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EXAMINING COMMUNICATION AND EMOTIONAL CHARACTERISTICS OF PARENTS OF EMERGING ADULT CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD)

GRACE SCHWEIZER
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Reviewed and approved* by the following:

Kathryn Drager
Professor of Communication Sciences and Disorders
Thesis Supervisor

Carol Miller
Professor of Communication Sciences and Disorders
Honors Adviser

* Electronic approvals are on file.

ABSTRACT

This study investigates the experiences of parents of young adult children with autism spectrum disorder (ASD). Via a daily diary procedure, parents reported information regarding interactions with their child and supports provided daily for fourteen days. Participants specified the details of their communication interactions and also reported their emotional affect both pre- and post-interaction. As a descriptive investigation, there are no specific hypotheses to be tested. Rather, this study aims to clarify the perspectives and daily experiences of parents of adults with ASD. Families often act as primary care provider through adulthood for individuals with ASD; this study seeks to consider and analyze parents' circumstances and communicative relationships with their children.

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Chapter 1

Introduction

Definition of Autism

Autism Spectrum Disorder (ASD) is a developmental disorder defined along two dimensions, marked by difficulties related to social-communicative skills and specific, repetitive behaviors. Social- communicative difficulties can be categorized according to deficits in social-emotional reciprocity, non-verbal communicative behaviors, and the development and maintenance of social relationships (Lord et al., 2018). Individuals with deficits in social-emotional reciprocity may have difficulty engaging in an equal interaction with their conversation partner, with limited sharing of interest, emotions and affect (Lord et al., 2018). Deficits in non-verbal communicative behaviors include difficulty maintaining eye contact, unusual body language, and a lack of or inappropriate use of gestures in isolation or in coordination with verbal expression (Lord et al., 2018). Deficits in the development and maintenance of social relationships involves difficulty adapting behavior to varying social contexts and making friends (Lord et al., 2018).

The second dimension of ASD, restricted, repetitive patterns of behavior, often manifests according to persistent behaviors or preferences. Many individuals with ASD engage in persistent repetition in the form of motor movement (e.g. hand-flapping), speech (e.g. echolalia) and objects (e.g. lining up toys in the same way every time) (Lord et al., 2018). Deficits in this area also include rigidity in schedules and day-to-day patterns. Individuals with ASD may have difficulty with transitions throughout the day or changes to their usual/expected schedule (Lord

et al., 2018). For example, an individual with ASD may struggle moving from lunch to the classroom during the school day, especially if eating lunch is a preferred activity. Individuals with ASD also tend to have restricted, fixated interests for an object or activity. For example, an individual with ASD who has a fixated interest in firetrucks may spend much of their time playing with firetruck toys, talking about firetrucks and even visiting fire stations (Lord et al., 2018).

While defining ASD and its various characteristics provides a framework for the deficits related to the disorder, ASD is a spectrum and its manifestation in each individual is heterogeneous. To account for this significant variation in the manifestation of ASD symptoms, there are three distinct severity levels of ASD, as determined by the Diagnostic and Statistical Manual of Mental Disorders. Level 3 indicates that the individual requires very substantial support in day-to-day life (American Psychiatric Association, 2013). These individuals have severe deficits in social and communication skills; they exhibit challenging behaviors consistently and struggle to transition throughout the day (American Psychiatric Association, 2013). Level 2 shares characteristics with Level 3, but to a less severe degree. Individuals may still have significant deficits in social-communicative skills and restricted, repetitive behaviors, but they require less support than individuals in Level 3 (American Psychiatric Association, 2013). Level 1 includes individuals with ASD who have difficulty in social situations and with changes in schedule, but given supports, experience minimal impairments (American Psychiatric Association, 2013).

With respect to parent experience, autism severity has been negatively correlated with a difficult transition experience post-high school (Wong et al., 2020). Parents of adult children with more severe ASD symptoms reported higher levels of worrying, somewhat related to

expectations for their child's ability to obtain employment and live independently (Wong et al., 2020). Typically, the less severe the ASD symptoms, the higher chance an individual has of being employed and living independently; furthermore, as parents age and also lose support services provided during school years, they may experience worry about being able to care for their child both physically and financially.

Developmental Trajectory in ASD and Impacts on Parents and Families

Infancy Social Development Related to Parents

While ASD is not diagnosed at birth and can often take a few years to identify in a child, there are many indicators that are present from the moment infants begin to communicate. Prior to speech, typically-developing infants use a variety of gestures to communicate wants or needs to their caregivers. However, infants later diagnosed with ASD often demonstrate a diminished use of gestures to communicate (Volkmar et al., 2005). Furthermore, the frequency of gestures used by infants may predict communicative outcomes. Thus, a diminished use of gestures often predicts poorer communicative outcomes later in life. Infants later diagnosed with ASD also demonstrate reductions in eye contact as well as little to no joint attention (Volkmar et al., 2005). When bonding with their caregivers, neuro-typical infants begin to make eye contact with their caregiver and then with an object/activity of interest to create a shared experience. However, infants with ASD tend to be less interested in creating a shared experience and are often more focused on the preferred object or activity than the communication partner; they prefer to play alone rather than with a partner (Volkmar, 2005). Infants with ASD also demonstrate reduced sharing of positive and negative affect, a key part of developing emotional connections with

caregivers and others (Volkmar et al., 2005). This decreased social responsivity that is characteristic in infants with ASD can sometimes result in diminished social initiation on behalf of parents; without reciprocity from the child, a parent may be less likely to provide the social input that is necessary in cultivating a child's social and communicative development (Wan et al., 2019). As a result, not only is the parent-child attachment negatively affected, but the social-communicative deficits already present in an infant with ASD may continue to worsen (Wan et al., 2019).

