

Review Article

How do Parents Respond to Stigma and Hurtful Words Said to or about their Child on the Autism Spectrum?

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No published empirical studies could be found that investigate how parents of a child with Autism Spectrum Disorder (ASD) respond to the stigma and hurtful comments said to or about their child. Filling this gap, we documented parent's reported frequencies of their child's ASD-associated behaviors, specific hurtful words these behaviors elicited from others, and the strategies parents used to manage the consequent stigma. Participants were parents (N=502) included in the Simons Simplex Collection (SSC) who have been well described in the Simons Foundation Autism Research Initiative (SFARI). Coming from 35 states and 3 Canadian provinces, 95% were mothers between 28-65 years, predominantly white, highly educated, and living with a spouse or partner. Of the probands, 86% were boys between 5 to 18 years with relatively high non-verbal IQs of 85. Parents responded to a 72-item telephone survey. Data revealed 95% of parents think individuals with autism are stigmatized, 98% reported difficulty raising a child with autism, and 95% reported stigma associated with autism had been difficult for the child and family to deal with. Parents reported hearing 82 hurtful words said to or about their child. Parents responded differently to hurtful words with 52% proactively educating offenders while 24% passively ignored or avoided anticipated hurtful situations. Active-responding parents reported less social isolation and difficulty raising a child with ASD than passive-responding parents.

Conclusion: Educating the public about behaviors associated with ASD should decrease stigma and increase understanding, tolerance, and acceptance of those on the autism spectrum and their families.

Keywords: Autism, Autism Spectrum Disorder, Stigma, Parents, Bullying, Children, Stereotype

Abbreviations

ASD: Autism Spectrum Disorder; SFARI: Simons Foundation Autism Research Initiative; SSC: Simons Simplex Collection; IAN: Interactive Autism Network; CSR: Center for Survey Research; CATI: Computer-Assisted Telephone Interview; UMASS Boston: University of Massachusetts Boston; ARP: Active Responding Parents; PRP: Passive Responding Parents

Introduction

Stigma is commonly associated with Autism Spectrum Disorder (ASD). Previous studies have specifically documented that parents of children with ASD think that individuals with ASD are stigmatized [1,3,14]. Interviewed parents have revealed that "enacted stigmas" are driven by the misconception that these families are "bad parents with naughty children" in public settings when the child on the spectrum exhibits atypical behavior. While recent studies have investigated how parents cope with the diagnosis and behaviors associated with ASD [4,5], there are no published empirical studies that investigated how parents of a child with ASD respond to hurtful comments they hear said to or about their child and the subsequent stigma they perceived. In an effort to fill this gap, our study sought to investigate the frequency of their child's ASD-associated behaviors, the specific hurtful words and phrases these behaviors elicited from others, and

the strategies parents then used to deal with the stigma these insults provoked.

Stigma associated with ASD

This study follows Link and Phelan's model of the stigma process in which stigma acts as the link between an attribute and a stereotype that may promote discrimination [6,7]. The Link and Phelan model involves five components beginning with the identification and labelling of a "human difference" that leads to the presence of a stereotype in which the labelled attribute is seen as undesirable [7]. This is followed by the separation of the stigmatized group from the stigmatizing group, then discrimination due to this separation, and finally the enacted differences in "power" or social status [7].

Gray [11,8] has attributed stigma associated with children with ASD to deviations from socially typical behaviors with no superficial indication of a disorder. Individuals with ASD present a variety of the classical behaviors of autism in which they deviate from social norms in communication and social interaction, and display ritualistic or repetitive behaviors [9]. The extent to which mothers of children with ASD feel stigmatized seems to be linked to the severity of their child's autistic behaviors [1].

Caregivers of children with ASD

In addition to the psychological impacts of coping with a child

with ASD, caregivers deal with financial burdens and employment difficulties. Saunders and colleagues [10] reported that about a third of parents of children with ASD report financial strain and another third of parents reported having to stop working in order to care for their child. To give a quantitative estimate of the financial burden, Buescher and colleagues [11] used archival data in the US, estimating more than \$50,000 as the annual cost of care for a child with ASD and no other disabilities.

