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Focus Autism Other Dev Disabl published online 18 January 2013
DOI: 10.1177/1088357612472932

The online version of this article can be found at:
http://foa.sagepub.com/content/early/2013/01/18/1088357612472932
A more recent version of this article was published on - Jul 24, 2013
Home Sweet Home? Families’ Experiences With Aggression in Children With Autism Spectrum Disorders

Sandra Hodgetts, PhD¹, David Nicholas, PhD², and Lonnie Zwaigenbaum, MD¹

Abstract

Although not inherent to the diagnosis, many individuals with autism spectrum disorders (ASD) display aggressive behavior. This study examined the experiences of families living with individuals with ASD who also demonstrate aggressive behaviors. Using a qualitative approach, semistructured interviews were conducted with parents of nine males with autism and aggression. Eight families’ homes also were observed. Through constant-comparison analysis of interview data, triangulated with home observations, three central processes were identified: deleterious impact on daily routines and well-being of family members, limited supports and services, and financial strain. Emergent themes included isolation, exhaustion, safety concerns, home expenses, respite needs, and limited professional supports and alternative housing. Examination of families’ experiences living with someone with ASD who is aggressive, and the impact of aggression on the supports and services that families receive, constitutes an important step in tailoring resources to best meet families’ needs.

Keywords

autism, aggression, family life

Although not inherent in autism spectrum disorders (ASD), aggressive behaviors commonly occur in individuals with ASD (Farmer & Aman, 2011; Kanne & Mazurek, 2011). There is little consensus of a definition of aggression and how to measure it, although the perception of causing intentional distress or harm is consistent across most definitions. The prevalence of aggression is higher in individuals with ASD compared with those with other developmental disabilities or the general population (Matson & Rivet, 2008). Furthermore, aggression is more prevalent in individuals with more severe symptoms of ASD (i.e., autistic disorder vs. pervasive developmental disorder—not otherwise specified; Matson, Wilkins, & Macken, 2009). Specifically, increased rates of aggression against others and property destruction have been most commonly reported, with rates for these aggressive behaviors reported to occur in up to 68% of individuals with ASD at some point in their lives (Lecavalier, 2006).

Predictors of aggression in individuals with ASD are not well understood (Kanne & Mazurek, 2011). It has been postulated that aggression in individuals with ASD may stem from social difficulties resulting in frustration and difficulties with communication (Simpson & Myles, 1998), or from deficits in theory of mind (Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007). Regardless of the cause, aggression can profoundly influence the daily lives of individuals with ASD and their families. If left untreated, challenging behaviors, including aggression, are likely to continue into adulthood, becoming more severe over time (Horner, Carr, Strain, Todd, & Reed, 2002; Murphy et al., 2005). Aggression can be physically dangerous to the individual with ASD and others in the environment, limit access to treatment, interfere with learning, reduce opportunities for interpersonal relationships, increase hospitalization rates, and impede participation in everyday activities. In addition, aggressive behavior is the leading cause of residential placement, although, paradoxically, it also can limit access to respite and residential programs (Mandell, 2008; Matson & Nebel-Schwalm, 2007).

The presence of aggression in a child with ASD is the strongest predictor of parental stress, above and beyond other child and caregiver factors, and also results in increased social isolation and feelings of stigmatization (Gray, 1993;
Gupta & Singhal, 2005). This increase in parental stress due to aggression is significant because families of children with ASD without aggression already are at increased risk for stress, depression, and marital discord, and experience decreased social support, parenting satisfaction, and confidence compared with the general population and parents of children with other disabilities (Estes et al., 2009; Gabovich & Curtin, 2009). Furthermore, families provide the majority of care for youth with ASD, and stressed parents are more likely to respond to their children in ways that exacerbate or reinforce problem behaviors (Hastings, 2002). This response can foster a downward spiral involving a chain of actions and reactions in which circumstances get progressively worse.

Although to date researchers have found that challenging behaviors, including aggression, increase parental stress, there is limited research about how aggression affects the daily experiences of families living with an aggressive individual with ASD. This calls for an exploratory examination of (a) the experiences of family members who are living with someone with ASD and aggressive behavior and (b) the impact that aggression has on the supports and services the families receive. This study examined the perceptions and experiences of parents of a child, adolescent, or adult with ASD and aggression, grounded in real-life experiences. Research aims included an examination of how aggression influenced (a) the daily lives of families and (b) the supports and services that the individual with ASD and his or her family received.

