements” were rated as having between “very low” and “no” side effects, with the majority of medications rated between “low” to “moderate” on average.

Effect of EB Frequency on Intervention and Medication Use, Parent-Reported Effectiveness, and Burden

Caregivers rated the overall effectiveness of their interventions to prevent EB as significantly worse with increasing EB frequency, decreasing from 3.48 among those with low EB to 2.67 among those with high EB ($p < 0.001$). The overall burden of interventions increased significantly with increasing EB, from 2.08 for those with no EB, to 3.34 for those with the high EB ($p < 0.001$). The mean number of interventions ever used for EB increased significantly with EB frequency, from a mean of 4.7 for those with no EB, 5.9 in those with low EB, to 7.4 for those with high EB ($p < 0.001$). The median overall out of pocket expense of interventions for EB over the last two years also increased significantly from a median of $100-499 for those with no EB, to $500 to $900 for low EB, to $5000 or more for those with high EB ($p < 0.001$).

As a secondary analysis, we examined whether there were differences between intervention use, effectiveness, and burden among those with high frequency EB but low rates of successful elopement versus those with high frequency EB attempts and high rates of successful elopement. Among those with high EB frequency, 75 (50%) had more than two successful elopements in the past year, while 75 (50%) had two or fewer successful elopements. Those with high EB but low successes did not report having tried a greater number of elopement interventions ($p > 0.05$), spending more on interventions ($p > 0.05$), or experiencing a greater overall burden of using interventions ($p > 0.05$) but did report their

interventions were overall more effective on average ($p < 0.001$) than those with high EB and high successes. Interestingly, there were no differences in frequency of use of any individual intervention between the two groups after correcting for multiple comparisons, but one intervention, deadbolts, was rated as more significantly more effective ($p < 0.01$) by those whose child/dependent had high frequency EB but low successes.

Effect of Psychiatric Diagnoses on Elopement Patterns, Intervention and Medication Use, Parent-Reported Effectiveness, and Burden

Among children/dependents with and without the three most common diagnoses reported by caregivers, ADHD, Anxiety Disorder, NOS, and LD, elopement patterns did vary by co-occurring diagnosis. After correcting for multiple comparisons, EB was more likely to occur when the child/dependents was described as having “too much energy” in children/dependents with ADHD (35%) compared to those without ADHD (17%), X^2 (1, N=526) = 20.471, $p < 0.001$. Environments described as “stressful” were more likely to provoke EB in children/dependents with Anxiety Disorder, NOS (57%) compared to those without (35%) X^2 (1, N=526) = 14.661, $p < 0.001$. Finally, EB occurring during times of transition was more likely to occur in those with LD (40%) than without LD (22%), X^2 (1, N=526) = 15.915, $p < 0.001$.

Caregivers of children/dependents with ADHD (28%) were more likely to have tried exercise to reduce EB compared to those without (15%), X^2 (1, N=526) = 11.252, $p < 0.001$, but there was no difference in parent-reported effectiveness for EB among those with or without ADHD. For Anxiety Disorder, NOS, there were no differences in frequency of intervention use or parent-reported effectiveness of any intervention between children/dependents with and without the diagnosis. For children/dependents with LD, caregivers reported more frequent use of three interventions: fencing (32% vs. 16%), X^2 (1, N=526) = 16.34, $p < 0.001$, additional locks (42% vs. 26%), X^2 (1, N=526) = 13.45, $p < 0.001$, and having an individual behavioral aide (51% vs. 34%), X^2 (1, N=526) = 13.35, $p < 0.001$. However there was no reported difference in parent-reported effectiveness of any intervention based on the diagnosis of LD. Finally, there was no difference in the parent-reported effectiveness of any medication for EB associated with the presence of ADHD, Anxiety Disorder, NOS, or LD.

Discussion

ASD is associated with an increased mortality rate. Prior epidemiological work has demonstrated some contribution of comorbid epilepsy and other neurological disorders (Gillberg, Billstedt, Sundh, & Gillberg, 2010; Guan & Li, 2017; Mouridsen, 2013; Schendel et al., 2016) to elevated mortality in ASD, but behavioral and environmental factors have been under examined as sources of risk. Emerging epidemiologic evidence suggests that EB may also be a contributor to increased mortality in ASD through mechanisms such as drowning and traffic accidents. Previous investigations (Anderson et al., 2012; Barnard-Brak, Richman, & Moreno, 2016; Kiely et al., 2016; Rice et al., 2016) of EB have focused on establishing its prevalence in the ASD population, understanding risk factors for the behavior, or establishing the effectiveness of specific behavioral treatments such as ABA. In

the current study, we sought to fill the knowledge gap on the perceived effectiveness, burden of use, and cost of a broad range of real-world interventions used by caregivers in dealing with EB.