Caregivers of children with neurodevelopmental disorders also report greater psychological and psychosocial distress than caregivers of neurotypical children [12,13]. According to Higgins and colleagues, two-fifths of caregivers of children with ASD reported “some form of physical, emotional, financial or marital relationship stress”, with a quarter reporting negative effects on family life. Although the physical, social, and financial burden of caring for a child with a disability may cause much of the psychological distress felt by caregivers, these difficulties may be exacerbated by stigma.

Stigma as perceived by caregivers presents a unique opportunity for study from a novel perspective. Link and Phelan [6] stated that one major challenge to studying stigma is the lack of perspective since most scientists do not belong to the stigmatized group. As neurotypical caregivers of children on the spectrum, the parents who participated in our study could act as the bridge between the stigmatized group and creation of a better understanding of stigma enacted against children with ASD. In particular, we were interested in exploring the strategies these parents used to respond to perceived and enacted stigma that the Link and Phelan model describes.

Our study sought to explore stigma associated with ASD through the reports of the child’s parents. Specifically, we were interested in documenting hurtful words that parents of children with ASD heard in public situations. Another major aim of this study was to investigate whether the themes of parent’s response strategies emerge as they grappled with hurtful statements and stigma. Finally, we analyzed parent’s responses to isolate the strategy that appeared more advantageous to parents when responding to people making hurtful statements. The significant conclusion from this study is that the educational efforts of parents, who used proactive strategies to educate the public about autism spectrum disorders, are likely to decrease stigma and increase understanding, tolerance, and acceptance of those on the spectrum and their parents.

Methods

Participants

The study sample and surveying procedures have been described previously [3,14,15].

Sample identification and selection

Participants in the study were parents included in the Simons Simplex Collection (SSC) who were participants in the Simons Foundation Autism Research Initiative (SFARI). The Interactive Autism Network (IAN) was hired to manage participant’s data in “SSC@IAN”. SSC@IAN is an international sample of 1,460 families who consented to have their genotypic and phenotypic information used by researchers.

Comprehensively evaluated, the SSC families include one child,

the proband, who has an ASD, and one or more neurotypical siblings and unaffected biological parents [15]. Five hundred fifty-four parents who were the primary caregiver of the proband were randomly selected from this “SSC@IAN” population to participate in the study. Of those, 502 completed the interview as 41 were unreachable after several attempts, 2 were ineligible, and 9 refused to participate. This resulted in a response rate of 91% [3,14].

Participating parents came from all 12 SFARI research sites located in 35 states and 3 Canadian provinces. Of the parents, 95% were mothers who ranged in age from 28-65 (median = 43.7 years old, SD = 5.36), were predominantly white (82%), highly educated (71% had at least a college degree), and were living with a spouse or partner (92%). Of the probands, 86% were boys between 5 and 18 years old (median = 11), and they had relatively high non-verbal IQ of 85.

Survey design and implementation: Columbia University investigators, in collaboration with survey design experts from the Center for Survey Research (CSR) located at the University of Massachusetts (UMASS Boston), designed the 72-item survey based on a review of the literature and a series of three parent focus groups and three focus groups with young adults who were on the autism spectrum. Cognitive interviews and pretesting led to the development of a Computer-Assisted Telephone Interview (CATI) to survey the participants. The survey instrument was designed to capture how parents responded to hurtful situations that occurred in the last 6 months.

The study was approved by the Institutional Review Boards at both Columbia and UMass Boston. Informed Consent was obtained from all participants who were provided \$25 as compensation.

Results

Data analysis

The primary goal of this study was to obtain data from a sample of parents who reported hearing hurtful words said to or about their child and the subsequent strategies they used to deal with the stigma generated by those hurtful words. Descriptive analysis included frequencies of reported autistic behaviors of the child, hurtful words said to or about the child, and response strategies used by parents. Two researchers independently coded parent’s responses to hurtful words they heard. Inter-rater reliability was assessed and found to be concordant ($\kappa = .96$). Inferential statistics were computed using chi-square tests of independence.