Method

Research Design

This study was conducted as part of a larger mixed-methods study (in progress) that incorporates questionnaire data and grounded theory methodology to investigate the processes by which families navigate systems of care for their children with ASD. A grounded theory approach is ideally suited to studies that explore social processes, particularly when there is little prior research on the topic (Strauss & Corbin, 1998).

Following convention in qualitative research, rigor was demonstrated by established methods of trustworthiness and authenticity, including critical reflective dialogue with colleagues about the research process and data, prolonged engagement by team members immersed in autism, negative case analysis, and member-checking (Charmaz, 2006). These steps to establish rigor are explained in more detail under the section titled “Data Analysis.”

Recruitment

Ethical approval was obtained through the Health Research Ethics Board of the institution through which this research took place. Potential participants included parents of 3- to 29-year-old individuals with ASD living in an urban area in Western Canada, with a population of approximately 1 million people. Participants were informed of the larger study through an email listserv accessed through this city’s Autism Society. Interested families contacted the researchers and were provided with further study information. Families that participated gave informed consent. Pseudonyms are used in reporting the results to protect confidentiality.

Participants

A total of 15 families were recruited for the larger study. Of those 15 participants, 9 (60%) discussed the impact of aggression on their daily lives and experiences with supports and services. Thus, the final sample included parents of 9 individuals with an ASD. All of the individuals with ASD and aggression were male, ranging in age from 6 to 29 years, with 7 children between 6 and 10 years of age, 1 young adult who was 19 years old, and 1 adult who was 29 years old. Five of the 9 individuals with ASD, including the 29-year-old adult and 4 children, were diagnosed with autistic disorder (hereafter referred to as autism). Based on parent report, 3 of these 5 individuals had some functional language, 2 did not have functional language, and all had moderate to severe intellectual disability. The other four individuals with ASD were diagnosed with Asperger syndrome, had mild or no intellectual impairment, and demonstrated conversational language skills.

The person who self-identified as the primary caregiver (eight mothers, one father) participated in all interviews, and a spouse also participated in four interviews. All families’ self-identified cultural background was North American Caucasian. Eight children with ASD resided full-time in the family home, and one individual with ASD resided in the family home 3 days per week and in supported housing (outside the family home) for the remainder of the week. Six families included two biological parents, one was a single-father, and two families were blended. All participants’ had at minimum a high school level education, and annual income was in the CAD$40,000 to $60,000 range for one family, $60,000 to $100,000 range for one family, more than $100,000 for five families, and not reported for two families. Four of the families included at least one sibling living at home.

Data Collection

An in-depth, face-to-face, semistructured interview lasting 1.5 to 2 hr was conducted with each family. A postdoctoral research fellow with prior experience in qualitative interviewing and experience working with families with children with ASD conducted all interviews. An interview guide outlined broad, open-ended questions, which allowed participants the opportunity to describe their perceptions.
and experiences while ensuring common coverage of topical areas between interviews. Although all nine parent participants included in this analysis discussed the impact of their children’s aggression on their daily lives and on the supports and services they received, none of the interview questions specifically asked about aggression. For example, questions included “How has your child’s diagnosis of autism affected your social life?” or “What challenges have you had accessing supports and services?”

The interviewer also observed the home environments of eight families. All of these families were keen to take the interviewer on a tour of their homes to show her examples of property destruction and adaptations that had been made to their living environment. The ninth participant, for whom the interview took place at a restaurant, stated that the interview was not conducted at her home because “we try not to have people to our house because we are pretty embarrassed about our damaged house.”