Sample Characteristics

Demographic and clinical characteristics within our sample were generally similar to other studies of EB. Similar to the study of Anderson and colleagues (Anderson et al., 2012), our sample was primarily male, white, and higher-income. In contrast to that and other studies of EB, however, we did not find associations between EB and race, SES, or child/dependent gender (Anderson et al., 2012; Barnard-Brak et al., 2016; Kiely et al., 2016; Rice et al., 2016). However, our sample may have been underpowered to detect these associations.

The level of severity of ASD symptomatology in our sample was nearly identical to that of Anderson and colleagues, and ASD severity was associated with increased EB as reported in that and other recent studies of EB (Anderson et al., 2012; Barnard-Brak et al., 2016; Kiely et al., 2016; Rice et al., 2016). In our study, post-hoc analysis suggested that the association between younger age and EB frequency was not due to confounding between ASD severity and younger age. EB frequency in our study was also associated with ID, LD, and communication difficulties, similar to findings by Rice and colleagues (Rice et al., 2016), indicating comorbidity may be a marker for overall ASD severity.

Rates of Anxiety Disorder, NOS, Depressive Disorder NOS, ADHD, and functional impairment in learning and communication were similar to those reported by Anderson and colleagues (Anderson et al., 2012). We found a significant relationship between the presence of Anxiety Disorder NOS and EB, specifically low EB versus high or no EB in contrast to the other reports that did not show associations between EB and psychiatric diagnoses (Anderson et al., 2012; Barnard-Brak et al., 2016). This same group was also more likely to have ever taken benzodiazepine medications, which are commonly prescribed for anxiety. The novel finding of an association between EB and anxiety may be due to the fact that we distinguished between high and low levels of EB frequency. In addition, we found evidence of a relationship between ADHD and greater frequency of EB. Together with the findings that EB among those with Anxiety Disorder, NOS was associated with stressful situations, and among those with ADHD with having too much energy, our study offers preliminary support the idea that different patterns of EB may be associated with specific co-occurring conditions, including ADHD and Anxiety Disorder, NOS. Further study is needed to confirm or disconfirm these suggestive findings.

Interventions for EB

In terms of interventions for EB, our results are broadly encouraging in that nearly all families had found an intervention rated as effective for EB, with most reporting the use of multiple types of interventions, including physical barriers, tracking devices, and behavioral interventions. Unfortunately, there was a high rate of burden and significant out of pocket costs associated with these interventions across all children/dependents, with more frequent EB associated with a greater number interventions being used, and greater cost and burden. These results suggest that most caregivers combine interventions for EB, and individuals

with more EB require a greater number of interventions to be kept safe. The cumulative toll of providing these interventions is likely to add to the significant stress and cost borne by families dealing with EB (Anderson et al., 2012). Understandably, families may be eager for greater guidance on what interventions may be effective, affordable, and easy to use for their child.

As seen above, a few interventions stood out in terms of favorable profile of parent-reported effectiveness, burden, and cost. Both window locks and physical fencing were rated as moderately expensive were among the more frequently used interventions, indicating many families view them as worth the expense. Among those with high frequency EB, door latches appeared to be associated with greater success in limiting successful elopements, indicating this inexpensive intervention may be effective in preventing elopement, though it was associated with greater burden than some interventions. Other interventions with favorable profiles were used less frequently, possibly for different reasons. In the case of Project Lifesaver bracelets, lack of awareness is a plausible explanation, suggesting that clinician guidance may be useful in this area. For other interventions like service animals, the level of burden and expense may simply be too high for many families.

Applied Behavioral Analysis (ABA) therapy has been found to be an effective treatment for EB, with an effect size of 1.18 (Cohen’s d) after an average of 37 sessions reported in one recent study (Call, Alvarez, Simmons, Lomas Mevers, & Scheithauer, 2017). In our study, both individual behavioral aides and behavioral specialist services were rated by parents as highly effective. The most common sources of funding for these interventions were schools and insurance, respectively, rather than out of pocket spending, suggesting that access and the intensity of treatment required may serve to limit access despite the good ratings observed.