Children’s autistic behaviors

Descriptive analyses revealed that 8% of the sampled children were nonverbal and 29% had physical characteristics that parents reported might draw attention from others. Table 1 presents frequencies in the last six months of autistic behaviors of the children as reported by their parents (Table 1).

Impact on parent’s lives

Descriptive analyses of survey questions revealed that of the parents: 66% reported hearing hurtful words said to or about their child on the spectrum; 56% cut back on work hours because of their child on the spectrum; 49% reported having financial problems due to caring for their child; and 10% reported being divorced or separated

Table 1: Frequency of child’s autistic behaviors in the last six months reported by their parent.

Behavior in the last 6 months (N = 502)	Often (%)	Sometimes (%)	Rarely (%)	Never (%)
Difficulty making friends	55	28	11	5
Trouble making eye contact	43	36	17	5
Noticeable repetitive behavior	34	23	16	28
Becomes upset with routine change	23	43	27	8
Serious tantrums or meltdowns	15	30	33	23
Trouble with bladder or bowel control	10	11	13	66
Threat toward others	6	20	27	47
Head banging	2	6	11	81

Table 2: Difficulty for parents.

QUESTION	Extremely (%)	Very (%)	Somewhat (%)	A Little (%)	Not At All (%)
How difficult is raising a child with autism?	18	32	39	9	2
How difficult has stigma been for your child and your family?	9	22	48	16	5

Table 3: Parent’s social interactions.

QUESTION	Often (%)	Sometimes (%)	Rarely (%)	Never (%)
How often did you (parent) decide not to spend time with family and friends because of {child’s} behavior?	15	25	26	34
How often did you and your family feel excluded from events and activities?	8	23	29	39

Table 4: Number of autistic behaviors vs. difficulty of stigma.

Difficulty of stigma for parent and family	Number of Autistic Behaviors Exhibited		
	Few (0-3)	Moderate (4-6)	Many (7-10)
Extremely/Very	6.0%	32.4%	37.6%
Somewhat/ A Little	88.0%	63.6%	57.6%
Not at all	6.0 %	4.0%	4.7%

consequent to caring for their child.

Ninety-five percent of parents reported that they “think individuals with autism are stigmatized”. As seen in Table 2, 98% of parents reported at least “a little” difficulty raising a child with autism. Additionally, 95% percent of parents said that the stigma against individuals with autism had been at least “a little” difficult for the child and the family to deal with (Table 2).

The impact of stigma on social interactions was also present. Table 3 displays how often parent’s social interactions were curtailed by perceived stigma (Table 3).

Additionally, parent’s reports of having difficulty with stigma is positively associated with the number of autistic behaviors the child exhibits ($X^2 = 18.41, p < .01$) (Table 4).

Hurtful words

Three hundred and twenty-nine parents (65.5%) responded affirmatively to the question “Have people ever called {CHILD’S NAME} hurtful names or words because of (his/her) autistic behaviors?” A total of 82 discrete words and phrases were reported with “weird,” “stupid,” and “retard” being reported most frequently.

Table 5 shows the words reported by three or more parents (Table 5).

Parents response strategies to hurtful words

Parents reported their most effective strategy used in response to the question, “What have you found most helpful in handling the kinds of situations that I just asked you about?”:

- **The active response strategy:** 52% of the parents made proactive efforts that included (1) telling someone that it offended them when someone said something hurtful about their child because of his or her autistic behaviors, or (2) they corrected someone who made an inaccurate statement about people with autism, or (3) they tried to educate the person who said something hurtful. In other words, the parents responded actively to hurtful statements after hearing them.
- **The passive response strategy:** 24% of the parents reported that they simply ignored other people when they said something hurtful about their child or they chose to avoid situations in which a hurtful statement could be anticipated.
- **The support-seeking strategy:** 9% of parents turned to other parents, family members, or professionals for support when hearing a hurtful statement.
- **The preparing their child strategy:** 5% of parents attempted to prepare their child with distractions and instructions on behavior before facing situations in which a hurtful statement could be anticipated.
- **The reducing stress strategy:** 2% of parents sought to reduce personal stress after hearing a hurtful statement.
- 7% of parents suggested **miscellaneous strategies.**