Data Analysis

Interviews were audiotaped and subsequently transcribed verbatim by a professional transcriptionist, with names and other identifiers removed. The interviewer then checked all transcripts for accuracy. Interview transcripts were content analyzed using constant-comparison methods consistent with a grounded theory approach (Creswell, 1998; Strauss & Corbin, 1998). A hard copy of each transcript was open coded through line-by-line coding by one of three team members (postdoctoral fellow and two graduate-level research assistants with interests and experience in similar substantive areas). Open coding searches for meaning in the data that emerge by identifying naturally occurring categories depicted by participants (Charmaz, 2006; Strauss & Corbin, 1998). Terms that appeared to refer specifically to experiences of dealing with aggression (in vivo codes, for example, temper, crisis) were documented, and the electronic copy of each transcript was searched for every mention of these terms. Phrases that contained in vivo codes were labeled to reflect concepts of dealing with aggression with a more descriptive code (e.g., safety, expenses, exhaustion). Consistent with the emergent nature of qualitative research methods (Schwandt, 2007), codes were refined and coded concepts were clustered into themes, depicting the perceptions and experiences of families living with individuals with ASD who were aggressive. Triangulation of data, including information from home observations, memos, codes, frequency of occurrences, and interview quotes provided corroborating evidence for established themes (Creswell, 1998).

The three team members met regularly during initial analysis to review and verify codes and themes, and any disagreements were resolved through discussion so consensus was achieved at this level of analysis. Broad processes, themes, and codes were then presented to the entire research team for review and discussion (including the second and third authors), and consensus was achieved. Member checking was done in the form of clarification probes throughout each interview to ensure that the interviewer understood the information as the participant intended (Rubin & Rubin, 2005), by asking questions such as “Are you saying . . . ?” or “Can you please provide an example of . . . ?” In addition, the nine families included in this analysis were sent an email that provided a summary of emergent themes, which was followed by a phone call from the first author to check whether the experiences and viewpoints expressed in their interview were accurately represented. All participants agreed with the themes obtained by the research team.

Results

The impact of living with someone with ASD and aggression involved three processes, which occurred simultaneously:

1. impact on the daily routines and well-being of immediate family members,
2. financial strain, and
3. availability and access to supports and services.

Key themes were social isolation; exhaustion; safety of people and property; out-of-pocket expenses for repairs and home adaptations; the immense need for, but lack of, respite; limited availability of professional supports to decrease or deal with aggression; and the assumption that the individual with ASD will live with the parents for an extended period of time because of a lack of appropriate and safe alternatives. Each of these processes and themes is discussed in turn, illustrated with examples drawn from the interviews. Although these themes have been presented independently, their interconnectedness is acknowledged.

Impact on Family

Participants in all interviews described a range of difficult experiences in living with a child, adolescent, or young adult with ASD who was aggressive, centering on the themes of isolation, exhaustion, and personal safety for parents and siblings.

Isolation. Participants in all interviews discussed feelings of isolation attributed to aggressive behaviors in their children with ASD. They highlighted their perceived inability to go out in their community, socialize, or take holidays, both as a family unit and without their child (due to lack of alternate care), because of the aggression. All parents talked about ensuring that their homes were relatively safe environments by eliminating or hiding breakable and sharp items. However, eight parents also talked about their inability to visit
other people’s homes, even close friends or family, because of safety issues. For example, Alice, the parent of Alex, a 10-year-old boy with autism, reported, “You don’t want to go visit friends and spend your whole time keeping your kid out of trouble because then you’re not visiting.”

Five families also experienced isolation because they avoided social situations in general due to their children’s aggression because of feelings of shame or fears for the safety of other people or their property. For example, Beth, the mother of Brian, a 19-year-old with Asperger syndrome, stated that she has never accepted her extended family’s frequent offers to stay with Brian so she and her husband could go out because “I don’t want them to see that side of him.” This is despite her acknowledgment of needing a break from her son. For example, Beth stated, “We’ve had times where Brian’s aggression has gotten so bad that I’m just about ready to be locked up.”

**Exhaustion.** As reflected in Beth’s previous statement, participants acknowledged feeling physically and emotionally exhausted, to a large extent attributed to the aggression of their children with ASD. This was reflected in all interviews. Parents used descriptors reflecting that the impact of aggression was “constant” or “never ending” and that the “cumulative fatigue was almost unbearable.”

Exhaustion related to the cumulative demands of having a child with ASD who was aggressive was especially apparent in Mary’s interview, whose adult son with autism, Mark, has displayed extremely disruptive behaviors, including severe aggression, for most of his life. Mary suffered from cumulative sleep deprivation, stating, “We never slept. You’re always listening for him. He was a wanderer, and would get into trouble and light fires and leave and unlock the house.”