Friendship and Parent-Child Relationship Throughout Childhood

One significant impairment included in the social-communicative aspects of ASD is the difficulty in forming meaningful friendships. Developmental research indicates that a child's development of cognitive, social and emotional competence is related to their friendships, as interacting with friends promotes mutual learning and understanding (Finke, 2016). However, individuals with ASD have difficulty creating meaningful or plentiful relationships; some research even suggests that children with ASD have the least friendships when compared to other disability groups (Finke, 2016). While some social-skills programs have been shown to be successful within a given study, these results fail to generalize to the individual's friendships outside of the study (Finke, 2016). Therefore, it is clear that despite intervention efforts and abundant research in the area of social skills and friendship-building, it may not always be realistic to expect social skills to extend beyond the scope of focused teaching and direct instruction. This trend follows individuals with ASD into adulthood, as most of their interactions are limited to close family, and their difficulty with social competence may impact their ability to obtain employment or independent living.

The parent-child relationship varies significantly based upon parent responsivity and severity level of ASD (Beurkens et al., 2012). Children are more likely to develop a secure attachment to their primary caregiver if the caregiver is more sensitive, regardless of autism severity; however, autism severity is negatively correlated with the degree of closeness between a parent and child, as more severe developmental issues can yield more stress and burden on the family system (Beurkens et al., 2012). Beurkens et al. (2012) examined the parent-child relationship based on children with ASD aged 4 to 14 years old. The majority of parents indicated low or very low scores in relation to the quality of communication between themselves and their children (Beurkens et al., 2012). These obstacles in communication contribute to feelings of frustration and stress, as parents have difficulty interpreting the needs of their child or developing an emotional relationship (Beurkens et al., 2012).

Post-Schooling/Transition to Adulthood

The stage of life post-schooling and the transition to adulthood tends to be a difficult time for individuals with ASD, as they may improve in several deficits areas over time, but initiating and engaging in reciprocal social relationships typically continues to be an area of weakness or difficulty (Tobin et al., 2014). The persistence of social deficits is a significant factor in the pattern of unemployment and lack of independent living in adulthood (Tobin et al., 2014). About 80% of adult individuals with ASD remain living with their parents post-high school (Wong et al., 2020). In a study conducted by Jantz (2011), participants reported that they had few social relationships outside of family members, which also correlated with more feelings of loneliness (Tobin et al., 2014). Due to the social and communicative deficits that accompany individuals with ASD, acquiring and keeping a job can be very difficult (Hendricks, 2010). Furthermore, given that ASD is a spectrum, each individual presents unique needs and difficulties, making

vocational adaptation an individual challenge, rather than one that can be analyzed from the scope of ASD more broadly (Hendricks, 2010). About 50-75% of adults with ASD are unemployed, even for individuals with higher intellectual abilities (Hendricks, 2010). Compared to neurotypical peers, adults with ASD experience job turnover more frequently, experience difficulty adjusting to job settings, make less money, and are less likely to gain employment (Hendricks, 2010). This comparison applies to individuals with other language disorders and learning disabilities as well (Hendricks, 2010). Due to this difficulty obtaining and maintaining employment, independent living is fairly uncommon in individuals with ASD, requiring them to rely on parents or legal guardians for support.

Parent Experience with Children with Autism

Parents provide support to their autistic children throughout all stages of their life. Parents of children with ASD tend to experience more stress than parents of neuro-typical children, even children with other developmental disabilities (Taylor & Seltzer, 2011). Due to less time for their careers and more time spent caring for their child, many parents feel isolated from friends and family (Finke et al., 2019). In addition to the emotional and social strains, parents often experience a financial burden as a result of increased costs related to raising a child with ASD (Finke et al., 2019). However, parents also indicate concern regarding the future of their child, especially once they can no longer take care of them (Finke et al., 2019).

The transition out of high school often results in a loss of services for individuals with ASD, placing more responsibility on parents/caretakers (Taylor & Seltzer, 2011). In addition to this increased responsibility, behavioral symptoms that often improve in individuals with ASD during high school years tend to slow or worsen post-graduation, placing even more strain on the parent-child relationship (Taylor & Seltzer, 2011). Several studies have examined the experience