Active response strategy

More than half of the parents reported that they responded “actively” to hurtful words or statements said about their children. The following excerpts are examples parents offered:

1. “I try to take a collaborative approach and point out what I think are the reasons behind his behaviors for people who are upset about what has happened. I just try to help educate them a little bit about how autism impacts him and why he’s doing what he’s doing”.
2. “I am usually quite direct with people about it and explain that certain behaviors are quite challenging for CHILD and I would anticipate that, as a friend, they’d be supportive”.
3. “Explaining to people what autism is, that usually seems to work”.

Parents who reported active responses to hurtful statements seem to project a hope for reducing future hurtful experiences. They apparently share the belief that educating individuals ignorant about autism could lessen stigma associated with their child’s behaviors. One mother who responded actively stated:

“I believe information is power and if you let people know what’s going on they get kinder and more tolerant, though it doesn’t always work on the checkout line”.

Another parent who responded actively stated:

Table 5: Hurtful words reported by three or more parents.

Word	# of Parents reporting	Word	# of parents reporting	Word	# of parents reporting	Word	# of parents reporting
Weird	160	Crazy	26	Annoying	6	Gay	3
Stupid	108	Odd	18	Different	6	Goofy	3
Retard	104	Slow	11	Dork	6	Imbecile	3
Strange	37	Baby/ Babyish	10	Loser	4	Jerk	3
Freak	30	Brat	10	Mental	4	Out-of-control	3
Idiot	29	Spoiled	8	Brain-damaged	3	Psycho	3
Dumb	27	Mean	7	Bully	3	Wild	3

“Just educating people, let them know - the more they understand autism, the better off they are”.

However, such an effort does not have to be as exhaustive as face-to-face confrontation with strangers in grocery stores. Some parents opted for educating others differently. In her effort to take a proactive stance against stigma, one mother reported:

“I carry cards with me that explain autism; part of my job as a parent of an autistic child is to educate people”.

Passive strategy

About a quarter of the parents who had reported hearing hurtful words in the past six months reported using a passive strategy. Examples of responses that were categorized as passive responses include:

1. “The way to handle it is we don’t look at people, we tend not to make eye contact and look at people when we’re in public; it’s too overwhelming sometimes, we don’t want the conflict; the world’s like a blank screen so we don’t make eye contact with people. In some ways, we kind of screen it and see if we’re getting an OK response but most of the time we just tend to not look at people”.
2. “I just tell myself they are ignorant, they don’t know any better and they don’t want to know any better, and then I walk away”.
3. “Acceptance of ignorance of other people who don’t have a clue”.

This group of parents most frequently reported ignoring or avoiding situations in which hurtful statements were heard. Despite not responding to the person who made the hurtful statement, these parents acknowledged that the hurtful statements came from people who appear not to understand their child’s condition. One parent reported presuming lack of awareness by people who make hurtful statements about her child, stating:

“We approach the situation, assuming that the person doesn’t have a bad intention; they’re just not educated about the condition”.

Interestingly, however, these parents do not appear to find it beneficial to respond to the situation by educating the person who made the hurtful statement. Instead, they seem to find it easier to ignore and avoid these situations.

Factors influencing frequency of insults or hurtful statements

Table 6 indicates that the number of autistic behaviors the

Table 6: Number of autistic behaviors vs. frequency of being teased or insulted.

Frequency of being teased or insulted	Number of Autistic Behaviors Exhibited		
	Few (0-3)	Moderate (4-6)	Many (7-10)
Often	2.0%	9.8%	9.9%
Sometimes	12.0%	26.4%	34.3%
Rarely	42.0%	38.4%	33.1%
Never	44.0%	25.4%	22.7%

Table 7: Gender of child vs. frequency of being teased or insulted.

Frequency of being teased or insulted	Gender of Child	
	Boy	Girl
Often	9.8%	4.2%
Sometimes	28.3%	23.9%
Rarely	38.2%	29.6%
Never	23.7%	42.3%

Table 8: Response strategy vs. difficulty of raising a child with autism.