The other eight families also talked about the exhaustion of always having to be “on,” referring to the need to be constantly vigilant. For example, Jane, the mother of four young children, including a 7-year-old boy with autism, stated, “You always have to be there. To avoid damage, you have to grab him, and you have to be super fast.” Kate and Keith, parents of a 6-year-old boy with Asperger syndrome, also suffered sleep deprivation, reporting that they slept in shifts at night so someone could monitor their son, who did not sleep through the night. They also discussed the impact of his aggressive behavior on their ability to socialize, stating, “We go to family get-togethers, and their kids just run around, the parents are drinking wine and not paying attention, and the two of us, they’re like, ‘you need to relax.’ We can’t. We literally have to be there around our kids for safety.”

**Safety.** Five families, including Kate and Keith, talked about the effects of their children’s aggression on the safety of personal items and property. In addition to this type of damage, two of the families dealt with significant physical aggression toward family members, which they identified as the most difficult part of living with their children. Eleanor and her family were in such a dangerous living situation that friends suggested that it was not safe for Emmett, their 10-year-old boy with autism, to live with them any longer. However, Eleanor stated, “I can’t even get my head around that, because that’s not an option for me. If there came a time where I was forced into that—say he stabbed [his sibling]—that’s a different story.” The day prior to the interview, Emmett had hit his sibling quite hard, and Eleanor reported, “He can’t even be in the same room with [his sibling]. We can’t eat dinner together.” The emotional toll of Eleanor’s struggles with Emmett’s aggression and his sibling’s safety was very obvious during the interview. She became teary on many occasions when talking about the impact on her other child, and when asked her hopes for the future, Eleanor’s statement reflected that they lived in a war zone: “My hope is just that we can get Emmett to a point that he can function with a little bit of peace in his life, that [his sibling] can find that peace, and we can find that peace in our life.”

**Impact on Supports and Services**

Interestingly, even though Eleanor and her family were living in a “war zone,” and acknowledged that they required professional help, their multidisciplinary home-based supports were discontinued because of their son’s aggression. They were informed that Emmett was not an appropriate candidate for home-based services because the strategies professionals had previously tried were not effective in decreasing his disruptive behaviors; thus, it was not a safe or productive working environment for home-based services. Participants across interviews also conveyed negative impacts of aggression on their experiences with, and access to, formal supports and services for their children with ASD and their family. Concerns regarding supports and services focused on the lack of respite care, other professional supports specifically intended to help deal with aggression, and appropriate alternative housing for young adults with ASD who are aggressive.

**Respite care.** All participants talked about an immense need for, but an inability to access, respite care. Participants indicated that respite care in general was hard to access, but was made significantly more difficult to find or maintain because of their children’s aggression. This lack of respite care was reportedly due to both a lack of appropriate caregivers and a perceived lack of adequate funding by the government. Five participants reported trying multiple methods to find respite care, including advertisements through free on-line services, paid newspapers, postings at the local university and community college, postings at local grocery stores, and
word-of-mouth through friends or acquaintances, reporting that the seemingly constant search and the lack of consistency were exhausting. For example, Alice stated, “I just sort of gave up. It seems like we go back to not having workers no matter how you do it.” Jane, whose son was 7 years old, reported that “this is the first time in 3 years we’ve ever been able to find someone who’s willing to work with him.”

Five participants also discussed frustrations with perceived barriers to respite care at the systems level. Mark, the father of a 7-year-old boy with autism, said, “We had one aide, who you’re not supposed to hire for respite; that was kind of the deal with [our service provider]. But whatever! She’s the only one who would work with him and she’s great.”

Three participants also reported difficulty finding day care or out-of-school care if they acknowledged their sons aggressive behavior. For example, Kate noted, “We tried—we called five different day-home providers, plus Montessori schools, but once I mentioned my son had autism and aggression, no one called me back. When you can fill space without that, why would you?”

**Professional supports.** Most participants were happy with the general medical, educational, and multidisciplinary supports they received for their children and family related to the core symptoms of ASD and overall development. However, seven participants talked about the limited professional knowledge and support specific to their children’s aggression. This perceived lack of professional knowledge referred to both medications and multidisciplinary behavioral supports. Three families reported that the professionals they met did not appreciate what they went through on a daily basis, ignoring their concerns because their child appeared “typical” in the professional’s office. Eleanor articulated this perspective:

> Every time that Emmett would go in the office, [the psychiatrist] would say, “Well, he seems fine to me. Look at him; he’s playing there with the toys.” I mean that’s typical, right? Get them at home and it’s a different story.