of parents of adolescent/adult children with ASD. According to Smith et al. (2010), in comparison to co-residing mothers of individuals with no disabilities, co-residing mothers of individuals with ASD reported significantly lower levels of positive affect and significantly higher levels of negative affect. This same cohort of mothers reported more fatigue and time spent in childcare activities, as well as less time doing leisure activities (Smith et al., 2010). A longitudinal study by Barker et al. (2011) focusing on mothers of adolescents or adults with ASD found that while depressive symptoms increased across time, anxiety overall decreased. However, in terms of child context variables, behavior problems were shown to be a source of anxiety and depressive symptoms more so than autism symptoms more broadly (Barker et al., 2011). This notion was mirrored in a study by Wong et al. (2020), which found that mental health crisis and challenging behaviors were the most significant predictors of parent burden among all stressors in the study. Regardless, the presence of larger social support networks and less stressful events were associated with fewer depressive symptoms (Barker et al., 2011). Other studies examined factors outside of the child when considering the parent experience. Wong et al. (2020) found that the more access parents have to resources, the greater their ability to adapt to their child's transition to adulthood; however, access to resources was also positively correlated with the parents' demonstration of optimism and emotion-focused coping (Wong et al., 2020). Therefore, a parent's ability to develop methods of coping with stressors may be dependent on the parent's outlook and problem-solving methods. While problem-focused coping predicted lower stress, it was also correlated with a poorer transition experience (Wong et al., 2020). The results of this study indicated that maintaining optimism and emphasizing emotion-focused coping could be central for manifesting a more positive transition to adulthood for

parents with children with ASD. However, ultimately, more stressors are correlated with less optimism, thus less resources and poorer adaptive outcomes overall (Wong et al., 2020).

Despite this knowledge surrounding the parent experience with adult children with ASD, there is limited access to supports and services post-high school (Wilson et al., 2021). These issues stem from difficulty with finding supports suitable for adults, receiving financial assistance and a limited ability on behalf of support services to serve a larger population of those in need (Wilson et al., 2021). This trouble in accessing said services often results in a reduced quality of life for adult individuals with ASD (Wilson et al., 2021). Speech-language services are especially useful in addressing the continued social communicative deficits that continue into adulthood. However, in a study by Turcotte et al. (2016), results indicated that the percentage of individuals with ASD receiving speech therapy dropped from 50% to 10% post-high school (Wilson et al., 2021). As a result of this lack of services, the burden falls on parents to advocate for and find adequate services for their children. Though there is abundant research regarding the scarcity of services, there is little research surrounding the parent experience and their role in the life of adults with ASD. This paper aims to analyze the communication patterns between parents and their adult children with ASD as well as how those communication patterns relate to a parent's emotional affect.

Chapter 2

Methodology

Participants

Participants of this study included parents of children who were over the age of 18 with an Autism Spectrum Disorder (ASD) diagnosis. The participants had to be the primary source of support for the adult child and be fluent in English. Based on this criteria, 18 participants were recruited and deemed eligible. Participants were recruited via service providers and online social media groups, and potential participants expressed interest via email or phone. After expressing interest, potential participants completed a screening form to determine eligibility, and upon approval, also completed a demographic questionnaire and informed consent form.

Figure 1: Child Employment Status

Sixteen participants reported on one child, while two participants (P4, P5) reported on two children with ASD diagnoses. All of the participants were white mothers and their average age was 53 with ages ranging from 47 to 65 years old. Fifteen out of eighteen mothers (83%) were married or in a domestic partnership. Conversely, of the adult children, only three, or 15%, were involved in a relationship. Fig. 1 and Fig. 2 display employment status for both the mothers and their children. Per Fig. 1, 20% of

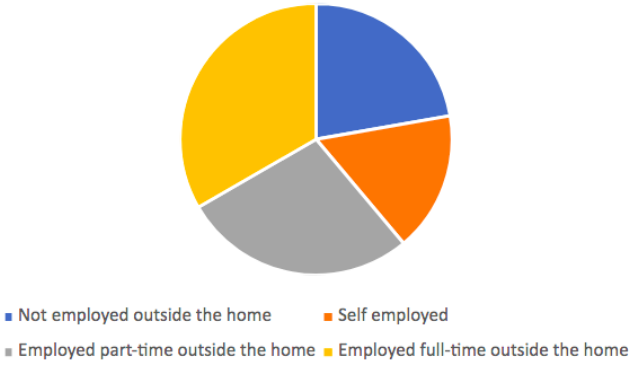

Figure 2: Mother Employment Status

adult children were employed full-time. Fig. 2 reveals that six, or 33.3%, of mothers were employed full-time, while the remaining participants were employed part-time, self-employed or not employed.

Procedure

Daily diary studies are a qualitative way of collecting information regarding participants' behaviors and experiences as they are happening. The length of such studies can vary, but the purpose is to gather data from the viewpoint of the participant over a set period of time—longer than what is typical in a laboratory setting or other types of research methods (Salazar, 2016). While other research methods like questionnaires or surveys can only probe for information about a specific activity, point in time or general topic, daily diary studies allow flexibility in the level of detail provided in the answers as well as when participants can record information (Salazar, 2016).

This study was conducted qualitatively via electronic daily diaries. Each morning and evening, participants received an email with a link to a survey. Participants were encouraged to fill out this survey any time they communicated with their son or daughter, but requested to fill it out at least once a day for 14 days. Within the survey, participants answered multiple choice questions, text-based questions, scale questions and logic-branching questions regarding their communication with their child as well as both their own and their child's perceived emotional affect. At the end of the 14-day period, participants were asked to participate in one 20-60 min phone interview regarding the ways in which they provide support to their son/daughter.