Difficulty of raising child with autism	Response Strategy	
	Active	Passive
Extremely/Very	53.5%	67.1%
Somewhat / A little	46.5%	31.4%
Not at all	0%	1.4%

children exhibited was a significant predictor of how frequently parents reported their child being teased or insulted ($X^2 = 18.44, p < .01$). By reading across the rows, one can see that children who exhibit many behaviors associated with ASD are more “Often” teased than those with few behaviors. Children who exhibit few behaviors are likely to be “Never” teased (Table 6).

As seen in Table 7, a Pearson Chi-Square test of independence revealed that boys were more frequently reported being teased or insulted than girls ($X^2 = 11.77, p < .01$) (Table 7).

Of interest, whether a child had noticeable physical characteristics was not associated with the frequency of being teased or insulted ($X^2 = 3.14, p = .37$).

How parents incorporated active vs. passive response strategies when dealing with difficult situations

As seen in Table 8, a Pearson Chi-Square test revealed that Passive Responding Parents (PRP) reported more difficulty raising a child with autism than active responding parents (ARP) ($X^2 =$

Table 9: Response strategy vs. difficulty of stigma for family.

Difficulty of stigma for family	Response Strategy	
	Active	Passive
Extremely/Very	38.7%	53.6%
Somewhat/ A little	58.1%	46.4%
Not at all	3.2%	0%

Table 10: Response strategy vs. telling others about autism.

Uncomfortable telling others that child has autism?	Response Strategy	
	Active	Passive
Yes	26.8%	38.6%
No	73.2%	61.4%

6.43, $p < .05$). Table 9 shows that PRP also reported greater difficulty with stigma than ARP ($X^2 = 5.88$, $p = .05$), although both parents largely report at least some difficulty with stigma. Table 10 shows an insignificant ($p = .07$) trend in which PRP reported feeling slightly more uncomfortable about telling others that their child has an ASD. Finally, Table 11 shows that PRP reported feeling excluded from events or activities more often than did ARP ($X^2 = 10.07$, $p < .05$). More than a quarter of ARP stated that they never felt excluded from events or activities.

Discussion

Demographics

The probands in this study were similar to those in previous studies. This large, well-described sample, a subpart of the SSC, was composed of 86% boys, similar to 81.6% of Saunders et al. [10] and 83% of Higgins et al. [4]. The mean age of the children (11 years) was in line with 10 years and 10 months of Higgins et al. [4]. This sample, however, varied in the relatively high non-verbal IQ average (85) of the children. The parent participants were noted for their high level of education (71% had at least a college education).

Children's autistic behaviors

Our study gathered crucial data to describe the lives of a child with ASD to see the connection with reported hurtful words. Table 1 indicated that social interactions as listed in the DSM-IV [9] were the most frequently exhibited ASD behaviors. In the last six months, 95% of the parents reported that their child had "difficulty making friends" and had "trouble making eye contact," and 77% noted "serious tantrums or meltdowns". Most parents (92%) reported their child "became upset with routine change" and 72% noted "repetitive behavior". Higgins et al. collected a sample of Australian parents of children with ASD and found 69% of the parents reported their child had repetitive behavior and 66% reported serious tantrums [4].

Behaviors of greater concern, such as "trouble with bladder or bowel control", "head banging", and "being a threat towards others", were infrequent in this sample with a majority of parents stating they "rarely/never" observed these behaviors in their children in the last six months.

Our results differ from those found by Higgins and colleagues who reported that 62% of children exhibited aggressive behavior that was "somewhat or great" concern to 100% of parents [4]. Our findings indicate that these behaviors were much less prevalent in our

Table 11: Response strategy vs. feeling excluded from events or activities.

Feeling excluded from events or activities	Response Strategy	
	Active	Passive
Often	9.6%	15.7%
Sometimes	33.1%	31.4%
Rarely	30.6%	42.9%
Never	26.8%	10.0%

sample. Forty-seven percent reported these behaviors (i.e., "threats to others") were rarely seen and only six percent reported they were often observed. As the SSC is a relatively high functioning sample with the mean IQ in the mid-80s, this might account for the disparity in aggression other studies observed.