Five participants expressed concerns that, even if their physician recognized the difficulties they faced in dealing with aggression, there were still limited treatments offered. For example, Lee, in crisis with her son Lanny, experienced frustration when she “brought him to our [family physician], who was like, ‘Now, Lanny, you know you shouldn’t do that’—you know, totally useless. I was, like, ‘I need help!'” Mary tried various medications for her son for years without success, but she excitedly reported recent success with medications attributed to the first physician they had been able to see with expertise in adults with ASD.

Although participants focused on the use of medications to decrease aggression, four families also discussed nonpharmacological behavior-management strategies recommended by various professionals, including psychologists, behaviorists, and occupational therapists. Overall, these families’ appreciated that these professionals generally saw them in their homes where they could witness the challenges the aggression caused, but they were at a loss as to how to treat aggression. For example, Beth reported, Brian’s biggest issue has always been anger management—that was the biggest barrier to him having a regular childhood and a regular education, because he would just go off so easily and so violently. There just didn’t seem to be any good answers, no good fixes other than drugs to sedate him. [Multidisciplinary intervention services] tried to teach him some skills. They came for several months once a week, and then they wrote up their report and gave us recommendations, blah-blah-blah. Didn’t really do anything. Another year, it was “Let’s give that another go around, cause we don’t know what else to do.” So they came again.

**Lifelong care.** The final theme related to supports and services that all parents talked about was the assumption that they will be the primary caregivers for their children for the rest of their lives because they perceived that alternative living arrangements were either not appropriate or not available, in part due to their children’s aggression and other disruptive behaviors. Regarding staffed out-of-home placement, seven participants reported that there already was a shortage of options, so no one would accept anyone with aggression or other disruptive behaviors. Parents of younger children were already concerned about their children’s future, especially after they are no longer able to provide care. For example, Kate, whose son with Asperger syndrome, Karl, is only 6 years old, reported,

> I don’t know if Karl will have anyone outside his sister to help him. It’s not a degenerative condition; his normal life expectancy is on the table. That’s distressing to me. We’re going to have a dependent for what, as long as we live? The government’s not going to see him as that, but . . .

**Financial Impact**

All participants reported that they had incurred significant financial costs related to their child’s aggression. These costs included both expenses for repairs to personal property and home adaptations for safety. Seven of the families had installed security systems in their homes so they could monitor when doors or windows were opened. One family built a new home to accommodate the safety needs of their child with autism and his sibling, including elaborate and expensive security features, such as “cameras in every room and a camera out back, special door locks and cabinet locks.” Three families talked about having to redrywall...
their homes multiple times because of damage due to aggression, and two families had reinforced their child’s bedroom walls with materials that were more durable than drywall (i.e., puck-board such as that used around hockey rinks). Four families also reported significant damage to furniture, doors, windows, and other property. Beth reported one instance of damage to the family car when she “was a few minutes late picking [Brian] up; he kicked the door so hard he dented it.”

Loss of employment income in the context of aggression also was discussed in five interviews, related to difficulties finding jobs that accommodated the unpredictable needs of their children or because they were unable to work typical daytime hours because of a lack of out-of-school care that would accommodate their children’s aggression. Emmett’s mother stated that she had to “be there to take him to school and when he was out of school because, really, it’s difficult to find any kind of day care for kids like that. He gets aggressive with the other kids, so he can’t go.” Another mother put employment possibilities into context, stating that, “I’d need a job where I wouldn’t have to work March break, Christmas break, summer break, PA days, sick days, behavior days, doctor days, you know, which is pretty much impossible, so I have to stay home.” Two of the mothers gave up paid work entirely, and two mothers changed from full-time to part-time work. Parents who worked full-time talked about their appreciation of flexible work hours to accommodate child care needs and about supportive work environments.