Measures

Within each daily survey, participants answered questions in a set order. They were first asked whether they had communicated with their son or daughter at all on the day of reporting, and if so, how many separate times they communicated. They were then asked to specify the general topics discussed during those times of communication. Participants then elaborated on the detailed nature of one to three interactions, including method of communication (phone, text message, in person, email, other), length of interaction, nature of interaction (planned or spontaneous) and party that initiated communication (parent or child). Upon specifying who initiated communication, participants were asked to specify the purpose of initiation (check-in, news, problem, request, or other). After establishing the general purpose they were given follow-up questions that aligned with their answer.

The second part of the survey sought to determine the parents' general affect at the start and end of each interaction as well as their child's perceived general affect at the start and end of each interaction. Participants addressed this question by dragging an indicator along a toolbar that changed an emoticon from a sad face to a happy face, where there were five possible answer choices.

The last part of the survey first asked participants to indicate whether their son/daughter had communicated with any other individuals throughout the day and to indicate whether they had planned for future communication with their child. Following those two questions, participants were given a series of scale-based questions that aimed to capture their overall general affect after all communicative interactions on that given day. These four questions addressed participants' feelings of confidence, comfort, calmness and encouragement.

Chapter 3

Results

Parents' Emotional States After Interacting with Their Adult Children

Table 1 collates the parents' average self-reported emotional states before and after interactions with their children over the span of 14 days. The third column represents the parents' changes in affect. A positive number indicates that a parent reported a more positive emotional affect post-interaction, while a negative number indicates that a parent reported a more negative emotional affect post-interaction compared to pre-interaction. The average change in affect across the entire participant pool was 0.187, indicating that as a group, there was a moderate increase in affect post-interaction with their children. The Sign Test, a nonparametric test comparing direction of change of parent affect before and after interactions, was conducted for the entire subject pool. After removing participants who did not exhibit a positive or negative change in affect, the test revealed that a statistically significant number of times ($p<.001$), more parents demonstrated a positive change in affect at the end of their conversation than a negative change. Fig. 3 displays the average difference in emotional affect rating among parents both pre and post-interaction.

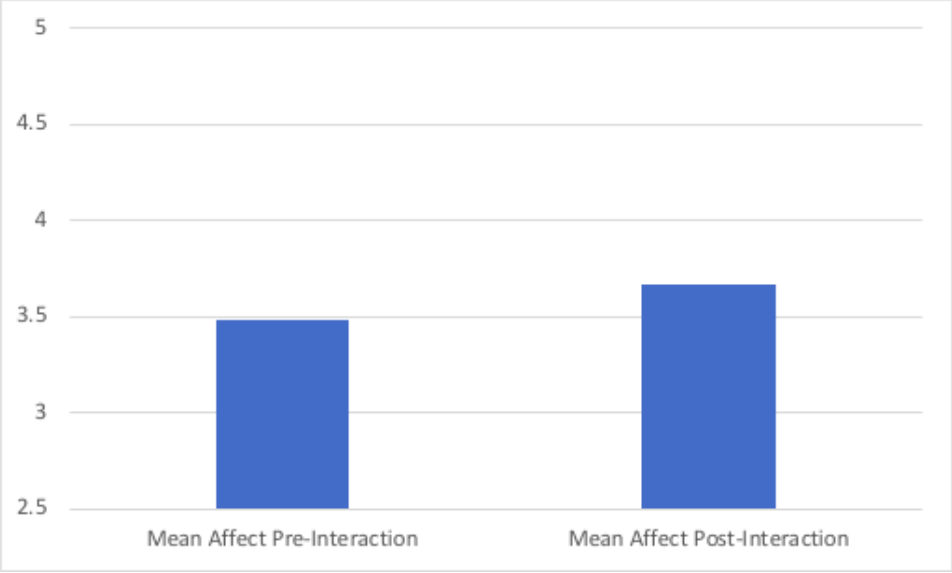

Figure 3: Parent Emotional Affect Pre and Post-Interaction

Table 1: Parent Affect Pre and Post-Interaction

Table 1

Descriptive Data of Parents' Self-reported Emotional States Before and After Interaction with Their Children

Participants	Parent mean general affect pre-interactions	Parent mean general affect post-interactions	Parent change in affect (end-beginning)
P1	2.97	3.77	0.8
P2	5	5	0
P3	3.7	3.5	-0.2
P4.o	3.43	3.57	0.14
P4.y	3.63	3.63	0
P5.o	3.27	3.8	0.53
P5.y	3	3.5	0.5
P6	3.75	4.06	0.31
P7	3.18	3.36	0.18
P8	3.25	3	-0.25
P9	3.72	3.88	0.16
P10	3	3.43	0.43
P11	3.23	2.58	-0.65
P12	3.41	3.19	-0.32
P13	2.67	2.29	-0.38
P14	3.18	4.29	1.12
P15	3.27	3.77	0.5
P16	3.4	3.87	0.47
PJ	4	4	0
PK	4.5	4.9	0.4
AVERAGES	3.478	3.6695	0.187

Table 2 depicts the parents' self-reported emotional states as it relates to confidence, comfortability, calmness and encouragement post-interactions. Parents' ratings remained fairly stable across all four categories, with slight variation; however, there were notable differences in ratings across individuals. Additionally, participants with a negative change in affect in Table 1 were more likely to report higher (more negative) numbers in the questions from Table 2. The Sign Test was used to examine the parents' ratings within these four categories. As represented graphically in Fig. 4, for all four categories, the results were statistically significant ($p<.05$), indicating that parents tended to feel more positive in all four categories post-interactions.