Impact on parent's lives

Our results capture the extent to which ASD has an impact on the family's social functioning. Almost all parents reported having at least some difficulty raising their child with Autism, two thirds of parents reported hearing hurtful words said to or about their child on the spectrum, and half reported having financial problems. Our sample reported a comparatively low 10% divorce or separation rate due to having a child on the spectrum whereas Higgin's [4] Australian sample reported 24% divorce or separation rate. Yet a recent study by Namkung and colleagues found that raising a child with a developmental disability did not change the relative risk of divorce [16]. The lower rate of separation found in our sample of parents was not statistically associated with the parent's level of education or the reported difficulty of raising a child on the spectrum.

While Saunders and others [10] reported a third of parents had to stop working to care for their child, our study found that more than half of our sample reported having to cut back on work to care for their child [3,14]. Marital separation and unemployment or under-employment are apparent factors in the estimated \$50,000 annual cost of caring for a child with ASD [17]. These data suggest that, given the lofty health care costs, a financially challenging situation is exacerbated by having to reduce work hours.

Whereas the impact of ASD itself on parent's personal lives is apparent, the harm other's adverse perception of these families is also apparent. Parents, almost universally, reported that individuals with autism are stigmatized. A majority reported they decided not to spend time with family and friends, and they felt excluded from events and activities because of their child's autism-associated behaviors. Farrugia reported similar findings of parents of children on the spectrum who restricted "their daily activities to avoid public situations with their children" [2]. He called these experiences of backlash against parents of children with ASD "enacted stigmas" [2]. With 95% of our study sample reporting that they think people with ASD are stigmatized, finding about their limited social interactions was not surprising.

Hurtful words

One aim of the study was to document ways stigma attached to children with ASD manifested itself in the hurtful words parents reported they heard said to or about their child. The range of reported words showed a general misunderstanding of ASD and associated behaviors. Included among the reported words were "weird",

“stupid”, “strange”, “freak”, “brat”, “crazy”, “odd”, “aggressive”, “mumbler”, “nerd”, “psycho”, “dork,” and “jerk”. Parents reported a panoply of words heard that described negative cognitive ability and mental disorders, which inaccurately describe children with ASD and likely lead to stigma.

Preferred words

Farrugia suggested calling children with ASD a “more ambiguous construct, a kinder, less pejorative label” to engender more understanding responses from others. Parents of his sample “assert the individuality and uniqueness of their child [2]”.

In a recent study, Kenny and colleagues explored optional descriptive terms that could be applied to a person with ASD [18]. Most parents preferred “has autism”, whereas the probands preferred “on the autism spectrum”. The least preferred terms included “Aspie” and “autistic person” [18]. Their findings show that what are undesirable words are labels that group all people with ASD as having the same condition. Of interest, even the term “Autism Spectrum Disorder (ASD)” was less desirable than “on the autism spectrum” likely because this phrase avoids the use of the word “disorder”.

Response strategies

Parent’s open-ended responses regarding how they dealt with hearing hurtful words revealed the stigma that they and their children experienced; the lack of public acceptance and understanding towards autism was apparent.

About half of parents in our sample reported **active response strategies** that involved proactive advocacy efforts to educate others about autism. They reported varied and creative methods of educating others, ranging from humor or sarcasm to handing out pamphlets or informative business cards. Sample responses suggest their belief in both improving other’s perception of their children and the value of making a proactive effort to fix an incorrect or ignorant judgment about autism. These actions may be responsible for the apparent benefits of active response strategies presented above and discussed below.

A quarter of our sample engaged in **passive response strategies** in situations where they heard a hurtful word said to or about their child. Parents who chose this strategy reported that they attempted to ignore the hurtful statements and they avoided situations in which hurtful statements could be anticipated.