**Overall Experience**

Head Smashed in Buffalo Jump is a United Nations Educational, Scientific and Cultural Organization (UNESCO) World Heritage Site located in the foothills of the Rocky Mountains in Alberta, Canada. For thousands of years, indigenous people of the plains killed buffalo by running them from the plains to the edge of a high cliff at full gallop. Mary made an especially profound and revealing statement at the end of her interview, using this landmark as an analogy for their daily lives. Although her statement does not reflect the experiences of everyone living with someone with ASD, it summarized her perception of the pervasive effects that living with someone with ASD and aggression can have on parents and other family members:

We’re in jail; we’re in jail for life. We’re in jail because we can’t go on vacations for any lengthy period because we have no backup staff. They’re ill-equipped; we would have to train them about all his behaviors; I mean, it’s just unreasonable. We’re in jail because we can’t even go for a walk around the block, we can’t even leave the room where he is, because he gets into trouble. It’s like living “Head smashed in Buffalo Jump.” You’re driven to the edge, and then you just go and then die—I mean, you can’t die, you’re not allowed to die. But you’re forced to go to the edge. We just pray he dies before we do.

**Discussion**

Although not inherent in ASD, many individuals with ASD display aggression, which can have a significant impact on long-term individual and family outcomes, and profound effects on the daily lives of families and access to supports and services (Kanne & Mazurek, 2011). In this study, parents conveyed a range of perceptions about and experiences with living with their children with ASD who have aggressive behavior, including the impact this had on the supports, services, and resources their families received. Surprisingly, although a small and nonrepresentative sample, 60% of families in the larger study reported aggression as a major challenge in their daily lives. Of note, participants were not recruited for a study focused on aggression, nor were parents asked explicitly about aggression. Accordingly, the question that arises is whether these accounts of aggression-related challenges and impact on the family may benefit from more attention than is currently recognized in the literature and clinical practice. It is important to note that there were many similarities in families’ experiences despite much diversity in child and family characteristics, such as child age and type of aggressive behavior. Specifically, families talked about the significant impact their child’s aggression had on the routines and well-being of other family members, finances, and the availability of and access to supports and services.

The families who participated in this study demonstrated great resiliency in the face of adverse living situations. Many families of individuals with ASD become more optimistic and accepting of their children’s diagnoses over time, relying less on formal supports and services (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009). Unfortunately, this optimism was not expressed by the families who participated in this study because aggression presented significant and pervasive challenges to their families, for which adequate knowledge, supports, and services were not in place. Many of the families in this study received ASD-specific medical, home- and community-based services in a geographic location known to have a relatively high level of service for individuals with ASD; however, parents perceived that none of these services were equipped to deal with aggression. This finding was surprising, given that there is a rich body of literature supporting assessment and intervention for various types of challenging behavior, including aggression, in individuals with autism (Matson & Nebel-Schwalm, 2007). For example, functional behavior analysis, which seeks to understand the function of a behavior by identifying the contextual and social variables that
predict and maintain the problem behavior, and the resulting intervention, which focuses on changing these identified variables to support or encourage appropriate behavior, are empirically based (Horner et al., 2002). The families who participated in this study wanted professional help with aggression, and, in one case, were outright denied multidisciplinary services because of their child’s aggression. There also was a reported lack of respite, housing, and crisis services appropriate for someone with ASD who was aggressive. This lack of professional knowledge, services, and resources to deal with aggression was crucial because the parents in this study reported that the aggression, not the core symptoms of ASD (i.e., deficits in socialization and communication), was the greatest challenge in living with and accessing currently available supports and services for their child.

The impact of aggression on families and the lack of appropriate resources are concerning on a number of levels. Families with children with ASD who are not aggressive experience decreased social support and increased stress, which is further increased with aggression (Gabovich & Curtin, 2009; Gupta & Singhal, 2005). Participants reported social isolation, exhaustion, and safety concerns for themselves, other family members, and their children exhibiting aggression. From the perspective of the participants, there appears to be an urgent need for multidisciplinary professional services that adequately addresses aggression in individuals with ASD across the life span. Overall, gaps in supports and services for the participants appeared to be related to many factors, including the lack of supports and services, and professionals’ expertise and time. Many of the empirically based interventions that target disruptive behavior in autism are relatively labor-intensive, requiring expertise and time (Matson & Minshawi, 2007) and support at the systems or organizational level (Horner et al., 2002). Furthermore, standardized tools (checklists and scales), which may be more time-efficient and require less expertise, are limited (Matson & Minshawi, 2007; Matson & Nebel-Schwalm, 2007).