Table 2: Parents' Self-Reported Emotional States Across Four Dimensions

Table 2

Descriptive Data of Parents' Self-reported States of Emotion in Relation to Confidence, Comfort, Calmness, and Encouragement

Participants	More confident or more uncertain	More comforted or more worried	More calm or more aggravated	More encouraged or more discouraged	Individual means across all categories
P1	2.6	2.6	2.5	2.5	2.55
P2	1.2	1.5	1.1	1	1.2
P3	2.9	2.9	2.5	2.6	2.725
P4.o	2.6	2.8	2.7	2.8	2.725
P4.y	2.7	2.8	2.8	2.8	2.775
P5.o	2.6	2.5	2.4	2.5	2.5
P5.y	2.7	2.7	2.5	2.9	2.7
P6	2.2	2.3	2.6	2.6	2.425
P7	3.1	3	3	3.1	3.05
P8	2.9	3.2	3.3	3.1	3.125
P9	2.7	2.6	2.6	2.7	2.65
P10	2.8	2.7	2.6	2.7	2.7
P11	4.2	4	4.3	4.2	4.175
P12	2.8	3	2.7	2.8	2.825
P13	4.3	4.4	4.4	4.4	4.375
P14	2.2	2.5	2	2.2	2.225
P15	2	1.8	1.6	2.2	1.9
P16	2.5	2.5	2.5	2.5	2.5
PJ	4	3	3	3	3.25
PK	1.9	1.8	2.2	1.9	1.95
OVERALL MEAN FOR EACH CATEGORY	2.745	2.73	2.665	2.725	

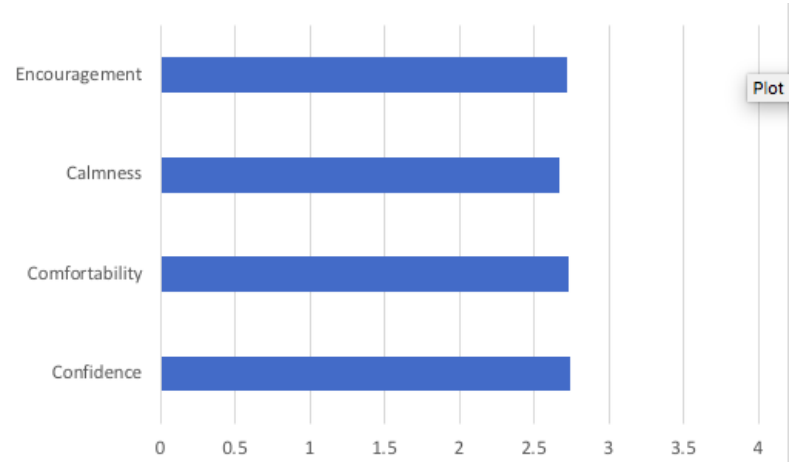

Figure 4: Parent Ratings Along 4 Dimensions Post-Interaction

Observable Patterns in Emotional States of Parents

Tables 3-5 show the relationship between change in parent affect and number of interactions they had with their child each day. Table 3 depicts the change in general affect among parents who reported communicating once or twice a day with their child the majority of the time (>50%). The average change in affect among all participants in that category was 0.077, 0.1 lower than the average change in affect among the entire participant pool.

Table 3: Parent Affect When Communicating 1-2 Times per Day

Table 3

Change in General Affect Among Parents Who Reported Communicating with Their Child 1-2 Times per Day the Majority of the Time (>50%)

Participants	Change in Affect
P2	0
P4.o	0.14
P4.y	0
P6	0.31
P7	0.18
P8	-0.25
P9	0.16

Similarly, Table 4 depicts the change in general affect among parents who reported communicating 3 or 4 times a day with their child the majority of the time (>50%). The average change in general affect among participants in this category was 0.465, 0.278 higher than the average of the entire participant pool, and 0.388 higher than the average of the parents who reported communicating with their child 1-2 times per day.

Table 4: Parent Affect Among Those Communicating 3-4 Times per Day

Table 4

Change in General Affect Among Parents who Reported Communicating with Their Child 3-4 Times per Day the Majority of the Time (>50%)

Participants	Change in Affect
P10	0.43
P15	0.5

Table 5 depicts the change in general affect among parents who reported communicating on and off throughout the day with their child the majority of the time (>50%). This group's average change in affect was 0.208—higher than that of the entire participant pool and the parents communicating 1-2 times per day, but lower than the parents communicating 3-4 times per day with their child.

Table 5: Parent Affect Among Those Communicating On and Off Throughout the Day

Table 5

Change in General Affect Among Parents who Reported Communicating with Their Child on and off Throughout the Day the Majority of the Time (>50%)

Participants	Change in Affect
P1	0.8
P3	-0.2
P5.o	0.53
P5.y	0.5
P11	-0.65
P12	-0.32
P13	-0.38
P14	1.12
P16	0.47

Table 6 reports the length of interactions among parents who reported a negative change in affect. All participants who reported a negative change in affect also reported that a majority (>50%) of their interactions with their child were less than 30 min.