A similar but much smaller group of parents fell into the “preparing their child” **response strategy**. Some chose to offer their child distractions or gave them instructions on preferred behaviors before entering situations in which hurtful statements could be anticipated. Still others may have tried active responses in the past and had tired of them or had given up. Our sample of these parents was too small for us to include this group in our inferential statistics.

Finally, the **reducing stress response strategy** resembles the passive response strategy but in this case, parents took a proactive role in bettering their own mental health. Responses included exercise, speaking with supportive family members about hurtful situations, or seeking help from other parents of children on the spectrum. Our sample of these parents was too small to include them in our

inferential statistics.

Factors influencing the frequency of being teased or insulted

We sought to explore factors likely to influence the frequency of the child being teased or insulted. While there was no significant association with noticeable physical features, children who exhibited more autistic behaviors (e.g., head banging, trouble making eye contact) were more frequently reported being teased or insulted. It is likely that children who exhibit an atypical behavior in public are noticed and consequently are insulted by offenders. These findings suggest that children on the spectrum likely are insulted or judged based more on their behaviors than on their appearance.

Although gender did not correlate with the number of autistic behaviors, we did find that parents of girls reported their child being teased or insulted less frequently than reported by parents of boys. One possible explanation of the paucity of teasing may be that girls on the spectrum are more likely to disguise rather than to display the autistic behaviors typically seen in boys. Davidson [19] described the tendency of girls to control their emotions by closing themselves out both spatially and socially. The female experience of autism is described as “characterized by a profound sense of alienation”, which may be the cause of fewer insults overheard by parents.

Another explanation may be that the behaviors of children with ASD are less noticeable when enacted by a girl. Though the females in our sample were reported to exhibit the same number of autistic behaviors as boys, they may have exhibited a higher capacity for empathy, which may have allowed them to avoid being noticed in public situations and thus they were able to evade hurtful comments [20].

Impact of the choice of response strategy

A major goal of this study was to find response strategies that help parents manage the sequelae of hurtful statements and stigma. Given the uneven proportions of parents using the different response categories, we were only able to run inferential statistics to reveal differences between active and passive response strategies used by parents.

Our comparison of active and passive response strategies highlight the apparent benefits of being proactive in dealing with stressful situations. Parents using passive response strategies reported greater levels of difficulty in raising a child with ASD and greater difficulty of stigma for the family. It may be that parents using active response strategies are accommodating better to their child’s behaviors by proactively educating offenders. This was supported by the trend of parents using active response strategies feeling more comfortable than parents using passive response strategies in telling others about their child’s being on the autism spectrum.

Role of stigma

Our study suggests an additional factor in the previous model of stigma and its psychosocial effects. Link and Phelan list individual discrimination, structural discrimination, and loss of status as the three ways stigma may be manifested and enacted [6]. Our study indicates that parents have developed strategies to manage individual discrimination, as seen by the prevalence of hurtful statements and parent’s responses to the discrimination. While parents using

either active or passive response strategies reported similar levels of individual discrimination, as documented by the reported frequencies of teasing or insults, parents using passive response strategies reported greater levels of social isolation and difficulty of raising a child with ASD.

Further study

This study reports novel findings that would benefit from further research involving stigma associated with ASD. First, a more diverse sample of parents, including more fathers and less well-educated individuals should be studied to improve the generalizability of the sample. Secondly, our findings call for further investigation of the reasons why parent's reported their active or passive responses to what they heard or felt. Third, in future studies seeking to better establish levels of stigma, it would be useful to measure autism-related behaviors more accurately with a scale for the severity of each behavior. In our innovative study, associations were significant, but were measured using categorical variables. Use of continuous variables would provide further insights as to why and how often children with ASD are teased and subjected to hurtful comments. Finally, future research should explore ways of reducing stigma. Remedies could include public service announcements and general education of the broad community regarding developmental disorders as well as providing a glossary or lexicon of "helpful" words to offset the harmful words that were reported.