Pharmaceutical approaches to decrease aggression in persons with ASD have received significant attention in the literature, with antipsychotic medications, especially risperidone, showing some positive effects in decreasing aggression for many individuals with ASD (Parikh, Kolevzon, & Hollander, 2008). However, many clinicians and parents advocate for the use of behavioral interventions over pharmacological approaches, perhaps due to potential adverse side effects of medications or a lack of knowledge about the long-term tolerability of medications to treat aggression in individuals with ASD (Scahill, 2008). However, participants either had not used behavioral or pharmacological treatments, or had found them ineffective with their children.

The parents who participated in this study had few resources in terms of respite options, crisis services, and safe, alternative living environments across the life span. This paucity of resources for families of children with ASD has been reported by researchers internationally (Gupta & Singhal, 2005; Mandell, 2008). The presence of aggression in individuals with an ASD can further decrease access to these much-needed resources, which is very unfortunate because these services have been shown to decrease stress for parents of children with ASD (Gray, 2002; Phelps, Hodgson, McCammon, & Lamson, 2009). The need for these services often increases as children with ASD enter adolescence, when increasing physical size and strength can become an issue (Gray, 1993); a problem that most of the participants have yet to deal with. This lack of services increases the worry that many parents of children with ASD already have about their children’s future, especially when they (the parents) are no longer able to act as the primary caregivers (Gray, 2002; Phelps et al., 2009). A critical need for both behavioral and crisis services specific to aggression has been identified; however, cost and a lack of appropriate infrastructure often preclude the development of such services (Mandell, 2008). In his longitudinal study of families of children with ASD, Gray (2002) found that aggression in individuals with ASD rendered families at the greatest risk for stress and decreased quality of life. Thus, the development of appropriate and accessible services to address aggression in individuals with ASD appears to be of utmost priority.

Conclusions and Implications for Practice

It is important to stress that many persons with ASD are not aggressive; however, it is relatively common and can significantly impact the daily lives of individuals with ASD and their families. Although a large body of research exists about functional assessment and interventions for challenging behaviors, including aggression, there are currently limited treatment options and resources to help support families dealing with aggression in persons with ASD. A few researchers have systematically examined the impact on the family of aggressive behavior in individuals with ASD. Accordingly, no qualitative studies were found in which researchers investigated the experiences of families living with children with ASD who were aggressive. In a review of interventions for challenging behaviors in children with ASD, Horner and colleagues (2002) stated, “available research indicates that . . . the impact of problem behaviors on educational, social, and community opportunities is dramatic and detrimental” (p. 424). Although accurate, this important statement is incomplete: It does not acknowledge the profound impact that aggression in children with ASD has on the entire family. However, it highlights the gap
that exists both in the literature and in recognizing the impact of aggression on the family.

Although aggression in individuals with ASD is rarely malicious, these behaviors are serious and make a strong impact (Farmer & Aman, 2011); clearly, this is a difficult issue for families that invites more careful clinical and research examination. Stakeholders, including clinicians, educators, administrators, funders, and policy makers, need to be aware of judgments they make about the lived experiences of families, and the implications that aggression has for the provision and availability of services. Ongoing research is needed that includes examination of (a) potential mediators of these behaviors in the context of family life; (b) a more thorough investigation of individual, caregiver, and family impacts; (c) targeted interventions at both the individual and family level; (d) feasible and sustainable supports to families from a life span perspective; and (e) investigation of these issues from the perspective of other stakeholders, for example, service providers. This study, which engages in the process of listening to the experiences and challenges of families living with an individual with ASD and aggressive behavior, constitutes an important step in tailoring resources to best meet individual and family needs.

Acknowledgment

The authors gratefully acknowledge the parents who took time from their busy lives to participate in this study.

Authors’ Note

At the time of publication, Dr. Hodgetts was a postdoctoral trainee in the Canadian Institutes of Health Research (CIHR) Canadian Child Health Clinician Scientist Training Program (CCHCSP).

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded through a grant from the Alberta Centre for Child, Family and Community Research (sm10-Zwaigenbaum).

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