Table 6: Length of Interaction Among Parents Reporting Negative Change in Affect

Table 6

Length of Interactions Among Parents who Reported a Negative Change in Affect

Participants	% less than 10 min	% 10-29 min	% 30-59 min	% 60-119 min	% 2 hours or more
P3	0	91.67	8.33	0	0
P8	5.56	44.44	27.78	16.67	5.56
P11	82.93	17.07	0	0	0
P12	46.15	15.38	10.26	23.08	5.13
P13	14.29	46.43	10.71	17.86	10.71

Chapter 4

Discussion

The descriptive data from Table 1 along with the statistical results from the nonparametric test indicate that more parents are experiencing a positive change in affect after interacting with their child than a negative change. This pattern persisted when analyzing data from Table 2—parents tended to feel more positive in all categories post-interaction with their children. These results may indicate that communication between parent and child, regardless of topic, purpose or length, may contribute to a more positive emotional affect in parents with adult children with autism. When differentiating change in affect based on number of times parents interacted with their child each day, results indicated that parents who communicated with their child more often throughout the day reported larger positive changes in emotional affect than parents who only communicated with their child once or twice per day, although these changes may not be statistically significant. These observations may indicate that more frequent communication contributes to a more positive emotional affect in the parent. Lastly, all participants who reported an overall negative change in affect also indicated that a majority of their interactions with their child lasted 30 min or less.

Clinical Implications

Although it is encouraging that parents tended to report a more positive affect after interacting with their adult children, this was merely an average across participants. Some of the parents were reporting no change or a negative change in affect; furthermore, when there were positive changes in affect, those changes were small. Therefore, the question of what supports

are still needed for parents of adult children with autism is still of vital importance. About 75% of individuals with intellectual and developmental disabilities do not have access to support services upon graduating the school system (Lee et al., 2018). In fact, even if parents do manage to identify or acquire some kind of formal support system, they report that these programs are often confusing, constantly changing, and overly complex (Lee et al., 2018). Furthermore, such services do not always come with sufficient funding, requiring parents to pay out-of-pocket, despite financial burden already being a principal barrier among parents of adults with autism (Lee et al., 2018). Though improving funding to these programs may be a more systematic issue, current efforts should focus on making system navigation more comprehensible and accessible. If parents cannot determine how to navigate a service system, then that system is not providing any benefit in regards to supporting the adult with autism. Given these obstacles with formal supports, the burden often falls on parents to identify and develop their own support system for their children, primarily through friends and family. Many parents report a need for information and peer support with regards to providing support to their adult children with ASD (Lee et al., 2018). Though these services are not always easily accessible, research shows that when parents do receive this kind of support, they experience more success in providing service delivery to their children (Lee et al., 2018). Given this information, if formal support services are not plentiful, more emphasis should be placed on cultivating a community of peers and providing informal services to parents.

Limitations and Future Directions

There are some limitations to this study. First of all, given its qualitative nature, none of the observations or results can be interpreted as causal and cannot be readily generalized to the larger population of parents of adult children with autism. Furthermore, there were only 18 participants included in the subject pool; due to this small sample size, the results may not be representative and should be interpreted with caution. With regards to the demographics of the parents included in the subject pool, every participant was a mother; therefore, there was no father perspective included in the study.

Future studies may want to focus on recruiting a larger participant pool. By nature, daily diary studies cannot claim causality and thus be generalized to a larger population; however, if a similar study conducted with a larger subject pool found similar results and patterns, the findings would garner more credence and substantiation than this study, which can only speak to the results of eighteen participants. Future studies should also recruit a more diverse participant pool, including fathers or other caregivers outside of parents, and families from different racial and ethnic backgrounds. Results from this study indicated that parents who communicated with their child less times per day demonstrated a smaller increase in affect than parents who communicated with their child at least three times per day. Future studies may further analyze this to determine whether communication frequency is correlated with parent emotional affect.

Conclusion

Parents of individuals with ASD face behavioral and emotional challenges that can affect their emotional well-being and ability to cope effectively. However, during childhood years,

parents can rely on the support of school and social services to not only help their child improve with respect to their social and communicative difficulties, but to perhaps minimize the emotional burden that is often present in parents. Yet, as individuals with ASD enter into adulthood , and as the majority of said individuals continue to live with their parents, less services are available and accessible to parents of adults with ASD. This combination of increased caretaking responsibilities and decreased accessibility to services can create an emotional and stressful situation for parents, especially as they age and worry about the future of their child. The results of this study indicate that in general, communication between parent and child results in a more positive emotional affect in parents as compared to pre-communication. However, these positive changes are small and some participants even demonstrated a negative change in affect. Based on these results and current literature, it is vital that emphasis is placed on the accessibility of formal services and the existence of informal services like support groups for parents of adults with ASD.

Appendix

Daily Diary Template

Start of Block: Default Question Block

Q1 What day is this response about?

- today (1)
- yesterday (2)

Q2 Did you communicate with your son/daughter on this day?