Conclusion

Despite the varied experiences and response strategies our parents reported, two significant findings from this study seem clear: first, individuals with ASD still experience stigma that is profound, pervasive, and difficult. Second, the need for public education is evident given the frequency of hurtful words said to or about their children that was reported by parents. Parents at all levels of education appeared to be highly proficient in advocacy skills. Educating the public about the behaviors associated with ASD should increase public understanding, tolerance, and acceptance. By reducing situations in which parents hear hurtful words said to or about their child, the challenges they face in raising a child with ASD are likely to decrease. With greater social involvement of parents and children with an educated public, indeed, the level of stigma should be diminished while concomitantly, the quality of life for the entire family should be expected to improve.

References

- Gray DE. Perceptions of stigma: The Parents of Autistic Children. *Social of Health Illn.* 1993; 15: 102-120.
- Farrugia D. Exploring Stigma: Medical Knowledge and the Stigmatisation of Parents of Children Diagnosed with Autism Spectrum Disorder. *Social Health Illn.* 2009; 31: 1011-1027.
- Fischbach RL, Harris MJ, Ballan MS, Fischbach GD, Link BG. Is there Concordance in Attitudes and Beliefs Between Parents and Scientists about Autism Spectrum Disorder? *Autism.* 2016; 20: 335-363.
- Higgins DJ, Bailey SR, Pearce JC. Factors Associated with Functioning Style and Coping Strategies of Families with a Child with an Autism Spectrum Disorder. *Autism.* 2005; 9: 125-137.
- Benson PR. Coping, Distress, and Well-Being in Mothers of Children with Autism. *Res Autism Spectr Disord.* 2010; 4: 217-228.
- Link BG, Phelan JC. Conceptualizing Stigma. *Annu Rev of Sociol.* 2001: 363-385.
- Link BG, Phelan JC. Stigma and Its Public Health Implications. *Lancet.* 2006; 367: 528-529.
- Gray DE. 'Everybody Just Freezes. Everybody is Just Embarrassed': Felt and Enacted Stigma among Parents of Children with High Functioning Autism. *Social Health Illn.* 2002; 24: 734-749.
- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders. DSM-IV-TR Fourth Edition (Text Revision).*
- Saunders BS, Tilford JM, Fussell JJ, Schulz EG, Casey PH, Kuo DZ. Financial and Employment Impact of Intellectual Disability on Families of Children with Autism. *Fam Syst Health.* 2015; 33: 36.
- Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of Autism Spectrum Disorders in The United Kingdom and The United States. *JAMA Pediatr.* 2014; 168: 721-728.
- Fisman S, Wolf L. The Handicapped Child: Psychological Effects of Parental, Marital, and Sibling Relationships. *Psychiatr Clin of North Am.* 1991; 14: 199-217.
- Lach LM, Kohen DE, Garner RE, Brehaut JC, Miller AR, Klassen AF, et al. The Health and Psychosocial Functioning of Caregivers of Children with Neurodevelopmental Disorders. *Disabil Rehabil.* 2009; 31: 607-618.
- Kinnear SH, Link BG, Ballan MS, Fischbach RL. Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Familie's Lives. *J Autism Dev Disord.* 2016; 46: 942-953.
- Fischbach GD, Lord C. The Simons Simplex Collection: A Resource for Identification of Autism Genetic Risk Factors. *Neuron.* 2010; 68: 192-195.
- Namkung EH, Song J, Greenberg JS, Mailick MR, Floyd FJ. The Relative Risk of Divorce in Parents of Children with Developmental Disabilities: Impacts of Lifelong Parenting. *Am J Intellect Dev Dis.* 2015; 120: 514-526.
- Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A National Profile of The Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in The United States, 2005-2006. *Pediatrics.* 2008; 122: 1149-1158.
- Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which Terms Should be Used to Describe Autism? Perspectives from the UK Autism Community. *Autism.* 2015.
- Davidson J. 'In a World of Her Own...': Re-presenting Alienation and Emotion in the Lives and Writings of Women with Autism. *Gend Place Cult.* 2007; 14: 659-677.
- Baron-Cohen S, Wheelwright S. The Empathy Quotient: An Investigation of Adults with Asperger Syndrome or High Functioning Autism, and Normal Sex Differences. *J Autism Dev Disord.* 2004; 34: 163-175.