GPS technologies are an emerging area of interest (Hayward et al., 2016), but their effectiveness and cost-efficiency are not well established. We found that GPS trackers were used infrequently and rated as less effective than the majority of other interventions. Our results are similar to those of Kiely and colleagues, who reported that physical barriers were used six to ten times as often as electronic measures by caregivers seeking to prevent EB among children/dependents with ASD (Kiely et al., 2016). It is possible that expense and lack of awareness of their existence contribute to their low rate of use. More controlled studies of GPS trackers are needed to support their use as cost-effective interventions to prevent EB.

Medications for EB

There are no FDA-approved medications for EB, and psychiatric medications administered for EB may be both ineffective and expose the individual significant medical risks. Nonetheless, because of the possibility of that psychiatric medications might be administered to children/dependents in the hopes of reducing the behavior, whether due to viewing it as a manifestation of another disorder for which FDA-approval exists or not, we asked parents to report on their use of such medications, whether they were given for EB or another reason, and the perceived benefit of medications for EB as well as their side effect burden. Caregivers reported that off-label use of medications to prevent EB was generally

ineffective, and that most medications were associated with high rates of side effects. Although we did find associations between EB and ADHD, Anxiety Disorder, and LD, there was no evidence that any specific medication was more effective for EB in children/dependents with those disorders. Despite the surprisingly high rate of medication being used partially or specifically for EB observed here, we reiterate that off-label use of psychiatric medication for EB is not recommended by current clinical guidelines and is not supported by the findings of this study. We remind caregivers and providers that psychiatric medications carry significant risks.

Study Limitations

Some limitations of this study are worth noting, the most significant being that our findings are based on parent report rather than objective measurement. This may be true of parental observations of EB frequency, EB associated patterns, and the effectiveness of interventions for EB. First, parents may miss elopement attempts and episodes, particularly those occurring when the child is not in the parent's care, leading to inaccurate estimates of the frequency of the behavior. Attributions of cause or pattern related to the EB may also be subject to error. For example, a parent may attribute their child's EB to distress due to a change in routine, when in fact it is driven by desire to explore or seek a special interest. Although not possible in all cases, incorporating self-report data on the subjective experience of the child/dependent and their perceived motivations for EB would improve our understanding of the behavior. Parent attributions of the motivation of EB could also be influenced by what they have been told about their child by professionals or what diagnoses the child has been given. Furthermore, diagnoses received by the child could have been influenced by the presence and severity of EB itself. For example, a psychiatrist might be more likely to diagnose a child with ADHD if they engaged in more "impulsive" EB, or alternately diagnose them with an anxiety disorder if the EB appeared to be driven by distress. For this reason, we emphasize that our findings of different "subtypes" of EB are suggestive only, and in need of more controlled study.

Parent reports on the effectiveness of interventions are likely to be subject to biased reporting and recall to some degree. Perhaps the greatest potential source of bias stems from the fact that the intended effect of an intervention for EB is the absence of an event rather than the presence of an event, making assessment of effectiveness inherently difficult. Some the interventions assessed may also be simply easier to rate accurately than others. For example, it may be relatively easy to tell if a GPS tracking device has fulfilled its purpose in locating a missing child, but harder to determine if increased exercise or a change in sleep routine has reduced EB. Additionally, in the interest of maximizing their child's safety, many parents employ multiple interventions for EB, but at the potential cost of increased difficulty in determining which among them should be credited to a greater or lesser degree if the behavior improves.

We note as a limitation that we did not ask parents to distinguish between different types of behavioral specialist services employed in preventing EB. These could include the services of an expert trained in behavioral analysis tasked with functionally assessing the behavior, a person involved in implementing such a plan in the home or school setting, or a psychiatrist

primarily involved in medical management of a co-occurring condition such as ADHD. Although not all parents may be able to fully distinguish between these roles, more specific questions about subtypes of behavioral specialist services would have been helpful in interpreting our results.

Similarly, we note as a weakness that we did not ask parents to distinguish between the differing mechanisms that interventions may operate by when rating their effectiveness. All interventions were assessed using an identical question ("how would you rate the effectiveness of [intervention]") without asking parents to clarify whether the intervention was intended to reduce EB attempts, blocked attempt, alert caregivers of the event, or mitigate risks of EB such as drowning. For some interventions, there may be dual effects. For example a lock may both prevent a door from opening and discourage future attempts. However, we are not able to examine this possibility in the current study.