- yes (1)
- no (2)

Skip To: End of Survey If Did you communicate with your son/daughter on this day? = no

End of Block: Default Question Block

Start of Block: Block 2

Q3 How many times did you communicate with your son/daughter on this day?

- ○ 1-2 (1)
- ○ 3-4 (7)
- ○ on and off throughout the day (6)

Q4

One of the goals of this research is to learn about the general topics you discuss when you are in contact with your son or daughter.

With this purpose in mind, please list 1-5 words that characterize the topics you discussed on this day.

_____

_____

_____

_____

_____

Q5

The main goal of this research is to learn about the types of support you provide your son or daughter each day.

With this purpose in mind, how many specific interactions would you like to tell us about from this day? Please consider identifying between 1-3 specific interactions to tell us about in greater detail.

- ○ 1 (7)
- ○ 2 (8)
- ○ 3 (9)

End of Block: Block 2

Start of Block: Block 3

Q6 How did you communicate with your son/daughter the ${lm://Field/1}${lm://Field/2} time you interacted?

- ☐ phone (1)
- ☐ text message (2)
- ☐ in person (3)
- ☐ email (5)
- ☐ other (4) _____

Q7 How long did this ${lm://Field/1}${lm://Field/2} interaction last?

_____

_____

_____

_____

_____

Q8 Was this communication planned or spontaneous?

- planned (1)
- spontaneous (2)

Q9 Who initiated the communication the ${lm://Field/1}${lm://Field/2} you interacted?

- I did. (1)
- My son/daughter did. (2)

Display This Question:

If Who initiated the communication the ${lm://Field/1}${lm://Field/2} you interacted? = I did.

Q10 What prompted you to reach out? (select all that apply)

☐ **check in**–a brief exchange, initiated mainly for the purpose of making contact or providing a status report (Example: "I was just calling to see how things were going.") (1)

☐ **news**–a report of a recent event or new information (Example: "I saw the funniest thing on my way to work this morning.") (2)

☐ **problem**–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I'm worried that you don't have a plan to get to the grocery store this week.") (3)

☐ **request**–an appeal for something or some action (Example: "Can you feed the dog this weekend?") (5)

☐ **other**–anything that does not fit into one of the categories listed above (4)

_____

Display This Question:

If Who initiated the communication the ${lm://Field/1}${lm://Field/2} you interacted? = My son/daughter did.

Q11 What do you believe prompted your son/daughter to reach out? (select all that apply)

☐ **check in**–a brief exchange, initiated mainly for the purpose of making contact or providing a status report (Example: "I was just calling to see how things were going.") (1)

☐ **news**–a report of a recent event or new information (Example: "Guess what happened this morning!?!") (2)

☐ **problem**–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I feel sick." "I got locked out.") (3)

☐ **request**–an appeal for something or some action (Example: "Can I borrow some money?") (5)

☐ **other**–anything that does not fit into one of the categories listed above (4)

_____

Display This Question:

If What prompted you to reach out? (select all that apply) = check in–a brief exchange, initiated mainly for the purpose of making contact or providing a status report (Example: "I was just calling to see how things were going.")

Or What do you believe prompted your son/daughter to reach out? (select all that apply) = check in–a brief exchange, initiated mainly for the purpose of making contact or providing a status report (Example: "I was just calling to see how things were going.")

Q12 After the initial check-in was completed, did you move on to another topic? If yes, please briefly explain what else you discussed.

- ○ yes (1) _____
- ○ no (2)

Display This Question:

If What prompted you to reach out? (select all that apply) = news–a report of a recent event or new information (Example: "I saw the funniest thing on my way to work this morning.")

Or What do you believe prompted your son/daughter to reach out? (select all that apply) = news–a report of a recent event or new information (Example: "Guess what happened this morning!?!")

Q13 Was it good news, or bad news, or both? Please briefly explain what news you discussed.

☐ good news (1) _____

☐ bad news (2) _____Display This Question:

If What prompted you to reach out? (select all that apply) = problem–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I'm worried that you don't have a plan to get to the grocery store this week.")

Or What do you believe prompted your son/daughter to reach out? (select all that apply) = problem–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I feel sick." "I got locked out.")

Q14 Please describe the nature of the problem.

_____

_____

_____

_____

_____

Display This Question:

If What prompted you to reach out? (select all that apply) = problem–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I'm worried that you don't have a plan to get to the grocery store this week.")

Or What do you believe prompted your son/daughter to reach out? (select all that apply) = problem–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I feel sick." "I got locked out.")

Q15 Were you able to make progress toward addressing the problem? Please tell us a little more about this aspect of your conversation.

- yes (1) _____
- no (2) _____
- unsure (3) _____

Display This Question:

If What prompted you to reach out? (select all that apply) = request–an appeal for something or some action (Example: "Can you feed the dog this weekend?")

Or What do you believe prompted your son/daughter to reach out? (select all that apply) = request–an appeal for something or some action (Example: "Can I borrow some money?")

Q16 Were the request(s) granted? Please tell us a little more about this aspect of your conversation.

- ☐ yes (1) _____
- ☐ no (2) _____

Display This Question:

If What prompted you to reach out? (select all that apply) != problem–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I'm worried that you don't have a plan to get to the grocery store this week.")