As a cross-sectional survey study, it is also important to appreciate that our correlational analyses have limited ability to determine cause and effect. For example, although we found that greater EB frequency was associated with lower ratings of the effectiveness of interventions overall, it is not clear whether interventions work less well for those with more severe EB, or whether parents are more likely to view EB as severe if interventions are not working well.

Lastly, our sample is not representative of all individuals with ASD and EB. Those who responded to our survey had children/dependents who were younger and had more severe ASD on average, consistent with prior reports that EB is more severe among those groups. Future studies may wish to examine the EB among children with ASD under the age of 4, as the fact that EB is more normative in that age range may lead to differing parental responses and strategies. We also note that the majority of children/dependents participating in this study were white and had higher household incomes than the general population, which may also limit generalizability. For example, some more expensive interventions such as security systems are likely to be less accessible to families with lower incomes, while others like window bars may be more familiar to those living in low-income neighborhoods and for that reason more likely to be used. Finally, we note that the current study was focused primarily on children/dependents living at home with their parents, and does not address challenges in preventing EB in adults or those living in group homes.

Conclusions

Emerging epidemiological evidence has demonstrated the high prevalence of EB and a markedly increased risk of injury and drowning in the ASD population. Numerous reports from parents and ASD advocates suggest a direct link between EB, drowning, and other accidents. Prevention of EB in the ASD population appears to be a critical factor in preventing injury and death in the ASD population, but there is little evidence on the optimum approach among a broad range of interventions used by parents to prevent EB.

This study, based on real world caregiver experiences, provides support for relatively inexpensive and simple environmental modifications like window bars and fencing as cost-

effective interventions that can be recommended by clinicians. Going forward, controlled studies of the effectiveness, burden, and relative costs of specific interventions are needed to inform families and allow clinicians to make evidence-based recommendations on interventions that will be effective, feasible, and affordable for most children/dependents with EB. Research into specific barriers to implementation such as cost, insurance access, and awareness of EB interventions is also needed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

We acknowledge the individuals with ASD, their families, the researchers, and the health care professionals who make the Interactive Autism Network possible through the generous contribution of their time and effort.

This work was supported by National Institutes of Health grants T32MH019113 (Andersen), T32MH014592 (Andersen), and K12DA000357 (Andersen).

The Interactive Autism Network is a partnership of Kennedy Krieger Institute and the Simons Foundation. Research reported in this article was partially funded through a Patient-Centered Outcomes Research Award (PCORI/PPRN-1501-26462). The opinions in this article are solely the responsibility of the authors and do not necessarily represent the views of the Patient Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee or the National Institutes of Health.

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Table 1.

Sample characteristics by frequency of EB

Sociodemographic characteristics	Total Sample (n=526)	No EB (n=118)	Low EB (n=258)	High EB (n=150)	P Value
Child age, mean (sd)	10.9 (3.8)	12.2 (3.7)	11.2 (3.5)	9.2 (3.6)	< 0.01
Child gender					
Male, n (%)	431 (82)	99 (84)	210 (81)	122 (81)	0.61
Female, n (%)	95 (18)	19 (16)	48 (19)	28 (19)	
Race, n (%)					
White	399 (76)	92 (78)	200 (78)	107 (71)	0.18
Non-White	127 (24)	26 (22)	58 (22)	43 (29)	
Household income, range (%) (n=466)					
< $30,000	86 (18)	24 (26)	29 (13)	33 (23)	
$30,000 - $60,000	118 (25)	27 (29)	56 (24)	35 (25)	0.51
$60,000 - $90,000	104 (22)	16 (17)	67 (29)	21 (15)	
> $90,000	158 (34)	27 (29)	79 (34)	52 (37)	
Clinical Characteristics					
SRS score, mean (sd) (n=486)	114.4 (25.7)	108.0 (26.6)	113.1 (25.2)	122.0 (23.9)	< 0.01
Functioning Characteristics					
Intellectual impairment, n (%) (n=523)					0.07
at or above age level	164 (31)	38 (32)	84 (33)	42 (28)	
below age level	187 (36)	48 (41)	90 (35)	49 (33)	
significantly below age level	172 (33)	31 (26)	82 (32)	59 (39)	
Unable to communicate name/address, n (%)					
rarely or never able to communicate	230 (44)	38 (32)	95 (37)	97 (65)	< 0.01
Co-Occurring Conditions, n (%) (n=526)					
Attention-Deficit Hyperactivity Disorder	220 (42)	39 (33)	113 (44)	68 (45)	0.05
Oppositional-Defiant Disorder	39 (7)	8 (7)	21 (8)	10 (7)	0.91
Disruptive Behavior Disorder, NOS	23 (4)	3 (3)	12 (5)	8 (5)	0.26
Mood Disorder, NOS	29 (6)	4 (3)	16 (6)	9 (6)	0.36
Depressive Disorder, NOS	21 (4)	5 (4)	14 (5)	2 (1)	0.10
Major Depressive Disorder	2 (0)	0 (0)	1 (0)	1 (1)	0.360
Bipolar Disorder	7 (1)	1 (1)	5 (2)	1 (1)	0.73

Sociodemographic characteristics	Total Sample (n=526)	No EB (n=118)	Low EB (n=258)	High EB (n=150)	P Value
Anxiety Disorder, NOS	95 (18)	14 (12)	61 (24)	20 (13)	0.95
Social Anxiety Disorder	31 (6)	7 (6)	17 (7)	7 (5)	0.59
Separation Anxiety Disorder	26 (5)	5 (4)	12 (5)	9 (6)	0.50
Generalized Anxiety Disorder	55 (10)	13 (11)	28 (11)	14 (9)	0.63
Obsessive Compulsive Disorder	79 (15)	14 (12)	43 (17)	22 (15)	0.59
Intellectual Disability	85 (16)	13 (11)	42 (16)	30 (20)	< 0.05
Language Disorder	164 (31)	24 (20)	86 (33)	54 (36)	< 0.01
Insomnia	26 (5)	8 (7)	13 (5)	5 (3)	0.20
Aggressive Behavior	107 (20)	13 (11)	49 (19)	45 (30)	< 0.01
Self-Injurious Behavior	124 (24)	14 (12)	63 (24)	47 (31)	< 0.01
Disruptive Behavior	89 (17)	7 (6)	45 (17)	37 (25)	< 0.01
Ever Taken Meds for Mood or Behavior, n (%) (n=526)	255 (48)	53 (45)	139 (54)	63 (42)	0.46
Ever Taken ADHD Meds, n (%) (n=526)	129 (25)	25 (21)	69 (27)	35 (23)	0.78
Ever Taken Antipsychotic , n (%) (n=526)	153 (29)	27 (23)	82 (32)	44 (29)	0.30
Ever Taken Mood Stabilizer , n (%) (n=526)	54 (10)	4 (3)	32 (12)	18 (12)	0.02
Ever Taken Antidepressant , n (%) (n=526)	134 (25)	28 (24)	79 (31)	27 (18)	0.15
Ever Taken Benzodiazepine, n (%) (n=526)	52 (10)	8 (8)	37 (14)	7 (5)	0.24

Table 2.

Effectiveness, burden, and out of pocket spending over the last 2 years for EB interventions. Numbers in parentheses indicate frequency of use as a percent.

Effectiveness	Good/Very Good	* Individual behavioral aide (39)	* Behavioral specialist (40)
		$$$ Window locks (27)	$$$ Swimming lessons (35)
		$$$ Physical fencing (21)	$$$ Security system (13)
			$$$ Window bars (7)
			$$$$ Service animal (3)
	Adequate	$ Social stories (39)	$$ Latches on door (48)
		$$ Dead bolts (50)	$$ Baby gates/other gates (35)
		$$ Headphones (30)	$$ Additional locks/keys on doors (30)
		$$ ID bracelet or shoe tag (24)	$$ Door alarms (28)
		$$ Door chimes or bells (24)	$$ Changed sleep routine (15)
		$$ Temporary tattoo with ID (6)	$$$ Increased exercise (20)
		$$ Project Lifesaver (5)	$$$ GPS Trackers (6)
		$$ Medic Alert bracelet (7)	
		$$$ Cell phone with GPS (7)	
		$$$ Security cameras (12)	
Burden		None/Very Low	Low/Moderate

Coding for cost of interventions:

$ None

$$ 0-99

$$$ 100-499

$$$$ 500 or more

* Paid for by school or insurance