And What do you believe prompted your son/daughter to reach out? (select all that apply) != problem–an issue that needs to be solved, often a source of unwelcome difficulty or distress (Example: "I feel sick." "I got locked out.")

Q17 Did you problem-solve with your son/daughter during the course of your ${lm://Field/1}${lm://Field/2} interaction?

- ○ yes (1)
- ○ no (2)

Display This Question:

If Did you problem-solve with your son/daughter during the course of your ${lm://Field/1}... = yes

Q18 Please describe the nature of the problem.

_____

_____

_____

_____

_____

Display This Question:

If Did you problem-solve with your son/daughter during the course of your ${lm://Field/1}... = yes

Q19 Were you able to make progress toward addressing the problem? Please tell us a little more about this aspect of your conversation.

- yes (1) _____
- no (2) _____
- unsure (3) _____

Q20 How would you describe your *son/daughter's* general affect at the START of this ${lm://Field/1}${lm://Field/2} interaction?

1 (1)
2 (2)
3 (3)
4 (4)
5 (5)

Q21 How would you describe your *son/daughter's* general affect at the END of this ${lm://Field/1}${lm://Field/2} interaction?

1 (1)
2 (2)
3 (3)
4 (4)
5 (5)

Q22 How would you describe *your* general affect at the at the START of this ${lm://Field/1}${lm://Field/2} interaction?

1 (1)
2 (2)
3 (3)
4 (4)
5 (5)

Q23 How would you describe *your* general affect at the END of this ${lm://Field/1}${lm://Field/2} interaction?

1 (1)
2 (2)
3 (3)
4 (4)
5 (5)

End of Block: Block 3

Start of Block: Block 4

Q24 Are you aware that your son/daughter spoke with anyone else about any of these topic(s)?

- ○ yes (1)
- ○ no (2)
- ○ unsure (3)

Display This Question:

If Are you aware that your son/daughter spoke with anyone else about any of these topic(s)? = yes

Q25 With whom did your son/daughter speak? (select all that apply)

- ☐ other parent (1)
- ☐ sibling (2)
- ☐ friend (3)
- ☐ romantic partner (5)
- ☐ other (4) _____

Q26 Did you make a plan for future communication with your son/daughter? If yes, please briefly describe the nature of the plan.

- yes (1) _____
- no (2)

Q27 Please use the sliders below to provide additional information about *your* general affect after all of the interactions you described above.

Q28 Did you feel more confident or more uncertain?

	confident	uncertain
()		

Q29 Did you feel more comforted or more worried?

	comforted	worried

()	

Q30 Did you feel more calm or more aggravated?

	calm	aggravated
()		

Q31 Did you feel more encouraged or more discouraged?

	encouraged	discouraged
()		

End of Block: Block 4

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ACADEMIC VITA

Grace Schweizer

Gvs5365@psu.edu

EDUCATION

Pennsylvania State University, University Park, PA
Schreyer's Honors College
Bachelor of Science in Communication Sciences and Disorders Graduation Date: May 2022
Minors in Spanish and Psychology

RELATED EXPERIENCE

YMCA of Doylestown—Camp Bucks, PA **June- August 2020-2021**
Ability Counselor

- Provided one-on-one support to children with Autism, mood disorders, Down Syndrome, and intellectual disabilities
- Managed individual, behavioral, emotional, communicative and physical needs
- Communicated daily with parents and supervisors to improve experience for my campers
- Strived to mainstream campers into traditional camp activities
- Promoted social interactions between my campers and their peers

Schreyer's Honors College—Research Thesis **September 2020-Present**
Research Assistant, "Examining Communication and Emotional Characteristics of Parents of Emerging Adult Children with Autism Spectrum Disorder (ASD)"

- Transported data from Qualtrics into Excel files
- Analyzed data
- Collaborated with faculty member to identify significant patterns within the data
- Formulated a thesis related to connections between communication patterns and parent affect

National Speech Language and Hearing Association (NSSLHA) **September 2020-Present**

- Participate in volunteer services such as donating to voice banks, walking/running for charity, planting flowers, donating to food banks, etc.
- Enhance cultural competence by listening to podcasts and seminars

LEADERSHIP EXPERIENCE

Penn State Women's Club Volleyball Team **September 2018-Present**
Captain

- Practice three days a week for two hours each
- Travel to other colleges for weekend tournaments in PA, VA, OH
- Travel to nationals each year to compete in a 3-day tournament
- Manage all safety concerns and injuries by filling out injury reports
- Executive decision maker as captain of the team

COMMUNITY SERVICE

Trenton Soup Kitchen—Trenton, NJ **December 2012-Present**

- Cook and serve breakfast to homeless population in Trenton, NJ

Wrightstown Food Cupboard—Wrightstown, PA **July 2012-Present**

- Pack and deliver boxes of food to people in need during holiday seasons

THON Trip—Colombus, Ohio **September 2018**

- Participated in face painting to fundraise for THON

Beaver Stadium Clean-Up—University Park, PA **September 2018-2021**

- Clean up garbage following football games

Working Varsity PSU Volleyball Games **September 2018-Present**

- Orchestrate the organization and timeliness of varsity games